Caring Communities Program - Project Overview

Organisation: Motor Neurone Disease Association of NSW Inc.
Name of Project: Motor Neurone Disease Volunteer Visitor Pilot Program
Length of Project: 2.5 years

Project Summary

To develop and implement an MND volunteer visitor program to maximise quality of life for people with MNS, their family and their carer to enable them to continue to be cared for in the setting of their choice and to provide ongoing bereavement support for the carer and family for up to six months following death.

Project Objectives

1. To determine the benefits and efficacy of a volunteer visitor program for people with MND, their family and carer and the volunteers.

2. To develop and implement a sustainable volunteer recruitment strategy and policy and procedure documentation.

3. To develop and implement an MND specific education program and training manual MND for volunteers including ongoing training and support on care issues related to people with MND and grief and loss.

4. To encourage and maintain close links between local palliative care services, MNDA NSW family support, volunteers and MND support groups.

5. To train volunteers to provide the types of care and support required by people with MND in the later stages to augment existing palliative care services and to ensure that they are adequately supported in their volunteer role.

6. To support carers in their caring role by recruiting past carers and/or training the volunteers to provide peer support in the later stages of the disease and up to 6 months following bereavement.

Project Activities

1. Meet with local Palliative Care Teams and volunteer coordinators to discuss training program, recruitment of volunteers and opportunities for partnerships and grief and loss training.

2. Identify suitable pw MND, past carers, MND support group members, key palliative care personnel and invite to focus group meetings to ascertain the types of support they seek from volunteer visitors.

3. Develop policy and procedures manual, MND specific training manual (modify existing Carers Kit), a PowerPoint training program, bereavement follow up protocol, evaluation tools and performance/outcome indicators.

4. Develop strategies to recruit suitable volunteers with local support groups, past carers and establish community interest.

5. Develop strategies to support the volunteers and ways to ensure ongoing communication with the MNDA regional adviser.

6. Implement a four week training program and implement the friendly visiting program.

7. Project team to meet regularly to discuss project, progress reports and final report.

Main Message

What you did

- Recruited, educated and supported 10 MND volunteers to provide support for people living with MND and their families in the Hunter/Newcastle/Central Coast communities
- Provided MND education to 6 palliative care volunteers to assist them to better support MND patients and their families in their communities
- Developed and published an MND Volunteer Visitor Resource Manual and facilitators kit
- Developed and implemented a Bereavement Protocol

What has been learned?

- Volunteers are key in supporting people with MND in the community
- Volunteers need appropriate support, education and resources
- Providing resources and network support to volunteers sustains their involvement

What is useful to other projects/communities?

- The education program and resource manual developed for this project can be used either directly or with some modification in other communities
- This will help reduce duplication and ensure a consistent level of MND knowledge for volunteers and other service providers across all communities
- This project has also improved the capacity of the community by ensuring a skilled, supported and well-connected group of MND volunteers
- The bereavement component can be used with some modification in other communities

What have been the benefits of disseminating information about this project?

- Dissemination through the media and the MNDA NSW newsletter of stories describing the important role of MND volunteers in the community has served to make more people aware of MND and its relevance to palliative care
- Dissemination through the palliative care volunteer coordinators networks has improved awareness of the importance of MND specific education for palliative care volunteers in their communities
- Dissemination through International and National conference presentations has highlighted to health providers the important role of MND volunteers for people with MND and the need for MND specific education for palliative care volunteers in their communities

What needs to happen in order to sustain the key achievements of this project?

- Maintain the support of the MND volunteers by maintaining the currency of the resource manual, liaising with volunteers and facilitating positive stories to the media and Association members about volunteering.

- A modest amount of funding to cover existing volunteer costs such as travel and telephone
- Funding through the Association and its local support groups to recruit and educate more MND Volunteers in the Newcastle/Hunter/ Central Coast regions and to establish the MND Volunteer Visitor Program in other areas of NSW
- Education for MNDA family support on how to initiate and promote MND specific education for palliative care volunteers in their regions using the MND Volunteer Visitor Resource Manual
- Other State based MND organisations to be informed about the MND Volunteer Visitor Resource Manual and MND Volunteer Visitor Program

What resources did you develop and are they available to others?

- A resource manual for palliative care services ordered through our website www.mndnsw.asn.au
- A Bereavement Flyer which can could be adapted for use by other MND Associations and is available from the MND Association of NSW Inc. 1800 640 144