Senate Committee Inquiry

Palliative Care in Australia

Submitted online on:

23 March 2012

On behalf of:

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Appendix A

Executive Summary

MND Australia expects that any reform of Palliative Care will include the following key characteristics in order to meet the palliative needs of Australians who have motor neurone disease (MND) and their carers:

1. **Access to services provided by Palliative Care** 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
2. **Efficient use of palliative, health and aged care resources** through the coordination of care for people with MND and their families using a key worker model and by formalising regular case conferencing and/or multidisciplinary team meetings within the healthcare system
3. **Access to MND specific information** to all service providers including primary health, allied health and palliative care involved in MND care to assist them to adopt a palliative approach to care from diagnosis through to bereavement
4. **Workforce education and training** to ensure that Palliative Care providers understand the specific needs of people with MND
5. Access to nationally consistent information on **Advance Care Planning** to support people diagnosed with MND and their carers to communicate with health and community professionals about end of life care as soon as they are ready, preferably before speech is affected, to ensure optimal interaction to address their more profound concerns
6. **Funding of research** to develop a national framework for people living with rapidly progressive neurological diseases, such as MND, when receiving palliative care services

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 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, no known cure and no effective treatments. 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 and changing 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 spiralling 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 services, community care, and aged care providers involved in meeting the variable and complex care needs, particularly in regional, rural and remote areas of Australia.

At present treatments for MND only offer the potential to slow the disease process. A palliative care approach is therefore required from diagnosis to ensure that early discussions around future care management and advance care planning are held and optimal symptom management for the person with MND and their family is achieved[1]. Discussions around end-of-life care need to be instigated as soon as the person with MND is ready, preferably before speech is affected, to ensure optimal interaction and communication to address their more profound concerns.

It is very important that people living with MND are able to access quality end of life care based on the needs and wishes of that individual and their family. There is considerable evidence that palliative care intervention improves quality of life for people living with MND and their carers[2].

The MND Australia Palliative Care Policy states that:

MND Australia will promote Palliative Care as a quality of life service available to meet 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 supports a coordinated key worker, multi and inter-disciplinary team approach that includes specialist palliative care from diagnosis, whenever appropriate, to help to improve outcomes for all Australians living with MND.

MND Australia will promote the benefits of Palliative Care to its members and will work to support Palliative Care providers to access information on the special needs of people with MND and their families.

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[1] D Oliver, D Walsh & GD Borasio (eds) *Palliative care in amyotrophic lateral sclerosis: from diagnosis to bereavement*, 2nd edn, Oxford University Press, New York, 2006.

2 Bede P, Oliver D, Stodart J, van den Berg L, Simmons Z, O Brannagáin D,Borasio GD, Hardiman O. *Palliative care in amyotrophic lateral sclerosis: a review of current international guidelines and initiatives*. J Neurol Neurosurg Psychiatry. 2011 Apr;82(4):413-8.

Submission:

Motor neurone disease (MND) or Amyotrophic Lateral Sclerosis (ALS) is a terminal illness with an average life expectancy of two to three years – however the rate of progression varies considerably. Ideally referral to palliative care services takes place soon after diagnosis with palliative care services moving in and out alongside disability, aged and health care services to ensure that a person's needs are met as and when they arise. Specialist palliative care services provide expert symptom management and vital emotional and psychosocial support for the person with MND and their families. Discussions around end of life care can be instigated as soon as the person with MND indicates and their wishes discussed.

MND care must be addressed through a coordinated multi/interdisciplinary team approach with timely referrals to services that will address identified needs[3].

This approach is supported by the key findings of the MND Pathways Project undertaken by MND Victoria and the Victorian Department of Human Services (2008)[4]. This project investigated the need for a framework to assist people living with MND to access palliative care services and to assist palliative care services to support people living with MND. Recommendations from the Interim Report of this project include the development, implementation and funding of a key worker based multidisciplinary model for people living with MND when receiving palliative care services. This model promotes early referral and assured access to appropriate services with emphasis on the importance of co-ordination between MND service providers and families. It also identifies the need for the development and delivery of MND specific education to empower service providers and to support them to provide a coordinated, palliative, multidisciplinary approach from diagnosis through to bereavement.

Access to specialist palliative care services in Australia

Access varies significantly between and within States precluding equal access to optimal end of life care for many people diagnosed with MND in Australia.

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[3] Ng, L.; Khan, F. & Mathers, S. (2009), *Multidisciplinary care for adults with amyotrophic lateral sclerosis or motor neuron disease,'* Cochrane Database Systematic Review (4), CD007425.

[4] Victorian Government Department of Human Services, *Motor neurone disease and palliative care: interim report on the MND pathway project*, Melbourne, 2008.

Furthermore in some regional, rural and remote areas of Australia specialist palliative care services may be limited or non-existent.

A recent exploratory qualitative study[5] to investigate MND carers' experiences of caring, palliative care and bereavement identified that on the whole, the participants' experiences with palliative care services were reported in positive and appreciative terms. However, the timeliness of, and access to, palliative care was a common issue. Only one participant indicated that palliative care services were offered and accessed right from the point of diagnosis, with the other participants reporting that services were accessed from 2.5 to 15 months before the death. On average, the participants' spouses received palliative care services less than two months before their deaths. Two participants reported feeling unclear at the time about what help was actually available from palliative care services. One stated, *'Unless you know the services are there, you don't get them'*. The six participants who met the criteria for prolonged grief disorder accessed palliative care at a later stage in the disease trajectory.

NSW and ACT:

Access to Palliative care currently varies significantly from one area to another. Eligibility varies but overall they require the person to have complex care needs to receive specialist palliative care services. In some areas this includes a multidisciplinary team and in others this may be a palliative care nurse. It is getting more difficult to access a palliative care multidisciplinary team for people with MND in NSW. There is no consistency across the state or between local health networks. Some services do provide excellent service to our members and assist in people having a peaceful death while other areas have no such involvement and people die in distressing situations. Often people need to be at end of life before referrals are accepted by some services and in many areas a person must be referred by a medical practitioner. With MND it is not easy to know when a person is at the end stage of their disease.

Victoria:

In Victoria people with MND are eligible to access palliative care services from the time of diagnosis or when they first need a service provided by a palliative care service. This "pre eligibility" facilitates earlier access to support and services, and

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[5] Samar M Aoun, Sianne Lee Connors, Lynn Priddis, Lauren J Breen and Sue Colyer, (2011), *Motor Neurone Disease family carers'experiences of caring, palliative care and bereavement: An exploratory qualitative study*, Palliative Med published online 20 July 2011

removes waiting lists. The key worker role provides support for palliative care staff, carers and patients. This removes the fear and concern about MND and palliative care respectively.

Top up funding for services addresses the increased costs of providing palliative care support over longer periods, delivering improved core care services in in-patient services and quality of life support for community based clients.

Information flow between palliative care providers and MND Victoria improves support for service provision and a coordinated approach to the overall care and support of people living with MND.

Western Australia,

In Western Australia people with MND are not able to access palliative care at diagnosis. The multidisciplinary care team introduces palliative care services as and when specialist symptom management is required.

Depending on the clients symptom management needs they may be referred to Silver Chain by a registered health professional for assessment of symptoms andl needs. Once registered with Silver chain the client then has access to the Priority Response Assessment (PRA) team as needs arise. A palliative care referral can be accessed thought Silver Chain as required or on a case by case basis by a health professional for end of life care issues.

South Australia,

In South Australia palliative care services are immediately available to people with a confirmed diagnosis of MND. The Palliative Care led MND Clinic in Adelaide works closely with the MND association in South Australia and with local services to provide a coordinated approach to care.

Tasmania

People living with MND in Tasmania are eligible to access palliative care services from diagnosis. Frequently a palliative care worker will take the leading role in the multidisciplinary care team as the key worker. However in areas where there are limited palliative care resources services for people living with MND are limited accordingly. Access to a neurologist is often difficult for people with a diagnosis of MND in Tasmania. Palliative care physicians have been involved in managing the care of people with MND and assisting them with advance care planning in Tasmania for many years.

Efficient use of palliative, health and aged care resources

Care provision for people with MND crosses traditional funding silos including: health, disability, equipment, respite, chronic disease, and aged and palliative care. It also involves a combination of state and federal funding. This system is a major barrier to efficient use of palliative, health, disability and aged care resources and equitable access to quality needs-based care.

The UK publication *Improving end of life care in neurological disease a framework for implementation*[6] highlights that from diagnosis any changes in neurological disease progression should be recognised by all health and community professionals as triggers for the introduction and subsequent involvement of palliative care. The framework states that care should be based on holistic assessment that includes multidisciplinary and service provider collaboration, good communication, regular review and the needs of carers. It recommends multidisciplinary team involvement from diagnosis and that co-ordination of care is therefore essential. Like the MND Pathways Project undertaken by MND Victoria and the Victorian Department of Human Services (2008)[7] a single point of initial contact is also recommended, using a key worker model.

MND Palliative Models of Care:

There are a number of state-funded initiatives that provide palliative models incorporating case management, flexible respite and 'top-up' funding to allow a rapid response and additional levels of support and service provision.

In some areas palliative care teams have established MND specific models of care to ensure a seamless multi/interdisciplinary approach to care from diagnosis through to bereavement without any financial support from state or federal governments. These models of care have been integral to optimal care of people with MND but have not been translated widely due to lack of capacity and funding. Regular case coordination meetings with the GP and all service providers involved in the care of people with MND and the MND Association Regional Advisor help to promote the

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6 National End of Life Care Programme, (2010), *Improving end of life care in neurological disease a framework for implementation,* National Council for Palliative Care, the neurological alliance, UK http://www.endoflifecareforadults.nhs.uk/assets/downloads/FC_2010_17___neurology_report___Final_draft___20110208.pdf

[7] Victorian Government Department of Human Services, *Motor neurone disease and palliative care: interim report on the MND pathway project*, Melbourne, 2008.

efficient use of services, minimise duplication and promote palliative led integrated multidisciplinary care.

MND associations play a vital role in helping people with MND to navigate the complex healthcare system and to ensure that appropriate referrals are made in a timely manner. MND associations work in partnership with other services including; palliative care, volunteers, case management, respite care, equipment and rural and remote providers, to improve outcomes and overcome barriers related to access to services. Some state MND associations have formed innovative formal partnerships to promote access to palliative care services. These partnerships, outlined below, are cost effective but are only available in specific states and often in specific regions as well.

NSW:

MND NSW has established a consortium with MSL (Multiple Sclerosis Limited) and the Muscular Dystrophy Association of NSW. This consortium has been successful in obtaining funding from NSW Health to provide flexible and innovative respite options for people with these progressive neurological conditions to support the carers to maintain their caring role.

Community Options NSW (COPS) has received funding from Ageing Disability and Home Care (ADHC) to provide extra ‘top up’ funding for up to six weeks until additional mainstream services can be arranged when there is rapid deterioration and 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.

Victoria:

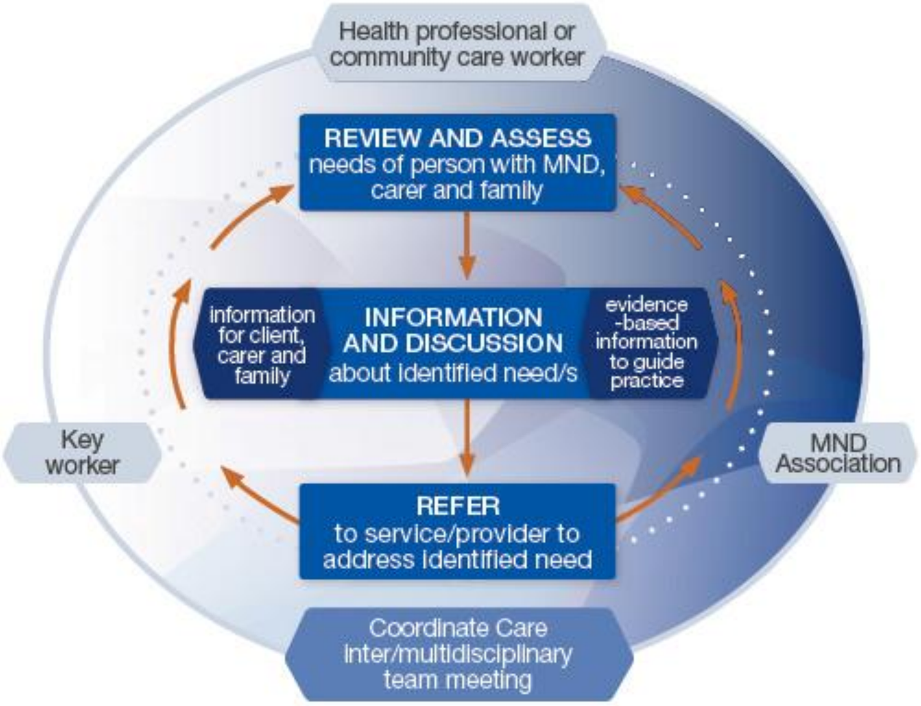
Following the Motor Neurone Disease Pathway Project state funding has been provided to MND Victoria to implement the key worker model through the employment of MND shared care workers within existing palliative care services and to support top-up funding for palliative care services supporting people living with MND. This project has proven to be very successful for both palliative care services in Victoria and for people living with MND. Palliative care providers feel supported and knowledgeable when providing palliative care to people living with MND and their families. This strategy could easily be applied to support primary health care teams.

Queensland:

MND Australia received funding through the Australian Department of Health and Ageing Palliative Care Grants round 4 to conduct the Confident Caring Pilot Project. This project was conducted in partnership with MND Queensland and NSW. The project provided education programs and sessions for people recently diagnosed and their family and friends, carers of people with MND, health and community care providers and palliative care volunteers in Brisbane and surrounding areas to support home based care. Existing MNDNSW education modules and information were adapted for Queensland and are an ongoing resource for MND Q. This 12 month project ended in May 2009

Nationally

MND Australia, through the MNDcare website[8] for health and community care professionals, has developed the MNDcare approach. The aim is to promote the best possible care and support for people living with MND and their families through the provision of timely and targeted information and referral pathways to facilitate referral to right provider at the right time.



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[8] http://www.mndcare.net.au/overview/mndcare-approach

Supporting health professionals and service providers to provide a coordinated multi and inter disciplinary palliative approach to MND care from diagnosis would ensure more efficient use of palliative, health, disability and aged care resources in the future. The UK framework, existing MND models of care and the MNDcare approach provide a strong foundation for the development of national guidelines for access to palliative care for people with progressive neurological diseases.

Access to MND and palliative care information

Information is a key strategy to address equity issues related to access to palliative care for people living with MND and their families. Palliative Care Australia takes a leading role in educating the community about palliative and end-of-life care. MND Australia provides information on the benefits of palliative care through MND associations nationally. In addition the National Palliative Care Program has helped to promote palliative care and build knowledge and services related to MND.

Primary generalist providers, especially those in rural and remote areas, 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 to assist all providers to improve their confidence and competence in providing timely and quality end-of-life care to people with MND.

More widespread promotion of the specialist information available from MND Associations to primary health providers through Medicare Locals, Community Health and Aged Care services would improve access to MND and promote a palliative care approach to care from diagnosis.

Workforce education and training

Capacity and culture of some palliative care services precludes involvement with MND clients. Barriers to entry include ineligibility, scarce resources and, significantly, lack of understanding of MND. Providing MND specific education and training is a key to improving access to optimal palliative care for people living with MND.

WA Centre for Cancer and Palliative Care, Curtin University received funding from NHMRC to develop and test a set of teaching resources for service providers to guide palliative care for people with MND. This collaborative project with MND Victoria, South

Australia and Western Australia was very well received by service providers and feedback was very positive:

"…definitely with some of the staff who went on the course who didn't have a lot of experience with working with people with MND, it was extremely helpful…having the booklet and guidelines and hearing it through people who have MND was very helpful …. I'm sure some of the staff, particularly who went from our facility do have more confidence in dealing with people with MND."

The project ended in 2010 and funding has not been forthcoming to date to roll out the training program and resources nationally.

The NSW Department of Ageing Disability and Home Care (ADHC) provided funding to MND NSW to develop a suite of online training resources for frontline health professionals, case managers and community service providers. These online resources, MND Aware[9], are available on the MNDcare website. Funding includes the provision of face to face training by MND NSW to providers throughout NSW as an introduction to the MND Aware modules.

MND Australia recommends funding a training program on palliative care and MND for primary and allied health professionals and service providers nationally using existing MND specific education and training resources.

Advance Care Planning

Access to nationally consistent information on Advance Care Planning for health care professionals and people living with MND and their families is vital. People diagnosed with MND and their carers must be supported to communicate with health professionals about end of life care as soon as they are ready, preferably before speech is affected, to ensure optimal interaction to address their more profound concerns.

Mitsomoto and others (2005)[10] identified that the timing of when health professionals should introduce end-of-life discussions with MND patients and their families is

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[9] http://www.mndcare.net.au/overview/online-training-for-service-providers/mnd-aware

[10] Mitsumoto and others, (2005), *'Promoting excellence in end-of-life care in ALS.',* Amyotroph Lateral Scler Other Motor Neuron Disord 6(3), 145--154

uncertain. Their Workgroup developed six triggers for identifying when end-of-life discussions should be introduced:

1. The patient or family asks – or ‘opens the door’ – for end-of-life information and/or interventions (elicited or spontaneous, verbal or non-verbal)
2. Severe psychological and/or social or spiritual distress or suffering
3. Pain requiring high dosages of analgesic medications
4. Dysphagia requiring feeding tube
5. Dyspnea or symptoms of hypoventilation, a forced vital capacity of 50% or less
6. Loss of function in two body regions (regions include bulbar, arms, and legs)

Palliative care involvement from diagnosis assists the multidisciplinary team with the initiation and timing of end of life discussions. Specific information on MND and Advance Care Planning as part of a national framework would assist health professionals to introduce end of life care discussions.

Including advance care plans within personal electronic health records will encourage people to talk about their wishes at end of life with their families and will assist in breaking down barriers related to talking about death and dying in the community.

Funding of research

Funding of research to provide information and data about palliative care needs of Australians is important in ensuring needs based access to palliative care in the future. Understanding the palliative care needs of people diagnosed with MND and their families will assist in developing a national framework for people living with rapidly progressive neurological disease, such as MND, when receiving palliative care services as recommended by the MND Pathways Project undertaken by MND Victoria and the Victorian Department of Human Services (2008).

Translation, promotion and funding of research to support evidence based practice to improve quality and length of life for people living with MND and their families is vital.

4. Conclusion

Recommendations for a National Palliative Care Strategy

1. Promote a quality of life vision for Palliative Care services nationally
2. Promote a palliative approach for people living with MND from diagnosis
    a. Improve access to palliative care services nationally for people living with MND and their families
    b. Translate successful innovative models of care nationally
    c. Provide MND information and education to support all practitioners to provide quality end of life care
    d. Provide information to the community about palliative and end of life care
3. Commit funding to extend the recommendations of the Victorian MND Pathway Project nationally to support providers to provide high quality palliative care to people living with MND
    a. Key worker model
    b. MND information and education for palliative care staff
    c. Timely and appropriate respite
    d. Top up funding to address high needs
    e. After hours support
4. Engage with MND associations to promote a collaborative approach to research and MND and palliative care related issues and the translation of research into practice and policy.

MND Australia welcomes this inquiry and hope that any reforms will support all health professionals to provide a coordinated palliative approach to MND care. Any reforms must also ensure access to quality specialist palliative care services for people with MND from the time of diagnosis, or from when they first need a service provided by a palliative care, through to bereavement. It is essential that people with a diagnosis of MND are able to maximise quality of life and dignity in living and dying.

Adopting a national coordinated MND specific palliative framework would promote equitable access to needs based services provided by palliative care and ensure the efficient use of palliative, health, disability and aged care resources. The ultimate aim of any reforms must be to improve outcomes for all Australians living with MND and their families.

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

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5. MND Australia Members - the State MND Associations:

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APPENDIX A

PALLIATIVE CARE AND PEOPLE LIVING WITH MND

POSITION STATEMENT

Motor neurone disease (MND) is a fatal condition with treatments that, at present, only slow the disease process. It is a complex disease of progressive loss and increasing disability with an average life expectancy of two to three years. A palliative care approach is required from diagnosis to ensure that early discussions around end of life decisions are held and optimal symptom management for the person with MND and their family is achieved.

MND Australia believes:

1. Palliative Care must be viewed as a quality of life service integral throughout the continuum of care for people living with MND not only at end-of-life.
2. People living with MND must be informed about and be eligible to access any service or intervention available that improves quality of life at any time during the course of the disease, in their accommodation of choice, to the last days of life.
3. Palliative care services must be involved as early as possible to manage evolving palliative care needs throughout the course of the disease and to facilitate end of life discussion and decision making.
4. The provision of Palliative Care can occur simultaneously with interventions aimed at ameliorating the underlying disease process.
5. Palliative Care providers must be aware that the needs of persons with MND are different from other life-threatening illness and therefore develop programs to address these needs
6. Palliative care providers must be familiar with recommended best practice for people with MND and link into established guidelines for evidence based best practice in managing MND
7. Access to a support system to help family members cope during the course of MND and after death must be included in Palliative Care service plans.
8. A comprehensive education and support program must be available for palliative care service providers involved with the care of people with MND.

MND Australia calls for:

1. Palliative Care services to be available to meet 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
2. The promotion of the benefits of Palliative Care to all people living with MND and their families
3. The development of a funded **national** framework for people living with MND when receiving palliative care services as recommended by the MND Pathways Project undertaken by MND Victoria and the Victorian Department of Human Services (2008).
4. Palliative Care providers to understand the special needs of people with MND
5. Coordination of care for people with MND and their families through the identification of a key worker and regular case conferencing and/or multidisciplinary team meetings

6. Access to MND specific information to all service providers including primary health, allied health and palliative care involved in MND care to assist them to adopt a palliative approach to care from diagnosis through to bereavement

Background:

MND care must be addressed as early as possible through a coordinated multi and interdisciplinary team approach with timely referrals to services that will address needs. This approach is supported by the key findings of the MND Pathways Project undertaken by MND Victoria and the Victorian Department off Human Services (2009). This project investigated the need for a framework to assist people living with MND to access palliative care services and to assist palliative care services manage and support people living with MND. Recommendations from the Interim Report of this project include the development, implementation and funding of a key worker based multidisciplinary model for people living with MND when receiving palliative care services. This model would promote early referral and assured access to appropriate services. The model emphasises the importance of co-ordination between MND service providers and families. It also identifies the need for the development and delivery of MND specific education to empower service providers and to support them to provide a coordinated, palliative, multidisciplinary approach from diagnosis through to bereavement.

In addition discussions around end of life care must be instigated as soon as the person with MND is ready, preferably before speech is affected, to ensure optimal interaction and communication to address their more profound concerns and optimise advanced care planning. It is very important that people living with MND are able to access quality end of life care based on the needs and wishes of that individual and their family. The aim of care is to assist people with MND to maintain quality of life for as long as possible.

Considered by the Executive Management Group April 2010
Considered and endorsed by MND Australia board June 2010

Signed: Ralph Warren (President) **Review date …………………..**

Acknowledgement: International Alliance of ALS/MND Associations Statement of Palliative Care in ALS/MND March 2009