



## **Palliative Care Partnership: a successful model of primary/secondary integration**

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### **Abstract**

The health reforms of the 1990s and early 21st century have seen unheralded change in the delivery of health services in New Zealand, and the concept of integration of primary and specialist or secondary services into a seamless health delivery service is one of the key planks of national and regional healthcare planning in New Zealand.<sup>1,2</sup>

This paper reports on a successful primary secondary integration project. Starting with commentary on the historical difficulties that acted as a catalyst to this initiative, it reports on the development process, how the model works in practice, and outlines some initial evaluation work done as part of its quality improvement component. Given the collaborative nature of this project and its scope across primary and specialist care sectors, the authors believe this model has implications and relevance across a wide spectrum of the New Zealand health service.

The concept of partnership between palliative care services and primary care is a well established internationally.<sup>3,4</sup> The consensus has been that a partnership approach to palliative care provision has many benefits in terms of maximising existing services in the face of rising referral rates<sup>5</sup> and preventing fragmentation of services.<sup>6,7</sup>

Clarke and Neale<sup>8</sup> suggested that building palliative care services exclusively around a specialist hospice service only served to de-skill general practitioners and district nurses which had a flow on effect regarding the standard of care delivery.

An ideal of general practice involvement is suggested by Thomas:<sup>9,10</sup>

Caring for the dying is a challenging but rewarding business. Many GPs and district nurses feel that palliative care represents the best of all medical care, bringing together the clinical, holistic, and human dimensions of primary care, and bonding us with our patients in very special way.

In the same way as it matures as a specialty, specialist palliative care has been defining its relationship with primary care:

Specialist palliative care builds on the palliative approach adopted by primary care providers and reflects a higher level of expertise in complex symptom control, loss grief and bereavement. Specialist palliative care works in two ways: first by providing the direct care to referred individuals and their families and secondly by providing a consultancy service to primary care providers and therefore supporting their care of the patient and family.<sup>11</sup>

These ideals are consistent with the *New Zealand Palliative Care Strategy*<sup>12</sup> which states that the provision of palliative care should happen across a range of agencies and involve a partnership between primary care and a specialist palliative care provider.

The perception of Manawatu general practice providers in the early 21st century was that their situation was less than the international ideal. General practice perceived that the Hospice Service had ‘captured’ palliative care, often to the exclusion of general practice.

Contemporaneously, in response to a growing awareness of the need to find a more integrated approach to manage the growing palliative care need, Arohanui Hospice staff looked for ways to work more closely with general practice teams (GPTs), and the scene was set for open dialogue.

In 2002, Arohanui Hospice in conjunction with the Manawatu Independent Practice Association (MIPA) commissioned a survey of GPTs in the greater Manawatu, Horowhenua, and Tararua region.<sup>13</sup>

This survey demonstrated that although Arohanui Hospice was respected as a specialist palliative care service, the earlier perceptions of general practice providers were reinforced and responses clearly signaled:

- GPTs feeling marginalised in palliative care provision;
- Cost as a barrier for patients accessing GPTs;
- Acknowledgement of a need for ongoing learning in palliative care by GPT members; and
- A strong willingness on the part of GPTs to participate in meeting the palliative care needs of their patients.

Arohanui Hospice and MIPA responded with the establishment of a multidisciplinary working party to address the issue of provision of community-based palliative care.

The working party developed a set of key aims for the project:

- Enhance patient and family access to palliative care services;
- Remove financial barriers for those with a terminal illness in their region;
- Maximise the appropriate use of specialist palliative care services;
- Promote a coordinated service responsive to patient and family needs;
- Increase knowledge of GPTs in palliative care principles and practices; and
- Promote a highly effective working relationship between specialist palliative care services and primary healthcare providers.

Following on from these aims, the working party developed the concept of the *Partnership of Care*—with a vision for palliative service delivery in the MidCentral region (see Box 1).

## Box 1

### Partnership of Care between:

*Specialist palliative care:* an essential service of quality, evidence based, specialist care provided by a qualified interdisciplinary team.<sup>12</sup>

*Generalist palliative care:* the patient and family's primary professional carers providing palliative care as a vital and integral part of their routine clinical practice.<sup>14</sup>

### Vision

“The Palliative Care Partnership attempts to maximise the skills and experience of both generalist and specialist services to provide the best possible palliative care to the community”

As this partnership model was consistent with the MidCentral District Health Board's vision for primary secondary multidisciplinary service integration, the project was able to attract significant district health board funding as a new primary care initiative. This funding provides for equitable access to primary level palliative care by reducing financial barriers to patients accessing general practice care.

## The Palliative Care Partnership (PCP)

In essence, the PCP is community palliative care based on a partnership between GPTs and the Specialist Palliative Care Service. The cornerstone of the PCP is the effective working relationship between the GPTs and Arohanui Hospice. Central to the effectiveness of the model is the role of the Palliative Care Coordinator (PCC), an advanced nursing role within the Arohanui Hospice interdisciplinary team. The PCC has the twin responsibilities of bringing specialist palliative care assessment and nursing support to patients and families and facilitating coordination of care between providers. This creates the true 'partnership' between primary care and specialist care for the benefit of the patient and their family/whānau.

Key aspects of the partnership are:

- Good communication.
- Joint decision-making.
- Respect of all providers' skills.
- Specialist resource and support.
- Shared responsibility for the care plan.
- Ongoing case management review.
- Appropriate use of ancillary services (including MidCentral District Nursing Service and Arohanui Hospice day stay).

## Partners

The Palliative Care project has three main partners: the Arohanui Hospice Palliative Care Service, General Practice Teams (general practitioners, practice nurses, and support staff), and the Manawatu Independent Practice Association.

## Key linkages

Supporting and interacting with the partners are several key groups. The most important linkage is with the MidCentral Health District Nursing Service. This service often plays a significant role by providing 24-hour clinical and personal care for patients and their families/whānau during the final phase of care.

Other linkages include the Cancer Society, Aged Residential Care, and Māori and Iwi health providers.

## Components

There are four main components to this Partnership:

- **Participation framework**, which describes
  - the providers' roles and responsibilities.
  - how patients will move through the Partnership of Care.
- **Education programme**
  - which includes a resource folder.
- **Partnership administration**
  - which provides the business framework and funding information.
- **Governance Group.**

## Participation framework

Patients are referred to the partnership via the following health providers:

- MidCentral Health or other secondary care provider.
- General Practice Team.
- District Nurse.
- Private medical or surgical consultant.
- Self referral.

All referrals are made to Arohanui Hospice; the hospice team conducts an initial assessment which integrates physical, spiritual, cultural, and psychosocial elements of the patient and family/whānau. This assessment is usually conducted by the PCC but may involve any member of the Hospice team—doctor, nurse, social worker, or other (as appropriate to each case).

As part of this assessment, a care plan is developed to which all parties are encouraged to contribute to and update. The care plan is held by the patient who takes it to all care review discussions.

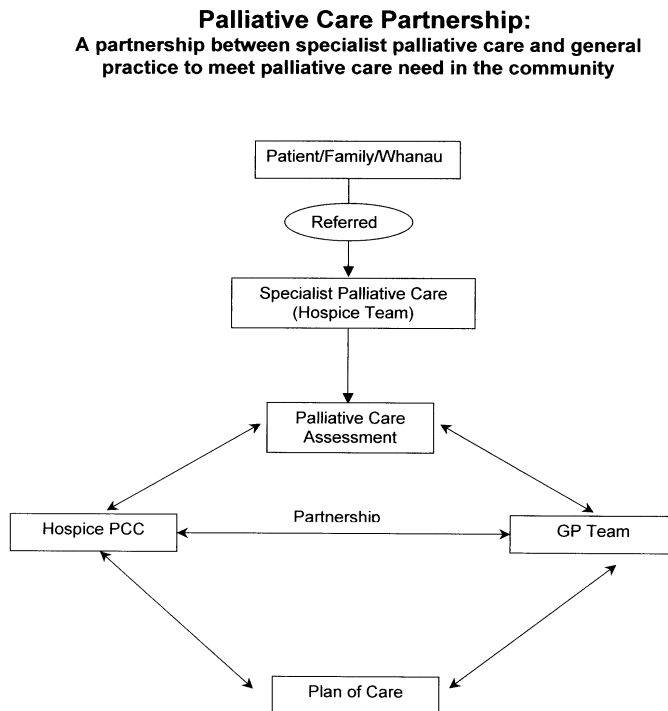
Depending on need, ongoing care is then provided across the agencies involved with the PCC as the primary coordinator of care and the GPT as the patient's first point of contact. Patient review by the specialist hospice team is provided as required. This review may be requested by either the GPT, PCC, the patient and/or family/whānau, District Nurse, or hospice staff. The PCC will usually be the communication conduit for key decisions made

As part of the partnership, after-hours availability (including weekend and annual leave cover) is discussed, agreed, and documented in the patient's care plan. In situations where patients cannot be managed effectively in the community, admission to the Arohanui Inpatient Unit may be required and will be negotiated between the PCC and/or GPT and the Inpatient Unit Team.

The GPT is informed of a patient's admission, discharge from and/or death in the hospice and is encouraged to visit and contribute to the management plan, however the Hospice team has overall responsibility for inpatient management.

The participation pathway (Figure 1) outlines the roles and responsibilities within the partnership model, and how the patient moves through the Partnership of Care. The PCCs provide the link between the GPTs and the specialist interdisciplinary team at Arohanui Hospice.

**Figure 1: Participation pathway**



To encourage an interdisciplinary approach, registration for participation in the PCP by interested GPTs is only accepted if both general practitioners and practice nurses participate. Completion of the education programme and yearly updates is mandatory for registration on the programme.

## **Education programme**

The education component of the partnership programme is framed around the Gold Standard Framework (GSF) developed by Keri Thomas.<sup>15</sup> The GSF was developed in the United Kingdom as a tool to support and facilitate the primary care practice team to 'raise their game' towards the highest quality care for patients with any diagnosis in the last stages of life.

The education programme is able to cover a comprehensive range of material necessary to explore a palliative approach within primary care. It highlights all aspects of care and goes beyond physical symptom control and management issues which could have easily become the focus of a standard GPT education programme.

The three 2-hour education workshops cover areas such as:

- Communication.
- Symptom control.
- Continuity of care (including after-hours responsibilities).
- Coordination of services.
- Carer support (respite care).
- Care of the dying.

Delivery of the education sessions utilises the expertise of the wider interdisciplinary team within the specialist palliative care service and is supported by a resource manual of area-specific information written by the interdisciplinary team.

Update sessions are an annual requirement of the partnership; so far they have focused on case reviews and medication updates as well as being used as a vehicle for introducing initiatives developed by the specialist palliative care service.

## **Partnership administration**

MIPA provides the administration support for the partnership, this involves ensuring compliance with contractual requirements, facilitating the ongoing education sessions, organising on going robust evaluation, and administering the monetary payments to general practice providers.

MidCentral District Health Board provided funding under the following formula:

- General practitioners and practice nurses are paid for attendance at the education sessions.
- A funding envelope of up to \$400 per registered patient is paid on a fee for service basis under the following formula:

General practitioner consultation	\$30
General practitioner home visit	\$40
Practice nurse consultation	\$25
Repeat prescription	\$15

The Practice Nurse consultation includes significant telephone consultations.

If need exceeds the \$400 per patient limit, then additional funding is negotiated between the provider and the project coordinator.

- Administrative support.

## Governance group

The PCP working party now maintains a role as the management group for the programme with administrative support provided by MIPA.

The governance is shared, with the Arohanui Hospice Community Reference Group providing the palliative care philosophical direction and the recently formed Midcentral DHB Cancer District Management Group responsible for the long-term sustainability of the partnership.

## Outcomes

During 2005, a provider feedback survey was conducted. This survey suggested there has been a positive change in the culture of palliative care service delivery in the primary care setting.

Outcomes so far can be explained using the following themes.

## Participation

Recruitment of MidCentral District general practice teams for the programme was done through MIPA networks and the project coordinator.

	<b>Practices</b>	<b>General practitioners</b>	<b>Practice nurses</b>
Total (% of total)	30 (73%)	54 (62%)	73 (67%)

## Communication

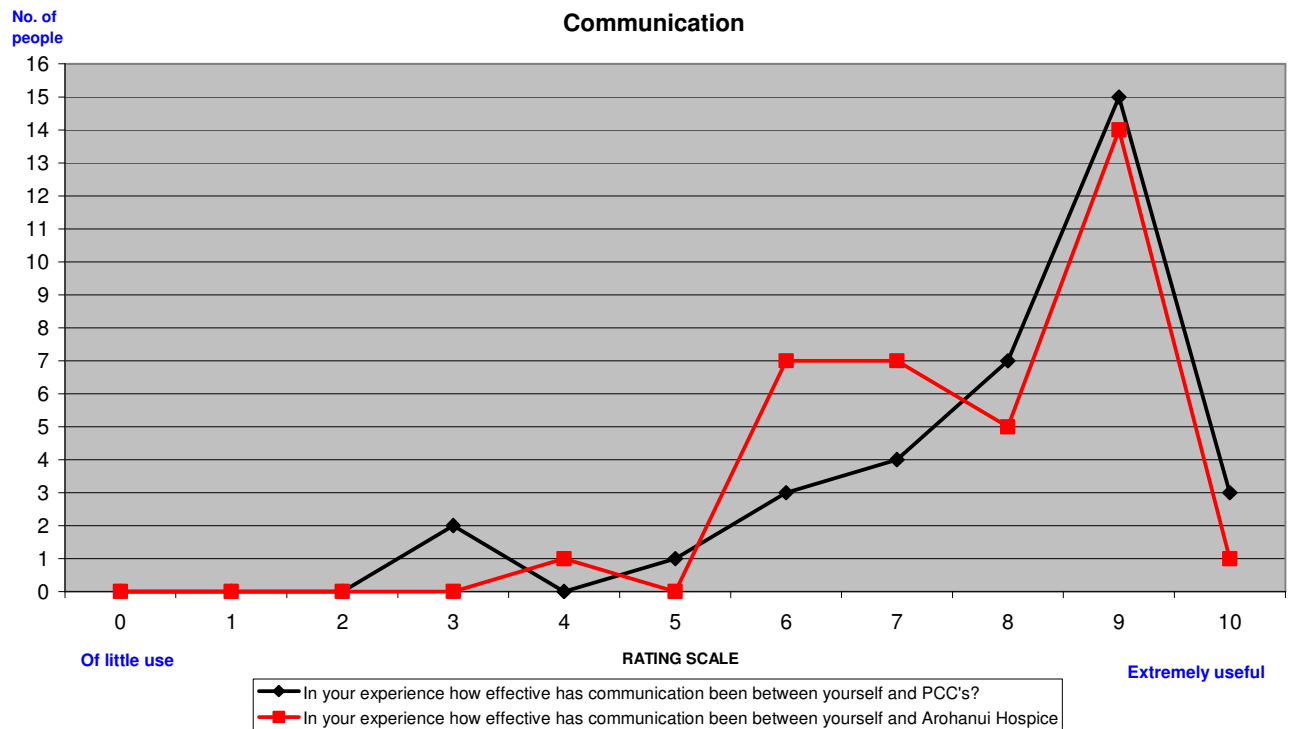
Both GPTs and PCCs response to the staff survey (Figure 2) suggested that historically the relationship had generally been a good one and that communication had improved since the introduction of the partnership programme. Specifically, more face-to-face and telephone contact resulted in their relationship having a greater sense of partnership.

I think that there is more of a partnership feel in the care, less of patients being taken over (GP)

It has opened the door for freer [sic] communication (PCC)

Some GPTs' responses still suggested that Hospice 'take over' was still a concern, but comments from the PCCs suggested that (in terms of ways of working) they were much more likely to involve GPT involvement than in the past.

**Figure 2. Effectiveness of communication**



### Professional development

The training component of the programme appears to have been well received by the GPTs and well supported by the PCCs themselves (Figure 3).

Feedback from the survey indicated that the training programme had two main benefits; the first being enhanced knowledge and confidence in management of patients with palliative care need and secondly familiarity with the Hospice staff and its way of working:

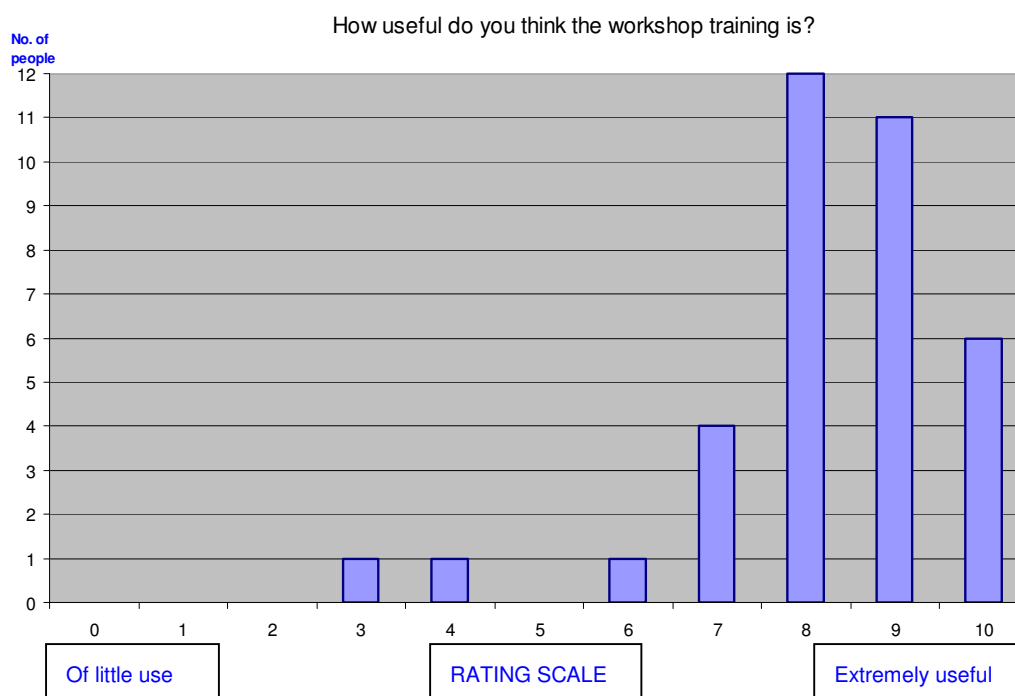
[I] feel more confident and more personally involved in treatment management—more comfortable using hospice and discussing progress with staff (GP)

### Funding

The project is well within budget for the first year.

GPT feedback suggests that the removal of cost as a barrier to visiting the general practitioner may have been a significant component in the success of this programme. From the GPT perspective, it has meant that general practitioners felt more comfortable about visiting palliative care patients knowing that they don't have to charge.

**Figure 3. Opinions on the effectiveness of training**



### **Hospice impact**

Referrals to the specialist palliative care outpatient clinics have decreased, however their complexity increased. This suggests a greater number of less complex problems are being resolved in the community.

### **Patient impact**

In the first 14 months, 255 patients were part of the partnership. Of these, 82.5% were cancer patients, 8.2% were cardiovascular disease patients, 3.9% were respiratory patients, and 6.1% had another (including renal, dementia, and neurological) disease. Approximately 60% of partnership patient deaths occurred in the community; very few occurred within the hospital setting [ $<5\%$ ].

### **Linkages**

An important (though unexpected) outcome has been the strengthening of service relationships with the Midcentral Health District Nursing Service via increased communication and teamwork with general practice and hospice staff. The coordination role of the PCC has been pivotal to this enhancement.

The limited evaluation completed in 2005 has not addressed the impact of the partnership on patients and families or fully addressed the impact on providers.

The Midcentral District Health Board and the working party are currently working with the Wellington School of Medicine to develop a robust and detailed reporting and evaluation package that will examine the outcomes of the partnership in much greater depth. This process will be completed in late 2006.

## Summary

The care of patients with palliative care needs presents us with considerable challenges. This partnership initiative supports and enhances the provision of palliative care by both specialist and generalist providers within our region. The patient and family/whānau remain at the centre of this partnership, and the special relationship between the patient and their primary healthcare providers is maintained and integrated within the provision of palliative care. Coordination of care between providers is a key element of effective palliative care provision.

While more evaluation is required, early indications suggest that the main benefits to emerge from this partnership (at the 'coalface') are effective communication, a better understanding and respect of roles, and responsibilities between providers, which enhances patient choice and coordination of their care. In this regard, the partnership has partly met its original goals.

A factor that has helped provide a sound foundation for this programmes is the often under-recognised administration component. Utilising the networks of a well-organised IPA, the partnership has succeeded in achieving a 73% participation rate for GPTs, which is impressive by any standards.

Other spin-offs include consolidation of Arohanui Hospice's role as a provider of community palliative care education, and (through the PCP management group) a forum to address ongoing interface issues such as after hours care, referral criteria, or scope of practice.

Another benefit has been the recognition by the MidCentral District Health Board of the value of such a partnership in the provision of community palliative care. This recognition is important to the partnerships long-term sustainability.

The success of this integrated care model has attracted interest from outside the Midcentral region. For instance, in July 2005, representatives of the PCP working party were invited to present the partnership model to the Hawke's Bay District Health Board's Community Public Health Advisory Committee.

We believe that this model has relevance across a broad spectrum of primary/secondary interfaces, not just palliative care. Indeed, the model could be adapted for use as a blueprint for a wide range of health services.

The detailed reporting and evaluation to be undertaken in 2006 will, we believe, validate the approach taken with this model further enhancing its position as an integration model.

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## References:

1. Ministry of Health. The Primary Health Care Strategy. Wellington: MOH; 2001.
2. Midcentral District Health Board. Primary Health Care Strategy. Palmerston North: Midcentral District Health Board; 2004.
3. Daniels L. Palliative care in a primary care-led NHS. *Professional Nurse*. 2000;15:471–5.
4. Nicols J. Operating a community palliative care service. *New Ethicals Journal*. May 1998;Volume 1(5).
5. Bosanquet N. Cost effective palliative care in the 21<sup>st</sup> Century. National Council for Hospice and Specialist Palliative Care Services, UK; 2002.
6. Beaver K, Luker A, Woods S. Primary care services received during terminal illness. *Int J Pall Nursing*, 2000;6:220–7.
7. Cowley S, Bliss J, Mathew A, McVey G. Effective interagency and interdisciplinary working. *Int J Pall Nursing*. 2002;8:30–9.
8. Clarke D, Neale B. Independent hospice care in the community: two case studies. *Health and Social Care*. 1994;2:203–12.
9. Thomas K. The gold standards framework—a programme for community palliative care. Macmillan Cancer Relief Publication, January 2003.
10. Thomas K. The gold standards framework in community palliative care. *Euro J Pall Care*. 2003;10:113–15.
11. Palliative Care Australia. Standards for providing quality palliative care for all Australians. PCA. 2005:May:12.
12. Ministry of Health. The New Zealand Palliative Care Strategy. Wellington: MOH; 2001.
13. Wilson L. Unpublished survey – GP attitudes to palliative care. Palmerston North: Arohanui Hospice; 2002.
14. Tebbit P. Definitions of supportive and palliative care. *Progress on Palliative Care*. 2002;9:187–9.
15. Thomas K. *Caring for the dying at home*. Oxford, UK: Radcliffe Medical Press; 2000, p176.