



MND Palliative Care Pathway

**Rodney Harris, MND Victoria
on behalf of G Anderson, J Arnel, H Austin, G Dalton,
C Duck, R Harris, J Kenwright, S Mathers, J Noonan.**

Palliative Care in Victoria



- **Community (in home) and in-patient**
- **Blend of hospice and palliative care beds in an acute hospital**
- **Open referral system**
- **Proximity to death not an eligibility factor**

Background



- **DHS project to assist:**
 - **Access to palliative care**
 - **Palliative care services manage and support**
- **Despite MND being a life-limiting illness there is uncertainty about**
 - **how and when to refer**
 - **palliative care services**
 - **the interface between palliative care and community services**

Governance and management



- **Governance**
 - Project managed by advisory group
 - Representing palliative care, MND and DHS
- **Management**
 - MND Vic and DHS undertook the project
 - Project officer at MND Vic

Methodology – Literature review



- **Literature review**
 - **Systematic review by Monash University**
 - **Combinations of key words**
 - **Identified 315 citations for review**
 - **30 were relevant for project**
 - **Hand search of MND Association library, Palliative Care Australia, Palliative Care Victoria and DHS publications.**

Methodology - Interviews/questionnaires



- **Face to face or via teleconference**
- **Individual and focus groups**
- **Interview – semi-structured format**
- **Population**
 - **People with MND, carers, former carers**
 - **Representatives from palliative care services**
 - **Key opinion leaders in palliative care**

Findings – Framework for integrated care



- **No existing reported pathway providing coordinated integration of palliative care**
- **Lack of understanding and knowledge of the sector (MND client).**
- **Good support when linked with palliative care (carer)**
- **Referrals not timely – model dependant**
- **Unsure where to refer for other services when accessing palliative care (PC staff)**
- **Palliative care becomes the sole provider – complete care – total responsibility (PC)**
- **Frustrated - lack of resources, skills and knowledge to meet needs (PC)**

Findings - Education



- **Clients indicate that clinicians do not understand MND**
- **Palliative care workers reported lower self confidence with MND clients than clients with other conditions**
- **MND requires specialist skills yet it is a relatively uncommon condition**
- **MND clients and carers do not have a clear understanding of palliative care**

Findings – Key worker



- **Inflexible, costly and disjointed healthcare system, uncommon disease**
- **Confusion by clients, carers and providers**
- **Lack of communication and coordination between providers results in**
 - **Delays in starting conversations about end of life care.**
 - **Less likely to remain at home**
- **Care coordinators to promote early and appropriate referral to palliative care**

Findings - Funding



- **Small proportion of MND clients require extensive amounts of care – may compromise the quality and quantity of care to others**
- **Inpatient services – communication, swallowing, showering, toileting**
- **Community palliative care services – amount of counselling and quality of life therapy and services**

Findings – Respite care



- **Limited range of respite options – significant concern**
- **Limited places, lack of awareness of MND and lack of skills and time to care for someone with MND.**
- **Carers losing social networks, spouse and companion, retirement years and dreams**
- **Carers do a median of 11 hours per day – physical and psychological ill health**
- **Carers want access to in-home and residential respite from their carer role.**

Findings – After hours support



- **Clients who have access to after hours support report higher satisfaction levels associated with palliative care.**
- **Presence of after hours support provides confidence, reassurance and peace of mind even though it is rarely used.**

Recommendations



- **Development of a framework document**
- **Develop a key worker model**
- **Develop and implement an education and support program**
- **Guidelines and mechanism for supplementary funding**
- **Importance of respite**
- **Policy on after hours support**

DHS response



- **2008-09 state budget - \$400,000 recurrent funding provided to MND Victoria**
- **Targeted to 3 initiatives**
 - **Shared Care Workers**
 - **Top Up funding**
 - **Education**

MND Shared Care Worker



- **Each DHS Consortia**
- **Roles in direct care and secondary consultation**
- **Promote early referral**
- **Coordinate care**
- **Provide education**
- **Commenced 1 January 2009**

Top Up Funding



- **Inpatient top up funding source**
 - **Flexible funds to increase resources for clients with high and complex needs**
- **Community top up funding source**
 - **Flexible funds for the provision of longer access to activities, assets and therapies to improve quality of life.**
- **Commenced August 2008**

Education



- **To up-skill MND Shared Care Workers**
 - about MND
 - adult training techniques
- **To educate palliative care staff**
- **To inform people with MND and Carers**
- **To include development of facilitator's kit and information**

Implementation



- **Development of process for top-up funding**
- **Funding available from 25 August 2008 and being accessed**
- **Discussions with consortia re shared care workers**
- **Clarification of role and responsibility**
- **Commenced 1 January 2009**

Implementation



- **Training of shared care workers in February 2009**
- **Attendance at National MND Conference in June 2009 funded by MND Victoria through Nina Buscombe Awards**
- **Facilitator's manual and information booklet for palliative care staff and people living with MND finalised by September 2009**

Impact – Shared Care Workers



- **As at 30 June 2009, all eight MND Shared Care positions filled**
- **Have some direct caseload**
- **Primary and secondary consultation**
- **Provided 38 training sessions with 266 people attending**

Impact – In Patient Top Up



- **25 applications received**
- **All approved – \$66,000 provided**
- **Invested in additional staffing resources**
- **“I could commit time to the patient who needed time, because I was not required elsewhere”**

Impact – Community Top Up



- **28 top up applications**
- **All approved - \$54,500 provided**
- **Support included massage, respite, travel, building a pergola, flat screen TV and Foxtel**
- **“It is great seeing him have his mates around, watching the football, and enjoying life. They look after him. I go out!”**

Impact – the numbers



- 40 new referrals to palliative care
- 60 (Q3) and 65 (Q4) receiving support
- 109 client specific inquiries from staff to Shared Care Workers and 71 general inquiries
- 25 inquiries re Top Up funding
- 6 presentations to people with MND

Conclusion



- **Research based service initiative funded!**
- **Support palliative care services, recognising importance of input**
- **Recurrent investment in palliative care services**
- **People with MND living better**
- **Palliative care - a quality of life service**

Web Information



- Interim Report – www.health.vic.gov.au/palliativecare/mnd-report.pdf
- MND Victoria – www.mnd.asn.au
- Thank you to people living with MND, carers, palliative care staff and the reference group for informing this project