

Motor Neurone Disease Shared Care Worker Gippsland

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August 2010

Outline of presentation

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Background to the project

- In July 2007, the MND Vic Pathways Project was established to develop a framework to assist:
 - people with MND to access palliative care services
 - palliative care services to manage and support people living with MND

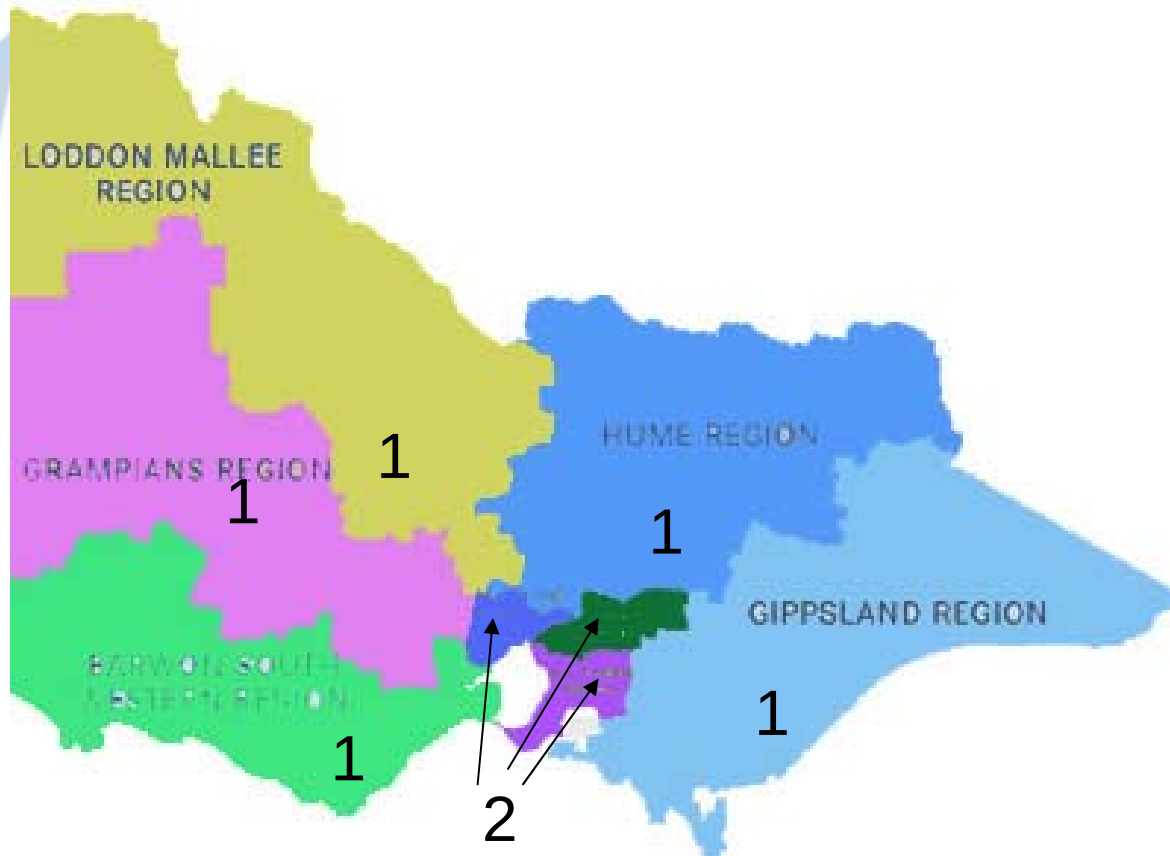
Funding

- The funding for SCW's is a recurrent grant from the Department of Health to MND Victoria.
- \$435,140 indexed (4.3%%) funding 2010/2011
- \$184,935 to fund 8 Shared Care Workers SCW
 - \$16,812 for rural & \$33,624 for Metro SCW rounded off by MND Vic to \$17,500 & \$35.000
- \$184,000 to provide in-patient and community top up funding (\$92.000 each)
- The remainder to cover MND Victoria costs

Introduction to the MND Shared Care Worker Role

- Role commenced early 2009
- Each Palliative Care Consortium has a MND Shared Care Worker funded.
- Employed by Consortia
- 3 metropolitan – 2 days per week
- 5 rural – 1 day per week
- The majority are nurses and currently work within palliative care services

Regions



Education

- MND SCW received an initial 2 day training @ Calvary Health Care Bethlehem and MND Vic
- Twice yearly training and meeting with key staff of MND Victoria, other SCW's and MND Vic Regional Advisors
- Attended National and local MND and Palliative Care conferences

Aim of SCW role

- Support patients with MND, their carers and health professionals
- Provide training and education about MND and palliative care
- To coordinate the access to palliative care services
- Develop close relationships with Regional Advisor and Calvary Health Care Bethlehem

The MND SCW role

- Appropriate to identified regional needs
- Supports community palliative care services through ongoing support and information
- Promotes early referral
- Supports palliative care staff to assist clients with decision making
- Participate in joint home visits with RA to assist clients to make decisions about palliative care

The MND Shared Care Worker Gippsland

- Covers Gippsland Region Palliative Care Consortium
- Shared position 1 day per week.
- MND Vic funds the Gippsland Regional Palliative Care Consortium to employ the SCW
- Based at and employed by the West Gippsland Healthcare Group Palliative Care Service in Warragul, West Gippsland who provide accountability and supervision

The Gippsland Team

- Jane is a WGHG District Nurse and has palliative care and education qualifications
- I am one of two WGHG palliative care team leaders, and have a Graduate Certificate in Cancer/Palliative Care Nursing @ La Trobe University
- Jenny Waites MND Vic Regional Advisor

How did we promote the role

- Gippsland is a vast and varied area
- We needed to introduce ourselves and our role to health professionals.
- We sent flyers either electronically or by mail
- We wrote articles in the Gippsland Region Palliative Care Consortium Newsletter and utilised any opportunity to promote the role (and continue to do so)



Introducing Toine Bovill & Jane Law MND Shared Care workers for Gippsland



**Support Information
Professional Development
To Health Professionals in the community
Caring for Motor Neurone Disease Clients requiring Palliative Care**

Please contact us at
West Gippsland Healthcare Group
Palliative Care Service
5623 0870



Challenges

- Geography/distances to travel
- Demand (for time) may exceed funding
- Maintaining clarity of roles
- Each palliative care team provides a different range of services through different models of care
- How to best distribute information to health professionals caring for patients with MND

Challenges for the SCW

- Time constraints for both SCW and RA
- Coordination and communication with many support and care services involved in the patient's care
- Geography
- A new position delivering a new concept

Challenges for the patient

- For the patient and carer - another person involved in the care team
- There is no hospice in Gippsland
- Respite is offered in aged care facilities regardless of age of patient

Dealing with the challenges

We held two MND Forums for health professionals caring for patients in South Gippsland and East Gippsland.

- We showed a DVD on MND
- Presented a “no frills, nuts and bolts” power point presentation on MND and the challenges faced by patients, carers and health professionals
- Displayed a variety of DVD's and books to highlight the issues that patients with MND and their carers face
- Activities to highlight communication & swallowing issues
- 60 and 40 health professionals respectively attended these no cost forums

Positives

- Stronger links and relationships between MND Victoria and palliative care staff and Calvary Health Care Bethlehem and other service providers
- Case management meetings for complex patient care
- Ease of access to funding
- Home visits by SCW to address apprehension about palliative care referral

Positives

- Increased knowledge and understanding of complex care needs, resulting in high quality care
- Information and support to palliative care staff empowering them in caring for MND patients with all their complexities
- Individualised approach
- Increased referrals to palliative care services at an earlier stage
- Increased confidence of Regional Advisor to promote palliative care

Outcomes of the project

- SCW and RA roles within the project are better established and still evolving
- Increase in numbers of people with MND accessing palliative care at an earlier stage
- SCW's a key source of knowledge, support and referral
- Palliative care staff feel better supported when caring for people with MND
- People with MND have the best possible home based clinical and pastoral supports
- Access to funding resulting in additional care and services to people with MND
- Program developed for newly diagnosed to assist them to make care choices

Evaluation

- Quantitative evaluations/statistical data collected and submitted quarterly
- Qualitative data of stories from clients, carers and staff with their consent
- Evaluation forms from MND Forums

Data 2009-2010

• Number of MND Client referrals via SCW	58
• Quarterly average MND Clients accessing a palliative care service compared to 40 people receiving a service in 2006/07	86.5
• Enquiries from palliative care staff-client specific	366
• Enquiries from palliative care staff-general	105
• Enquiries re Top-Up funding	81
• SCW-direct care involvement	25.5
• Staff-Number of Presentations	66
• Number attending	1026
• People with MND-Presentations	9
• Number attending	30
• SCW-training/development sessions attended	32



Top up Funding

Top Up Funding – Community Based Services

- To promote quality of life and wellbeing
- 42 people funded in 2009/10

Eligibility

- 90 days post registration with palliative care service
- Up to \$2000 for quality of life services determined by the client
- Simple electronic application
- Average 2 business days response for funding

Community Top-up funding

Funded items have included in-home respite; massage; short holidays; flat screen TV; DVD player; airline tickets for compassionate visits; a pergola providing shade to increase participation at family bbq's and enjoy the garden; and creative software for a client to research his family history

- Must be linked to quality of life

Top Up Funding – In Patient Services

- \$1000 on day 1 of admission
- Further \$3000 on day 19
- Funding can be requested for each admission
- Simple electronic application - 2 day response
- Additional core services - nursing or allied health
- Funded 41 applications in 2009/10

References

- <http://www.mndcare.net.au/>
- info@mnd.asn.au
- Jenny Waites, MND Regional Advisor
- Mr Rodney Harris, CEO MND Vic
- *Talking about MND & Palliative Care, a Guide for MND Shared Care Workers.* (February 2009) MND Vic.
- www.gippslandtourism.com.au/Maps
- www.visitvictoria.com

Gippsland Region

**Palliative Care
Consortium**



South Gippsland



Gippsland Region
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