

National Disability Insurance Agency

Towards Solutions for Assistive Technology Feedback on the discussion Paper

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By:

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Feedback on the discussion paper and the approach to assistive technology solutions outlined:

There are approximately 1900 people living with MND. Around 50% of these people were diagnosed when under the age of 65 and will be eligible to become NDIS participants. Due to the often rapid rate of progression and increasing and changing levels of disability people living with MND need timely access to a wide range of assistive technology. MND associations have long played a vital role in assisting people to access assistive technology, including communication aids, from the State based equipment services in a timely and responsive manner. MND associations provide information and support to assist the person with MND to plan ahead for their current and future equipment needs, facilitate referrals for assessment and advocate for a timely response. To date in many cases the waiting period and response to need has been untenable.

In response to long waiting periods MND Associations have developed equipment loan services. These will become assistive technology “rental” services under the NDIS – a fee for service. The number and types of assistive technology available from the State MND Association varies. Some State MND Associations are able to provide a wide variety assistive technology in a very responsive manner whilst others may only be able to provide a limited range. However, all target the needs created by MND.

Some State MND Associations have also developed programs related to provision of communication technology and respiratory support equipment where these items are not available through state government services or programs. Other State MND Associations provide information on these types of specialised assistive technology and advocate on behalf of the person for access to meet the needs of individuals.

Due to the progressive and rapidly changing needs created by MND and other rapidly progressive neurological diseases, rental of assistive technology is a cost and time effective means of supply when compared to outright purchase by NDIS (See Appendices). While rental will not always deliver the perfect or customized pieces of equipment for each person, supply via rental is cost effective, includes all maintenance, and can include delivery and recovery when the equipment is no longer required.

Rental ensures that planning for equipment can take place ahead of need, resulting in earlier and faster provision when need is identified. Rental also ensures that effective return on capital is achieved, as against purchasing a new piece of equipment each time it is needed. Rental for rapidly progressive disabilities, like MND, also satisfies the requirements of the NDIS to deliver “reasonable and necessary” supports for people with disabilities and efficient and effective use of NDIS funds

Appendix 1 highlights the range of assistive technology and periods of use by five (5) different clients of MND Victoria (note that communication devices are not supplied by MND Victoria as provided by ComTec, a division of Yooralla and funded by the Victorian Government). Note the range of equipment required and the varying periods of effective use. Appendix 2 provides a history of six pieces of equipment needed by nearly every person with MND. It highlights the effective use of each item purchased over the lifetime of the piece of equipment. Rental enhances the value to be attained from each purchased item.

Assessment and identification of effective solutions

It is essential that proper assessment of needs and prescription are required for assistive technology. Poorly suited technology is like the boomerang that doesn't come back – the

technology hinders rather than assists and becomes a disadvantage - just as the non-returning boomerang is just a stick.

MND Australia recommends that assessment be undertaken by trained health professionals, supported by advice from MND Association Regional Advisors who have participated in the planning process. Participation in the planning process by Regional MND Advisors is essential if early access to Assistive Technology is to be included in a participants plan. This needs to be supported by effective assessment by appropriately trained and experienced health professionals supported by the Regional MND Advisor who provides information about MND and its rapid and changing progression.

Within the NDIS trial sites of the Hunter and Barwon MND NSW and Victoria have rental equipment available as a package for people with rapidly progressive neurological disease. The package draws from the Equipment Loan Pools (ELP) available in MND NSW and Victoria and provides a rapidly responsive, cost effective short term rental.

The equipment is unmodified and costs \$5,500 per annum saving the NDIS substantially (see Appendix 2) and provides immediate access to high quality equipment that over a combined 60 year period MND Associations have found to be the most commonly used items. Cost savings to the NDIS include negating the need for people with rapidly progressive neurological disease for continuous plan revision. As the disease progresses health professionals refer to the nominated ELP.

By housing a ready supply of unmodified equipment waiting times are substantially reduced. The referral and supply of equipment to people with MND and for people with multiple sclerosis and muscular dystrophy has been shown to be more responsive than state government ELPs and enhances the services available.

Advisers

Advisers, including Regional MND Advisors, health professionals and equipment suppliers, are essential to ensure that the pieces of equipment supplied address the needs of the individual. The existing requirement that people seeking equipment from SWEP, and other State-wide equipment programs, that people trial three pieces of equipment before purchase should be abandoned. However, there needs to be capacity for people to look at, trial, sit in and examine equipment before committing to purchase. Currently this service is provided at no charge by equipment wholesalers and retailers, and needs to be funded.

MND Association Regional Advisors are integral to the assistive technology supply process. They know the disease. Our experience of over 34 years working with people with MND is that individuals and their families have had little previous engagement with the community sector. They don't know about services and the NDIS. They don't really know much about MND other than they have been told they have a disease that will probably kill them in between 2 and 3 years. Therefore there is a need for guidance, and information. Information that is relevant to the person, their family and circumstances as and when they need it.

They also need support to identify that they need services, especially early intervention and assistive technology. Working closely with families, Regional MND Advisors identify the approaching need for assistive technology, introduce the concept and benefits of it and encourage adoption prior to the need becoming urgent. Further, people living with MND need rapid access as needs change, and this approach needs to be cost effective for the NDIA, as well as meeting the reasonable and necessary needs of people with MND.

The state MND Association model of MND support is world's best practice and aims to support people living with MND to make informed decisions about living with MND so as to achieve quality of life, and dignity in living and dying. These services empower people living with MND to adopt a proactive approach to disease management whilst respecting the

needs and wishes of the individual and their carers. The Association moves in and out of the lives of people with MND, and their service providers, as their personal needs demand.

Given the relatively short life expectancy of people diagnosed with MND (27 months from time of diagnosis), coordination of services, the monitoring and reassessment of needs and timely referrals is an essential element in ensuring that they are able to appropriately access quality services and assistive technology as and when they need them. The aim is to maximise choice and control to assist people to live as well as possible with MND. MND Associations play a vital role in providing specialist information and education to providers across all sectors and specialities to support them to provide quality services.

Conclusion

MND Australia has 6 key recommendations to ensure a cost effective mechanism to support **all** people living with MND to access appropriate and timely assistive technology to meet their identified needs.

Recommendation 1: The NDIS must support people with MND to have access to a full range of assistive technology, including communication aids and technology to maintain their independence and community access

Recommendation 2: Assessment must be undertaken by trained health professionals, supported by advice from MND Association Regional Advisors who have participated in the planning process. Participation in the planning process by Regional MND Advisors is essential if early access to Assistive Technology is to be included in a participants plan.

Recommendation 3: The NDIA should consider and include funding for rental of assistive technology for people with rapidly progressive conditions like MND as a supply mechanism, and that rental be considered for others with progressive conditions where there is a waiting list for assistive technology purchase.

Recommendation 4: The NDIA should adopt the annual “bundle” approach for the funding of assistive technology for people with MND and other rapidly progressive neurological conditions. This will negate the need for people to present to the NDIA for a plan amendment as the disease rapidly progresses

Recommendation 5: Assistive technology providers and advisers should draw on the expertise and commitment of organisations such as MND associations with respect to specialist information and education and expert individualised and personalised support and services.

Recommendation 6: National Guidelines for the management of people with rapidly progressive neurological conditions should be developed, supported and implemented to assist with establishing and maintaining interfaces between different sectors, facilitate timely, coordinated inter/multidisciplinary care, ensure timely access to supports and assistive technology to meet identified needs and to reduce cost, duplication, crisis management and admission to residential aged care or hospital.

We thank you for the opportunity to comment on this discussion paper and we would be happy to discuss further at any time.

Carol Birks

National Executive Director

BACKGROUND:

MND Australia is the national peak organisation representing all across Australia who share the vision of a world without motor neurone disease. We work collaboratively with our member organisations, the state MND Associations, to influence policies and services at a national level and to advance research to ultimately end MND. The state MND Associations provide information, equipment and support services to people diagnosed with MND, their family and friends and the health, aged, disability and community care providers involved in their care. The MND Associations in NSW and Victoria are NDIS service providers.

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. In approximately 60% of cases cognition is affected but in the majority of these individuals the impact is mild.

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 treatment and no cure. There are no remissions and progression of MND is usually rapid, creating high levels of disability.

THE CHALLENGES

The rapid progression of MND results in increasing support needs and reliance on a range of assistive technology to maintain quality of life and social inclusion. The type of assistive technology an individual needs change as their disability progresses. Support needs can include assistance with: feeding, communication, breathing, movement, transferring, toileting and all daily activities. The social impact of MND is amplified by its complex nature, the speed of its progression and the spiralling series of losses, which pose:

- huge problems of adjustment for people who have MND;
- an escalating burden on carers and families; and
- a challenge to health, aged, disability and community care professionals involved in meeting the variable and complex care needs

MND care must be addressed through a coordinated multi/interdisciplinary team approach with timely referrals to services that will address identified needs.

The key issue in providing support for people living with MND is time – rapid progression and changing needs do not wait, and the assistive technology, or services, that are perfect today may not be perfect tomorrow. Timely early intervention and access to assistive technology, flexible respite, specialist planning and assessment and coordination of care, including a proactive framework for decision-making, play vital roles in maintaining quality of life and independence for as long as possible. 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 living with MND have complex and progressing needs related to assistive technology. The provision of MND specific information is vital for people living with MND and their families as well as providers involved in assessment, planning and delivery of assistive technology services. The timely provision of quality assistive technology to meet identified needs is imperative to support quality of life for the person with MND and their carer.

APPENDIX 1

CLIENT	MA -Blackburn	DH - Kerang	HC - Kew	MA - Springvale	PC - Bendigo
Months registered with MND Vic ES	68	38	2	27	68
ITEM	TIME ON LOAN IN MONTHS				
Shower chair				25	46
Over toilet frame	15			10	
Bedstick	25			15	62
Walking frame	2				
Roho pressure cushion			2		
Overbed table	6			15	
Electric riser armchair	9	11			
Manual wheelchair	64		2	17	64
Tilt manual wheelchair		9			
Powerchair				6	
Tilt powerchair	54	32		13	51
Ramps				18	

Mobile commode	9		1	14	8
Tilt mobile commode	24			3	
Hoist & slings	18	5	1	12	52
Electric bed			2	5	52
Air mattress	3		2	5	13
Call bell	61			6	
Mattress overlay				3	
Transfer board				6	
Bedside commode			2	7	
Pillow wedge	31				
Bridge chair	5				



Equipment Service – Asset Loan History Examples

Appendix 2

ITEM	Electric bed	ELR armchair – single action	ELR armchair – dual action	Electric hoist	Manual wheelchair	Tilt powerchair
DATE PURCHASED	2002	2008	2009	2007	2005	2008
Purchase** \$	\$2,645	\$2,200	\$2,200	\$2,200	\$1,035	\$15,520
Rent*	\$30/\$110/\$1100	\$30/\$100/\$1000	\$30/\$100/\$1000	\$20/\$70/\$750	\$12/\$45/\$500	\$100/\$350/\$3,600
CLIENT #	TIME ON LOAN IN MONTHS					
1	18	10	12	13	19	25
2	6	16	7	12	26	11
3	2	1	11	1	7	1
4	4	2	12	18	23	8
5	5	13	16	6	13	16
6	3	23		4	2	9
7	1			2	12	
8	8			7		
9	13			15		
10	1					
11	4					
12	5					
13	15					
14	28					

*Rent is weekly/monthly/annual **Purchase is current price