Senate Community Affairs References Committee

Delivery of outcomes under the National Disability Strategy 2010-2020 to build inclusive and accessible communities

Submitted online

MND Australia

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Background

MND Australia is the national peak advocate for motor neurone disease (MND). Together with the state MND associations and our research arm, the MND Research Institute of Australia (MNDRIA) we advance, promote and influence MND care and research with a vision to achieving a world without MND. The six state MND associations provide direct support to people living with MND in all states and territories.

ABOUT MND

MND is the name given to a group of neurological diseases in which motor neurones, the nerve cells that control the movement of voluntary muscles, progressively weaken and die. With no nerves to activate them, the muscles of movement, speech, swallowing and breathing gradually weaken and waste, and paralysis ensues. MND affects each person differently with respect to initial symptoms, rate and pattern of progression, and survival time.

Average life expectancy is 2 to 3 years from diagnosis.

There is no known cause for MND (except in a very small number of genetic cases), no effective treatments and no cure. There are no remissions and progression of MND is usually rapid and relentless creating high levels of disability and a consequent need for a wide range of progressively changing supports.

THE CHALLENGES

The social and emotional impact of MND is amplified by its complex nature, the speed of its progression and the spiraling series of losses that pose:

1. huge problems of adjustment for people who have MND;
2. an escalating and stressful burden on carers and families
3. a challenge to health professionals, disability services, community care, and aged care providers involved in meeting the variable, progressing and complex care needs, particularly in regional, rural and remote; and
4. the need for a coordinated response that addresses the person's disability

Timely early intervention and access to expert multidisciplinary care, assistive technology (aids and equipment), specialist planning and assessment and coordination of support, including a proactive framework for decision-making, play vital roles in maintaining quality of life, independence and community engagement. It also helps people to plan ahead to prevent crisis and avoidable hospital/residential aged care admissions.

Although early intervention will not slow down the disease process in MND it will strengthen the informal supports available to the person, including supporting the primary carer to maintain the caring role and their own health and wellbeing.

People impacted by MND have two crucial needs:

1. CARE to meet identified needs from diagnosis through to bereavement and
2. RESEARCH to find effective therapies to stop MND

April 2017

People living with MND face many challenges but accessing the right care, in the right place, at the right time should not be one of them. The complex and progressing nature of MND requires a coordinated interdisciplinary approach encompassing health (GPs, neurology, respiratory, gastroenterology, neuropsychology, nursing, palliative care and allied health), disability, community, aged, respite and carer support services.

A recent Deloitte Access Economics Report reveals that in Australia the per person cost of MND in 2015 was $1.1 million, dwarfing the cost of many other chronic health conditions. The report, commissioned by MND Australia, is the first Australian study of the economic impact of MND.

The report states that the total cost of MND in Australia was $2.37 billion in 2015, comprising $430.9 million in economic costs and $1.94 billion in burden of disease costs. These costs include $32,728 per person related to the estimated 7.5 hours of care per day provided by family carers in addition to formal care.

The enormity of the cost is akin to the brutality of MND.

Assistive technology (aids and equipment) comprise one of the highest per person costs highlighting their importance. The often rapid rate of progression requires fast track access to a wide range and number of pieces of equipment as items may only be required for a short period of time, and multiple items may be required at any time.

For people living with MND the full range of assistive technology may include aids and equipment to support comfort, independence and daily living, communication technology and non-invasive ventilation to support breathing, quality and length of life. **Non Invasive ventilation (NIV) improves survival by 13 months on average[1].**

The report confirms the MND association equipment loan service as a cost effective model in providing assistive technology to maintain independence and communication as needs arise.

It is estimated that there are 2,000 people living with MND at any time. Around 50 % of these people were diagnosed when under the age of 65 and will therefore be eligible to disability services and support through the NDIS. The other 50% were diagnosed when aged 65 or older and will only be eligible for services and support provided by aged care.

A rapid response to service provision from a range of providers with an understanding of MND, timely access to assistive technology, coordination and regular review is imperative in meeting the individual needs of a person living with MND no matter how old they are or where they live.

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[1] Berlowitz et al, 2016 –Identifying who will benefit from non-invasive ventilation in amyotrophic lateral sclerosis/motor neurone disease in a clinical cohort, *J Neurol Neurosurg Psychiatry*, 2016 Mar; 87(3): 280-6.

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Response to Terms of Reference

Terms of Reference:

The delivery of outcomes under the National Disability Strategy 2010-2020 to build inclusive and accessible communities, with reference to:

a. the planning, design, management, and regulation of:
    i. the built and natural environment, including commercial premises, housing, public spaces and amenities,
    ii. transport services and infrastructure, and
    iii. communication and information systems, including Australian electronic media and the emerging Internet of things;
b. potential barriers to progress or innovation and how these might be addressed;
c. the impact of restricted access for people with disability on inclusion and participation in economic, cultural, social, civil and political life; and
d. any other related matters.

Access to a full range of assistive technology based on a person's needs, not age, is vital to ensure independence, inclusivity and access to electronic media and internet

The delivery of appropriate and timely assistive technology based on identified need has benefits including: improving the quality of life for those with MND and their families; reducing reliance on expensive personal support; lessening the need for residential care admissions; reducing family carer injuries and stress; increasing participation in employment and education; reducing hospital admissions; and shortening hospital stays.

Maintaining communication is key to maintaining community engagement and quality of life for people living with MND and their families. Communication is impacted not only by difficulty with, and ultimately loss of, speech but also increasing upper limb weakness.

As MND progresses and people lose limb function and/ or lose their voice then a range of technologies may be embraced by those that have access to and understanding of emerging technologies.

Examples include:

- Computer eye tracking devices and scanning programs for word processing, text to speech, email, internet etc
- Voice banking
- Voice recognition
- Tablets and smart phones
    - specialized 'apps' for people with communication and hand difficulties

These technologies have potential to transform the way people with MND communicate with their community enabling them to remain connected with work, family and friends and to remain socially connected even when all movement and communication is lost. One of the major advantages is the use of smart phones and tablets to provide updates and information to the health and community care providers involved in their care. A person with MND may be cared for by up to 14 different health professionals and services. One email is able to inform all involved of their status and current needs promoting a coordinated approach to care with the person at the centre of that care.

Access to the timely provision of assistive technology is an issue for people living with MND. Due to the often very rapid rate of progression waiting lists are not an option as by the time a piece of assistive technology becomes available the person will have progressed and that piece of assistive technology will no longer meet their needs. MND Associations have played a major role in providing or facilitating access to assistive technology, including communication aids, for many years. Most have developed comprehensive equipment loan pools to ensure a rapid response to the provision of assistive technology. However, it is beyond the capacity of most state MND association to provide hi-tech, needs specific, communication technology to their members with upper limb weakness and communication difficulties.

With the role out of the NDIS it is hoped that people diagnosed with MND when under the age of 65 will have plans developed based on their reasonable and necessary support needs. For a person with upper limb weakness and developing communication difficulties this should include funding to provide assistive technology to maintain effective communication. Unfortunately some people with MND under the NDIS at present are being denied these supports within their plans necessitating repeated plan reviews as the disease progresses – see http://www.abc.net.au/news/2017-04-15/terminally-ill-mother-fears-ndis-writes-off-people/8445228

People over the age of 65 must have access to the full range of assistive technology to ensure the delivery of outcomes under the National Disability Strategy 2010-2020

The gap between access to support and services to address disability needs for people diagnosed with MND aged 65 and over compared to those under 65 and eligible for the NDIS continues to widen. This has created significant disadvantage for older people diagnosed with MND with respect to their participation in the community and their continued social engagement.

Aged care does not and cannot provide the same or even similar services to address the disabilities created by MND as the NDIS can and does. It is unfair and discriminatory that a person who is diagnosed with MND at age 64 is eligible for NDIS and will receive the services that are reasonable and necessary for their disability, while a person aged 66 can only access aged care, which is focused on frailty and dementia, and does not understand disability and the needs it creates, nor the cost of services and support to assist someone to remain at home.

MND Australia welcomes this inquiry and is available to provide further information if required.

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