

MEDIA RELEASE – EMBARGOED WEDNESDAY 22 MARCH 2017

LAUNCH OF NEUROLOGICAL ALLIANCE AUSTRALIA JOINT POSITION PAPER PARLIAMENT HOUSE, CANBERRA - WEDNESDAY 22 MARCH 2017

People with progressive neurodegenerative diseases in the NDIS

Ten national peak not-for-profit health organisations making up the Neurological Alliance Australia (NAA) are calling for the National Disability Insurance Scheme (NDIS) to transform the lives of over 850,000 Australians living with progressive neurological or neuromuscular conditions that have no known cause and no cure, outlined in a Joint Position Paper, *People with progressive neurodegenerative diseases in the NDIS*, which accompanies this release.

Dealing with progressive neurological or neuromuscular conditions comes at an annual cost of almost \$30 billion to the Australian economy.

Deidre Mackechnie, CEO of MS Australia and NAA Chair says the NAA is an alliance representing adults and children living with progressive neurological and neuromuscular diseases in Australia. The Alliance was established in 2010 to promote improved quality of life, coordinated services and greater research investment.

“The impact of progressive neurological conditions on individuals and families can be significant both financially and emotionally and can have a huge impact on their ability to remain engaged in their community to maintain a life of meaning and purpose,” continues Ms Mackechnie.

The NAA believes that the NDIS has the ability to transform the lives of people living with progressive neurodegenerative diseases and has promoted and supported the Scheme since its inception. To date, some NDIS participants have received plans that have had positive, life-changing impacts on their lives, however, many others have received insufficient plans that will adversely affect their quality of life and place some at risk of avoidable hospitalisation.

To ensure the best outcomes for people with progressive neurodegenerative diseases under the NDIS, the NAA recommends:

- 1. Improved pre-planning support for people with a progressive neurodegenerative disease;**
- 2. NDIS planning sessions that recognise the unique needs of people with a progressive neurodegenerative disease;**
- 3. Mandatory inclusion of Coordination of Support in all NDIS plans for people living with a progressive neurodegenerative disease; and**
- 4. The needs of people with a progressive neurodegenerative disease be addressed in the Productivity Commission’s upcoming *Review of NDIS Costs*.**

Ms Mackechnie says, “The NAA remains an advocate of the NDIS and understands the roll out of this Scheme is one of the greatest changes to healthcare since the introduction of Medicare. However, if people with a progressive neurological disease are to receive equitable and effective support within the NDIS it is imperative that the NDIA and government addresses these unmet needs. The recommendations outlined in the Position Paper launched today will go a significant way to aligning the original intent of the NDIS with its practical application”.

statement ends

NEUROLOGICAL ALLIANCE AUSTRALIA



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