

NEUROLOGICAL ALLIANCE AUSTRALIA



Position statement: Aged Care and People with Progressive Neurodegenerative Conditions

December 2020

The Neurological Alliance Australia (NAA) believes:

- People diagnosed with neurodegenerative diseases must have access to a range of services to meet their care and disability needs irrespective of where they live, their age or which sector or sectors fund the required services.
- Access to reasonable and necessary government-funded disability supports based on the age of a person when they acquire, or are diagnosed with, a disability is discriminatory and contravenes [article 19 of the United Nations Convention on the Rights of Persons with Disabilities](#), that the Australian Government has ratified.
- Investment in Home Care Packages (HCPs) to reduce waiting list for home care, as recommended in the Royal Commission into Aged Care Quality and Safety Interim Report¹, will improve the lives of thousands of people, reduce the need for residential Aged Care and boost home care sector employment opportunities during a time of rising unemployment.

The NAA will continue to advocate for access to the NDIS for all people with a diagnosis of neurodegenerative diseases no matter their age when diagnosed.

Until this is achieved the NAA calls for:

- 1. Improvements to the ageing-disability interface to ensure access to supports equitable to the NDIS to meet the needs of people who acquire a disability when over the age of 65. For example:**
 - a. Immediate, substantial and sustained investment in the provision of HCPs to reduce the number of people waiting on the national queue and to boost employment opportunities in the community
 - b. Implementation of a streamlined and reliable assessment process using skilled, specialised, care provider assessors, to ensure proper assessment and allocation of appropriate care based on the individual's need
 - c. Introduce a process that allows "fast track" access for level 4 HCPs for those with rapidly progressing and complex disability needs to ensure early intervention and care
 - d. As Aged Care has been demonstrated to be unable to meet the disability needs of older people, the NDIS should develop a safety net model that provides for adequate top-up funding through the NDIS to address disability needs not met by Aged Care.
- 2. Timely availability of assistive technology to meet the needs of the individual:**
 - a. Provide an assistive technology supplement in addition to HCP or Commonwealth Home Support Program (CHSP) funding to ensure that older people diagnosed with neurodegenerative conditions

¹ <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>

living at home can access the assistive technologies they need to maintain their independence, quality of life, communication and community access and to support carer health and well-being

- b. Provide a supplement for people in residential aged care facilities to access assistive technologies when this would improve their wellbeing, independence, communication and care.

3. Improvements to the Aged Care - Health Care sector interface

- a. Increase access to multidisciplinary health care including access to general practitioners, specialists, palliative and allied health practitioners in both home care and residential care settings to address the diverse and complex need of older Australians.
- b. Explore innovative and appropriate ways of using Telehealth in Aged Care Settings and implement them in RACFs to overcome the time and distance limitations that prevent healthcare provider visits to RACFs and to people in regional, rural, and remote areas.

4. Standardised data collection and analysis to improve interface between Aged Care, Health Care and Disability sector

- a. Introduce standardised data collection in the Aged Care, Health Care and Disability sectors to better understand utilisation of these systems by older Australians.

Background:

People with progressive neurodegenerative diseases have specific and complex needs

The Neurological Alliance Australia (NAA) is a collective of national not-for-profit peak organisations representing adults and children living with progressive neurodegenerative diseases in Australia.

NAA believes that people diagnosed with progressive neurodegenerative conditions must have access to early intervention, specialised planning, ongoing expert assessment, complex support coordination, assistive technology and a range of services to meet their needs irrespective of where they live, their age or which sector funds the service.

NAA's members can demonstrate that access to early intervention, specialised planning, ongoing expert assessment, complex support coordination, assistive technology and services that meet their needs, improves well-being, delays institutionalisation and prevents avoidable health care utilisation, irrespective of where they live, their age or which sector funds the service.

The NAA represents more than 1.2 million people living with the progressive neurodegenerative diseases. Progressive neurodegenerative diseases are a set of complex and disabling conditions. While this broad group contains conditions with various characteristics, trajectories, and life expectancy, all are degenerative and incurable.

People with progressive neurodegenerative diseases have specific and complex needs that cannot be met by existing or traditional Aged Care services or facilities which are designed to address needs related to ageing, not complex conditions or disability.

In addition, HCPs are means tested and subsidy amount limited or capped (varying from \$8,785.55 for a Level 1 to \$50,990.50 for a Level 4 per annum)², in contrast to NDIS support which is not means tested and has no cap.

Home Care Package waiting lists are too long

The interim report of the Royal Commission into Aged Care Quality and Safety published October 2019³ confirms the shocking tale of neglect of people in the Aged Care system in Australia. The report highlights the long waiting times for HCPs with many people dying whilst on this waiting list. With the progressive nature of these conditions, waiting times for HCPs are frequently too long. For example, we are increasingly being told that people with Motor Neurone Disease (MND) are dying whilst on the waiting list for the HCP they had been assessed as needing. Waiting in a national queue is not tenable in the face of progressive loss of function, speech and swallowing, loss of ability to breathe and a life expectancy of just 2 to 3 years from diagnosis.

The NAA welcomed the Government's announcement in December of additional funding for the aged care sector, though we do not believe that an additional 10,000 Home Care Packages will adequately address the long waiting lists. A more significant investment is needed if we are ever to catch up to prevent older people being forced into residential care, or dying, before they receive a package.

The needs of people with disability aged over 65 are not being met

The crucial issue remains that people with a disability over the age of 65 are not able to access the full range of reasonable and necessary disability supports to meet individual needs. As the NDIS has rolled out nationally, the gap between the services available to people with disability due to progressive neurodegenerative diseases based on their age has widened. This is leading to increasing discrimination and contraventions of article 19 of the United Nations Convention on the Rights of Persons with Disabilities, to which the Australian Government is a signatory.

In addition, people with progressive neurodegenerative diseases have changing and complex care needs which are often not well understood by Aged Care staff. The Royal Commission interim report confirms that the assessment process via My Aged Care is confusing, confronting and access to specialised assessment problematic. Needs based support hinges on timely access to specialised assessment undertaken by professionals who understand the complex nature of progressive neurodegenerative diseases.

Under current Aged Care assessment processes consideration rarely occurs as to whether a person would benefit from a specialist disability service such as complex support coordination, flexible respite, assistive technology, specialised therapy, and communication aids. The use of assistive technologies, flexible respite, specialised therapy, and communication aids supports independence, lifestyle, wellness, health outcomes and satisfaction of the users. Therefore, NAA supports a comprehensive assessment and care planning process that allows consideration of assistive technology needs. Additionally, we believe access to assistive technologies should be supported through improved, nationally-consistent funding.

² Department of Health, Aged Care Subsidies and Supplements: New Rates of Daily Payments from 1 July 2019, 2019, https://agedcare.health.gov.au/sites/default/files/documents/06_2019/aged_care_subsidies_and_supplements_new_rates_of_daily_payments_from_1_july_2019.pdf, viewed 26 September 2019.

³ <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>

Support needed for innovative healthcare models that encourage the provision of multidisciplinary care

For people with progressive neurodegenerative diseases, access to multidisciplinary health care in both home and residential settings is a vital contributor to their wellbeing. However, residents in aged care facilities do not have the same level of access to allied health professionals, general practitioners or specialists as those living in the community. This is partially due to the payment models used to remunerate health practitioners and partially due to the difficulties in attending/providing treatment in residential aged care facilities.⁴The Government should support innovative healthcare models that encourage the provision of multidisciplinary care to enhance the management and wellbeing of people living with progressive neurodegenerative diseases. The Government should provide greater financial incentives to improve older Australians' access to GPs, specialists and allied health practitioners of their choice.

Aged Care, Health Care and Disability sector integration

There is urgent need to improve the connection between the Aged Care, Health Care and Disability sectors to improve care. The NAA argues strongly for the need to improve data collection and analytics across aged care, disability and the primary and acute health systems. For data to support effective policy, it will be important to invest in the development of minimum datasets and the linking of data across the three interfaces. Support will be needed to provide access to the tools needed for data extraction for allied health providers, specialists and aged care providers. Current systems used by most of these providers do not have the capacity to extract appropriate data.

Andrew Giles, MS Australia

Interim Convenor, Neurological Alliance Australia

December 2020

For more information about the contents of this Position Statement, please contact:
Andrew Giles, National Policy Officer, MS Australia by email: andrew.giles@msaustralia.org.au

⁴ Australian Medical Association, AMA Submission to the Royal Commission into Aged Care Quality and Safety, 2019