

**SENATE COMMUNITY AFFAIRS REFERENCES
COMMITTEE**

**INQUIRY INTO PLANNING OPTIONS AND
SERVICES FOR PEOPLE
AGEING WITH A DISABILITY**

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1. Executive Summary

People living with MND and their carers face a spiraling process of loss with consequent severe impact on physical, emotional, psychosocial and financial well-being. These impacts are compounded as the person with MND and their carer age.

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. Services are not provided based on the needs of the individual and their family. A whole of government approach to Disability and Aged Care services is needed to promote coordinated and seamless planning options and services for people and their carers ageing with MND. Access to assessment and services must be timely and appropriate.

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 ageing. Navigating the complex disability and aged care service system is an extra burden for ageing 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.

There are a number of state-based initiatives that provide models incorporating case management, flexible respite and 'top-up' funding to allow a rapid response and additional levels of support and service provision. These successful models, outlined in section 4, need to be supported nationally with recurrent funding available to ensure their sustainability. A national whole of government approach would promote the translation of successful state based pilot projects and models of care to support people with a disability and their carers as they age.

People living with MND and their carers who are ageing need

- effective case management
- mentoring and support for carers



- access to services to enable them to achieve short and long term aspirations
- effective management of transition:
 - i. from disability to aged care
 - ii. progression in disability
 - iii. movement between providers
- HACC services that are consistent across and within states
- services based on unmet needs, not on age.

Health care service providers working in partnership with MND Associations can provide evidence for models of care that could be further developed and extended nationally to better meet the needs of people with MND and their carers as they age.

2. Introduction

MND Associations in Australia were formed during the 1980s to meet the varying and complex support, equipment and information needs of people living with MND, their carers and their families. MND Australia was established in 1991 as a national peak body for motor neurone disease (MND). In 2010 the MND Australia network comprises of six MND Associations, representing all states and territories, and the MND Research Institute of Australia (MNDRIA).

MND Australia members work together to advance, promote and influence local 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 five 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 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.

3. Access to planning options and services for people with MND to ensure their quality of life as they and their carers age

The average age of onset for MND is 59 years and average life expectancy is two to three years. A number of people with MND are therefore over 65 or older when diagnosed. In addition a significant number of people with MND are diagnosed whilst they and their carers are in their 60s. They will experience additional impacts on their quality of life related to ageing during the course of their disease.

The current system distinguishes between services for people living with MND aged under 65 provided by disability services and services for people over 65 are provided by aged care services. This system has led to a fragmented and inequitable approach to care. The recent Australian Government proposal to take full responsibility for aged care, including home and community care (HACC) provided to older Australians has the potential to further widen the gap.

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 to ensure their quality of life. Planning options and services must also be equitable which means that people over 65 or over 70 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 people with MND and their carer as they age.

The rapid progression of MND results in increasing support needs and reliance on a range of services and aids and equipment to maintain quality of life and social inclusion. The rapid progression also means that people have little opportunity to plan ahead or adjust to increasing disability. A rapid response by service providers is therefore imperative 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 equipment 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 is respite for both the patient and carer.

The concept of a National Disability Insurance Scheme (NDIS) is receiving increasing support from a range of disability advocacy groups and the wider community. Current funding arrangements (that involve various local, state and federal funding streams) are inadequate. The proposed NDIS would provide a more sustainable funding structure for the government and the community as demand increases over time. Such a scheme would ensure adequate funding for essential care, support, case management, respite, therapy, aids, equipment and training so that people born with a disability or who acquire a disability through accident, injury or a medical condition, such as MND, would all be eligible for assistance based on need. This scheme would also need to take into account planning options and services for people with a disability as they age and be available to older people with a disability.

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.

People with MND can deteriorate rapidly from being active, independent individuals to a level of dependence that they or their carer could never have anticipated. The speed of this process severely impairs the capacity to plan ahead and to link into services in a timely manner. There is often a failure to come to terms with and face the personal level of need. Accessing adequate levels of support to maintain home based care, if that is the preferred option, can be challenging. The increasing burden on carers, both physically and emotionally, is particularly great for those carers who are ageing and who may have their own health issues.

“The rapid nature of the debilitating effects of motor neurone disease means that the individual will need an increasing amount of personal assistance as the disease progresses. This task usually falls to a partner, close relative or friend.”
(Mockford et al, 2006).

MND carers are often inspirational in the levels of care they are able to sustain during their loved one’s illness. They face a precipitous “learning curve” in undertaking and implementing new strategies to manage disability. Caring tasks are likely to include:

- transferring and repositioning the person with MND
 - This becomes more complex as the person with MND becomes increasingly disabled

- modifying food and fluids, feeding small, regular meals and undertaking alternative methods of feeding as swallowing deteriorates
- managing an increasing range of medical equipment to sustain home based care and independence. This may include technology to support breathing
- learning and applying strategies to communicate including use of new technology as intelligibility of speech deteriorates
- striving to plan ahead to manage a situation of constant change and increasing need
- caring around the clock during the later stages of MND
- providing emotional support to the person with MND and other family members and friends as they confront multiple levels of loss
- confronting their own grief and loss

The role and contribution of MND carers is immense and can have a traumatic impact on carers as they struggle to manage escalating levels of need.

The months of Deb's illness were marked by a game of chasing our tails. I was about to learn something that you know only too well: being a carer is very hard. Physically caring for Deb got hard very quickly. We had to learn new skills of lifting, showering, dressing and feeding. We learned on the run, for virtually every day presented a new challenge. (Armstrong. D, The Accidental Carer)

The current capacity of statutory services to provide even basic support for this level of need is minimal. MND carers therefore carry a tremendous burden of care. The impact that caring has on the social, emotional, financial and physical well-being of carers in general has been well established. The extreme 'burden of care' required in supporting a loved one with MND is likely to result in particularly high levels of anxiety, uncertainty, stress, fear and fatigue for carers.

The health of carers, particularly those who are ageing, will suffer due to long hours of caring and the physical strain involved. The impact of managing in this situation has long term emotional, psychosocial and financial implications for the carer and family. There are documented examples of carer illness, for example Mockford et al.



state “Carers may become ill themselves unless adequate support is given to them throughout the course of the disease.” (Mockford et al., 2006)

Goldstein et al. (1998) reported that the satisfaction of MND carers with formal services and the number of social groups to which carers belonged correlated with carers’ self predicted ability to cope in the future.

Quality of life for people with a disability and their carers who are ageing 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, basic services and packages of care, and
5. gaps in the system.

4. Inadequacies in the choice and funding of planning options currently available to people ageing with MND and their carers

People with MND and their carers need access to the following planning options and services as they age 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 needs based care
- vi. Flexible respite
- vii. Timely access to aids and equipment and home modifications
- viii. Services provided by state MND associations



Currently in Australia there are many inadequacies related to these services. Access to them varies in each state and even between regions in the same state. This may be due to funding mechanisms, variations in state government funding and priorities related to disability and aged care services and eligibility criteria.

i. **Service provision and funding mechanisms based on age rather than need.**

A whole of government approach for the provision of community and aged care services is essential to provide equity of access to service provision for people with MND and their carers throughout Australia.

Reform of the aged and disability care systems would enhance access to essential services for people with MND and their carers, but the system must be a needs-based, not aged-based, model of service delivery. Service delivery should strive to meet each person's needs with the consideration of individual symptoms, perceived needs and rate of disease progression. Care required by individual MND clients and carers is not a fixed quantity; it differs for each person over time. It is important that the individual needs of carers and families receive a greater focus in the aged and disability reform processes.

A national approach to choice and funding of options available for MND care management is important to avoid confusion, inequity of access and sometimes duplication of services.

ii. **An inadequately resourced and informed disability and aged care service workforce**

Ready access to quality services that strive to deliver care according to individual needs and preferences cannot be achieved without developing and sustaining an appropriately remunerated and qualified workforce with access to professional development in specialised areas.

Workforce shortages are a key barrier to the provision of client and family-centred care. Shortages in the number of appropriately qualified disability and aged care providers are associated with limited access to vital disability and aged care services, particularly in rural and remote Australia.



More emphasis should be given to MND specific information and education for care providers involved in the care of people with MND and their carers. MND Australia has recognised this need and is currently developing easily accessible, online MND information for providers specifically for those in rural and remote areas and those care providers that may not have encountered MND before.

iii. **Inadequate access to effective case management services**

The provision of timely and responsive community services is vital to the physical emotional and financial well-being of people with MND and their carers. The Home and Community Care Program (HACC) provides services for older people and people with disability and their carers. This program is jointly funded by the Australian government and state and territory governments.

Historically, there have been difficulties for people with MND and their carers accessing community services in a timely manner. The assessment process to determine eligibility for HACC services, including wait-time, fails to accommodate the situation of rapidly changing need. The needs of people living with MND can change daily, so wait lists are not appropriate as a rapid response.

Example: Several hours and 10 phone calls later a carer was told that the agency had used all its in-home respite funding for that quarter and was not able to offer any options other than the phone number of a private, high cost agency.

MND carers are often too busy with 'hands-on' care to be able to investigate and source the services they need. A seamless case management model for community and aged care service provision is essential to help carers access and obtain vital community support services. Where capacity allows state based MND Associations contribute and facilitate the case management process. The Associations move in and out of lives of people with MND, while operating continuously in the background to ensure that the emerging needs of people with the disease, their carers and service providers are adequately identified assessed and addressed.

Effective and timely case management services to support the carer in providing home based care and to assist with managing transitions as the disease progresses and with transitions to and from different funded services need to be available throughout Australia to all people living with MND based on need not their age.

iv. Inadequate access to appropriate and timely packages of care

Timely access to a package of care is imperative to support home based care for people with MND. At present the type and number of packages available vary considerably in each state and region. This leads to confusion, and consequently people with high needs are more likely to fall through the gaps of service provision.

The wait for an assessment to confirm eligibility can be weeks or even months. Then eligibility does not necessarily equate to access and there is often a long wait until a package becomes available. This is totally inadequate for people with MND. Their disease will continue to progress relentlessly, which means that a crisis often occurs necessitating a hospital or residential aged care admission. Frequently the person dies before the package becomes available.

Example: A person living with MND based in a capital city aged in his 40's was assessed as eligible for an Extended Aged Care in the Home (EACH) package. However there were no packages available and his wife and teenage daughter were forced to continue to provide all his personal care until a package became available.

The hours and services available as a package of care funded by disability services are usually different to those available through aged care funded packages and this increases confusion and inequities.

v. Limited access to 'top-up' funding to address rapidly changing/escalating need

The rate of progression of MND results in failure to access existing funding packages that require a lengthy assessment and wait-listing. Many people have no option but to accept a limited number of hours of help that will not address their needs.



Dedicated funding available nationally to address rapidly changing needs and facilitate timely access to services must be considered. Existing state based models for targeted funding include dedicated funding packages for rapidly progressive diseases or 'top-up' funding to address timely access to existing services and high level need. Life expectancy in MND limits the length of time that individuals are likely to receive targeted funding, therefore funding packages have the potential to assist a number of individual clients within a relatively short time frame.

Partnership initiatives in Victoria, NSW and Western Australia provide models incorporating case management and 'top-up' funding to allow rapid response and additional levels of service provision:

- The Victorian State Government has provided funding to implement some of the recommendations of The Motor Neurone Disease Pathway Project report to develop the key worker model within palliative care services and to provide top-up funding for palliative care services supporting people living with MND.
- The Western Australian State Government Disability Services Commission has directed specific funding for progressive neurological diseases to provide equipment and extra services based on needs (e.g. the Neurodegenerative Conditions Coordinated Care Program - NCCCCP).
- Community Options NSW (COPS) has received funding from Human Services Ageing, Disability and Home Care (ADHC) to pilot a project providing extra services to people with MND when their needs become more complex. COPS works in partnership with MND NSW to identify people with MND who need extra services and to ensure a timely and coordinated response.

The number of initiatives involving 'top up' funding demonstrates the high level of need for this type of service. These initiatives need to be supported with recurrent funding nationally to enable access in every state and territory.

vi. Inadequate access to flexible respite care

Service provision for MND carers, especially those who are ageing, must include adequate levels of emergency and planned in home and residential respite care from appropriately trained staff in a variety of locations. Timely and flexible respite options



are essential to support carer wellbeing and continued participation in the community and in the workforce for as long as possible.

Example: A regional community respite service “stretched” its rules to provide more than the weekly support hours for in home respite for an MND patient as the limits were insufficient.

- *Overnight respite*
As MND progresses care is necessary around the clock and sleep deprivation becomes a major stressor for MND carers. It is extremely detrimental to the health of the older carer and their ability to maintain home based care. Currently the cost of overnight respite precludes this option for most carers – even if it can be obtained.
- *Respite within a residential aged care facility*
Carers sometimes need to be able to take a complete break. Ideally, this type of respite needs to be introduced early and continue on a regular basis to sustain the carer. Respite care should be flexible and appropriate. Staff of the facility must be adequately trained and resourced to manage complex and high level need.
- *Holiday respite*
Holidays strengthen the family unit and allow continued community participation for the family that is vital for quality of life.
- *Respite for education and support*
Education and support programs can be a great benefit for MND carers. However, they may be anxious about taking ‘time-out’ even for a short time to attend education and support programs unless flexible and appropriate respite care is available.

A recent partnership initiative in NSW is the flexible respite program - FlexiRest - which provides a model that has the potential to be translated nationally. MND NSW has established a consortium with Multiple Sclerosis Limited and the Muscular Dystrophy Association of NSW. This consortium has been successful in obtaining funding from ADHC to provide flexible and innovative respite options for people with these progressive neurological conditions to support the carers to maintain their caring



role. Investigating the potential to extend the FlexiRest concept nationally would provide a practical measure to support carers who are ageing.

vii. Inadequate access to aids and equipment and home modifications in a timely manner

Aids and equipment and home modification services are available in each state and territory, however once again these services vary. Timely access to aids and equipment and home modification programs is usually inadequate. Waiting times for assessment's and then for the service or the piece of equipment are often lengthy.

These services are integral to support home based care and the health of the carer. Aids and equipment related to mobility, communication, feeding and breathing are vital to the quality of life of people living with MND to help them to live better for longer.

viii. Access to services from MND Associations varies between states

MND Association family support services work in partnership with statutory services to cost effectively supplement service provision in the areas of loan of specialised equipment, MND specific information and education and individual and group support from professional staff experienced in MND. Where capacity allows state based MND Associations also provide important carer specific and service provider programs and services.

It is estimated that there are around 1400 people living with MND at any given time in Australia. Statistics collected from the state MND Associations indicates that the number of people with MND registered with the associations has increased each year. Almost 1000 people with MND plus their carers, their family and service providers are currently accessing the services that they provide. Adequate support and funding for these associations nationally is therefore imperative to support equitable access to the following services:

- ***Specialised aids and equipment***

Access to aids and equipment from the state based equipment programs is usually inadequate for people with MND. The better resourced MND Associations can supply most of their clients' equipment needs as soon as the need arises. Statutory



equipment service reviews in NSW and Victoria by external consultants promote alternative models of equipment distribution to those currently in existence and cite these MND Associations equipment loan service as appropriate and efficient models. These models could be used to establish a national model of equipment provision.

- **Information**

Miller et al. (1999) confirmed that people with their families need *'printed information about the disease and the support available at diagnosis and MND specific information that is timed appropriately for decision making and delivered well in advance of major management crossroads'*.

The right information at the right time is essential to support people living with MND and their carers to empower them in decision making and planning their changed life journey. MND Associations are able to provide timely information and support.

- **Carer education**

There is considerable evidence that educational support groups can improve carers' knowledge of the condition and competence in coping (ADD 1999). This is particularly true in the case of MND where rapid change and complex need leaves many carers unprepared and floundering. Preliminary studies presented by Adams et al. (2000) and Carroll et al. (2000) at the Eleventh International Symposium for ALS/MND, confirmed the value of group support in mutual problem solving and sharing of issues. They also reported that the care and training of the caregiver has a positive effect on keeping the person with MND in the community.

Carer education should include strategies to manage symptoms, the use of aids and equipment, familiarisation with service provision including respite care and dealing with the emotional aspects of caring. It should also include the personal safety of carers. Occupational health and safety training is mandatory for professional care staff. However, MND carers are usually required to use assistive devices to lift, transfer, reposition and feed the severely disabled care recipient without adequate preparation or training.



More established MND Associations are able to provide specific education and support programs for carers. This has often been achieved through specific seed funding to pilot and develop support models eg the Carer for Carers project funded through NSW Health. This model was recently translated in Brisbane as part of the MND Australia Confident Caring Project funded through the Dept of Health and Ageing Local Palliative Care Grants Round 4, Transition to Home.

- ***Information and education of health and community care providers regarding the needs of MND carers***

People with MND and their carers consistently report the need for care providers to have a greater understanding of this disease. MND Associations provide a range of information for professional care providers including bi-monthly special interest group e-bulletins.

Regional Advisors from the MND Associations play a vital role in providing education sessions/in-services for a range of health professionals, residential care staff and community care providers on MND and symptom management. The needs of MND carers are also highlighted through these sessions enhancing the advocacy role of the regional advisors.

- ***Individual and group support***

The MND Association's family support model enables Regional/Care Advisors to assist the transition of people with MND to, from and through the service sector by providing, information, education, ongoing support, timely referrals. A large part of the Regional/Care Advisors' role is to support individual carers directly; to provide timely information and to talk through options, plans and decisions.

MND Associations also strive to provide group support programs for both people with MND and their carers, either through face to face contact or by telephone link. Their capacity to achieve this again depends on their staffing levels and funding base.

5. Conclusion

Considerable variation exists in the level of support that people living with MND receive in Australia, both through statutory services and through state-based MND



Associations that play a pivotal role in providing specialised support. There is growing evidence that people living with MND live better for longer when they are able to access coordinated interdisciplinary care. There is also growing evidence to demonstrate that inadequate levels of support will be detrimental to the long-term physical, emotional, psychosocial and financial well-being of carers. These long term effects are compounded for carers who are ageing.

A whole of government approach and investment in disability and aged care services is vital if we are to overcome current inequities in Australia. Services must be provided based on the needs of the individual and their family. The under/over age 65 criteria must end and a planned, seamless, coordinated approach to disability and aged care service provision must be implemented in order to ensure quality and length of life for all people with a disability and their carer as they age.

The current political climate offers an exciting opportunity to work towards achieving national consistency and equity of support. Relatively small amounts of recurrent and seed funding would assist states to utilise and translate existing models of care to facilitate this process in a cost and time effective manner.

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

A handwritten signature in black ink, appearing to read 'Carol Birks', written over a light blue rectangular background.

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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.

November 1999 © Revised: November 2007