

# Submission to the Senate Community Affairs Legislation Committee

## Inquiry into Aged Care

**Submitted on:**

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**By:**

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**On behalf of:**

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MND Australia would like to thank the Senate Community Affairs Legislation Committee (the Committee) for providing an opportunity to comment on the following Bills:

*Aged Care (Living Longer Living Better) Bill 2013;*  
*Australian Aged Care Quality Agency Bill 2013;*  
*Australian Aged Care Quality Agency (Transitional Provisions) Bill 2013;*  
*Aged Care (Bond Security) Amendment Bill 2013;* and  
*Aged Care (Bond Security) Levy Amendment Bill 2013*

Our submission will address the first of these five bills.

## **INTRODUCTION:**

MND Australia is the national voice for people living with motor neurone disease (MND). We promote MND care and research to improve the outcomes for people living with MND today and in the future as we work towards our goal of a world free from MND. The state MND Associations provide information and support to people diagnosed with MND, their family and friends and the health 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. 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 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 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.

The introduction of a national disability insurance scheme (NDIS) has the potential to transform the lives of people living with MND who are diagnosed when aged 64 or younger. However it is proposed that the needs of people who acquire a disability after pension age would be best met by the aged care system.

There are currently 1500 people living with MND and around 50% of these people were diagnosed aged 65 or older. From experience we know that the needs of people living with rapidly progressive neurological diseases such as MND cannot be met by existing or traditional aged care services or facilities. Even with the proposed improvements and changes to the aged care system the focus remains on addressing needs related to ageing.

## ***Aged Care (Living Longer Living Better) Bill 2013***

### ***Home Care***

From 1 July 2013, community care (Community Aged Care Packages) and two kinds of flexible care, Extended Aged Care at Home and Extended Aged Care at Home Dementia, will be replaced with home care. Home care will consist of four levels to provide a continuum of home care options.

The aged care system is designed to address needs related to ageing, not disability, and there are currently major gaps with respect to choice and the range, level, and hours of services available (see Appendix 1).

For older people diagnosed with MND it is imperative that these four home care options encompass access to initial low level assistance with increased funding and services to meet assessed need available in a timely manner as the disability level escalates and progresses.

If the highest level of home care is unable to meet the disability needs of older people living with progressive diseases such as MND then top up funding through the NDIS should be available to address needs not met by Aged Care. This model of care would support the commitment already made that the NDIS or DisabilityCare will **complement** aged care services.

If older people diagnosed with MND are only eligible for home care services, access to disability services and hours of support to meet a person's needs would remain limited. Consequently major gaps with respect to the range and level of services available, including access to aids and equipment, will continue (see Appendix 2).

The Bill states:

- *That when providers claim higher care funding for a recipient of a home care package, the provider must demonstrate, within a stipulated time frame, a corresponding increase in skill mix and nursing care hours provided to the recipient*
- *That home care providers be required to undergo the same level of scrutiny as residential services regarding the provision of quality care, professional nursing standards, sustainable workloads, adequate staffing and appropriate skill mix.*

People living with MND often have complex and progressing needs that require adequate staffing and hours of care. The provision of quality care is imperative to support quality of life for the person with MND and their carer. Providers will need to have access to MND specific training and information to support the development of skills to enable them to provide quality care. Aged Care providers should draw on the expertise and commitment of organisations such as MND associations with respect to specialist information and education for providers and expert individualised and personalised support and services.

### ***Assessment***

Currently only residential care has specified levels of care requiring an assessment process. With the introduction of levels of home care all aged care recipients will need assessment of care needs and eligibility for the different levels of care.

Older people with rapidly progressive neurological and neuromuscular disorders should be able to access qualified, experienced assessors to assist them with their individual service plans. The complex nature of these diseases and the speed of progression will require a very different assessment process to a person who has needs related to ageing alone.

There should also be clear assessment and referral processes and protocols for the interface between aged care, health and disability services to facilitate timely, coordinated inter/multidisciplinary care and to reduce duplication and crisis management.

### ***Behaviour Supplement***

An additional behaviour supplement will be paid to providers caring for people with dementia providing the implementation of a model of care that, at its core, has dementia care being provided by appropriately skilled registered nurses and enrolled nurses working under registered nurse supervision.

A similar supplement should be considered for providers caring for people who have other progressive neurological diseases such as MND and who have complex and rapidly progressing needs.

### ***Conclusion***

The Minister states '*This Bill is compatible with human rights because it promotes the human rights to the highest attainable standard of physical and mental health and achieves a balance in relation to the human rights of equity and non-discrimination*'.

If the 50% of people diagnosed with MND when aged over 64 are unable to access care and support to meet their assessed needs, whilst those diagnosed when younger and have access to DisabilityCare and a full range of supports, then the Bill cannot achieve a balance in relation to the human rights of equity and non-discrimination.

MND Australia has six key recommendations to ensure that **all** people living with MND are supported to live better for longer.

**Recommendation 1:** All people diagnosed with MND must be eligible for and have access to early intervention services, across disease transition changes, to reduce economic and social burden and improve quality of life.

**Recommendation 2:** People who acquire a rapidly progressive disability creating changing and escalating needs when over the pension age must have equal access to care and support to address needs related to their disability as well as their age.

**Recommendation 3:** Home care for older people diagnosed with MND must encompass access to initial low level assistance with increased funding and services to meet assessed need available as the disability level escalates and progresses.

**Recommendation 4:** Aged Care providers should draw on the expertise and commitment of organisations such as MND associations with respect to specialist information and education for providers and expert individualised and personalised support and services.

**Recommendation 5:** Older people with rapidly progressive neurological and neuromuscular disorders should be able to access qualified, experienced assessors to assist them with their individual service plans.

**Recommendation 6:** Clear assessment and referral processes and protocols for the interface between DisabilityCare, health and the aged care systems must be developed, supported and implemented to facilitate timely, coordinated inter/multidisciplinary care and to reduce duplication and crisis management.

## Appendix 1

# Aged Care and people diagnosed with MND

## POSITION STATEMENT

### Background:

The needs of people living with rapidly progressive neurological diseases, such as motor neurone disease (MND), cannot be met by existing or traditional aged care services or facilities.

The introduction of a national disability insurance scheme (NDIS) has the potential to transform the lives of people living with MND who are diagnosed when aged 64 or younger. However it has been proposed that the needs of those people who acquire a disability after pension age would be best met by the aged care system. The crucial issue is then how do people acquiring a disability over age 64 (pension age) access services based on need.

Responding to this concern requires considering not just the design of the NDIS but also the reforms proposed for the aged care system under the Living Better for Longer aged care reform package. The aged care system is designed to address needs related to ageing not disability and there are currently major gaps with respect to choice and the range, level, and hours of services available.

MND is not a disease related to ageing but approximately 50% of people are diagnosed when they are over the pension age. People over pension age diagnosed with MND need the same services and supports that a person under pension age requires. Both need services from the disability and aged care systems to address changing and complex needs related to their disability and ageing to ensure their quality of life.

The Living Better, Living Longer reforms to aged care specify that more packages of care will be available and that four levels of home care packages will be established to provide a continuum of home care options covering basic home care support through to complex home care. However, the focus remains on addressing needs related to ageing. Access to disability services and hours of support available will therefore remain limited and the gap between what is available under NDIS and Aged Care will widen.

A person diagnosed with MND aged 66 must be able to access the same range and level of service to meet their assessed needs as those diagnosed aged 64 no matter which system funds or delivers the services. A rapid response to service provision from a range of services based on the needs of the individual not their age is imperative.

To close the gap, and to prevent the gap widening following the introduction of NDIS, specialist disability services need to be available to support older people with complex needs created by disability. These services must include aids and equipment, flexible respite options, case management, therapy and hours of support to remain at home via packages of care in excess of the current 12 - 15 hours per week.

The exclusion of people who acquire a disability when over the pension age from the NDIS will lead to discrimination against older Australians unless provisions are made to ensure equitable access to needs based care.

People with rapidly progressive neurological disease living in residential aged care have changing and complex care needs which very often cannot be met by aged care staff. In some cases people living with MND have been refused access to residential aged care due to the high level of care required.

Needs based support hinges on careful and appropriate assessment. Currently, Aged Care Assessment Teams are the gateway to aged care services but extensive anecdotal evidence indicates that they frequently refuse to assess older people with complex needs or, when they do, that they have difficulty in determining what level and types of support the individual needs. Under current aged care assessment processes consideration of whether a person would benefit from a specialist

disability service such as case management, flexible respite, aids and equipment, specialised therapy and communication aids rarely occurs.

**MND Australia believes:**

- People diagnosed with rapidly progressive neurological disease must have access to early intervention, ongoing expert assessment and a range of services to meet their assessed needs irrespective of where they live, their age or which sector funds the service
- MND associations will play a vital role within the NDIS and aged care sectors to deliver specialist MND information, training and education and expert individualised and personalised support and services

**MND Australia calls for:**

- 1. Improvements to the ageing-disability interface to ensure access to needs based services for people who acquire a disability when over the pension age for example:**
  - a. Aged Care make provisions to provide the full range of services
    - i. Introduce a rapidly progressive neurological disease supplement similar to the dementia/behaviour/veterans supplement to supplement both home care and residential care and to meet complex and changing needs
    - ii. Extend the provision of Aids and Equipment to ensure that older people diagnosed with MND and needing aids and equipment to maintain their independence and community access can get that equipment
  - b. If Aged Care is unable to meet the disability needs of older people, the NDIS should develop a safety net model that provides for top up funding through the NDIS to address needs not met by Aged Care
  - c. Special eligibility for the NDIS, on application and argument to the NDIA, in the event that Aged Care cannot provide the appropriate levels of care, support and services and the NDIS is not able to top up Aged Care
  - d. Clear assessment processes and protocols for the interface between the NDIS and the aged care system
- 2. Improvements to the health/allied health/palliative and aged care interface:**
  - a. Good interfaces with allied sectors, particularly health and palliative care, must be developed to ensure a coordinated inter and multidisciplinary approach to care
- 3. Timely availability of equipment and assistive technology:**
  - a. Aged Care sector to ensure equitable and cost effective access to equipment and assistive technology for people at home and in residential aged care to support their independence and community access
- 4. The development of National Guidelines for the management of people with rapidly progressive neurological conditions:**
  - a. to assist with establishing and maintaining interfaces between different sectors, to minimise duplication and to ensure timely and responsive access to reasonable and necessary supports to meet identified needs

*On behalf of the MND Australia board*

**Signed: Ralph Warren (President)**

**Dated: 7 February 2013**

## Appendix 2

### The story of two brothers

Two brothers were diagnosed with MND.

One brother was unlucky/lucky. Unlucky to have been diagnosed with MND and acquire a disability, but lucky that at age 64, he was entitled to support under the NDIS, the no fault scheme that funded the needs created by the disability acquired because of the disease. He had funds to purchase fast track rehabilitation to overcome some of his disabilities, and slow track to ensure sustained outcomes. He was able to purchase the wheelchair he needed, and for that to be replaced when he needed an electric wheelchair. The maintenance was provided and replacements when they wore out. He received funding to purchase support services to enable him to remain at home with his wife, to purchase respite care when she needed a break, and for modifications to his home to ensure he could remain there, living with his wife, for as long as he wanted. He was unlucky/lucky.

The other brother was unlucky/unlucky. Unlucky to have been diagnosed with MND and acquire a disability and unlucky that at age 66 he was not entitled to the NDIS. He had the same needs as his brother but he couldn't purchase aids and equipment he needed because Aged Care does not provide a comprehensive equipment program. He only received public health support for his rehabilitation - not enough, for not long enough. His only service options were aged care. He could access up to 11 hours of support per week to remain at home, but he needed more. His only option was a nursing home.

The story of two brothers highlights the inequity that arises when age is used to place boundaries around programs, or manage budgetary impact. Is this what we want for people over the age of 65 who acquire a disability? To only have very limited access to support to remain at home, or a nursing home bed? And not enough support to meet their needs?

We must retain our focus on needs to determine eligibility, not on age