# Helping Communities Care: Volunteer and Bereavement Support Networks

## Final Report

***A project funded***

***under***

## *The Caring Communities Program*

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| Project activities commencement date: | 12 January 2004 |
| Project completion date: | 5 May 2006 |
| Fund holder (auspice body): | Mid Western Area Health Service<br>Greater Western Area Health Service |
| Partner Organisation: | The Cancer Council, NSW |
| Name of service conducting the project: | Palliative Care Service |

# Executive Summary

## Background

Helping Communities Care: Volunteer and Bereavement Support Networks was an initiative of The Mid Western Area Health Service (MWAHS) now part of Greater Western Area Health Service (GWAHS), NSW Health. Project timeframe was 1st January 2003 to 30th April 2006.

Project managed by the Area Palliative Care Service.

The MWAHS covered an area of 55,000 sq km and was one of 8 rural health services in NSW. Lying west of the Blue Mountains, extending from Lithgow to Lake Cargelligo, and included 13 Local Government Areas. At the 2001 census thirty-six of the communities, which made up MWAHS, had populations less than 5,000 out of a total population of 164,683.

Specialist Palliative Care Services within the MWAHS have evolved over the last 15 years into an Area-wide consultative service. An integrated service model for Palliative Care and Oncology supports service providers in offering a palliative approach to care for people with advanced life limiting illnesses and their families.

Many small rural communities within the MWAHS lack the population base to attract a comprehensive range of services. Some rural villages and towns have no access to medical services and the primary health care service providers deliver the only health link. For those with a life limiting illness the ability to mobilise and 'shop around' for services is often difficult. Consequently, access is reduced to those who are likely to need services the most. This observation is supported by Medicare data that indicates those living in rural and remote communities access fewer services, and consult doctors less often than those living in metropolitan areas, and those in remote areas have higher hospitalisation rates.

Compounding this lack of services, there is often a lack of family to take on the role of caring, with younger family members migrating to larger regional or metropolitan centres. Rural communities also report social isolation, in particular when dealing with the experience of life threatening illness.

The above information was identified as key issues when developing the Mid Western Area Health Service *Strategic Plan for Palliative Care 2002-2004.*

## Project objectives

1 To develop and implement a model of volunteer coordination and bereavement support for rural communities, addressing the needs of people with advanced life limiting illnesses, their families and carers

2 To increase the support available to carers through the coordinated use of volunteers, assisting them in meeting the demands of their role as a carer, thereby enabling carers to exercise an increased control over personal health and well being

3 To reduce the feelings of social isolation experienced by people with advanced life limiting illnesses, by utilising a context specific volunteer program, with the potential to enhance these individual's Quality of Life

4 To enhance the capacity of Primary Health Care workers, both specialist and generalist to work with volunteers and communities to develop, implement and sustain the models of care that will be developed

## Methodology/Description

The project utilised a community development framework to guide its implementation. The target groups for activities included:

- Individuals with a life limiting illness, and their carers residing in a small rural community of less than 5,000 people and a major rural regional centre
- Primary Health Care Workers
- Specialist Palliative Care Staff
- Existing and potential volunteers

The following outlines the strategies utilised to meet the goals of the project:

1 Formal development of a partnership between the MWAHS and The Cancer Council, NSW (TCC)
2 Appointment of 'Caring Communities' Development Officer
3 Development of a Project Plan to guide the activities of the project
4 Establishment of a management group to guide and support the project
5 Review of current literature, resources and programs suitable for the project
6 Review current volunteer and bereavement activities within the communities of MWAHS
7 Focus group meetings in pilot sites to initiate the community development approach
8 Model development forum
9 Engagement of communities
10 Development of resources to support volunteers, clients, carers and primary health care workers
11 Pilot model
12 Evaluation of model, reorientation and implementation

A number of individuals played a leading role in the project. They included The Cancer Council, NSW staff, a peak volunteering body (Volunteering Central West) and GWAHS staff members employed within Population Health, Planning and Performance.

The main tool used for overall project evaluation was a tool developed by the Western Research Institute for the Regional Health Services Project within GWAHS. This encompasses need and goals identification, action planning, process and input evaluation planning, outcome evaluation planning and report writing.

## Results

| Expected project outcomes and contributions the project will make to community capacity | Actual Project Outcomes | Comments |
|---|---|---|
| A reduction in social isolation experienced by people with life threatening illnesses in rural areas | It is too early to state that this project has demonstrated a reduction in social isolation experienced by people with advanced life limiting illnesses | The literature states that trained and supported volunteers can make a positive difference to patients and their carers in terms of:<br>- Patient comfort<br>- Provision of information<br>- Practical care<br>- Emotional support<br>- Social support<br>- Reduction of stress |
| Improved carer health and wellbeing | It is too early to state that this project has improved carer health and wellbeing | |
| Increased input and support for bereaved families and carers | To date none of the volunteers recruited for this project have been involved in any bereavement volunteering | A Palliative Care and Bereavement Support Folder has been produced to provide support and access to information for those bereaved (following the death of an individual with an advanced life limiting illness) |
| Assessment and evaluation of available rural and remote models for bereavement support services and volunteers | Models were evaluated to assist with designing the project model | |
| Development of a comprehensive and sustainable model for both bereavement support services and volunteers throughout the communities of MWAHS | A comprehensive generic model for volunteer Palliative Care and Bereavement support has been developed. This model has the capacity to be adapted for local site use. | |
| Potential for model/s to be utilised in other rural and remote areas of Australia | As above | |

### Unexpected Outcomes

- Acting on recommendations from the project, The Cancer Council, NSW have demonstrated their organisation's commitment to supporting people with cancer by the creation of a funded position. This 2 year pilot position has dual roles:
  - Volunteer support and coordination within both The Cancer Council, NSW – Western Region and GWAHS
  - Navigation assistance for people with cancer by providing information and links to service providers

- Development of an extensive support information package (Palliative Care and Bereavement Support Folder) for volunteers, patients with advanced life limiting illness and their carers, and for people recently bereaved as a result of advanced life limiting illness

- Interest and requests from external agencies for the Palliative Care and Bereavement Support Folder (Aged Care facilities, Cancer Support Groups and Commonwealth Carelink Centre, Commonwealth Carer Respite Centre, The Cancer Council, NSW – Cancer Helpline)

- Volunteering Central West, as their core business, provide local mandatory training at no cost for a range of volunteers, and provided the mandatory training component for the Caring Communities volunteers

- The Caring Communities Project arranged access to the above mandatory training for other volunteers currently working within GWAHS who had not had an opportunity to complete this at a local level

- Development of a series of documentation sets for improved management and information systems for volunteers including:
  - Volunteer Training – Mandatory
  - Palliative Care and Bereavement training package (1 for trainers, and 1 for volunteers)
  - Volunteer recruitment
  - Volunteer coordination and ongoing management

## Discussion

The project has resulted in the development of a model of volunteer support for people with advanced life limiting Illnesses and those caring for them. It recognises death and bereavement as part of the Palliative Care continuum. Volunteers in this model are trained to provide support to clients and carers along the continuum and into the bereavement period.

For the past 12 months The Cancer Council, NSW has undergone a review of ways they can better support local communities. This review, in conjunction with the MWAHS Caring Communities Project, has led to The Cancer Council, NSW making a direct commitment to employ a Navigator / Volunteer Coordinator in their Western Region office.

The main resource developed for the project is a Palliative Care and Support Information folder. This resource has been distributed widely and has generated a large amount of positive interest and comment.

The partnerships developed between GWAHS, The Cancer Council, NSW and Volunteering Central West provide the cornerstone to the success of the project. This provided an opportunity to meet a key element of the National Palliative Care Strategy, ie to promote and support partnerships in the provision of care for people who are dying and their families, and the infrastructure for that care, to support delivery of high quality, effective palliative care across all settings. Recruitment constraints and restructure of NSW Health limited the continuity and scope of the project.

# Conclusion

## Project Recommendations

1 The Greater Western Area Health Service (GWAHS) conduct an Area-wide review of all volunteer services currently working within the health service and their support mechanisms

2 GWAHS recognise the role of volunteers by ensuring that systematic policies and procedures are developed and implemented across the Area – with reference to the Volunteering Australia National Standards

3 GWAHS further develop partnerships with The Cancer Council, NSW and Volunteering Central West guided by service agreements and participation in service planning

4 GWAHS Executive endorse the support information package (Palliative Care and Bereavement Support Folder) for volunteers, patients with advanced life limiting illness and their carers, and for people recently bereaved as a result of advanced life limiting illness for use across the Area

5 Area Oncology and Palliative Care Service take carriage of review and ongoing development of the documentation sets produced by the project including:
- Volunteer training resource – Mandatory (generic package for all volunteers)
- Palliative Care and Bereavement training package (1 for trainers, and 1 for volunteers)
- Volunteer recruitment resource
- Volunteer induction coordination and ongoing management resource
- Palliative Care and Bereavement Support folder

6 GWAHS demonstrate a commitment on the cost of involving volunteers in service delivery by including appropriate allocations in operational budgets

7 GWAHS meet Volunteering Australia's National Standards including volunteer insurance and reimbursement of out of pocket expenses

8 GWAHS Area and Local Health Service Management to take carriage of ongoing activities commenced during the Caring Communities Project