# Response from MND Australia to the Productivity Commission Caring for Older Australians Draft Report

As outlined in the original MND Australia submission MND Australia expects that any structural reform of the aged care system will include the following key characteristics in order to meet the needs of older Australians who have motor neurone disease (MND) and their carer:

- recognition that MND is not a disease related to normal ageing
- access to the same levels and types of service and support for people over 65 as for those under 65
- access to enhanced and flexible services and support to meet the individual needs of people living with MND and their families

The crucial issue for people living with MND and their carers is access to planning options and services to address changing and complex needs to ensure their quality of life. A seamless coordinated response from aged, disability and health care services should be integral to reforms related to these systems.

MND Australia congratulates the Productivity Commission on the breadth and depth of this draft report. Recognition that the system suffers key weaknesses including its complexity, quality and quantity of services, gaps in service and limited choices is welcomed. The draft report seeks to address important issues related to workforce shortages and financial contributions and confirms the need for simplified access to the aged care system. The draft report has also confirmed the need for higher quality care that addresses the needs of individuals – this is essential for people living with MND and their carer.

In our response to the draft report MND Australia has focused on the draft recommendations that will have a direct impact on the care and support of people living with MND and their carer. It is beyond our area of expertise to comment on the proposed funding and regulation models for residential aged care.

## Response to Draft Recommendations

### *6. Paying for Aged Care*

The reforms to paying for aged care needs to take into account the financial impact on younger people in nursing homes and their family. Most people living with MND prefer to remain at home. For those who do require residential aged care support they are often near the end of their life and their stay may only be for a short time. The option to pay for their accommodation through periodic payments for the duration of their stay may be preferable in these circumstances rather than paying a lump sum. A range of payment options need to be available.

### *8. Care and support*

8.1
The recommendation to create an Australian Seniors Gateway Agency raises some issues for people living with MND who are ageing:

- This agency will need to have formal links to disease specific and disability organisations for access to disease/disability specific information and support for people with chronic health issues, or with a disability, who are ageing
- Assessment processes must be timely and must be able to respond to needs that may be rapidly changing. The agency therefore needs to have available nationally consistent assessments that are both broad and shallow and also comprehensive and complex depending on the needs of the individual and their family.
    - A simple assessment process that could be completed online or via the telephone for people with low level needs
    - A more comprehensive and professional assessment process for people with complex and changing needs
    - The assessment process to be sensitive to anticipated and changing needs in order to negate the need for multiple assessments as needs change
    - The needs of the carer, and a response to those needs, must be part of the assessment and referral process
- Many people accessing the gateway will have needs related to ageing, health and disability.
    - Fast tracking assessment process for people with rapidly changing needs is recommended
        - Waiting lists are not an option for people living with MND – they die while waiting far too often
    - Seamless entitlement to services based on need is vital to ensure quality of life for all people with MND and their carer no matter how old they are
- Care coordination for people who have aged care needs and disability and health needs can be complex and expert knowledge of the disease or disability will be required
    - Electronic health and support records will assist providers to share information and minimise the need for multiple assessments

- Flexible options are vital and again formal links to disease specific and disability organisations is integral to developing models of care coordination and case management

8.2
The recommendation to replace the current system of discrete care packages with a single integrated, and flexible, system of care provision with provider choice is welcomed. Seamless entitlement, rapid decision making and response, however, are vital to ensure access to needs based care.

8.3
Optimal palliative and end of life care is imperative for people living with MND. Admission to an acute care hospital for end of life symptom management is usually not appropriate for people living with MND. On going in-home palliative care enables people to remain in their accommodation of choice for as long as possible.

It is appropriate, as recommended, that residential and community care providers receive case mix payments for delivering palliative and end-of-life care. These providers, however, must be accredited in palliative care, and have the necessary skills and training. Aged care facilities need ready access to primary care providers well skilled in palliative care and specialist palliative care physicians.

Community primary health care providers also need access to education and training in the provision of a palliative approach to care.

8.5
Improvements to the interface between aged care and health are important to achieve optimal care for people living with MND. Access to appropriate health and allied health services for people living in residential aged care facilities is crucial to their health and well being. The development of in-reach services and regionally or locally-based visiting multidisciplinary health care teams is a welcome recommendation.

We note the Productivity Commission's comments relating to the interface between aged care and disability.

We specifically welcome the following comment in the draft report:
***Irrespective of funding source or assessment arrangements, all people with a disability and all older people needing care and support should receive services appropriate to their needs, on a fair and equitable basis***.

We note the Productivity Commission recommendation in the Interim Report on Long Term Care and Support that people with a disability who reach retirement age can choose to opt out of the NDIS and opt in to aged care services. The preferred option for people living with MND would be to access services from whichever system best meets their needs and this would most likely be a combination of aged and disability services.

***9. Catering for diversity – caring for special needs groups***
MND Australia supports the recommendations in this section.

Special attention must, however, be paid to access to primary health care, allied health and palliative care in rural and remote communities. Younger people in nursing homes must also be recognised as a special needs group.

***10. Age friendly housing and retirement villages***

10.1
MND Australia supports the recommendation to develop a national approach to the provision of home maintenance and modification services.

Home modifications are usually necessary to assist people living with MND to remain at home. Delays in assessment and provision of the service are common. We request that emphasis be given for a fast track assessment process for people with rapidly changing and complex needs.

***11. Delivering care to the aged – workforce issues***

11.1

MND Australia supports the recommendation to assess the capacity of informal carers to provide ongoing support when assessing the care needs of older people. We welcome the Productivity Commission's recognition of the need for the proposed gateway agency to approve entitlements to services and/or assisted referral for:

- carer education and training
- planned and emergency respite
- carer counselling and peer group support
- advocacy services.

There is a need to also include case management, case coordination and facilitation. Not all carers are able to manage the complexities of the health and aged care systems.

Carers of people living with MND usually need all these forms of support to enable them to maintain their caring role and their social participation. MND Association family support services in most states provide carer information, education and support, as well as case management, coordination and facilitation where required. MND NSW provides flexible respite options through a consortium approach funded by the NSW Government. Engagement with disease/disability specific groups is vital in providing optimal information and support to carers of people who are ageing. Organisations such as the MND associations have developed a number of effective models of care related to carer support and education.

Assistive technologies (aids and equipment) have been mentioned in this section as being able to increase and maintain independence. Access to assistive technologies for older people however has not been addressed. The current system is fragmented and it is often difficult to access aids and equipment in a timely manner. The proposed interface between aged care services and assistive technology services needs to be articulated in the final report.

11.2, 3 and 4

MND Australia strongly supports the recommendation to pay competitive wages to nursing and other care staff delivering aged care services. This recommendation as well as the recommendations to promote skill development and fund the expansion of 'teaching aged care services' to promote the sector among medical, nursing and allied health students is welcomed. These changes will help to ensure that older people are provided with quality multidisciplinary care.

Coordinated multi-disciplinary team-based care is vital for all people living with MND. Access to these services in the community supports the person with MND and their carer to remain in their own home if that is what they wish. For those people who move to residential aged care it is important that this multidisciplinary approach continues to address symptoms related to increasing paralysis and speech, swallowing and breathing difficulties.

**Conclusion**

MND Australia thanks the Productivity Commission for the opportunity to comment on the draft report. The recommendations outlined in the draft go a long way in addressing many of key weaknesses of the current aged care system.

For people living with MND any changes to the aged care system need to accommodate rapidly changing and complex need. Access to primary health, palliative care and allied health both in the community and in aged care facilities is crucial to ensure a coordinated multidisciplinary and palliative approach to MND care from diagnosis through to end of life.

Services, no matter how they are funded, should not be capped and must be provided based on the needs and wishes of the individual and their family. The under/over age 65 criteria must end and seamless entitlement to coordinated health, disability and aged care service provision must be implemented in order to achieve quality and length of life for all people with MND and their carer no matter how old they are.

MND Australia welcomes this draft report and is available to provide further information or participate in any public hearings if required.

**Carol Birks**
National Executive Director, MND Australia
PO Box 990, Gladesville, NSW 1675