Response to Productivity Commission Draft Report

Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services

Submitted online

By

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Executive Summary

Thank you for the opportunity to contribute to the Productivity Commission inquiry ***Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services*** draft report.

Empowering individuals and their families is central to all Motor Neurone Disease (MND) Australia activities and we wholeheartedly support the intent of the inquiry to find ways to put people who use Human Services at the heart of service provision. We agree that change is needed to enable people to have more choice and a stronger voice in shaping the services they receive and who provides them.

People diagnosed with MND have an average life expectancy of just 2 to 3 years. They need timely access to diagnosis from a neurologist expert in MND and coordinated outpatient and community health care from specialised multidisciplinary and palliative care teams. There are estimated to be 2000 people living with MND at any time in Australia with around half diagnosed when under the age of 65.

The draft report sets out proposed reforms for: *end of life care services, social housing, government commissioned family and community services, services in remote indigenous communities, public hospitals and public dental health services.*

Of most relevance to people living with MND are the recommendations related to end of life care and public hospital services and our response to the recommendations form this submission.

We are pleased that the Productivity Commission has noted that competition and contestability are a means to an end and should only be pursued when they improve the effectiveness of service provision. Access to high quality health, palliative and end of life care services is necessary before choice is possible and there is still much to be achieved in this area for people living with MND and their families.

Investment in disease specific pathways of care, specialist multidisciplinary MND clinics and palliative care teams and telehealth will improve effectiveness of service provision and access for people with life limiting, complex and progressing conditions such as MND[1].

MND Australia agrees that high-quality data are central to improving the effectiveness of human services and believes that the collection and analysis of relevant information should proceed in tandem with improvements in access to health and palliative care.

Equally important to empowering people to exercise choice is access to reliable and trusted information and support from specialist disease specific organisations.

If you have any questions, please contact Carol Birks, CEO, MND Australia

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[1] MND Australia, 2016, National Action Framework

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.

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 are no remissions and progression of MND is usually rapid and relentless creating high levels of need.

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 areas

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[2] 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

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[2] Deloitte Access Economics, 2015, Economic Analysis of motor neurone disease in Australia, report for Motor Neurone Disease Australia

Submission

End of Life Care

Draft Recommendation 4.1

MND Australia supports this recommendation to ensure that people who prefer to die at home are able to access timely community –based palliative care services to enable them to do so. It is important to note however, that for some people the preference is to remain in their residence of choice for as long as possible but to die in hospital. This could be for a variety of reasons such as the needs and preferences of their carer or the availability of specialist support to address complex symptoms. Any measurement related to place of death should incorporate how long before death the person left home and the reason for the transfer. This will facilitate service and care improvements as well as provide better understanding for late in life residence changes.

At present treatments for MND only offer the potential to slow the disease process. A coordinated, palliative care approach is therefore required from diagnosis to ensure that early discussions around future care management and advance care planning are held and optimal symptom management for the person with MND and their family is achieved[3] . Early access to palliative care services and providers promotes effective use of these services. It is very important that people living with MND are able to access quality end of life care based on the needs and wishes of that individual and their family. There is considerable evidence that palliative care intervention improves quality of life for people living with MND and their carers[4.] and that most people with MND would prefer to die at home, or remain at home for as long as possible.

Key findings of the MND Pathways Project undertaken by MND Victoria and the Victorian Department of Human Services in 2009 recommend the development, implementation and funding of a key worker based multidisciplinary model for people living with MND when receiving palliative care services, as well as early referral to palliative care services and providers.

MND Australia supports this model to promote early referral and assured access to appropriate services[5]. The model emphasises the importance of coordination between MND service providers and families. It also identifies the need for the development and delivery of MND specific education to empower service providers and to support them to provide a coordinated, palliative, multidisciplinary approach from diagnosis through to end of life and bereavement.

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[3] D Oliver, D Walsh & GD Borasio (eds) *Palliative care in amyotrophic lateral sclerosis: from diagnosis to bereavement*, 2nd edn, Oxford University Press, New York, 2006.

4 Bede P, Oliver D, Stodart J, van den Berg L, Simmons Z, O Brannagáin D,Borasio GD, Hardiman O. *Palliative care in amyotrophic lateral sclerosis: a review of current international guidelines and initiatives*. J Neurol Neurosurg Psychiatry. 2011 Apr;82(4):413-8.

[5] MND Australia Position Statement Palliative Care and People living with MND

The community also needs to be better informed and supported to access services and support available at end of life. Many people who are caring for a loved one at end of life are not introduced to the full range of palliative care services available and will struggle to provide the care themselves. Early referral to palliative care and provision of a key worker to coordinate end of life care is applicable to everyone with a terminal condition.

Access to palliative care services to enhance quality of life as soon as a person is ready is crucial to effective end of life care and to enable the family to provide home based care if that is their wish.

Draft Recommendation 4.2

Most people living with MND will remain at home assuming they are able to access needs based community support and have a family carer. For those who do enter residential aged care, or who are diagnosed with MND when a resident, access to palliative and end of life care to address the myriad and progressing symptoms of MND is vital. Restrictions on duration, availability and quality of palliative care for people with a diagnosis of MND in residential aged care facilities should be removed as a matter of priority. The existing process of discharge to remove long lengths of stay from reporting processes should be actively discouraged and discontinued.

Draft Recommendations 4.3 and 4.4 - Advance care planning

Discussions around end-of-life care need to be instigated as soon as the person with MND is ready, preferably before speech is affected, to ensure optimal interaction and communication to address their more profound concerns. Access to flexible advance care planning tools and clinically trained staff and options for regular review will support people living with MND to be in control and exercise choice as their disease progresses.

Funding for these discussions should be initiated. While encouraging people to undertake advance care planning is everybody's responsibility, the identification and funding of those who sit down and develop the plan is essential. In relation to MND, the MND Associations are well placed to undertake and document advance care plans.

Public Hospital Services

Draft Recommendation 9.1

MND Australia supports the idea of choice of public outpatient clinic or specialist for their initial consultation. However for people with a suspected diagnosis of MND choice may be compromised by limited GP knowledge and access to a neurologist expert in MND. The way a diagnosis of MND is delivered can have a huge impact on an individual and their family's response and future quality of life. Aoun et al [6] highlighted the impact of giving and receiving a diagnosis of MND and the need for improved education for neurologists to support them to better deliver a diagnosis of

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[6] Aoun et al. *Breaking the news of a diagnosis of motor neurone disease: A national survey of neurologists' perspectives*, Journal of the Neurological Sciences 367 (2016) 368–374

MND. Improved disease specific information and education for GPs, specialists and the community is vital in supporting choice in the health care system.

GP referral to a neurologist expert in MND and specialist MND multidisciplinary outpatient clinics should be available and assessable to everyone with a diagnosis of MND. Evidence suggests that specialist multidisciplinary care supports patient choice in accessing evidence based interventions in a timely manner thereby improving quality and length of life[7].

At present there are specialist neurological led MND multidisciplinary clinics in each mainland state capital, the ACT and in some regional towns. Some are able to provide telehealth facilities or hub and spoke models of care to outreach more broadly. Federal government funding to support these clinics would enable a broader reach and provide people with a diagnosis of MND greater choice in accessing specialist healthcare to address their many complex and progressing needs[8].

Draft Recommendation 9. 2

The development of best practice guidelines to support patient choice should take into account the impact of the disease and progression. At present there are no practice guidelines for MND care and management in Australia. The Motor neurone disease: Assessment and Management NICE guidelines[9] published in February 2016 in the UK aims to improve care from the time of diagnosis and covers information and support, organisation of care, managing symptoms and preparing for end of life care. The development of similar guidelines for people with progressive neurological conditions such as MND would support choice and timely referrals across all settings of care.

Draft Recommendation 9.4

People with a diagnosis of MND in regional, rural and remote Australia face many challenges including access to specialised medical, multidisciplinary health and palliative care. Funding travel to get to the nearest provider may exclude access to providers with an understanding of MND.

Funding telehealth consultations would be a cost effective way to support patient choice and access.

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[7] Ng and others 2009 Multidisciplinary care for adults with amyotrophic lateral sclerosis or motor neuron disease

[8] MND Australia, 2016, National Action Framework

[9] *Motor neurone disease: assessment and management, NICE Guidelines, February, 2019*