



MOTOR NEURONE DISEASE ASSOCIATION OF VICTORIA INC.

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SUBMISSION STATE DISABILITY PLAN 2017 - 2020

MND Victoria has a vision of a world without motor neurone disease. We work collaboratively with the National peak body, MND Australia, and other State 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.

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.

In Victoria, MND Victoria has 400 people registered as at 30 June 2016 living with MND. During the year, 194 new people were registered, and 181 people died. While the average age of onset is 59 years 60% of MND Victoria's current clients were over the age of 65 when diagnosed.

THE CHALLENGES OF THE DISEASE

The rapid progression of MND results in increasing support needs and reliance on a range of aids and equipment to maintain quality of life and social inclusion. 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, particularly in regional, rural and remote Australia.

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

Timely early intervention, access to aids and equipment and 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.

BACKGROUND

Support for people living with MND since the introduction of the Disability Act 2006 has been significantly better than support in other States.

By not restricting the Act to a particular age group, people with disability in Victoria have been able to access a broad range of services to address their needs created by disability. Of course, this was an entitlement system, subject to the availability of funds. However, the key issue was that there was no discrimination based on the age of the person.

The introduction of the NDIS, specifically targeted to people who acquire a disability under the age of 65, is a significant step forward. The creation of an entitlement to support, based on an assessment of reasonable and necessary needs created by their disability, has meant that people with disability in the Barwon region to access funding to purchase services that meet their needs. The progressive rollout will extend that to all people with a disability acquired under the age of 65 across Victoria, and Australia.

However the introduction of My Aged Care by the Commonwealth has resulted in a different approach for those who acquire disability over the age of 65. My Aged Care is an eligibility system, and is subject to funding being available. My Aged Care is budget based, rather than needs based, and so is divided into three classes of service: HACC, Packages to remain at home, and residential or facility based care. Aged care is built around frailty and aging, not around individual needs.

The funding for aged care packages is based on 4 levels of assessment, with different levels of funding. One common element is that if a person can get an aged care package, they have to pay full price for other services provided. In Victoria, for example, this can mean paying \$100 per hour for nursing care from a community nursing service. For a person on a level 1 or 2 package, accessing one hour of nursing per week, this could absorb \$5200 of their package, already depleted by the cost of case management, and burdened by the need to make a private contribution to their care.

In relation to people with MND, one common and key need is for disability aids and equipment. Aids and equipment promote independence and community engagement, safety for the person with MND and their carers and facilitate them remaining in their accommodation of choice, usually their home. However, aged care packages are not large enough to provide the equipment needed, as well as meet the costs of care necessary to remain at home. In a recent study by Deloitte Access Economics (Economic Analysis of MND in Australia, 2016, Ch11), the cost of equipment for people using the NDIS was \$26,040. Given that the needs created by MND are very similar across the age range of diagnosis, this amount cannot be funded out of Aged Care packages. In fact, the Hon Sussan Ley, then Minister for Health, wrote to the Hon Jill Hennessy, MP, Minister for Health (Vic) on 4 February 2016 and stated "I understand that many people with Motor Neurone Disease require specialist aids and equipment. While not intended for this purpose. Some aids and equipment, including custom made aids, can be provided to a consumer through the Home Care Packages Programme where this is identified in their care plan and the item/s can be provided within the resources available for the package. As you are likely aware, state and territory governments operate specialised aids and equipment schemes to assist people with disabilities, including older people. It is expected that consumers will continue to be able to access specialised aids and equipment schemes where there is a need for support".

The NDIS and My Aged Care provide two different responses and level of response to disability, separated by age. Despite the circumstances of two people, one person aged 64 and one aged 66, both diagnosed with MND and both requiring support, the response to their needs discriminates on the basis of age.

The 64 year old has an entitlement to reasonable and necessary funding to address the needs created by their disability. The 66 year old is eligible to apply for a package to support living at home, but have to

contribute to their costs, pay full price for additional services provided at very low cost to non-package holders, and cannot access the appropriate equipment services to address their needs from their package.

The Disability Act 2006 and the State Disability Strategy 2017 to 2020 must address these issues.

THEMES

1. Active Citizenship

Active citizenship means many things, but it includes having the ability to participate in the community, access the community and its facilities, and move around in them. Participation in the life of their and our State means being able to move in and around. To do so requires appropriate levels of disability support, including disability aids and equipment.

For those under 65, and in receipt of a NDIA package of support, this is facilitated through their NDIA package of supports.

For those who acquire their disability over the age of 65, the Disability Strategy must make provision for those whose My Aged Care package is insufficient for appropriate care and support to participate in the life of their state, to venture into and enjoy their community, and be able to do so safely using appropriate aids and equipment.

The Disability Strategy should maintain and increase the level of support for services for people over the age of 65 who acquire a disability to add to existing packages under My Aged Care for those lucky enough to get one, and to fund the provision of services for those who cannot. We do not support the concept of “double dipping” – support from the State should be limited to those whose My Aged Care package is not sufficient to address their “reasonable and necessary” needs created by their disability and top up that package, and support those with a disability who cannot get a My Ages Care package due to budgetary constraints in the Commonwealth.

Similarly, the Disability Strategy should be commit to increase the level of funding for disability aids and equipment provision to ensure that all people with a disability are able to access appropriate aids and equipment to maintain their safety, and that of their carers and care professionals at home, and to facilitate active citizenship and access to the community.

2. Rights and Equality

The Disability Strategy must support equality for those under 65 and those who acquire a disability over the age of 65.

The strategy cannot fall back on the COAG agreement regarding responsibility for people over the age of 65 with a disability being the responsibility of the Commonwealth aged care platform.

As indicated above, equality is not achieved by a discriminatory system that provides differing levels of access and support based on age. The Strategy has an obligation to recognise that the Disability Act 2006 covers all people in Victoria who have a disability, and does not exclude anybody on the basis of age. The Strategy should therefore ensure that is encompasses the needs, hopes and aspirations of all Victorians with a disability, and ensure that those who acquire their disability over the age of 65 do not enjoy less support, service or

opportunity than those under the age of 65

3. **Economic Participation**

As most Victorians with MND cease work early due to the progression of their disease, we have no suggestions to be made other than all Victorians should be encouraged and supported to enjoy the fullest economic participation as is possible, and that the Strategy should have elements of support that include disability aids and equipment for all ages.

4. **Making the most of the NDIS**

One of the great gaps in the introduction of the NDIS has been the place of information and referral services.

While one would hope that eventually anybody born with or acquiring a disability under 65 will know to contact the NDIS/NDIA, this is not the case at present, and certainly not the case for diagnostic based disabilities like MND.

On diagnosis, our experience is that the MND Association is the first point of call post diagnosis. People contact us by phone, email and via the internet to find out more about their diagnoses, seek counsel and good advice, require assessment for immediately needed services and support, referral to services to address immediate needs, and commitment for future support.

At present, this is provided via information funding through the Department of Health and Human Services to specialist agencies. However, there is no current stated commitment for this to continue.

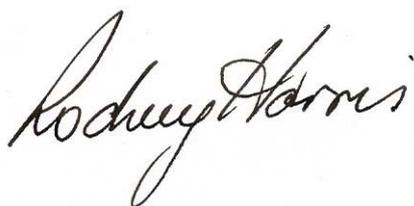
Further, despite the availability of Local Area Coordination, most people with MND do not contact them. If they do, the LAC have no knowledge or understanding of the disease and its impact, and the support that is required in those early days. They may have knowledge of local services, but don't recognise the needs that are present and emerging in the MND client. This is true across all of the neurodegenerative diagnoses.

To make the most of the NDIS, the Disability Strategy must retain and restate the importance of information and referral as a service for people with a disability. As the NDIA only gets involved when a person is a participant, it is essential that the pre participant stage is recognised and supported for all people with a disability, no matter what their age of diagnoses or onset.

IN addition, the Disability Strategy must continue to emphasise the place and role of disability aids and equipment in State responsibilities. There is an opportunity to benefit from the efficiencies and competition being driven by the NDIS to underpin the provision of aids and equipment for people who do not have a NDIA package of support and for those who acquire a disability over the age of 65.

Please contact the undersigned if further information is required on this submission.

Thank you for the opportunity to make a submission on this essential strategic document for people with a disability in Victoria.



Rodney Harris
Chief Executive Officer
6 July 2016