



## **POLICY NUMBER: 9**

### **PALLIATIVE CARE AND PEOPLE LIVING WITH MND**

#### **Background:**

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 care must be addressed as early as possible through a coordinated multi/interdisciplinary team approach and timely referrals to services that will address identified 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.

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.

#### **Policy:**

*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.*

**Endorsed by MND Australia June 21 2010**

**Signed: Ralph Warren (President)**

**Review date .....**

#### **Acknowledgements:**

- International Alliance of ALS/MND Associations Statement of Palliative Care in ALS/MND March 2009
- MND Australia Position Statement on Palliative Care June 2010

MND Australia Policy on Palliative Care