



Promoting confident caring and home based care for people living with MND

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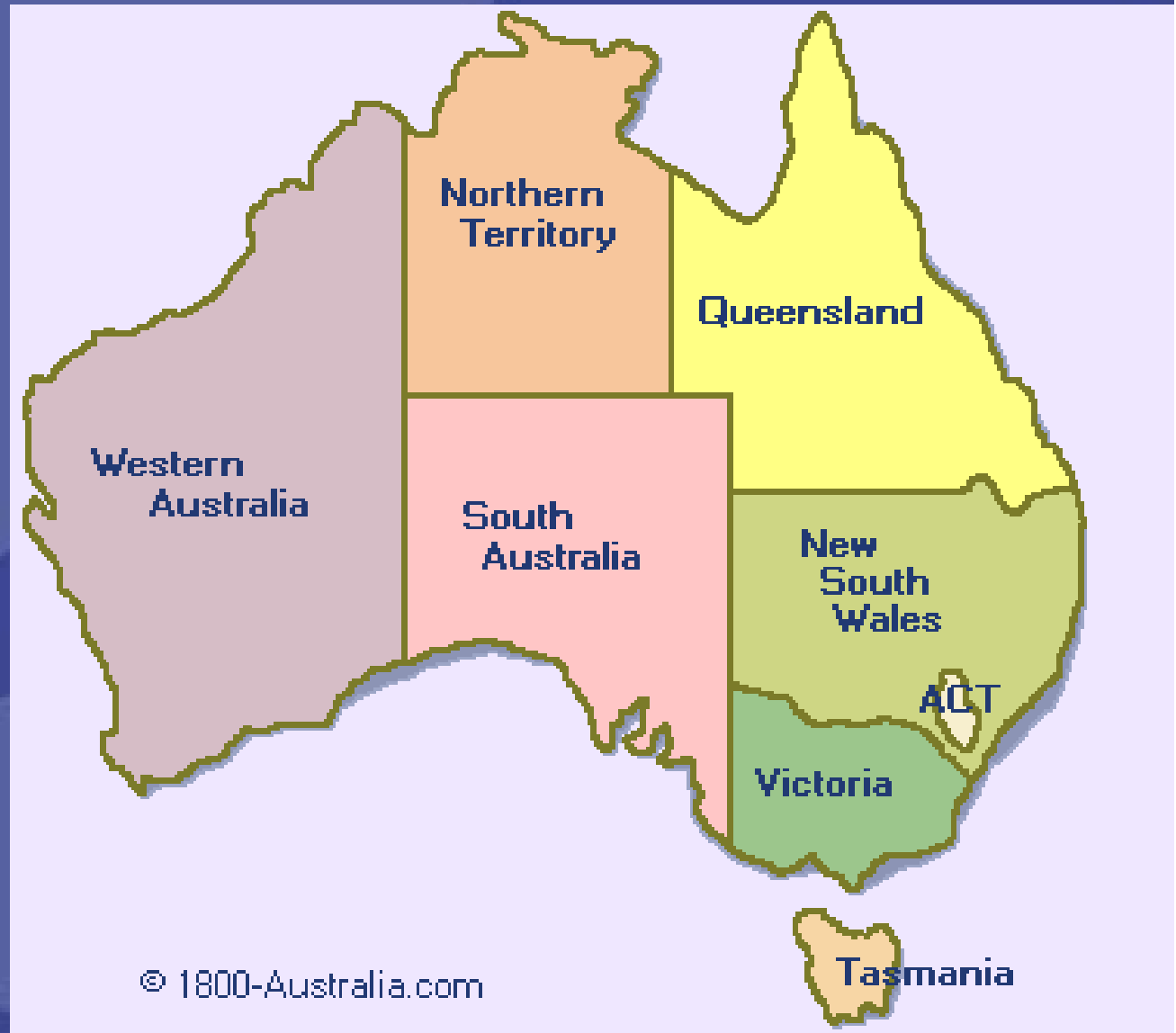
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Background

In Australia

- MND Australia
- MNDRIA
- 6 State MNDA's



Introduction to the Confident Caring Project

- Federal Department of Health and Ageing
 - Funding through Local Palliative Care Grants
- MND Australia application for funding
 - MND Qld, NSW and Brisbane MND Clinic
- Confident Caring Project
 - \$89,897 (ex GST)

Objectives

- To adapt existing MND NSW programs
- To provide programs to four specific groups
 1. People recently diagnosed with MND and their family and friends
 2. Family caregivers
 3. Health and community care providers including palliative care services
 4. Palliative Care volunteer visitors

What we did:

- Established a steering committee
- Employed a project officer in March 2008
- Developed a comprehensive orientation, mentoring and supervision program
- Reviewed and adapted MND NSW resources
- Advertised and promoted the programs
- Implemented the four programs

Information Evenings for people recently diagnosed their family and friends

- Two sessions were held in Brisbane
 - Introductions, overview of MND, impact of diagnosis and services available
- 40 people attended
- PowerPoint presentations developed

Feedback

- Evaluations confirmed:
 - Families valued these sessions
 - They need to be held regularly
 - Neurologists talk was highly valued
 - Time for introductions and informal discussion is very important

From the families:



“It was hard but important for me to see some other patients and families and getting an idea of what to expect”

“It was invaluable to meet others with MND”

“The most valuable part of the evening for me was learning what support is available for those with MND and also for family and carers”

Care for Carers

- Care for Carers course adapted
- Eight carers workshops were held:
 - Carers kit used for handouts
 - carers shared their experiences
 - helped link them to services
 - introduced the concept of respite
 - Support to access respite was provided
 - 30 Carers attended one or more

Feedback

- Evaluations and feedback confirmed:
 - Combining emotional and practical advice works well
 - Close bond develops within the group
 - Carers need to be encouraged to attend
 - Health professionals become more aware of the needs of MND carers

From the carers:

“there should be more of these available ..there have been lots of answers to many of my questions”

“A great introductory session ...it has helped me lose a lot of fear ..i would like to meet monthly for support from other carers”

“This course is wonderful because it brings carers together and I get tips from them to help me, we share ideas. Each course expands on the previous one”



Mmm... massage for our hardworking carers

Thanks to Karuna volunteers!

Education for health and community care providers

- 21 professional MND sessions to:
 - eight specialist palliative care services
 - three aged care services
 - 10 community care services
- Approximately 700 health and community care providers in total

Feedback

- Evaluations and feedback confirmed:
 - The value of health professional education
 - The need for more time and information
 - The need for professional MND education for health and community care providers on a regular basis
 - The need for a DVD relating to a person with MND

From the service providers:

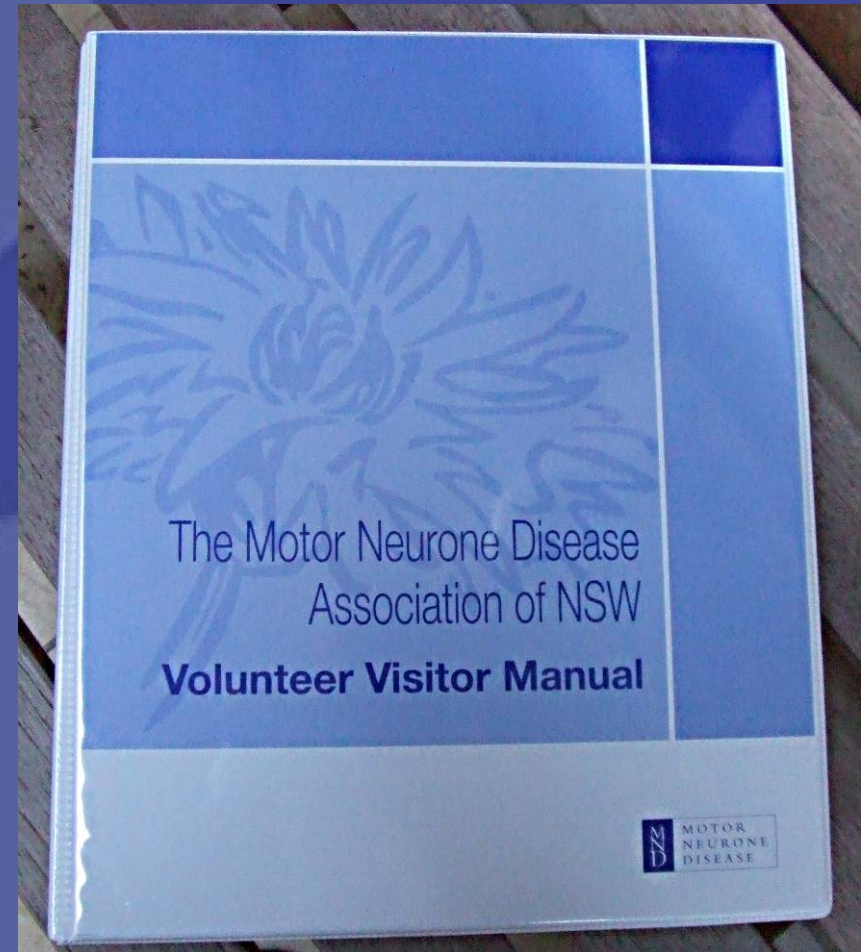
“I found the session very informative ..it will change how I care for people with MND in the community”

“We need continued delivery of MND education offered in flexible ways”

“ “We need more of this type of important information ... we’ve been in the dark about how to care for people with MND for too long”

Palliative care volunteers

- One day model was developed for Qld
- Three volunteer visitor education days
 - Five palliative care services involved
- 46 palliative care volunteers attended



Feedback

- Evaluations and feedback confirmed:
 - Value of the MND specific education and training to support existing PC volunteers
 - The need to include a mix of presentations, experiential and to cover emotional impacts
 - Need for as DVD depicting a person with MND

From the volunteers:

“Thank you – Monika was informative, helpful, sensitive and honest – I had no idea that MND was so horrible”

“Thank you MND Association for providing this training. Very much needed and long overdue – keep up the good work”

“Excellent – a valued experience”

Volunteer Training - Karuna



24th February, 2009

Have we built capacity?

In Brisbane and surrounding regions:

- Increased understanding of MND in the community to support home base care

The project:

- Demonstrated value of partnerships
- Developed a range of resources for MNDQ
- Established Information Evenings
- Provided Queensland specific evidence of unmet need

Recommendations

- There is no need to reinvent the wheel
 - share resources and create partnerships
- It takes time to establish interest and trust in new programs
- Flexibility is key
- MND specific information and peer support helps to increase confidence
- Funded pilot projects have been vital in MND association program development



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