

Project brief: Motor Neurone Disease Palliative Care Pathway Project

11 May 2007

Background

Motor neurone disease (MND) is a progressive degenerative disorder of the nervous system that destroys motor neurones causing increased levels of disability and, ultimately, death. MND has a short trajectory from diagnosis, with an average life expectancy being 27 months.

The incidence of MND is approximately 2 per 100,000 people (International Alliance of MND Associations). In Victoria it is estimated that at any point in time there are approximately 250 people diagnosed with MND. The disease is age linked, with the highest rate of incidence between the ages of 50 and 70 years.

In 2001 in Victoria, there were 121 deaths, 58 males and 63 females. These people were all over the age of 35 years, with the majority between 54 and 74 years. In 2001, MND accounted for approximately 1,413 years of life lost for those people who died. The total number of disability adjusted life years (DALYs) for MND patients in 2001 was estimated to be 1,504. As at 31 March 2007, MND Victoria had 264 clients registered with a confirmed diagnosis of MND.

The Motor Neurone Disease Australia is the peak body for people with MND in Australia, and there are member organisations in each state and territory in Australia. MNDA Victoria aims to provide and promote the best possible care and support for people living with MND. The association collects and shares the best available advice and information and fosters links between people with MND. The association has a strong focus on raising the awareness of the community, providing education and promoting and supporting research initiatives. The association provides a family support service with four main components:

- Regional advisors undertake counselling, assessment of needs, and referral to appropriate providers to address unmet needs and monitoring.
- Information services.
- Provision of volunteers.
- Provision of equipment to assist independence.

The degenerative nature of MND over a relatively short period of time, combined with increasing levels of disability and unmet needs, means that people with MND need to access a range of social, disability and health services to support independent living and quality of life. Carer needs also need to be addressed in order to provide ongoing support and respite.

MND is a life limiting disease and because of its nature most people will require and benefit from palliative care support throughout their disease trajectory. Despite the life limiting nature of MND, uncertainty exists between services about how, and when to appropriately refer to palliative care, and what role palliative care should play with those services already engaged in supporting people with MND.

At present the referral of people with MND to palliative care is not systematic with access to palliative care for people with MND being variable. The lack of a systematic, evidence based and

accepted framework for palliative care services to work in partnership with other service providers continues to hinder coordinated care for people with MND.

On the palliative care side, services report that people with MND have a high degree of acuity and complex care needs once they have reached the stage where direct palliation is required. Palliative care for people with MND is provided in inpatient and community settings. A better understanding is required of the service resources needed to care for people with MND receiving palliative care, and whether palliative care services are equipped to deliver this care.

Objectives

This project aims to achieve four outcomes:

- Establish a framework or pathway that uses the best available evidence including models already in practice that clearly identifies criteria that triggers a referral to a palliative care service¹.
- Develops and describes those mechanisms and processes that support communication between service providers and care coordination.
- Articulates the roles of the palliative care service provider.
- Identifies gaps in current palliative care service provision for people with MND and make recommendations to the department about models of care and resource implications for the provision of palliative care for people with MND.

Commencement date

The project will commence in June 2007

Completion date

The project will conclude in November 2007

Key tasks, deliverables and timeframes

Key tasks	Deliverables	Timeframes
Engage the Motor Neurone Disease Association of Victoria (MNDA) to lead the project	Adjust the service agreement between the MNDA and DHS to reflect the project goals and funding levels.	July 2007
Appoint a project worker	A project worker appointed by MNDA with appropriate skills and experience to undertake the project	July 2007
Form a steering committee to oversee the project, with Chair from Motor Neurone Disease Victoria	The first meeting of a representative steering committee undertaken with agreed terms of reference and project goals. The Chair of the steering committee will be a representative from Motor Neurone Disease Victoria An Expression of Interest (EOI) will be distributed to the palliative care sector to identify interested people. The steering committee will be selected from those that respond to the EOI.	July 2007
Undertake a literature review of models of palliative care for people with MND. Summary of evidence related to palliative care.	The creation of a stand alone document the outlines a systematic review of the literature concerning models of care for people with MND that incorporate palliative care.	July 2007

¹ A palliative care service in this document refers to a DHS funded organisation that provides specialist palliative care.

	This report should also identify the similarities and differences in current models in use by Victorian palliative care serviced for this client group.	
Undertake consultation with palliative care, neurological and MND stakeholder groups including people with MND.	The convening and moderating of a series of interviews or workshops that will hear from the stakeholders associated with this project in order to canvas the potential issues and solutions.	August 2007 – October 2007
Produce a draft pathway for sector comment	The creation of a draft pathway for people with MND to engage with palliative care service is produced and distributed to stakeholders for comment. The pathway will take into account the literature and the Victorian context.	October 2007
Report that identifies any resource gaps that hinder appropriate palliative care for people with MND and recommendations to address the gaps in palliative care.	The resource implications for the provision of palliative care for people with MND will be determined and valued.	October 2007
Final project report from Motor Neurone Disease Victoria is produced, endorsed by the Steering Committee and submitted to DHS.	A stand alone report detailing the findings of the literature review, information gathering of current practice in Victoria, the results of discussions and forums, the final version of the pathway with recommendation on methods to address service delivery gaps for people with MND is produced by Motor Neurone Disease Victoria. The report is endorsed by the project Steering Committee before submission to the DHS.	November 2007

Stakeholder and potential partnerships

The range of groups that this project will be of interest to are listed below.

- People with MND, their families and carers.
- Motor Neurone Disease Association Victoria and members.
- Palliative Care Victoria and members.
- Regional palliative care consortia.
- Health service based palliative care services, in particular
 - St Vincent's Health,
 - Calvary Health Care Bethlehem Palliative Care Service
 - Calvary Health Care Bethlehem Neurological Service
 - Victorian Respiratory Support Service, Austin Health
- Community palliative care services.
- Disability Services Unit, Department of Human Services.
- Home and Community Care and Assessment Unit, Department of Human Services
- Continuing Care Unit, Department of Human Services.
- Cancer and Palliative Care Unit, Department of Human Services.

Consultation

The project will engage with a broad range of stakeholders to engage the complete set of views. Consultation will occur with individuals and with groups, and be undertaken in both metropolitan and

regional areas. The views of present clients with MND, their families and former carers will be an important group to engage.

Communication plan/strategy

The palliative care sector will be notified and updated regarding the project and its progress through the monthly update to each regional consortium that is distributed to services. Other regular and ad hoc communications to services will also be used to promote the project as the opportunities present.

The resources of Palliative Care Victoria and the Motor Neurone Disease Association Victoria will be used to notify their members of the project and to provide updates regarding progress.

Communication topics will include:

- Invitations to participate in forums and provide comments on draft pathways
- Requests for palliative care services to share their current pathways of engaging with people with MND
- Findings and information to be shared with the relevant sectors.

Risks and their management

The main risks of undertaking a project to describe both a pathway and resources for implementing coordinated palliative care for people with MND is the expectation that the findings will be implemented, and implementation will be immediately following the conclusion of the project. It is likely there will be some delay in any possible implementation of the project's findings to coincide with the budget process and internal DHS processes. This risk can be reasonably managed by including a clear scope and purpose for the project in any communication with stakeholders and to provide updates on the progress and outcome of actions regarding the findings when they are progressed.

The project needs to be bounded very clearly to relate only to the palliative care requirements of people with MND. It will be easy for the project and the findings to be extended beyond the scope of palliative care and focus on the global needs of people with MND. This possible risk could be managed by clear communication of the focus of the project. The steering committee overseeing the project will need to be aware of this risk and provide guidance to ensure the scope of the project is not broadened inadvertently. Allowing the project to expand beyond the original goals will result in the waste of the resources provided to undertake this project.

Evaluation plan

The project will be evaluated in terms of the extent of clients and the health and community provider sector's involvement in developing the pathway and the comprehensiveness of the methodology employed to arrive at the conclusions.

In addition, the ease with which the final conclusions can be used within DHS to influence decision makers will be an evaluation of the comprehensiveness and rigour of the process.

Project costs

\$50,000 has been identified for the project in 2007-08.

The project will employ a project officer to be situated at the Motor Neurone Disease Association Victoria. Transport and venue costs to undertake forums will need to be included in the total overall budget.

Project officer (plus oncost and management costs)	\$45,000 (approximately)
Transport.....	\$2,000
Venue costs	\$3,000

Funds will be provided to the Motor Neurone Disease Association as an amendment to their service agreement and cash flowed fortnightly from 1 July 2007.

Project manager and team members

Jackie Kearney from DHS will manage the project.

The project team will include, Rod Harris and Jennene Arnel, and the appointed project officer from the Motor Neurone Disease Association and Gregory Dalton from DHS.