

# Motor Neurone Disease and palliative care

## Interim report on the MND Pathway Project



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## Foreword

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On behalf of the MND Association of Victoria, I would like to thank all of the contributors to this report. People with MND, their carers and former carers demonstrated their commitment to improve the service system and enhance the quality of life of people living with MND, both now and in the future. Staff and representatives of palliative care services were open, honest, reflective and innovative in discussing the issues they face in providing the best possible services for people living with MND from the palliative care perspective. They highlighted their strengths, weaknesses, fears and hopes to better inform this report.

The Steering Committee, with a broad range of backgrounds, came together to discuss and challenge the report and the material it presents. Representing service providers and government, they put aside their representative hats and focussed on the issue at hand – the best possible care and support for people living with MND, and supporting palliative care services to play their part.

Project management and coordination was undertaken by Jennene Arnel and Gregory Dalton, ably assisted by Liz Laffan, our Project Officer, who thumbed the literature and guided the discussion of teleconferences and face-to-face meetings, aggregated information and data and gave us the basis from which to develop the report.

I would also like to thank the various employers of the focus group participants and the Steering Committee for funding their role in this work.

Finally, thank you to the Department of Human Services, Cancer and Palliative Care Unit, for their vision, passion and commitment to deliver quality palliative care to all people in Victoria who need it and want it.

**Rodney Harris**  
**Chief Executive Officer**  
**MND Association of Victoria**



## Executive summary

In July 2007, the MND Pathway Project was established to develop a framework to assist people living with Motor Neurone Disease (MND) to access palliative care services, and to assist palliative care services manage and support people living with MND. The project was commissioned by the Cancer and Palliative Care Unit of the Department of Human Services. The project was undertaken by MND Victoria, supported by a project officer, and supervised by a committee selected from nominees with a background in palliative care and MND.

The objectives of the Motor Neurone Disease Palliative Care Pathway Project were to:

- Establish a framework or pathway, including models already in practice, that use the best available evidence to clearly identify the criteria to trigger a palliative care service referral.
- Develop and describe those mechanisms and processes that support communication between service providers and care coordination.
- Articulate the roles of the palliative care service provider.
- Identify 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.

Data to inform the project was collected through a literature review and discussion with people living with MND, past and present carers of people with MND, palliative care service representatives and key opinion leaders in the palliative care sector. Topic-specific information from the literature was combined with interview themes in order to construct a series of recommendations for the coordinated integration of palliative care into the overall management of people with MND and their carers.

The project found that there is no existing framework that can be implemented to integrate the palliative care of people with MND into the overall care received. Other key findings were that palliative care workers did not feel confident in their level of knowledge regarding MND and people with MND had a distorted understanding of the service that palliative care offered. Both palliative care workers and clients with MND reported that the rarity and the progression of the disease made coordinating care between numerous agencies difficult.

Inpatient palliative care services reported patients with MND had high resource needs. This view was supported by the literature, which shows that when a high-needs client with MND is admitted other patients receive less care through reduced staff time and resources. Carers highlighted the lack of appropriate and timely respite as causing considerable emotional, psychological and physical demands. The presence of after-hours palliative care support, while not widely used, offered carers and clients piece of mind as the disease progressed.

### The recommendations from this report are:

1. A document is developed for health professionals to illustrate the range of needs and availability of providers to assist people with MND to access appropriate palliative care and community services. The document should be piloted and further developed then provided to all palliative care providers in Victoria to use. In addition, the palliative care sector identify and agree on common points at which palliative care services can and should be involved for clients with MND within the currently employed models of care.
2. A key worker model be developed, funded and implemented for people living with MND when receiving palliative care services in order to promote early referral, support development and delivery of education to service providers and co-ordination between service providers and families.
3. A comprehensive education and support program be developed for palliative care staff involved with the care of people with MND by 30 June 2008. The program needs to include funding to establish, promote and maintain expert and palliative care peer support from specialist MND centres, an education and training package on MND for palliative staff when a service has a MND client and education about palliative care services for clients with MND and their families.
4. The establishment of guidelines and a suitable mechanism to provide supplementary funding for inpatient and community palliative care services to meet identified high care and ongoing needs of people with MND.
5. The Department of Human Services recognise the importance of timely access to appropriate respite for people with MND and their carers in order to reduce the significant, and rapidly growing, burden imposed by this disease. In addition, the Department of Human Services recognise the needs of people with MND in all future policy decision concerning access to respite care.
6. The Department of Human Services give specific consideration to the needs of people of MND and their families when considering future policy decisions regarding funding and access for after-hours palliative care support.



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## Perspectives on a case of MND

To highlight the impact and specific attributes of MND, a case is presented in the form of individual perspectives.

### The person with MND

I had never heard of the disease, what started out as slight difficulty doing normal things rapidly overtook my body so that I was completely dependent on others for everything. It seemed unreal to be told that I probably only had two or three years to live, but they were right. After coming to terms with this I quickly found out that few people know anything about MND, including most of the health professionals I was referred to. I have not been able to continue working and this has placed another burden on my family whose lives have all been turned upside down through the new things they have had to quickly learn. The disease progresses so fast that as soon as I start to experience difficulty doing something, like showering, my environment needs to be changed so I can maintain some independence, but the system is not geared up to help us help ourselves. My partner has had to stop working and the physical and emotional strain of my disease is seldom relieved through the current system of respite. While the house and my family's lives are changing, I am changing as well. I understand everything that is going on, but I am helpless to assist. The emotional journey of living this decline is being made positive through the involvement of skilled counsellors and the reassurance that my family will be supported after I am gone.

### The carer

Since my husband has been diagnosed with MND my whole life has changed. Within weeks and months I have had to stop work and take on other roles without any training. I am now a fulltime nurse, putting in 14-hour shifts, seven days a week, I am a case manager trying to understand the health sector with dozens of services and people entering and departing our lives at different times, all ignorant of each other and the complexity of accessing services that are virtually impossible to find, and I have become an educator to health professionals about MND and how to care for my husband. I thought this would be the other way around. With the progression of this disease, I am feeling more and more the relentless pressure of the physical and emotional burden of caring for someone I know will soon die. There are no appropriate respite services, they either don't know what to do when he is there or we can't get a place. I have started to think about how I will start my and my children's lives again after this chapter ends and we are released from our duty.

### The palliative care service

The referral of a person with MND makes my heart sink a little, because I don't have much experience with MND and I'm not sure where to go to get help for issues I can't deal with and to check the appropriateness of my approach for needs that I can address. As I become involved with the client I realise that I am one of a great many services currently involved and the family have very little idea of what palliative care is about.

While I've learnt about MND from them, they now know palliative care is not end-of-life care. We have started to talk about some of the emotional aspects of this journey, now that a lot of the typical issues involved in client's care are under control. His few days in the inpatient unit were fundamental in getting his pain, breathing and nutrition needs sorted out, but I know the pressure this put on the nurses caring from the other patients in the ward at the time. Despite all the activity that is going on, I don't feel that I am connected to the overall care plan for this man.



## Introduction

### Background

In July 2007, the Motor Neurone Disease Palliative Care Pathway Project was undertaken to develop a framework to assist people living with Motor Neurone Disease (MND) to access palliative care services, and to assist palliative care services manage and support people living with MND. The project was commissioned by the Cancer and Palliative Care Unit of the Department of Human Services. The project was undertaken by MND Victoria.

MND is a life-limiting disease and because of its nature people may require, and may benefit, from palliative care services during their disease trajectory. Despite the life-limiting nature of MND, uncertainty exists about how and when to refer to palliative services, the services palliative care offer and how the interface between palliative care services and community services works practically in order to support people with MND. Palliative care services for people with MND are provided in community and inpatient settings. These services report that people with MND often have a high degree of acuity and complex care needs that are different from other palliative care patients.

The referral of people with MND to Victorian palliative care services is not systematic and access is variable. The lack of coordinated care for people with MND through a palliative care and community service partnership is also hindered by the absence of a published, evidence-based and accepted framework.

### Objectives

The objectives of the Motor Neurone Disease Palliative Care Pathway Project were to:

- Establish a framework or pathway, including models already in practice, that use the best available evidence to clearly identify the criteria to trigger a palliative care service referral.
- Develop and describe mechanisms and processes that support communication between service providers and care coordination.
- Articulate the roles of the palliative care service provider.
- Identify 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.

### Governance

The project was governed by a Steering Committee made up of people who self nominated for a position by outlining the experience and skills they would bring to the project either in the area of working with people with MND or by providing specialist palliative care services. MND Victoria and the Department of Human Services jointly selected the Steering Committee using the supporting information contained in the nominations.

### Management

Motor Neurone Disease Victoria and the Department of Human Services undertook the project management, supported by a project officer located at MND Victoria.

## What is Motor Neurone Disease?

Motor neurone disease, amyotrophic lateral sclerosis (ALS) or Lou Gehrig's disease, is used to describe a group of diseases in which damage to motor neurones occurs. Motor neurones are nerve cells that control the movement of muscles that are under conscious control. These include all the muscles of the trunk and limbs and of speech and swallowing. Without activation, muscles gradually weaken and waste, resulting in paralysis. The initial symptoms of MND may be weakness in the hands or feet, swallowing difficulties or slurred speech. Muscle twitching and/or cramps may also occur. In the majority of cases the senses and intellect are not affected.

In Victoria the prevalence of MND is approximately 250 people, with an annual incidence rate of 100 new cases. It is estimated that for every person diagnosed with the disease another 14 family members and close friends will be impacted. As at 30 September 2007, 242 people with MND were registered with MND Victoria. In the year ended 30 June 2007, MND Victoria worked with 364 people with MND, with 140 new registrations and 110 deaths reported.

Each person with MND is affected differently in terms of their initial symptoms, the rate and pattern of disease progression and the length of time to death. There are no remissions and there is no cure. Some medications will increase life expectancy by three to six months. The average time between diagnosis and death is two to three years, with very few people surviving more than five years. Progression of MND is rapid, quickly creating high levels of disability and the consequent need for support, including assistance with feeding, communication, movement, transferring, toileting, and other personal care activities. MND has an impact on all activities of daily living.

The progression of MND means that the level of disability changes over months rather than years. Healthcare professionals who are unaccustomed to managing MND may not recognise the significance of progressive symptoms. This can lead to unnecessary hardship for those with the condition.

The speed of progression creates problems of adjustment for people who have MND, the escalating burden on carers and families and the challenges faced by service providers and their staff who are charged with meeting the variable and complex care needs.

## What is palliative care?

Palliative care is defined by the World Health Organisation as:

*“An approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering, early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” (World Health Organisation 2007)*

Palliative care in practice is the active total care offered to a person with a progressive illness and their family; it concentrates on the quality of life and the alleviation of distressing symptoms. There is evidence that palliative care can provide valued support for families as illness progresses, and during their bereavement, however, many families of individuals with chronic and progressive conditions may not be usual recipients of palliative care services.

The vision underpinning palliative care policy in Victoria is that all Victorians with a progressive life-threatening illness, and their families and carers, will have access to a high-quality service system that fosters innovation and provides co-ordinated care and support that is responsive to their needs.

Supporting this vision are a series of principles for practices and processes that guide health and community care providers to achieve the expected outcomes in caring for people with life-threatening illnesses and their carers and families.

**The principles are:**

1. People with a life-threatening illness and their carers and families have information about options for their future care and are actively involved in those decisions in the way that they wish.
2. Carers of people with a life-threatening illness are supported by health and community care providers.
3. People with a life-threatening illness and their carers and families have care that is underpinned by the palliative approach.
4. People with a life-threatening illness and their carers and families have access to specialist palliative care services when required.
5. People with a life-threatening illness and their carers and families have treatment and care that is co-ordinated and integrated across all settings.
6. People with a life-threatening illness and their carers and families have access to quality services and skilled staff to meet their needs.
7. People with a life-threatening illness and their carers and families are supported by their communities.

## **MND and palliative care**

The expansion of palliative care into non-malignant disease is being undertaken cautiously by the palliative care sector (Connolly 2000). As a consequence, many families of individuals with these diseases may not be usual recipients of palliative care services. Evidence is emerging of the extensive supportive care needs of people with non-malignant diseases that are linked to negative changes in quality of life, and their carers,

In 2005-06 and 2006-07 there were approximately 250 acute hospital admissions in Victoria primarily for the treatment of MND, compared to 23 and 13 palliative care admissions respectively. In any one year, approximately 40 people with MND are estimated to be receiving community palliative care.

There is mounting evidence that the palliative care model has much to offer an individual with MND and their family (Connolly 2000). The diagnosis of MND carries with it an inevitably fatal prognosis. In the absence of curative treatments, the focus is on enabling the patient to achieve maximal function and independence at each stage of illness by providing relief of the multiple symptoms that develop over time. Patients diagnosed with MND thus require palliative care, which seeks to prevent, relieve, reduce or soothe the client's symptoms without effecting a cure.

Palliative care specialists undertake to effectively balance managing the multiple symptoms while preserving the dignity and autonomy of the patient and minimising the fears and impact to the patients and their families. Family members and carers of patients continue to be supported by palliative care services after the death of the client through the routine use of bereavement care. It is through this service that many people are able to positively and constructively rebuild and reshape their lives after the death of a family member with MND.

MND is a life-threatening illness. It has a short life expectancy and results in death in all cases. People with MND, their families and carers, seek and require access to a broad range of services that can address the unmet needs created by MND. They require services that assist with the physical, psychological, emotional and spiritual impacts of the disease. Palliative care can provide many of the elements that make up these services.



## Methodology

Information gathered as part of this project was sourced using two methods; a review of the literature and interviews.

### Literature review

A systematic search of the published literature was undertaken by the Palliative Care Research Team, School of Nursing and Midwifery, Monash University. Combinations of the key words MND, motor neurone disease, palliative care, end-of-life care, ALS, amyotrophic lateral sclerosis, care pathways, non cancer and critical pathways were used in three databases: MEDLINE, CINAHL, PsychINFO (1982 to 1st week of 2007) and Google, which resulted in 315 identified documents.

Abstracts of the 315 identified documents were reviewed for relevance to the project. This resulted in 30 documents being identified and copies of these articles acquired.

In addition, the MND Association library was hand searched for key resources. Palliative Care Australia and Palliative Care Victoria publications were searched for relevant documents to be included as part of the literature review process. Publications produced by the Department of Human Services regarding palliative care, palliative care policy and future directions were included.

### Interviews

The majority of interviews were undertaken either face-to-face, via teleconferences, or as part of a focus group, depending on the preferences and availability of the interviewee. Some respondents participated by completing a questionnaire.

People with MND, their carers or former carers (those who cared for someone with MND who has since died), representatives of palliative care services from across Victoria and key opinion leaders in the palliative care sector were identified as important groups from whom to gather information to inform this project. The participants consented to detailed notes being taken of each interview.

### People with MND and their carers or former carers

Invitations were sent to all people with MND and their carers currently registered with MND Victoria (n=250) and to people who had cared for someone with MND who had died in the previous two years (n=200) (see Appendix 1). Of those, 70 expressed an interest in participating in the interviews but 30 were subsequently unable to attend. Of the 40 people remaining, 36 participated in interviews during the week of 13 August 2007, and four people were sent a questionnaire (nine people with MND, 12 carers and 19 former carers).

The interviews followed a semi-structured format with questions developed to facilitate discussion and information gathering.

### Palliative care services

Chief executive officers or managers of Victorian palliative care services (n=108) were invited to participate in one of five regional focus groups held between 20 August and 3 September 2007 (see Appendix 2). Thirty one individuals responded and participated. Interviews were conducted as a semi-structured dialogue. People unable to attend the focus groups, who wanted to contribute information, completed a questionnaire (n=four) regarding their organisation's experience in providing palliative care to people with MND.

### **Palliative care sector leaders**

Individual interviews were held with key opinion leaders to explore issues that impact on the effective delivery of palliative care for people with MND. The interviews were semi-structured and focused on the definition of palliative care, the rationale and changing model of palliative care service delivery, financial barriers and equity of access to palliative care and the impact on service provision on clients with numerous, complex and ongoing needs (see Appendix 3).

### **Analysis**

Major themes from the interviews were extracted from the notes of the interviews and relevant information from the published literature was used to compare and complement the views expressed. The information was collated and recommendations for improving the integration of palliative care services in the overall care of people with MND developed.



## Findings

The literature search did not yield an existing reported pathway or framework that described the coordinated integration of palliative care services into the overall care of people with MND. The published literature provided information focussed on specific issues faced by people with MND, their carers and family. Because of the lack of an existing model or framework, the information obtained during interviews formed the basis of the evidence for the findings and recommendations.

### Framework for integrated care

#### Literature review

The Motor Neurone Disease Association of England, Wales and Northern Ireland have developed and published a pathway associated with overall MND progression that identified appropriate services at specific patient milestones (Motor Neurone Disease Association 2007). Triggers are based largely on changes in physical function, with the pathway describing service providers, their role and estimated costs.

This pathway is not specific for palliative care, which is only indicated in one aspect of the document, and it could not be implemented in Victoria as it is tailored to reflect the structure of the United Kingdom health system. However, the document does provide information about the types of services that palliative care services provide and the concepts underlying the pathway are useful to guide the development of a document to describe the integration of palliative care into the overall management of people with MND.

No other pathway or framework was identified from the published literature.

#### Interviews

People with MND and their carers identified a clear need for a referral and intake system that gave them access to the services of palliative care agencies. They highlighted their general lack of understanding and knowledge of the service sector and were confused by the terminologies and descriptions of services provided. They highlighted the role of MND Victoria regional advisors as “a navigator” for them – identifying their needs and referring them to services that could address those needs.

Former carers who had support from palliative care providers highlighted the benefits of being linked to a palliative care service and the quality of support that they received while caring and post bereavement.

Palliative care interview participants raised two issues related to the coordinated integration of palliative care in the overall management of clients with MND – the timeliness and appropriateness of referrals to the palliative care service and information about where and how to refer people with MND to other service providers when they have needs outside the expertise of palliative care providers. The interviews suggested that some palliative care staff did not see themselves as part of a broader system of service providers for people with MND, but instead thought that the palliative care service should address all aspects of care, in effect being the sole health care provider for a person with MND.

Palliative care providers asserted that they have a role in the care of people with MND and referral of these clients should occur at appropriate times in the progression of the disease. There were a range of views expressed about when is an appropriate time for referral, which appeared to

coincide with the model of care employed by different palliative care services. Services that deliver a direct care model preferred early referral, at the time of diagnosis or soon after, in order to establish a relationship with the patient that could be built upon as the disease progressed to allow early identification and addressing of needs. Palliative care providers offering a consultative model of care preferred referral when a specific need arose that was within the sphere of expertise of palliative care, allowing specialist healthcare advice and practical support. Palliative care providers indicated that referral should occur for people wanting information about grief and loss or psychosocial support associated with changing roles or requiring assessment for ongoing pain or discomfort, spiritual support or access to complementary therapies.

However, palliative care providers expressed frustration that, despite feeling responsible for the client with MND, they did not have the resources or, in some cases, the skills or knowledge to ensure that all client needs were met. Other feelings expressed by palliative care workers were helplessness, hopelessness and fear when a new referral for a person with MND was received. These feelings were the result of the additional workload that the referral entails, the comparatively long length of time the patient could be cared for by the service, and concerns relating to the lack of knowledge of what is available in other health and community care services when additional care needs emerged. Many interviewees noted that they seldom have clients with MND and part of their unease associated with this client group is their unfamiliarity.

Palliative care interviewees suggested that any new framework for palliative care in the overall management of clients with MND should outline the key needs they are likely to experience as a result of their illness and identify the type of service that a referral should be made to, with a list of common and specialist providers. It was also expressed that an attempt should be made to indicate the range of factors that a person making a referral needs to consider such as geographical location, any previous contact with palliative care service, current waiting lists or clients preference.

Key palliative care informants highlighted the difficulties in identifying appropriate (non palliative care) services that could address issues caused by MND that were outside the remit of the palliative care service. There was common agreement that the community/health/disability service systems were confusing and that this was further complicated by the overlay of aged care services. They supported the views of their staff in identifying the need for information about service providers in other sectors that could support people with MND and the need for an appropriate framework to facilitate co-ordination to ensure that all of the services involved in supporting people with MND were aware of each other's role and responsibilities.

They saw the development of a framework that identified needs, key providers and outcomes to be achieved as an effective tool to support their workers understanding of the broader service system, their place in it (including their role and responsibilities) and as a referral tool for them when identifying new and emerging needs created by MND for the client and their family.

Importantly, key opinion leaders highlighted a positive consequence of describing a framework will be the weakening of the perception of absolute responsibility for a person with MND's support and care needs after referral. A framework indicating the multi-service engagement required to support a person with MND was seen as an effective mechanism to reduce stress and uncertainty and emphasise the strengths of multi-service delivery in this environment.

## Discussion

The lack of a published framework for the integration of palliative care into the overall service system for the care of people with MND has not been unexpected. The desire to integrate the palliative care for a person with MND with other service providers is necessary because the management of MND usually rests with a number of providers. The current lack of widespread integration has resulted in palliative care services feeling uneasy about caring for the person with MND, and therefore these individuals miss out on the specialist healthcare and practical support that the palliative care discipline is able to offer. In exploring these issues, it has become apparent that the framework for accessing palliative care services needs to achieve a number of objectives. First, it needs to indicate the needs of someone with MND that a palliative care service can reasonably meet, thus facilitating the appropriate and timely referral of someone to palliative care. In addition, the framework needs to show the role of palliative care as one part of an integrated team of providers.

Producing a framework will improve the integration of care, but from the interviews and literature it was evident that five additional initiatives are required to support service providers and client and carers in accessing and receiving best practice palliative care. These areas are:

- Education.
- A key worker model for coordination and communication.
- Funding for high-needs clients.
- Access to respite care.
- Access to after hours support.

## Recommendation

A document is developed for health professionals that illustrates the range of needs and providers to assist people with MND to access appropriate palliative care and community services. The document should be piloted and further developed then provided to all palliative care providers in Victoria to use.

The palliative care sector identify and agree on common points at which palliative care services can and should be involved for clients with MND within the currently employed models of care.

## Education

### Literature Review

A number of investigators have highlighted the core need of health professionals for accurate knowledge, which is updated regularly, about how to care for the person with MND. A 1995 questionnaire of British people affected by MND (clients and carers) indicated that GPs, palliative care hospice staff and home care workers were inadequately educated about MND and did not know how to assist (Birch, Ferlie et al. 1995).

A subsequent survey in 2002 showed that the top priority for carers of people with MND was increased knowledge of MND among the health professionals caring for their loved one (Motor Neurone Disease Association 2002). Supporting the evidence of carers not having confidence with inpatient palliative care staff, a study from New Zealand of health professionals' attitudes to caring for people with MND reported more negative attitudes in terms of confidence in their role compared to people with other neurological disorders (Carter, McKenna et al. 1998).

The specialist requirements of caring for a person with MND, combined with the relative rarity of the condition, hinders the palliative care worker's ability to acquire and maintain an up-to-date knowledge and skill base. The literature highlights the need to foster a greater awareness and understanding of MND within the community of health professionals. The inherent complexity of the healthcare system makes it unreasonable and unworkable to expect clients to navigate the service system and the range of providers they may require at any one point in time. Collaborative approaches between service providers and professional experts have been shown to be an effective means of providing education and assisting with the coordinated provision of services.

In addition to palliative care workers not comprehensively understanding MND, there is evidence in the literature that people with MND do not understand the role or purpose of modern day palliative care. Reports of patient's impressions suggest that palliative care is considered to be end-of-life care and is associated with the loss of hope and imminent death, rather than the provision of practical support and specialist health care throughout the progression of the disease.

### Interviews

The need for palliative care service providers to receive ongoing education in MND was highlighted in interviews. Palliative care staff emphasised the need to have a good understanding of MND and the needs created by the disease. In particular, a clear understanding of the rapidly changing nature of the disease, and the emerging needs as it progressed, were highlighted. Because most palliative care staff had had little if any experience with MND, they raised the need for current knowledge of the disease and the ability to easily and regularly receive ongoing support and updates. A commonly-held view was that there could never be enough education, with staff of the opinion that ongoing training would allow them to better deal with their own fears and lack of knowledge, ultimately removing barriers between people with MND and palliative care.

Access to specialist staff was raised, with palliative care staff wanting the ability to access both local peer support and experts in MND. The lack of confidence and knowledge in caring for people with MND was noted by carers with some interview participants recalling incidents of inappropriate remarks or actions by palliative care providers.

During interviews with carers and people with MND it was openly acknowledged that the majority of people had very little, if any, knowledge of palliative care with a common belief being that it dealt solely with end of life.

## Enhancing service provision

### **Adequate education of palliative care workers in MND:**

On-going education of palliative care staff, particularly at the time a service is working with a person with MND, is essential for quality health care. The satisfaction with palliative care services will be improved with confident, well-informed staff, resulting in improved outcomes for MND clients.

### **Early and comprehensive information to people with MND and carers about palliative care:**

Interviews indicated that there is limited accurate knowledge in the MND community about palliative care services, with the diversity between services across Victoria further confusing the issue. The general belief is that palliative care services are only involved with end-of-life care.

### **Expert and peer support for palliative care workers with MND clients:**

Timely access to expert and peer support for palliative care staff is likely to reduce the anxiety and fear associated with treating people with an uncommon condition. Expert support is available through Calvary Health Care Bethlehem and the Victorian Respiratory Support Service (VRSS). A mechanism for palliative care workers caring for clients with MND to support each other and exchange information would reduce the isolation felt by many.

## Discussion

Education needs to be done on two fronts; the palliative care workforce needs appropriate education regarding MND and the principles of managing people with MND, while clients with MND and their carers need to be informed about the modern role of palliative care and the practical and specialist help it is able to provide. Importantly, education needs to be available on demand, such as when a client with MND is referred to a palliative care service that has not cared for someone for a period of time. Education materials need to be updated at regular intervals to ensure the latest information is included. An important component of the education will be the framework developed as part of this project. People with MND and their carers need to be made aware early about the role that a palliative care service can provide. From the interviews, it was apparent that opinions about palliative care vary widely in the community and it is not until people have first hand experience or hear of others' experiences that their perceptions change and they become willing to invite the palliative care provider to become part of their management team. Education of people with MND would aim to provide a positive and realistic idea of the practical assistance and specialist healthcare that palliative care can provide, while carefully describing the boundaries of its role, the mechanism of accessing the service and its place in their team of providers.

## Recommendation

A comprehensive education and support program be developed for palliative care staff involved in the care of people with MND by 30 June 2008. The program needs to include funding to establish, promote and maintain links between palliative care providers and (1) MND specialist centres and (2) palliative care services with experience and expertise in treating people with MND, an education and training package on MND for palliative staff when a service has a MND client and education about palliative care services for clients with MND and their families and their treating clinical staff.

## Key worker and service coordination

### Literature review

After diagnosis, people with MND may find themselves negotiating an often inflexible, occasionally expensive and sometimes disjointed healthcare system, while coping with the trauma of a recent diagnosis. They must simultaneously come to terms with the prospect of reduced life expectancy, reduced income as their ability to work diminishes, confusion about help and support mechanisms, the disappointment associated with their lost future and fear for their family.

Compounding this experience for carers is the lack of communication and coordination between health and social service providers creating a further barrier to adequate care because of the resulting delay in providing services to people with MND (Motor Neurone Disease Association 2002). Hospice workers have also reported that communication problems were of concern and contributed to problems managing people with MND (Carter, McKenna et al. 1998). A study of carers and former carers in Australia identified a range of issues that included the lack of ongoing coordinated care as a significant contributor to poor palliative care (Parker, Forster et al. 2004).

An Australian study of five carers for people with MND reported their desire for increased information about resources and how to access services in the early stages after diagnosis and the importance of a case coordinator experienced in the care of people with MND as integral to avoiding a “palliative care crisis” by anticipating future requirements (Dawson and Kristjanson 2003). The role of the key worker becomes one of maintaining clear communication of current and anticipated needs with all service providers involved in the management of the client in order to deliver optimal palliative care.

Carers reported that health professionals often waited for families to ask about end-of-life care and this discussion therefore began too late in the disease trajectory (Dawson and Kristjanson 2003). Investigators have shown that effective and timely communication among health professionals is an important factor in realising a patient’s wish of staying at home while receiving optimal care.

A coordinated approach with effective communication and liaison between health professionals, regardless of the setting in which the clients find themselves, is proposed as a mechanism to address some of the concerns of both health professionals and carers. The introduction of care coordinators or key workers associated with palliative care services is one approach proposed in the literature for realising coordinated palliative care of MND clients. This is seen to promote early referral because these patients face physical and social problems from the time of their initial presentation, thus benefiting from early referral to palliative care (Carter, McKenna et al. 1998).

A study from Ireland has shown that the introduction of care coordinators working with a multidisciplinary clinic structure, increased average survival time for people with MND by seven and a half months (Traynor, M et al. 2003).

## Interviews

The number of different providers and different health professionals involved in the care of someone with MND was highlighted by the carers, with reports of approximately 15 different people attending a client's house each week. Consequently a lot of carers and people with MND interviewed reported being confused about who was from which service provider and what service they were providing. Further confusion was evident when one service either provided a similar or the same service as another provider or when they brokered the service to an external organisation. Some aspects of care provided by palliative care services are duplicated by other providers and clients with MND reported different entry requirements and processes for different palliative care services along with different models of care, all of which compounded the confusion.

The confusion regarding service provision was not isolated to the clients, service providers were also confused about who was doing what and when. Often no communication between providers was evident, with one client with MND receiving three wheelchair assessments and three wheelchairs all from different providers. The lack of coordination and effective communication due to the lack of a comprehensive overview of what is occurring and who is involved in each client's care was confirmed by palliative care workers and suggested as a component of increasing workloads and inefficiencies. The presence of a coordinating worker role was also seen as a mechanism to facilitate appropriate and timely referral to palliative care providers when the need arises.

## Discussion

A possible explanation for the frustration of carers and people with MND in managing the vast range of providers and the confusion between providers about the function and limits of the boundaries is the combination of the rarity of the disease and the processes in the current health system that provide efficiencies for common diseases that affect a large number of people. As the current system is not conducive to efficiently and adequately managing a rare disease that has an uncommon yet severe progression, there is a rationale for the management of these clients to be overseen. This role would enable a single point of contact for all palliative care providers, ensuring coordination of the current care and the ability to pre-emptively manage, through timely referral, future issues that would be appropriately managed by palliative care.

## Recommendation

A key worker model be developed, funded and implemented for people living with MND when receiving palliative care services in order to promote early referral, support development and delivery of education to service providers and co-ordination between service providers and families.

## Funding

### Literature review

An Australian case study reported the results of qualitative and quantitative data from nursing and personal care staff for the care of one terminal, but not acutely ill, MND client over a one-week period. This study showed that care of this client placed extraordinary demands on the nursing staff, with a total of 55.5 hours of nursing time devoted to this one client, which compromised the quantity and quality of care available to others (Zuch and De Bellis 1996).

Carers, participating in a qualitative study of Australian MND clients, reported that interactions with the health system were characterised for the most part by tension, varying levels of trust, uneven amounts of information sharing, and a sense of struggling to achieve what was needed for the individual with the illness. In addition, these carers, when discussing hospitalisation issues, reported problems obtaining appropriate care due to a lack of resources or understanding of the condition by health care workers (Dawson and Kristjanson 2003).

### Interviews

Palliative care worker representatives from both inpatient and community settings indicated that while most clients with MND do not use substantially more or less resources than any other client, there are a small proportion of people with MND that require an excessive amount of staff time in order to assist with issues such as communication, swallowing, showering and toileting and this level of support can be required for an extended period of time in some cases.

Inpatient palliative care representatives highlighted that current nursing levels meant a person with MND who required appropriate, yet-time intensive, care may be restricting the availability of staff to meet the needs of other patients. Because of this scenario, one inpatient facility has restricted the number of clients with MND able to access their service. The same inpatient facility has encouraged patients and carers to pay privately for additional support that the service cannot provide.

Community palliative care services expressed concerns regarding the length of time an MND client will require their services and the amount of counselling and complementary therapy resources that will be used. Community palliative care services indicated they were reluctant to deny or stop clients accessing these services while registered with the service due to their importance in establishing and maintaining quality of life through discussion and involvement in life affirming activities.

Key palliative care informants supported representatives' comments that funding was required in those cases where people with MND required higher levels of support or extended periods of support that were beyond the financial capacity of the palliative care service to provide.

### Enhancing service provision

#### Targeted funding for MND clients with high needs:

There is currently a gap in funding for service delivery when resource allocation and usage for a person with MND is greatly in excess of the average client. This applies to both inpatient and community care. It limits access to palliative care services for people with MND. Needs of an MND person that are in excess of the average client create an unequitable service for all other people receiving services from that palliative service and, at the same time, reduce the likelihood of future MND clients obtaining access to the service.

## Discussion

The interviews revealed that a significant barrier to palliative care for people with MND is the excessive resource use or high needs for a small percentage of clients. The ability for services to access one-off additional funding, to “buy” additional staff/resources to provide patients with MND access to essential health worker time, will improve the outcomes for people with MND and other patients also accessing care from an organisation.

### Recommendation

The establishment of guidelines and a suitable mechanism to provide supplementary funding for inpatient and community palliative care services to meet identified high-care and ongoing needs of people with MND.

## Respite care

### Literature review

The limited range of respite options was one factor that Australian carers and former carers of MND clients identified as a significant issue in the care of their loved one (Parker, Forster et al. 2004). Retrospective studies of people with MND admitted to respite care have shown that as a result of respite, symptoms were better managed through medication adjustment, patient communication was improved through identification of deficiencies and emotional support was provided to both patients and their carers. These outcomes were of significant value to clients and carers and the belief that this would lead to increased and long-term inpatient care were shown to be unjustified (Hicks and Corcoran 1993). Despite this evidence, more recent reports have shown that clients with MND are referred comparatively less often than cancer patients (O'Brien, Welsh et al. 1998).

A qualitative study of five carers of people with MND reported difficulty gaining access to respite. These people reported that their lives were on hold and their time was completely occupied with their role as a carer with them experiencing loss in a number of areas: social networks, spouse and companion, retirement years and dreams (Dawson and Kristjanson 2003). A cross sectional study of 98 people with MND in the United States showed that despite having home care assistance, carers provided a median of 11 hours per day caring for their loved one, which resulted in physical and psychological ill health (Krivickas, Shockley et al. 1997).

Other studies have shown carers of people with MND demonstrate signs of anxiety and depression and major components of the burden of care caused by physical and emotional ill-health and personal and social restrictions (Goldstein, Adamson et al. 1998; Hecht, Graesel et al. 2003). The steadily increasing need for physically demanding care and the decreasing possibility to carry on social relationships as well as the caring may steadily increase the two most important burden components and therefore the total burden of care.

### Interviews

Carers expressed strong views that access to appropriate respite care, both in-home and residential, was important to support and maintain their caring role. Carers expressed many incidents where the inability of residential respite services to adequately care for their loved one resulted in the person with MND not wanting to use respite again and, consequently, placing extra physical,

emotional and psychological burden on carers. The provision of in-home short-term respite, while helpful, is not an adequate replacement for residential respite where the carer is able to achieve an extended break from their caring role. Overall, carers were frustrated with the limited number of places available for residential respite, the lack of awareness of MND, and the skills and time needed to adequately care for someone with MND.

### Enhancing service provision

The lack of appropriate respite was identified by providers, carers and people with MND as a key issue. Maintaining the role, health and wellbeing of the carer is essential in effective management of people with MND. People with MND want to live and die at home. This is only possible if appropriate, regular respite is available for the carers.

#### Recommendation

The Department of Human Services recognise the importance of timely access to appropriate respite for people with MND and their carers in order to reduce the significant and rapidly growing burden imposed by this disease. In addition, the Department of Human Services recognise the needs of people with MND in all future policy decision concerning access to respite care.

## After hours support

### Literature review

Clients of palliative care services, who have access to after-hours support, report higher levels of satisfaction with the service provider, even when they do not use the after-hours support service. In an analysis by the Department of Human Services of four satisfaction surveys conducted with all palliative care clients in Victoria, the average decrease in satisfaction for people who did not have access to after hours support was 5.1% (Department of Human Services, unpublished data).

### Interviews

The findings from the literature were reiterated by carers and people with MND, who highly valued availability of after-hours support. They commented on the reassurance and confidence that after-hours access to people knowledgeable about the specific client and condition offers. This service was not commonly used, but interviewees noted and highly valued the peace of mind created for carers.

#### Recommendation

The Department of Human Service give specific consideration to the needs of people of MND and their families when considering future policy decisions regarding funding and access for after-hours palliative care support.



## Summary

The lack of an existing framework to describe the integration of palliative care into the management of MND clients that is suitable for implementation in Victoria has resulted in the project proposing a model for a framework. The framework is based on published reports from researchers exploring specific aspects of palliative care and their relevance to people with MND and their carers and family. It is supported by the evidence provided by palliative care workers, people with MND and their carers. The areas of adequate education and access to respite care were identified by people with MND and their carers as gaps that resulted in difficulty accessing palliative care.

The often poor communication and coordination between service providers, and between service providers and families, and the restrictions that some clients with very high needs pose on palliative care services, were described by health care professionals and families as issues preventing access. This report has attempted to combine these findings in a logical and practical manner to provide a framework arranged in terms of patient issues and decision-making considerations for appropriate referral. This project will need to be supported with future action so that clients with MND and their carers and families are able to receive the specialist healthcare and practical support that palliative care is able to offer.

## Map for integrated care

Health professionals need to consider a number of factors when making a referral to another service. In particular, consideration should be given to the length of a waiting list, whether the client has a current relationship with a provider that is able to meet the current need, the preference of the client (including the preference for a private provider), the rate at which the client's symptoms are progressing and the complexity and urgency of the client's needs.

### Key

Service provider	Code	Service provider	Code
MND Victoria	MNDV	Comtec	CT
MND Clinic at Bethlehem	MNDC	Home and Community Care Services	HACC
Occupational Therapy	OT	Residential care service	RCS
Specialist Neurologist	N	Inpatient palliative care	IPC
Social Worker	SW	Calvary Healthcare Bethlehem	CHB
Aust Centre for Grief and Bereavement	ACGB	Pastoral carers	Past
Palliative Care Service	PC	Case Managers	CM
General Practitioner	GP	Acute Hospital	Hosp
Victorian Respiratory Support Service	VRSS	Lawyer	L
Respiratory Physician	RP	Financial Advisor	FA
Dietician	D	Relationships Australia	RA
Public Advocate	PA	Community Health Centre	CHC
Neuropsychologist	NP	Grief Line	GL
Centrelink	C	Aids and Equipment Purchase	AEP
Department of Veterans Affairs	DVA		

## Integrated care

Client needs and outcomes	Required service	Key provider/s
<b>Information</b> Client, carer and family are confident, well informed and able to participate in decision making.	MND in general	MNDV
	Diagnosis	N, MNDC
	Aids and equipment	OT, MNDC, MNDV
	Respite	MNDV, MNDC
	Support at home	MNDV, SW
	Grief and loss	ACGB, MNDV, MNDC, PC
	Quality-of-life activities	MNDV, PC
	Respiratory support	MNDC, GP, VRSS, RP
	Pain management	MNDC, GP
	Mobility	OT, MNDC, MNDV
	Speech	SP, MNDC
	Swallowing	SP, MNDC D
	Psycho-social support	SW, MNDC, MNDV, PC
	End-of-life issues	PC, MNDC, MNDV, PA
<b>Assessment</b> Client receives timely and thorough assessment of needs by informed health professionals.	Disease progression	MNDC, N, GP, VRSS
	Aids and equipment	OT, MNDC
	Psychosocial wellbeing	MNDV, SW, NP, MNDC
	Respiratory function	MNDC, VRSS, RP
	Speech and swallowing	SP, MNDC, D
	Daily living activities	OT, MNDC, MNDV, PC, ACAS
<b>Counselling</b> Clients equipped with skills to address current and future concerns that impact on their emotional wellbeing.	Financial and/or legal	C, L, FA
	Relationship	RA, CHC
	Family	RA, CHC
	Personal	RA, CHC
	Bereavement	PC, GL, ACGB
<b>Equipment</b> Equipment enabling safe participation in activities.	Mobility and living	MNDV, PC, AEP, DVA
	Respiratory support	VRSS
	Communication	CT, MNDV
<b>Personal care</b> Clients accessing personal and home care for appropriate needs.	Support in the home	DVA, RDNS, PC, HACC
	Facility based	RCS
	Inpatient	Hosp, IPC
<b>Respite</b> Clients access appropriate accommodation at appropriate times.	Holiday	MNDV
	Home based	CHB, PC
	Inpatient	CHB, VRSS, IPC, RCS
<b>Pain</b> Client's pain managed expected levels.	Management	MNDC, PC, GP, N
<b>Spiritual support</b> The spiritual needs of clients and families are explored and appropriate assistance provided.	Support, guidance and counselling	PC, Past
<b>Case management</b> The client receives services that are coordinated and form part of a holistic approach to care.	Case coordination and communication	MNDV, CM, PC
<b>Community engagement</b> The client is able to engage in desired community activities through appropriate education and support.	Involvement in community, family and friend networks	MNDV, PC, CHC

## Appendix 1 – Correspondence and semi-structured interview questions to people with MND and their carers



**MOTOR NEURONE DISEASE  
ASSOCIATION OF VICTORIA INC.**

Registered Association No. A7518

265 Canterbury Road  
Canterbury 3126  
Tel: + 61 3 9830 2122  
Fax: + 61 3 9830 2228  
Email: [info@mnd.asn.au](mailto:info@mnd.asn.au)

Postal Address  
PO Box 23  
Canterbury 3126  
Australia

Dear

Re: MND Pathway Project

Over the next few months MND Victoria will be working with the Department of Human Services on a project to develop an effective pathway to palliative care services for people with MND.

We would like input from people with MND and their family carers and people who have previously cared for someone with MND.

To collect this information interested members will be invited to participate in focus groups or telephone conference call(s) in early to mid August to share their experiences with palliative services.

If you would like to participate, please complete the attached form and return in the enclosed pre paid envelope by 6 August 2007.

When we have your completed form we will contact you regarding sessions dates and times .

For further information about the project please contact Liz Laffan Pathways Project officer on 0398302122.

A handwritten signature in black ink that reads 'Rodney Harris'.

Rodney Harris  
Chief Executive Officer  
27 July 2007



**MOTOR NEURONE DISEASE  
ASSOCIATION OF VICTORIA INC.**

Registered Association No. A7518

265 Canterbury Road  
Canterbury 3126  
Tel: + 61 3 9830 2122  
Fax: + 61 3 9830 2228  
Email: [info@mnd.asn.au](mailto:info@mnd.asn.au)

Postal Address  
PO Box 23  
Canterbury 3126  
Australia

7 August 2007

Dear

Thank you for your response to our letter regarding participation in the MND Pathway Project.

Given the excellent response to the teleconference option, we are now organising teleconference groups for both metropolitan and rural members.

The date and time of your conference is:

We expect each teleconference to run for approximately 90 minutes.

Your dial in number

Your Passcode is ####

To access the teleconference please:

- Call your dial in number
- You will then be prompted to enter your participant Passcode and press #
- If the conference has not started when you dial in you will hear music.
- Please stay on the line.

If you are unable to participate it would be appreciated if you would let me know in advance.

My contact details are: Phone 03 9830 2122 Email [pathwaysproject@mnd.asn.au](mailto:pathwaysproject@mnd.asn.au)

Regards

A handwritten signature in black ink that reads 'Rodney Harris'.

Rodney Harris  
Chief Executive Officer  
27 July 2007

## Semi-structured interview framework

### Carers telelink questionnaire

MND Pathway Project is looking at the pathways between MND and Palliative Care

The focus will be confined to assessing Palliative care services and your experiences

What is Palliative Care?

Definition The Palliative approach improves quality of life by providing pain and symptom relief, spiritual and psychosocial support. (WHO definition)

### Carers Questions

Date

Name

Role/Community Clarify whether inpatient or community

### Service Provision

What Palliative care services have you accessed services?

Which of these services have been accessed most frequently?

What is the average length of involvement with palliative care services?

### Details

How does/did the palliative care system work for you?

What processes needed to be followed to access service?

What is/was the communication process to inform those dealing with your case?

Is/was this effective?

### Issues

What issues did you have in accessing Palliative care services?

### What works

What aspects of the system work?

Why did they work?

What didn't they work?

What aspects of the system don't work and why?

### Blockers what are they?

What is the one major block in your view?

How would you address these blockers?

### What is helpful/useful?

What would you do differently to achieve the desired results?

Were you reviewed to see if the services provided were still appropriate?

Is there capacity?

## Appendix 2 – Correspondence and questionnaire to palliative care services



**MOTOR NEURONE DISEASE  
ASSOCIATION OF VICTORIA INC.**

Registered Association No. A7518

265 Canterbury Road  
Canterbury 3126  
Tel: + 61 3 9830 2122  
Fax: + 61 3 9830 2228  
Email: [info@mnd.asn.au](mailto:info@mnd.asn.au)

Postal Address  
PO Box 23  
Canterbury 3126  
Australia

Dear

MND Palliative Care Pathway Project

Over the next few months MND Victoria will be working with the Department of Human Services to develop a pathway to palliative care services for people with MND.

The project aim is to develop a pathway that will assist people with MND and service providers to better utilise services and support available through palliative care services. The project will also identify any additional financial implications associated with providing support for people living with MND. The report is to be finalised by November 2007. For your information is a brief outline of the project is attached

To inform the project and underpin the development of the pathway, a series of consultation is being held with palliative care providers around Victoria. It is imperative that the outcomes of this project incorporate the views and experience of palliative care service providers. We hope that you will be able to share your experiences of working with people with MND in your service.

The meeting for your region will be held at \_\_\_ on \_\_\_

It would be wonderful if your organization could be represented at the meeting and contribute your experience to this project. Please RSVP by 14 August 2007 to [pathwaysproject@mnd.asn.au](mailto:pathwaysproject@mnd.asn.au) if your agency will be represented.

To further inform the project, it would be appreciated if you could provide some information about people with MND and your service. In particular, we would appreciate advice on:

- the number MND clients you have supported over the last 12 months,
- the number over last 3 years, and
- the elements of your service that people with MND accessed eg nursing/pain management; spiritual support, complementary therapies etc.

I would appreciate it if you could email this information to me at [pathwaysproject@mnd.asn.au](mailto:pathwaysproject@mnd.asn.au) by 10 August 2007.

For further information about the project please contact Liz Laffan, Pathways Project Officer on 03 9830 2122 or 1800 80 6632.

Yours sincerely

Rodney Harris  
Chief Executive Officer  
27 July 2007

## Palliative services questionnaire

### Palliative Care Services Sessions

Interview Questions

Date

Name/Organisation

How many people with MND would be referred to your service annually?

(Hopefully this information will be provided as requested, before the meetings happen)

How many referrals rejected and why

Role/Responsibilities Inpatient/Community Clarify whether inpatient or community

### Service provision

#### Describe your model of service delivery to plwmnd

What services do you deliver to plwmnd?

Which of these services do plwmnd and their carers use most regularly?

What do you perceive are the needs of people with MND?

What is the average length of involvement with plwmnd in your service?

### Details

How does the system work now?

What processes need to be followed to access service?

What should trigger the referral of person with MND to your service?

What is the communication process to inform others dealing with the case?

Would you change this?

### Issues

What issues are raised in servicing people with MND?

### What works

What aspects of the system work?

Why do they work?

What doesn't work?

What aspects of the system don't work and why?

### **Blockers what are they?**

What is the one major block in your view?

How would you address these blockers?

What stops you eg organizational culture, staffing, resources?

### **What is helpful/useful?**

What would you do differently to achieve the desired results?

Are clients reviewed to see if the services you provide are still needed/appropriate?

Is there capacity to terminate your service if it is no longer required at that time/no longer meeting the need?

Is there capacity to review a person's needs at a later date and reinstate or commence a service if deemed necessary?

What are the perceived differences between Rural and Metro if any?

## Appendix 3 – Palliative care sector leaders consulted

Discussions were held with the following:

### Individuals

Mr Kevin Larkins, Palliative Care Victoria

Professor Margaret O'Connor, Chair Palliative Care Australia

Mr Mark Cockayne, CEO, South Eastern Palliative Care

Dr Helen Austin, Palliative Care Physician, Caritas Christi Hospice

Dr Susan Mathers, Clinical Director Neurology, Calvary Health Care Bethlehem

### Agencies

Peninsula Health

La Trobe Regional Hospital

West Gippsland Health Care Group

Southern Health McCulloch House

Eastern Palliative Care

Calvary Health Care Bethlehem

Banksia Palliative Care Service

Caritas Christi

Western Health

Melbourne City Mission

Mercy Western

Bendigo Health

Loddon Mallee Palliative Care

Barwon Palliative Services

Wimmera Health Care group

Ballarat Health Service Gandarra Palliative Care

Ballarat Hospice Community Care

### People with MND, Carers and Former Carers

40 participants living with MND, their Carers and Former Carers were consulted.

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