RESPONSE TO HOME CARE PACKAGES PROGRAM GUIDELINES CONSULTATION DRAFT

Submitted on:

17 May 2013

By:

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On behalf of:

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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.

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 and a consequent need for a wide range of progressively changing supports.

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 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.

There are currently 1500 people living with MND and around 50% of these people were diagnosed when 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.

Access to disability services and hours of support to meet a person's needs will, therefore, remain limited and major gaps with respect to the range and level of services available, including access to respite and aids and equipment will continue.

Response

MND Australia congratulates the Australian Government on the increase to the number of aged care packages available under the Living Better Living Longer reforms. The inclusion of some disability supports and types of assistive technology in the new Home Care Packages Program is a welcome improvement to current arrangements.

It is also pleasing that from July 2013, all new packages are required to be delivered on a 'consumer directed care' basis, with all packages operating on this basis from 2015. This will allow people to make choices about the types of care they access and the delivery of those services, including who will deliver the services and when.

MND Australia remains concerned however that the highest level Home Care Package will not be sufficient to meet the needs of some people diagnosed with MND when aged over 64.

Home Care Packages

From 1 July 2013, four levels of Home Care Packages will be available to provide a continuum of home care options. Some people diagnosed with MND when over the pension age will have their needs met by one of the four packages.

The guidelines state, however, that the Home Care Packages Program is targeted at frail older people. There are currently major gaps with respect to choice and the range, level, and hours of services available within the aged care system and we are concerned that the needs of some people with MND will not be met by a home care package alone (see Appendix 1).

MND Australia seeks clarification within the guidelines regarding what will happen to people whose needs cannot be met by a Home Care Package.

In addition access to the program continues to be based on eligibility and the availability of funding. This is in stark contrast to the NDIS which will be an entitlement system based on the reasonable and necessary support needs of a person with a disability. This difference will lead to further inequity for people diagnosed with conditions such as MND when aged 65 and over compared to a person diagnosed aged 64 (see Appendix 2).

Services

MND Australia welcomes the introduction of greater flexibility in the range of care and services across all packages including access to nursing, allied health, respite and a wider range of aids and equipment including assistive technology to assist with communication. The recognition that some people may need to have a specific person as a case manager is also welcomed.

It is unlikely, however, that the funding available under each package will be sufficient to access the full range of supports and services for a person with progressing and complex disability to enable them to meet their goals and care needs. For example if a person needs to purchase an electric tilt in space wheelchair this could use up all the funding provided with no funding left for the provision of case management and personal and respite care.

Currently an EACH package translates to approximately 18 hours of funded support per week. This is almost half the hours available to people aged under 65 who are eligible for current disability packages of up to 34 hours per week. Under the NDIS the gap between the funded services available for people aged over 64 and those under the pension age will widen even further.

The guidelines state that a person may choose to 'top up' their package by purchasing an extension of care and services through their approved provider. For a person with a progressing disability such as MND this 'top up' could run to many thousands of dollars.

MND is not a disease of ageing but approximately 50% of people will be diagnosed when over the age of 64. Many older people living with MND will have their needs met by aged care services and the support of the MND association and their friends and family. Some people, however, will have a more rapid progression with consequent high level of complex needs. These people will need the same range of services as those people aged under 65 (see Appendix 2). Services required will include case management, respite, rehabilitation, allied health, personal care and timely access to a wide range of aids and equipment, including communication aids and respiratory support to maintain quality of life and social inclusion for the person with MND and their family carer.

Respite is listed as one of the services that can be provided at Home Care levels 1 to 4. **MND Australia seeks clarification within the guidelines as to what types of respite can be purchased and whether this relates solely to respite in a residential aged care facility or includes access to in-home respite.**

Respite for people living with MND and their family needs to be flexible and responsive. Carer burnout is a reality and regular, planned and timely in home respite, as well as in some circumstances respite in a residential aged care facility, is crucial in maintaining the carers health and well-being.

Assessment

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, palliative care and health and disability services to facilitate timely, coordinated inter/multidisciplinary care and to reduce duplication and crisis management.

Interface with other programs

Home Support Program

The new Commonwealth Home Support Program to be introduced from 1 July 2015 will incorporate the existing HACC Program and the National Respite for Carers Program (NRCP). Both these programs are integral to meeting the care and support needs of people living with MND. The guidelines state that as much as possible the consumers' care needs should be addressed through their Home Care Package but that additional HACC services may be considered in an emergency or for the provision of home modifications and/ or aids and equipment.

This access to additional HACC services and support will be vital for people living with MND many of whom will find that their Home Care Package funds will only just address their assessed priority needs. However, as priority for NRCP services will be given to carers who are not receiving carer support services, it is likely that people receiving a Home Care Package will find it difficult to access additional respite services.

Disability Programs

The guidelines state that a person cannot be a participant of DisabilityCare Australia or receive disability services at the same time as they receive aged care services (including a Home Care Package). There is, however, no minimum age requirement for eligibility purposes which will mean that younger people with a disability who also have needs related to ageing will be able to access a Home Care Package.

MND Australia, and other members of the Neurological Alliance Australia, recently congratulated the Australian Government on the amendments to the NDIS legislation to include a provision that *'people who need early intervention therapies and supports, including for degenerative conditions, and who are not better supported by another systems such as the health care system, can access the NDIS.*' In addition the amendments confirmed that the Australian Government would be fully responsible for funding services for people who chose to continue receiving DisabilityCare once they turn 65. Better coordination between the NDIS and the aged-care system to ensure a cohesive system to give people with disability, older people, their families and carers the support they need was also confirmed within the amendments (http://www.mndaust.asn.au/neurological-alliance-australia/).

Better coordination will not eventuate if older people who acquire a disability are only eligible to access a Home Care Package and are precluded from receiving disability services. Access to disability services and hours of support to meet a person's needs will remain limited. Consequently major gaps with respect to the range and level of services available, including access to case management, respite, allied health, rehabilitation and aids and equipment, will continue (see Appendix 2).

If the highest level of the Home Care Packages Program is unable to meet the disability needs of older people living with rapidly progressive and complex diseases such as MND then top up funding through the NDIS should be available to address needs not met by Aged Care. This 'safety net' model of care would support the commitment already made that the NDIS or DisabilityCare Australia will **complement** aged care services. This model, if funded by the Australian Government, would be a similar funding model to that proposed for people who chose to continue to receive DisabilityCare when they turn 65.

Aids and Equipment

The guidelines state that the Home Care Packages Program is not intended to be an aids and equipment scheme. The program will provide some aids and equipment to a consumer where this is identified in their care plan (within the limit of the package funding) but it is expected that consumers will continue to be able to access the state based specialised aids and equipment schemes.

MND associations have developed equipment loan services in response to the long waiting lists associated with the state and territory government operated specialised aids and equipment schemes. People with MND require timely access to a wide range of specialised aids and equipment including electric wheelchairs, communication aids and non-invasive ventilation masks and machinery. Need may only be for a relatively short period of time but flexible and timely access has a profound impact on quality of life and in supporting carers to maintain their caring role at home.

It is imperative that older people with disability needs have the same access to aids and equipment as younger people receiving DisabilityCare Australia funded supports.

Palliative Care

MND Australia promotes access to palliative care services to address the needs of people living with MND as early as possible following diagnosis thus enabling optimal quality of life, and dignity in living and dying.

MND Australia congratulates the Australian Government for including access to specialist palliative care and advance care planning expertise for aged care providers and GPs caring for recipients of aged care services as part of the aged care reform package. The development of an online education and training package to assist health workers, including general practitioners, nurses and care workers to implement the principles of the Guidelines for a Palliative Approach for Aged Care in the Community Setting is welcomed.

Primary generalist and home care providers providing services to people with MND, especially those in rural and remote areas, will also need MND specific information available in a timely manner. MND Australia offers a range of printed information for providers and information sessions are delivered by MND associations in most states. MND Australia has enhanced this approach by developing the MNDcare website (funded by the Australian Government) to assist all providers to improve their confidence and competence in providing timely and quality end-of-life care to people with MND.

Supplements

New dementia and Veterans supplements (for veterans with an accepted mental health condition) will apply to all package levels. An extra 10% funding supplement will be paid to an approved provider in recognition of the additional costs associated with certain care and service requirements for the consumer.

People with progressive neurological diseases, as well as dementia, require additional care and service provision. A similar supplement should be considered for providers caring for people who have other neurological diseases such as MND and who have variable, progressing and complex care and support needs.

Conclusion

MND Australia is hopeful that many people diagnosed with MND when over the pension age will have their needs met by one of the new Home Care Packages. MND Australia seeks clarification; however, regarding what will happen to those people whose needs cannot be met by a Home Care Package.

The fact that the aged care system will remain an eligibility based system with access to packages limited by whether a person is deemed eligible and funding available at that time is a very real concern. Under this eligibility system waiting lists will continue to be a major issue for people diagnosed with progressive conditions such as MND.

We were encouraged by the statement in the NDIS legislation that DisabilityCare Australia will complement aged care services. However, there is little evidence to support this statement in the Home Care Packages Program Guidelines.

Of particular concern is that the guidelines state that a person cannot be a participant of DisabilityCare Australia or receive disability services at the same time as they receive aged care services (including a Home Care Package). Access to respite, aids and equipment, and allied health services to meet assessed need will therefore remain limited for people diagnosed with MND and other progressive neurological conditions.

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

Recommendation 1:
People who acquire a rapidly progressive disability creating changing and escalating needs when over the pension age must be entitled to equal access to care and support to address needs related to their disability as well as their age.

Recommendation 2:
If a level 4 Home Care Package is unable to meet the disability needs of older people living with rapidly progressive conditions then 'top up' funding should be available to address those needs. This 'safety net' model of care would support the commitment already made that DisabilityCare Australia will **complement** aged care services.

Recommendation 3:
The Home Care Package Program must encompass timely access to initial low level assistance with increased funding and services to meet assessed need, including flexible in-home respite, available in a timely manner 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 the NDIS, health, palliative care 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.

On behalf of MND Australia and the state MND Associations I thank the Australian Government Department of Health and Ageing for the opportunity to comment on the draft guidelines. Please do not hesitate to contact me if you require any further information. I and/or the state MND association CEO's would be happy to meet with department staff should they wish to discuss our response further.

Yours faithfully,

Carol Birks

National Executive Director

MND Australia

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