Productivity Commission

Caring for Older Australians

Submitted via email to: agedcare@pc.gov.au

On behalf of:
MND Australia
Gladesville, NSW 1675

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TABLE OF CONTENTS

Appendix A

1. Executive Summary

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 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

2. Introduction

MND Associations in Australia were formed during the 1980s to meet the complex and changing support, equipment and information needs of people living with motor neurone disease (MND), their carers and their families. MND Australia was established in 1991 as a national peak body for motor neurone disease (MND).

MND Australia and its six State Association members work together to advance, promote and influence local, state and national efforts to achieve the vision of a World Free from MND.

Motor neurone disease (MND) is the name given to a group of rapidly progressive degenerative neurological diseases that cause increasing and complex levels of disability leading to death, usually within three years of diagnosis. The most common form of MND is amyotrophic lateral sclerosis (ALS). Currently around 1400 Australians are affected by MND and thousands more; family, friends and carers live daily with its effects. Each day **at least** one Australian dies of this cruel disease and a new person is diagnosed. Although MND was first described nearly 150 years ago there is still no known cause (in most cases), no known cure and no effective treatments. Average life expectancy from diagnosis is about 2 years (page 3, Sach 2003). Average age of onset is 59 years; however, the age range of onset is 18 to 90 years.

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 include assistance with: feeding, communication, breathing, movement, transferring, toileting and all daily activities. 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; and
3. a challenge to health professionals, disability service, community care, and aged care providers involved in meeting the variable and complex care needs, particularly in regional, rural and remote areas of Australia.

Rapid progression and the complex care needs in MND are either not met or poorly met by existing statutory services. Currently services are provided based on age, the type of disease or disability, and the availability of funding and services in a particular region. A whole of government approach to health, disability and aged Care services is needed to promote coordinated and seamless planning options and services for all people and their carers no matter how old they are. Services must be provided based on the needs and wishes of the individual and their family (see Appendix 1).

The rapid progression of MND necessitates a rapid response from service providers who understand the impacts of this disease. The rapid and appropriate responses must be anticipated and this means a spectrum of service with the flexibility to meet the rapidly changing needs should be available. Access to expert case management is vital especially for people with MND and their carers who are older. Navigating the complex health, disability and aged care service system is an extra burden for older carers who need assistance to access the myriad services that they require to assist them to continue to provide home based care, if that is what they wish.

Some people living with MND do need, or prefer to access, residential care in an aged care facility but that is usually a very poor option. The complex physical and emotional needs of people with MND are often poorly managed in these facilities. Aged care staff do not have the resources available to provide the intensity of 24 hour care nor the specialised knowledge to support a person with MND.

There are a number of state-based initiatives that provide models incorporating case management, flexible respite, timely access to packages of care and ‘top-up’ funding to allow a rapid response and additional levels of support and service provision. These successful models need to be supported nationally with recurrent funding available to ensure their sustainability.

3. Submission:

The average age of onset for MND is 59 years and average life expectancy is two to three years. The age range of onset is 18 to 90 years. Although a significant number of people living with MND are aged over 65 it should be recognised that MND is not a disease related to the normal process of ageing.

The current system distinguishes between services for people living with MND aged under 65 provided by disability services and services for people over 65 provided by aged care services. This system has led to a fragmented and inequitable approach to care. MND Australia argues that access to planning options and services for all people, particularly those diagnosed with rapidly progressive diseases such as MND, must be based on need and not age. Planning options and services must also be equitable which means that people over 65 must have access to the same disability services as younger people as well as access to services to address their needs related to ageing. A seamless approach to planning and service provision is vital to ensure quality of life for all people with MND and their carer no matter how old they are.

The rapid progression of MND necessitates a rapid response by service providers no matter the age of a person. At present most people living with MND have to wait for access to services. For many they are deemed eligible for a service but are placed on a waiting list often for long periods of time. Case management is not always available and packages of care often scarce. For many people the wait for aids and equipment and home modifications may be many months or be very costly. In some states people over 65 are unable to access the disability services they need and people under 65 are unable to access residential care if needed. One critical service that is often scarce is flexible respite options for both the patient and carer.

Most people with MND prefer to remain at home throughout the course of their disease providing they can access services to meet their needs. Some do need, or prefer to access, residential care in an aged care facility but that is usually a very poor option for people with MND. The complex physical needs of people with MND are often poorly managed in these facilities. MND Associations receive constant feedback that staff / time ratios are inadequate to meet the needs of their residents with MND. Staff lack expertise in managing complex and high dependency needs. Difficulties in communication can exacerbate the frustrations experienced by both the MND resident and the staff. The majority of residents of aged care facilities have dementia. In this situation, feelings of vulnerability and frustration can be extreme for the intellectually capable but physically dependent resident with MND who struggles to communicate basic needs. Carers fear that their loved one will not be attended to adequately. Staff in aged care facilities consistently report their fear and lack of knowledge in how to care for a person with MND.

Quality of life for people with a disability and their carers cannot be ensured as long as the following issues related to the current situation continue:

1. service provision based on age rather than need
2. blame and cost shifting between state and federal providers and funding bodies
3. lack of clear care planning, coordinated care and help to navigate the complex service system
4. waiting lists for assessment, aids and equipment, home modifications, basic services and packages of care, and
5. gaps in the system.

People with MND and their carers need access to the following planning options and services to ensure their quality of life:

i. Services based on needs related to their disability **and** their age
ii. A disability and aged care workforce that understands MND
iii. Effective case management and care coordination
iv. Packages of care to meet their needs
v. Top up funding to assist disability and aged care services to provide responsive and seamless needs based care
vi. Flexible respite options
vii. Timely access to aids and equipment and home modifications
viii. Services provided by state MND associations

4. Conclusion

MND Australia welcomes current and recent inquiries related to of the health, aged and disability care systems and anticipates that forthcoming reforms will enhance access to essential services for people living with MND and their carers. A whole of government approach for the provision of health, disability and aged care services is essential in achieving individualised needs based care.

It is imperative that any new systems introduced recognise that progressive neurological diseases such as MND are not diseases related to normal ageing. Any new systems introduced must be a needs-based, not aged-based, model of service delivery and service delivery should strive to meet each person's needs with the consideration of individual symptoms, perceived needs and rate of disease progression. It is also important that the individual needs of carers and families receive a greater focus in the health, aged and disability reform processes.

Services, no matter how they are funded, must be provided based on the needs and wishes of the individual and their family. The under/over age 65 criteria must end and a planned, seamless, coordinated approach to health, disability and aged care service provision must be implemented in order to achieve quality and length of life for all people with MND no matter how old they are.

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

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www.mndaust.asn.au

Productivity Commission Inquiry - Caring for Older Australians

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5. References

Sach, J., (2003) *Future Service Directions Review*. MND Victoria

6. MND Australia Members - the State MND Associations:

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APPENDIX A

THE INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS STATEMENT OF GOOD PRACTICE FOR THE MANAGEMENT OF ALS/ MND

Support and care management for people living with ALS/MND is underpinned by five basic principles:

1. Management of the disease determined by the needs and wishes of the person living with ALS/MND, treating the person with ALS/MND with care, respect and dignity
2. Timely response to identified needs
3. Access to a coordinated and integrated care plan
4. Regular monitoring and review of the person's condition, and appropriateness of the care plan
5. Information about the person's medical condition held in confidence

The International Alliance of ALS/MND Associations recommends the following good practice that will result in effective management of the diagnosis and care of people living with ALS/MND.

Before Diagnosis…
Early recognition of symptoms and access to a physician competent to diagnose complex neurological diseases

At Diagnosis…
Diagnosis given by a physician who is informed about ALS/MND, in a sensitive way appropriate to the person with ALS/MND and, in an appropriate setting with family and/or friend(s) present

Information provided in verbal and written forms about the disease, including its impact, sources of help and support, and referral to the ALS/MND Association as appropriate to the needs of the individual

Information sent to the patient's principal health practitioner about the disease, management implications, and the ALS/MND Association

The opportunity to return to the diagnosing physician for further information, care and follow up
After Diagnosis…
Access to:

- information and support services
- planning and coordination of support and care

These include:

- advice about personal care and equipment, clinical interventions, treatments and therapies, palliative care
- support for caregivers and families eg: respite care, bereavement support
- health and financial benefits
- research and clinical trials
- access to support from the ALS/MND Association

In summary, it is essential that people living with ALS/MND are enabled to make informed decisions about living with ALS/MND so as to achieve quality of life, and dignity in living and dying. Adopting a proactive approach to disease management and respecting the needs and wishes of the individual and their caregivers is imperative.
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