

Department of Broadband, Communications and the Digital Economy

Review of Access to telecommunication services by people with disabilities, older Australians and people experiencing illness

Submitted via email by:

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Background

MND Associations in Australia were formed during the 1980s to meet the complex and changing support, equipment, communication and information needs of people living with MND, their carers and their families. MND Australia was established in 1991 as a national body for motor neurone disease (MND).

MND Australia and the six state association members work together to advance, promote and influence local, state and national efforts to achieve the vision of 'a world free from MND'.

Motor neurone disease (MND) is the name given to a group of rapidly progressive degenerative neurological diseases that cause increasing and complex levels of disability leading to death, usually within three years of diagnosis. The most common form of MND is amyotrophic lateral sclerosis (ALS). Currently around 1400 Australians are affected by MND and thousands more; family, friends and carers live daily with its effects. Each day more than one Australian dies of this cruel disease and a new person is diagnosed. Although MND was first described nearly 150 years ago there is still no known cause, no cure and no effective treatments. Average age of onset is 59 years; however, the age range of onset is 18 to 90 years. MND is not acquired as part of a natural process of ageing.

The rapid progression of MND results in increasing and changing support needs and reliance on a range of aids and equipment to maintain quality of life and social inclusion. Support needs include assistance with: feeding, communication, breathing, movement, transferring, toileting and all daily activities. The social and emotional impact of MND is amplified by its complex nature and the speed of its progression that pose:

1. huge problems of adjustment for people who have MND;
2. an escalating and stressful burden on carers and families; and
3. a challenge to health professionals, disability services, community care, and aged care providers involved in meeting the variable and complex care needs, particularly in regional, rural and remote areas of Australia.



People living with MND and their carers face a spiraling series of losses – loss of speech, swallowing, mobility and breathing - with severe impact on physical, emotional, psychosocial and financial well-being.

The rapid progression of MND necessitates a rapid response from service providers who understand the impacts of this disease. The need for rapid and appropriate responses must be anticipated and this means a spectrum of services must be available, with the flexibility to meet the rapidly changing needs. .

Submission

Maintaining communication is key to maintaining 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. This progressive loss of speech and function has led to the MND community striving to adapt and adopt emerging technologies to meet the communication needs of people living with MND in Australia.

For many years the National Relay Service (NRS) has been an integral service assisting people with MND to remain connected to work, community, family and friends. MND is a very individual disease and each person is impacted differently with respect to symptoms and rate of progression. For people unable to speak but able to use their hands they are able to maintain communication through the NRS text to voice service. The services and support provided by the National Relay Service is valued by the MND community.

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
 - social networking

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- Voice banking
- Voice recognition
- Tablets and smart phones
 - specialized 'apps' for people with communication and hand difficulties

Already these technologies are transforming the way people with MND communicate with their community, enabling them to remain connected with work, family and friends and remain socially connected even when all movement and verbal communication is lost. One of the major advantages is the use of smart phones and tablets to provide updates and information to health and community care providers involved in personal care. A person with MND may be cared for by up to 14 different health professionals and services. One email can inform all involved of an individual's status and current needs, promoting a coordinated approach to person centred care.

Access to expert multi and interdisciplinary care improves quality and length of life. Many people with MND do not have access to expert health professionals and specialists and travel can be very difficult as the disease progresses. Some specialist MND clinics based in the capital cities have already started e-consultations. The introduction of the NBN, in partnership with appropriate medicare reimbursement, offers further opportunities to improve access and quality of health care for people living with MND in regional, rural and remote communities.

Many health professionals and service providers have very little knowledge of MND. One of the main roles of state and territory MND Associations is to provide information and education to health and community care providers involved in the care and support of people living with MND. MND Australia established a 'one stop shop' information website last year with funding from the Australian Government Department of Health and Ageing. This website offers future opportunities for further development in conjunction with the NBN roll out – www.mndcare.asn.au

Presentations at the 2011 International ALS/MND Meetings in Sydney commencing 27 November include a session on technology:

- E-solutions for people living with Motor Neurone Disease. What do they offer? Are they the answer?, Maryanne McPhee, Australia
- iPad and iPhone implementation in disabilities: access, communication, apps and mounting, Justin Ware, Australia

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- Inexpensive and flexible gaze tracking from bed, John Paulin Hansen, Denmark
- MND Aware: a web-based awareness training program about Motor Neurone Disease, Gina Svolos Australia
- Improving quality of care and empowering patients through electronic communication, Nicole Yarab, USA

These presentations highlight the importance of technology for people living with MND and the role of the Australian MND community in driving digital solutions.

Equitable access to emerging technologies for people living with MND is however difficult. Access to the timely provision of aids and equipment is an issue for people living with MND. Due to the often rapid rate of progression long waiting lists are not an option as by the time a piece of equipment becomes available the person will have progressed and that piece of equipment may no longer meet their needs. MND Associations have played a key role in providing or facilitating access to aids and equipment, including communication aids, for many years. Most have developed comprehensive equipment loan pools to ensure a rapid response to the provision of aids and equipment. In many cases, due to financial and resource constraints, it may be beyond the capacity of state MND associations to provide emerging computer and tablet based communication technology.

Our aim however will be to promote and facilitate the use of emerging technologies to improve quality of life for people living with MND and their families.

Education and access is vital to ensure equitable access to emerging technologies. The NRS could play a role in providing technology support and education. The numbers of people living with MND are relatively small but as a rapidly progressive disease that impacts on both speech and movement they can be an ideal population to trial or pilot communication projects.

For all people with rapidly progressive neurological disease timely access to communication technology is vital. Emerging technologies and the NBN offers untold opportunities for these groups of people providing access to health and community care and helping to maintain employment and social inclusion. The government will



need to consider ways of subsidising the cost of emerging technologies and the NBN if access to future telecommunication opportunities is to be realised.

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

Key summary points:

1. Ubiquitous and high speed telecommunications are vital requirements for people living with MND. The NRS or possible replacement is a vital underpinning infrastructure that must be maintained and continually enhanced.
2. Increasingly people with MND are making greater use of smart devices to support their health needs and social engagement, therefore high speed broadband rollout and equitable access is essential.
3. The Australian MND community represents a good potential audience for a case study on how to best utilize technology for communications and MND Australia would be pleased to engage with the Department to progress this idea.

On behalf of MND Australia

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