



**Motor Neurone Disease  
Association of Tasmania Inc**

ABN 21 877 144 292  
Registered Association No. 01323C

PO Box 379  
Sandy Bay, TAS 7006 Australia

Phone: 1800 80 6632 (1800 80 MNDA)  
Email: [info@mndatas.asn.au](mailto:info@mndatas.asn.au)  
Website: [www.mndatas.asn.au](http://www.mndatas.asn.au)

23 June 2016

Todd Buttsworth  
Secretary  
House of Assembly  
Parliament House  
Hobart, TAS, 7000  
E: [communitydevelopment@parliament.tas.gov.au](mailto:communitydevelopment@parliament.tas.gov.au)

**RE: Response to the Inquiry into Palliative Care in Tasmania**

Dear Todd,

Thank you for the letter inviting MND associations to contribute to the inquiry into Palliative Care in Tasmania. I am writing on behalf of MND Tasmania and have enclosed within a response for the consideration of Standing Committee members.

Below are our responses to the areas described below in the Terms of Reference. We hope to provide some valuable input from the perspective of people living with motor neurone disease in Tasmania.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'Tim Hynes', is written over a light blue circular stamp.

Tim Hynes  
President, MND Tasmania

## **Context**

MND Tasmania is responding to the Terms of Reference for the House of Assembly Standing Committee on Community Development outlined as follows:

*To inquire into and report upon the matter of care of palliative patients generally, specifically the matters of:*

- I. advance care directives*
- II. administration of medical treatment to minors*
- III. administration of emergency medical treatment; and,*
- IV. other matters incidental hitherto.*

## **What is MND?**

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.

Currently around 1,400 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.

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. 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.

## **Our position on Palliative Care**

As a member of MND Australia we subscribe to the following position statements for palliative care and people living with MND

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.

## ***Advance Care Directives***

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.

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.

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.

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.

## ***Other matters relating to Palliative Care***

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.

An exploratory qualitative study<sup>1</sup> in 2011 investigated 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.

Palliative care is delivered from the three major regions of Tasmania (North, South and North-West). The Tasmanian Health Service has Palliative Care Services in each of these regions and is supported by palliative care volunteers across the state. It is essential for our members that Palliative Care is an early referral service (when required) through the MND Regional Advisor. The Regional Advisor is a service currently provided through MND Victoria on behalf of MND Tasmania.

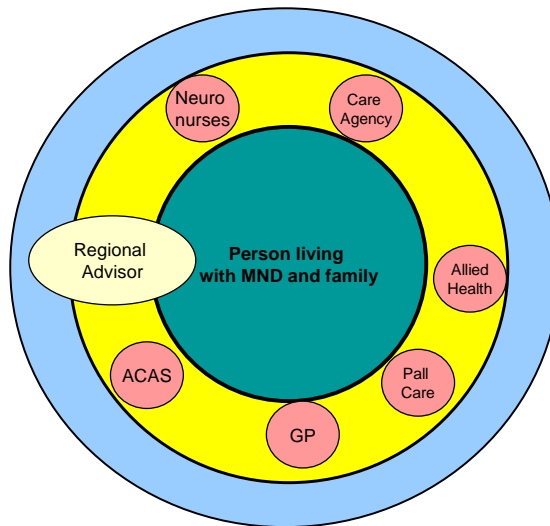
The Regional Advisor Service is delivered by a qualified health professional, who has knowledge of MND and extensive experience in the community services sector. The Regional Advisor will navigate the service system for people living with MND to ensure that they are linked in to services that will meet their needs.

The Regional Advisor makes contact with newly diagnosed people and their families to provide information about the disease, offer advice and support and arrange a meeting when an initial assessment will be made of their specific service and support needs. Ongoing support and advice is provided to meet the individual's changing circumstances.

The Regional Advisor aims to build a team of health professionals and care providers around the diagnosed person and their family to ensure appropriate and timely communication of needs and services being provided including Palliative Care teams.

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<sup>1</sup> 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



When making referrals, the Regional Advisor also refers to the Department of Health and Human Services Neurological Support Service nurses in the same manner that referrals will be made to other health professionals.

As per the current model that the Regional Advisor works from, it is important that Palliative Care like other services are engaged as early as possible for people living with MND in Tasmania and that the services provided are tightly linked together in a multi-disciplinary approach.