



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 (2009).
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 of 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