MND Volunteer Visitor Pilot Project
(VVPP)

Final Report

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Executive Summary -Volunteer Visitor Pilot Project

Background:
Commenced July 2003 and completed in March 2006
The Motor Neurone Disease Association of NSW Inc

The Motor Neurone Disease Association of NSW (MNDA NSW) is a registered charitable not for profit organisation established in 1981. The Association provides information, education, support and equipment for people with MND and their families throughout NSW and ACT. MNDA NSW also promotes best practice care and support for people living with MND through the provision of information, education and support for the health and community care providers involved in their care.

A comprehensive needs assessment conducted in 1997 identified that people with MND wanted to be cared for in their own community by people who understood MND. Ongoing feedback from people with MND identified that they needed more support. Volunteers could provide the type of support required; however, very few people with MND were able to access volunteers. Due to the varying lengths of time from diagnosis to death, and the constraints on palliative care services, people with MND are only usually able to access palliative care services and volunteers in the later stages.

Other MND Associations have well-established friendly volunteer visiting programs to augment the roles of the Regional Advisors. Also past carers often approach the Association wanting to support others with MND. MNDA NSW did not have the capacity to initiate and maintain such a program. MNDA NSW family support staff attended the MND/ALS International Symposium in November 2002. A number of the papers presented and the discussions with MND Association staff from around the World confirmed the value of specially trained Volunteer Visitors for people living with MND.

Feedback from palliative care volunteers indicated that they found supporting people with MND particularly difficult. The myriad symptoms of MND supported the need for MND specific education. Feedback related to difficulties in establishing a meaningful relationship with a person with MND who has speech difficulties highlighted the need for volunteers to meet the person in the earlier stages.

Project Objectives:
The objective of the pilot project was to establish an MND Volunteer Visitor program in the Newcastle/Hunter/Central Coast regions and to pilot a model of recruitment, education and ongoing support from the MNDA Regional Advisor. The development of an MND Resource Manual was also a primary objective of the project. A secondary objective was to develop a bereavement protocol to enable MNDA NSW to better support carers during the bereavement period.

Methodology:
Volunteers from MNDA NSW membership, MND support groups and local community were recruited from the regions, interviewed for suitability and enrolled in the program. Local Coordinators of Palliative Care Volunteers were invited to identify interested palliative care volunteers to also participate in the MND Education Program. An education program was developed and held in Newcastle. This included three MND specific education sessions for all volunteers and two sessions on volunteer policies and procedures and introduction to the MND Volunteer Visitor project for MND volunteers only. Following the education program people with MND in the area were contacted to elicit interest in receiving visits from the volunteers. Volunteers were then matched with suitable people with MND. The MNDA Regional Advisor (project officer) drew up a contract outlining the purpose of the visits and the types of support to be provided which both parties then signed. The Regional Advisor provided ongoing review of the visits and support. Regular peer support and education sessions were held for the volunteers.

Consultation with other MND Associations, palliative care bereavement services and bereavement counsellors assisted with the development of the Bereavement Flyer and protocol. MNDA NSW family support staff adopted the Bereavement Protocol. The Bereavement Flyer has been included

with the condolence letter sent following the death of a person with MND and a condolence card sent at 12 months, if appropriate, since January 2004.

Evaluations have been conducted throughout the project to elicit information related to the education program and to measure the satisfaction of the volunteers, person with MND and their carer with the volunteer visits. The volunteers were also surveyed to elicit their satisfaction with the support they have received from the Regional Advisor.

Results:
15 participants enrolled in the Education Program, these included seven MND volunteers and eight palliative care volunteers. Following the final MND session three of the palliative care volunteers enrolled as MND volunteers as well and completed the course. The education course was very positively evaluated and there was an overall demonstrated increase in knowledge related to MND.

Following the course five people with MND expressed a desire to receive visits from volunteers and four were matched up with a volunteer. Evaluation of the visits identified the potential for needs to change rapidly and for the visits to become inappropriate for the person with MND. This feedback highlighted the importance of the regular contact from the Regional Advisor to monitor the needs of the person with MND, the carer and the volunteer. Results of the surveys to elicit the volunteers feeling of support from the Regional Advisor were very positive. The regular meetings of volunteers, which provided the opportunity for peer support and ongoing education, were also rated highly.

All objectives identified in the initial project plan related to consultation and development were met. This can be demonstrated by the partnerships formed with the Coordinators of Palliative Care Volunteers, the interest from MND support groups in sustaining the project in the region and the successful development of the education program and the policies and procedures. Objectives identified related to recruitment and training were met and can be demonstrated by the recruitment of 10 MND volunteers and the successful implementation of the education program. Objectives related to the Volunteer Visitor stage were met. Volunteer visits commenced gradually as people with MND expressed a desire for visits. Satisfaction related to the visits and the support provided by the volunteers however varied. The objective to determine the benefits of the program and to demonstrate its sustainability and generalisability through evaluations and reports has been achieved. Funding has been established from the MND support group in Newcastle to progress the program in that region. The final report will be used to provide information on the project to the MNDA NSW Board and to assist with the development of the 2006-2009 Strategic Plan.

Fulfilling the objectives related to providing bereavement support for the MND carer and family for up to six months following death proved more problematic. A primary aim of the project was to introduce volunteers to a person with MND and their carer earlier in the disease trajectory. This was achieved, but had the unexpected outcome of impacting on the ability to pilot the efficacy of the volunteer providing support post death as none of the people with MND receiving visits has yet died. Informal feedback has confirmed the value of the Bereavement Flyer and the 12-month condolence card.

Discussion:
The major achievements of the project are the improved knowledge of MND within the palliative care services in the regions, the establishment of an MND Volunteer Visitor Program, the MND Education Program and Resource Manual for volunteers and other service providers and the establishment of a Bereavement Protocol for people with MND in NSW.

The breadth and depth of knowledge of the project management team was integral to the success overall of the project. The interest of the Palliative Care Services Coordinator of Volunteers and the MND support groups in the regions was also a major contributing factor to its success. The success of the Education Program was augmented by the knowledge and insights of the past MND carers who attended and shared their experiences of caring for a loved one with MND so generously.

The impact of 'adding on' the project to MNDA staff workloads limited the ability to meet the projects objectives on time due to increasing demands overall during the project. The reluctance of MND Volunteer Visitors to travel too far impacted on the ability to provide optimal opportunities for visiting. There have been times throughout the project when a volunteer has not been matched with someone to visit, as there was no one with MND in the area. It is anticipated that this will be an ongoing issue.

Initially there were concerns raised by the MND support groups that the project would duplicate existing services and impact on the time the project officer had for her existing Regional Advisor role. Distributing a fact sheet on the project and keeping the group informed of progress addressed this. Issues related to the expectations of the person with MND and their carer was highlighted through the satisfaction surveys three to six months post commencement of visits. One person with MND felt that the Volunteer Visitor's knowledge and the visits were 'inappropriate'. Terminating the visits and providing debriefing, support and feedback to everyone involved addressed this issue. Also, the Role and Procedures for Volunteer Visitors is now sent to people with MND and their carer prior to receiving visits from a Volunteer Visitor.

The Resource Manual will be sustained by extending its use to MNDA Regional Advisors, palliative care coordinators of volunteers and other service providers. The MND Education Program will be run again in Newcastle/Hunter in 2006 for new MND Volunteer Visitor recruits and existing palliative care volunteers. The MNDANSW Regional Advisor in Newcastle/Hunter will continue to support MND Volunteers and match them with interested people with MND as a need is identified.

The need to provide ongoing monitoring of visits and support and education for the volunteers is a valuable lesson for other MND Associations or organisations embarking on a similar project. MND Associations in other states, providing they had adequate resources, could replicate the project.

Information relating to the project has been disseminated widely to:

- MNDA NSW members through the quarterly newsletter "Forum"
- Communities in Newcastle/Hunter/Central Coast through the local papers and clubs
- Local service providers, people living with MND, carers, past carers through the focus groups
- Other MND Associations at the Annual National MND Family Support Networking meetings
- Newcastle and Central Coast MND Support Group
- Palliative Care Coordinators of Volunteers at their regular networking meetings
- Other palliative care services outside of the project area who have benefited from the education
- MND Special Interest E-Groups
- Members and stakeholders attending the official Launch of MND Week 2006

Papers or posters outlining the project have been, or will be, presented at arrange of conferences both nationally and internationally.

The National Palliative Care Strategy has three goals. The project has linked in with each of these goals firstly by improving community and professional awareness and commitment to the role of palliative care practices for people who are dying of Motor Neurone Disease. The education program and resource manual links in with the second goal as it supports continuous improvement in the quality and effectiveness of palliative care services for people with MND. The project links with the third goal, to promote and support partnerships in the provision of care for people who are dying and their families, through the provision of MND specific education by MNDA staff for palliative care volunteers and other service providers.

Conclusion:

From this project we can recommend that palliative care volunteers need MND specific information and education to assist them in their role when caring for a person with MND. We can also recommend that MND Volunteers are valuable additions to the provision of care and support for

people with MND earlier in the disease trajectory. These volunteers, however, must be adequately educated and supported to sustain them in their role.