Rural Palliative Care Resource Kit

Engagement and partnerships

Identifying, engaging and maintaining partnerships in rural palliative care

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Identifying, engaging and maintaining partnerships

What is palliative care?

The World Health Organization (WHO) defines palliative care as:

> *An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual*.[1]

In Australia, the approach to managing patients with life-limiting and life-threatening illnesses can fall into two categories: the palliative approach and specialist palliative care. **The palliative approach**[2] is defined as that which improves quality of life for individuals and their families when facing life-threatening illness. This approach improves pain and symptom management and provides spiritual and psychological support. **Specialist palliative care** is the care and expertise provided for higher level clinical and psychological management by care providers with extensive experience and qualifications in palliative care medicine.

The growing demand for palliative services

With an increasing portion of the Australian population moving into the older age groups, there will be a greater need for the provision of palliative care services. Historically, palliative care was borne out of the need for delivery of good terminal care for those with cancer. However, there is now a growing awareness of the increasing need to provide palliative services to those with advancing age and those with specific illnesses, such as dementia, neurodegenerative diseases and other chronic illnesses such as heart failure. Palliative care services, therefore, will need to be more broadly integrated across health services and will need to be more flexible and tailored to the needs of patients and their families and carers.

Families are becoming smaller, more dispersed and varied, leading to a decrease in the number of informal care givers[3]. Therefore, health care systems need to be developed that will meet care and service delivery needs both currently and in the future.

In 2003, Yuen and colleagues[4] found that most people with a terminal illness list home as the preferred place of death. This means that there is more demand for the services of general practitioners and the provision of community palliative care.

Access to specific palliative care services may be limited in rural areas. Evidence indicates that those less likely to receive specialist palliative care services are more likely to[5]:

- have a non-cancer-related illness/condition
- be single or widowed
- be aged over 85 years
- live in a region other than a major city
- identify as Indigenous.

In Western Australia, for example, it is estimated that between 0.28 and 0.50% of the population at any one time would benefit from palliative support. 59.5% of these people have cancer related needs, the remainder have chronic, life-limiting conditions such as heart failure and obstructive lung disease[6].

Partnerships in the development and organisation of palliative care services

Local partnership/collaboration formation is an efficient way to develop and organise services for a local area.

What is a partnership?

A partnership can be described as a group of organisations or people working together to tackle difficult problems, and to achieve more efficient and effective use of scarce resources. When organisations and individuals work well together the quality and cost effectiveness of services can be significantly improved, resulting in benefits for service users[7]. Forming care partnerships for the provision of palliative services is one goal in the (Australian) National Palliative Care Strategy[8].

Reasons for developing a partnership

The formation of partnerships is "one of the best mechanisms for improving the quality and co-ordination of services, particularly to vulnerable individuals whose needs might otherwise be neglected particularly if vulnerable people are only a small proportion of all service-users"[9]. In the case of the organisation and delivery of services for rural palliative care, availability of and access to specialist services can be restricted.

The UK Audit Commission[10] lists five main reasons for developing partnerships:

- to deliver co-ordinated packages of services to individuals
- to tackle so-called 'wicked issues'
- to reduce impact of organisational fragmentation and minimise the impact of any perverse incentives that result from it
- to bid for, or gain access to, new resources
- to meet a statutory requirement.

All these possible reasons for forming partnerships are relevant to the provision of palliative care, and in particular to the provision of palliative care in rural settings. Clinicians, service providers and patients seeking services in rural and remote communities face enormous challenges: long distances, high costs involved in travelling to access or to provide the service, reduced availability of specialist medical services, fewer hospital/hospice beds and, in some instances, higher needs for specific services for indigenous or marginalised communities.

There is a particular imperative for partnerships to improve the coordination and range of available services, as well as access to and the delivery of these palliative services in Australian rural communities.

Elements of successful partnership

A recent analysis of partnerships in palliative care concluded that for successful partnerships there must be the following elements[11]:

- acknowledgement by all members of the need for partnership
- common, shared and articulated objectives
- commitment by senior stakeholder organisations
- legitimacy of the members advocating for / representing community groups
- trust between partnership members
- clear and robust partnership / governance arrangements
- process of monitoring, review and organisational learning.

These elements identified by researchers in a recent review are consistent with the generic framework developed by Harris et al[12] for successful intersectoral collaboration. This framework is outlined in detail (INSERT HYPERLINK T0 Partnership checklist)

General challenges to the formation of partnerships

Walshe et al (2007) argue that while partnerships are increasingly promoted as the solution to coordination problems in health care there are a number of barriers that could be 'sufficient to destroy emerging partnerships.'[13] These barriers are:

- **Structural & procedural** (e.g. Differences in geographical boundaries, organisational size and capacity, operational systems and planning cycles are some of the potential barriers in this category.)
- **Financial** (funding streams, budget cycles, different accountabilities and perceived inequalities in budgets)
- **Professional** (different professional values and roles)
- **Status and legitimacy** (where different members of the partnership derive their legitimacy from different sources e.g. health care professionals have legitimacy by virtue of their professional position; local authorities, by electoral mandate; users, through their illness experience)[14]

It is vital to the success of partnerships to explicitly recognise and plan to overcome these barriers.

Specific challenges for palliative service provision in rural and non-urban communities

Rural and non-urban communities face specific challenges for the provision of palliative (and many other) community and health services. These include:

- lower population density
- distance to reach patients and services
- lack of available resources.

Primary care workers in rural and remote areas often have difficulty obtaining relevant education and training, there is a problem accessing specialist services, and they report feeling either unsupported or overwhelmed.[15] A partnership model allows agencies and care workers to access specialist care or to get advice from more specialised services as it is required.

Oliver, Penman and Ofner[16] point out that the resilience of rural communities contributes greatly to the development and success of palliative care partnerships. Also, the key for a successful partnership in a rural environment is the involvement of the community, both in planning and delivery of services.

Shepherd[17] notes that services for rural communities should be networked, accessible and improve population health with links to state-wide services as needed. Strategic partnerships should be developed within and outside the community to provide responsive and culturally appropriate services. She also points out that workforce development is crucial and should include new ways of working, with teams working across professional and organisational boundaries.

Types of partnership

There are many ways for organisations to work together and being prescriptive about the partnership model to be applied regardless of context can be a recipe for failure. Ideally, potential members of a partnership would collectively analyse local conditions and then develop a partnership model adapted to local needs drawing on knowledge of successful models, knowledge of the preconditions for effective partnerships and plans to overcome identified barriers to partnership.

Partnerships within palliative care have been formed at the:

- regional level (e.g. through a Memorandum of Understanding between relevant organisations within a geographic area, or, as in Victoria, through Consortia of local palliative care organisations for the purpose of regional planning)
- executive level (e.g. through formal and systematic communication between the Executive teams of participating organisations)
- multidisciplinary team level within an organisation (e.g. within a hospital or within a general practice) and through multidisciplinary teams across organisations. (link to the website section on the Multi Disciplinary Team)

There is obviously a need to consider partnerships at a range of levels to ensure adequate service delivery to patients and families, as well as cooperation between funding bodies and service providers at all levels.

Why should General Practitioners be involved in palliative care partnerships?

General practitioners play a crucial role in the care of palliative patients, although the nature and extent of the role is variable. At a minimum the GP is the medical manager in the community, responsible for medication management and symptom control. Even the most basic level of GP involvement requires the GP to work in partnership with all the other health professionals involved to ensure that:

(a) all, guided by the patient's wishes, share the same goals for care

(b) systems and processes are in place for transfer of information at critical points and

(c) when health professionals need to discuss patient care they have sufficient understanding of each other's roles and professional points of view to ensure the communication is effective.

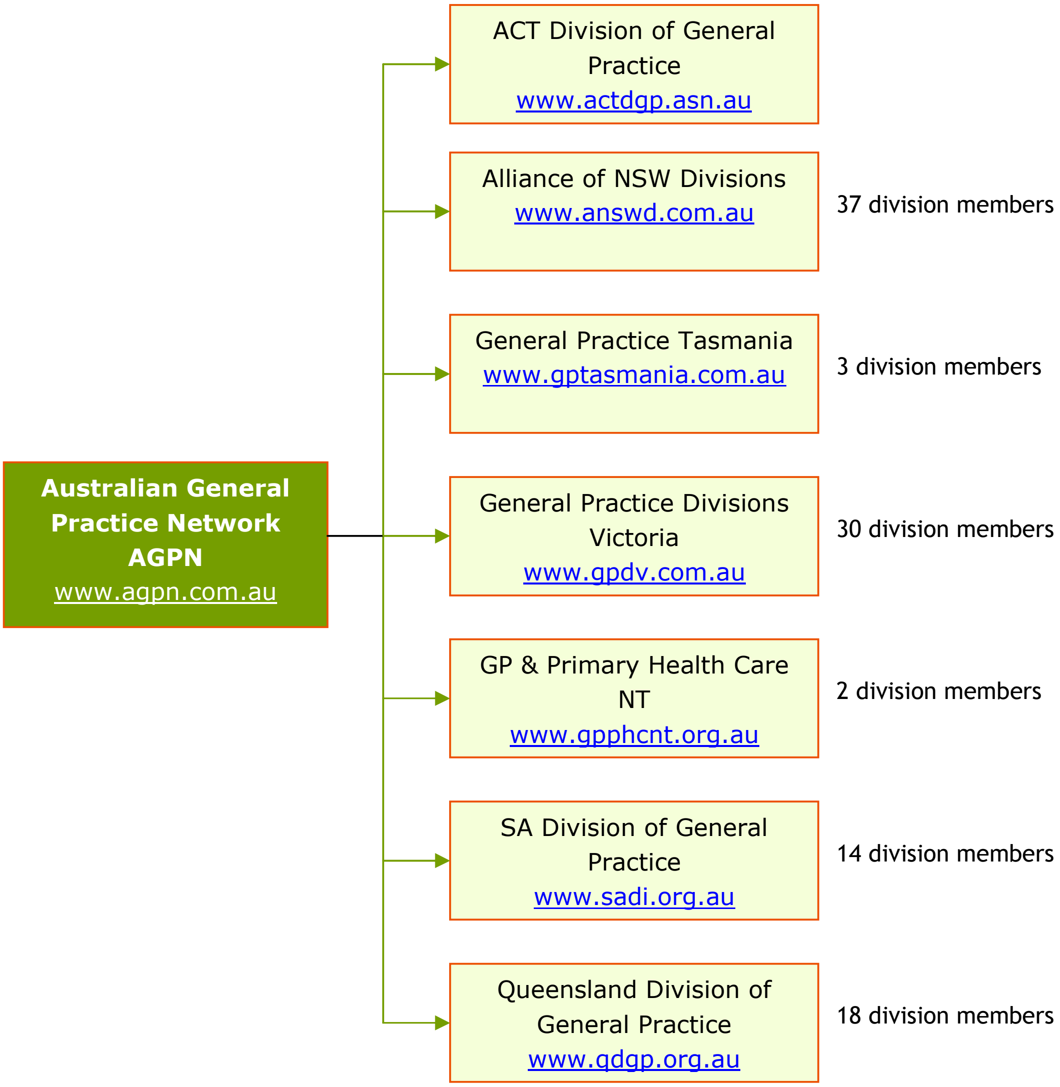
Why should divisions become involved in palliative care programs?

Divisions of general practice provide the single port of call for communication with all the GPs in a geographical area. As such they enable other organisations to negotiate with GPs as a group. There is much to be negotiated in the formation of partnerships for palliative care: roles, responsibilities, communication systems, agreements about when and how to case conference and the supply of medicines, approaches to training and development, strategies to develop a shared philosophy among health professionals and much more. Neither GPs, nor individual practices, especially within rural areas, are able to negotiate on this level. A division of general practice provides the organisational means to carry out this work. For those unfamiliar with the Division's program a flowchart (Diagram 1) below outlines the Divisions network structure and directs readers to their local state based organisation.

Partnerships between GPs and other palliative care health professionals tend to be much stronger where divisions of general practice have committed time and resources to developing GP capacity (especially through educational strategies and support for improved practice systems) and through supporting relationships between GPs and other relevant health service organisations.

The Divisions Network in Australia has a defined linkage between local, state and national arenas.

Diagram 1: Divisions Network Flowchart



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