



# PALLIATIVE CARE

*Collaborative Care Review  
2006*

NGĀ PEEHITANGA TĀNGATA O TE AO HURUHURI  
NGĀ WHAKARITENGA MO TE TIKA ME TE ORA MORIMORIMATAWHAI

THE TRIALS PEOPLE FACE IN A CHALLENGING WORLD  
CAN BE OVERCOME BY CARING FOR AND LOVING ONE ANOTHER

# Waikato District Health Board Palliative Collaborative Care Review – 2006

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2006

### **Acknowledgements**

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In particular recognition and appreciation to the following groups:

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- Tokoroa and District Community Hospice Trust
- Waikato Community Hospice Trust
- Taranaki Hospice Foundation Incorporated
- Arohanui Hospice Palliative Care Service

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## EXECUTIVE SUMMARY

The vision of the New Zealand Palliative Care Strategy (2001) is:

*“All people who are dying and their family/whānau who could benefit from palliative care have timely access to quality palliative care services that are culturally appropriate and are provided in a co-ordinated way” (pVII).*

On a national level, the New Zealand Palliative Care Strategy (2001), set in place a systematic and informed approach to the future provision and funding of palliative care services. This strategy emphasised the need for all people who are dying and their family / whānau have access to palliative care services, provided in a co-ordinated manner.

At a district level, the Waikato District Health Board (Waikato DHB) Palliative Care Strategy Plan 2005-2010 (strategy plan), provides direction for an integrated and co-ordinated palliative care service. The aim is that all people with palliative care needs and their family/whānau are offered timely access to quality palliative care services throughout the Waikato district.

In November 2003, Waikato DHB Rural Hospitals and Community Based Services (RH&CBS) District Nursing Service (DNS) and Waikato Community Hospice Trust (Hospice Waikato) commenced delivering a collaborative care community service, to patients with a palliative diagnosis, living in rural Waikato. This model of care offered patients and their family / whānau a choice of receiving both generalist DNS and specialist Hospice Waikato services simultaneously. Collaborative care aims to provide a complete service that includes assessment, care co-ordination, clinical care and support that can be accessed through one point of entry.

In November 2005, the Community and Public Health Advisory Committee of the Waikato DHB endorsed one-off funding for the formal review of collaborative care services. At around the same time, the Waikato Palliative Care Operations Network (network) was established to provide leadership with operational responsibility to oversee service development and provision of care as outlined within the strategic plan.

The network set four project objectives for the review of collaborative care services:

1. To identify the current level of palliative collaborative care service, including strengths, weaknesses, and opportunities
2. To review other palliative care models both nationally and internationally
3. To recommend the model for the future
4. To develop a collaborative care action plan

Using the above objectives this paper reports on the findings of Waikato DHB palliative collaborative care services.

The review found that efficiencies are possible through, for example, consistent information collection and reporting systems, clear networks of relationships and communication processes among and between all palliative care stakeholders.

The following goals and actions are recommended:

<p><b>1. Integrated Service</b></p> <p><b>Goal:</b> All palliative care services delivered in rural Waikato will be co-ordinated between providers.</p> <p><b>Actions:</b></p> <ul style="list-style-type: none"> <li>• Develop a process to ensure all patients receiving collaborative care have an identified care co-ordinator</li> <li>• Review, standardise and integrate information and documentation between the providers of palliative collaborative care</li> <li>• Inform the public and providers on what to expect from the Waikato DHB palliative collaborative care service</li> <li>• Determine the Regional Referral Centre (RRC) as the single point of entry for collaborative care services</li> <li>• Review and update the Memorandum of Understanding (1996) between RH&amp;CBS and Hospice Waikato</li> </ul>
<p><b>2. Improved Access of Service</b></p> <p><b>Goal:</b> All people throughout rural Waikato district have access to collaborative care services.</p> <p><b>Actions:</b></p> <ul style="list-style-type: none"> <li>• Hospice Waikato and RH&amp;CBS work collaboratively to support the extension of the collaborative care model to Coromandel Town, Whitianga, Tairua and Whangamata</li> <li>• Consider the options and implications of introducing a full range of specialist palliative care service components to the Tokoroa community</li> <li>• Develop a formal understanding of when, if ever, collaborative care may be considered within the Hamilton and hinterland areas for complex palliative care patients under the care of DNS</li> </ul>
<p><b>3. Workforce and Resource Development</b></p> <p><b>Goal:</b> All stages of collaborative care workforce development are aligned to service needs and available resources</p> <p><b>Actions:</b></p> <ul style="list-style-type: none"> <li>• Develop within the collaborative care model a 24 / 7 day a week specialist palliative care nurse on-call telephone consultancy service for health provider use only</li> <li>• Improve clinical care through the development and implementation of clinical pathways / guidelines and tools</li> <li>• Develop specialised educational packages for staff working within palliative care teams</li> </ul>
<p><b>4. Implementation of Quality Monitoring Systems</b></p> <p><b>Goal:</b> Information is available so reporting of collaborative care activities can be accurately monitored</p> <p><b>Actions:</b></p> <ul style="list-style-type: none"> <li>• Develop and implement a baseline data set that captures relevant data from integrated palliative care services</li> <li>• Develop a suitable collaborative care reporting and monitoring systems with agreed frequency of auditing</li> </ul>

The implementation of the recommendations are to be phased over 2006-2010 and within current existing resources with the exception of the establishment of a 24 / day a week integrated specialist palliative care nursing on call system.

This palliative care shared provider consultancy service is a new concept and it is recommended that a pilot be trialed prior to final endorsement of permanent implementation.

Funding for this initiative can only be estimated which is \$20,000 per annum. The pilot will determine accurate annual costings of this initiative.

## **INTRODUCTION**

The purpose of this report is to provide details of the project findings and make recommendations to the Palliative Care Operations Network for improvement initiatives.

This report is best understood if read in conjunction with Waikato District Health Board Palliative Care Strategy Plan 2005-2010.

The collaborative care service delivery model, which commenced in 2003, was put in place to give patients with a palliative diagnosis, living in rural Waikato, the choice to have both DNS and specialist Hospice Waikato services delivered simultaneously.

Collaborative care aims to provide a complete service that includes assessment, care co-ordination, clinical care and support that can be accessed through one point of entry.

The Waikato Palliative Collaborative Care Review Project team (appendix 1) was established (December 2005) to oversee the review and development of the project.

## **Project Methodology**

The network set four project objectives for the review of collaborative care services:

1. To identify the current level of palliative collaborative care service, including strengths, weaknesses, and opportunities
2. To review other palliative care models both nationally and internationally
3. To recommend the model for the future
4. To develop a collaborative care action plan

A process of consultation with key stakeholders was undertaken. Stakeholders included:

- Regional Referral Centre (RRC)
- District Nurse Services (DNS)
- Hospice Waikato
- Palliative Care Unit (PCU)
- Tokoroa Hospice
- Eventhorpe Resthome
- Community Health Forums
- Other New Zealand DHB district hospitals

In order to review the collaborative model the Review Project Team undertook the following project approaches:

- Review of other selected national community palliative models of care (Table 1)
- A stock-take and description of the current palliative collaborative care services and providers (Table 2 & appendix 2)
- Data analysis



- Strengths, weakness, opportunities and threats (SWOT) analysis (appendix 3)
- Literature review and analysis (appendix 4)
- Site visits to:
  - Taranaki Hospice Foundation Incorporated, New Plymouth
  - Arohanui Hospice Palliative Care Service, Palmerston North
- Analysis of findings against project objectives (appendix 5)

## **CURRENT SITUATION**

The structure of the document includes: and overview of:

- An overview of other national models of care
- Summary of Waikato palliative care community nursing models
- Description of the collaborative care model, overview of providers and analysis of the data
- Comparison of the literature review to Waikato's current model of care
- Recommendations
- Action plan for the future.

### ***NATIONAL MODELS OF CARE***

In New Zealand there is variation of palliative care models in operation. The four areas used to benchmark Waikato palliative care services were Taranaki, Midcentral, Midland and Capital Coast palliative care delivery (appendix 6).

The project found that the Waikato DHB palliative models of care is structured differently from the other national models of care reviewed and therefore at this point in time there is little ability to align with other New Zealand palliative care service model of care. In particular Hospice Waikato only operate a specialist home visiting nursing service, and currently do not provide a hospice specialist in-patient service nor do they employ medical staff.

**Table 1: National Models of Palliative Care Delivery**

	Midcentral DHB	Bay of Plenty DHB	Taranaki DHB	Capital Coast DHB
<b>Point of Entry for Referral</b>	To hospice	To hospice	To hospice	To agency (Nurse Maude) then onto either hospice if urban area or district nursing service for rural area.
<b>Care Co-ordination</b>	Team of specialist nurses whom co-ordinate care between primary providers and hospice. Work for hospice. Caseload 35-40 patients Do not usually undertake hands on nursing but will assist if required	All cares undertaken by hospice. No district nurse involvement at all.	One co-ordinator of discharge planning from hospital to whole Taranaki district. Based at hospice.  Co-ordinates discharge planning.  Patient care co-ordinated by hospice for urban area and district nurses rurally.	In rural areas district nurses with the support of Te Omanga hospice undertake all patient cares.  Currently changing model to the Macmillan model.
<b>Clinical Notes</b>	Client held notes.	Hospice	Patients living in urban area, notes are held by hospice  Rural patient's notes are held by the DNS but a shortened version is held at the hospice so care can be advised as and when required.	Hospice in the urban area and rurally notes held by district nursing service
<b>Assessment</b>	Undertaken by specialist care co-ordinator and updated by district nurses and/or GPs under guidance of co-ordinator	Hospice	In urban area assessment performed by hospice nurse in rural area assessment performed by district nurses who hold palliative qualifications.	In urban area assessment performed by hospice nurse in rural area assessment performed by district nurse
<b>Care Plan</b>	Undertaken by specialist care co-ordinator and updated by district nurses and/or GPs under guidance of co-ordinator	Hospice	Hospice nurse in urban area and district nurse in rural area. Weekly report sent to hospice	Hospice nurse in urban area and district nurse in rural area Regular report sent to hospice

## ***WAIKATO DHB PALLIATIVE CARE NURSING MODELS***

### **1. Hospice Waikato Home Care Model**

Hospice Waikato provides a package of home based palliative care services for patients in Hamilton, Cambridge and Ngaruawahia that includes the delivery of nursing care and access to the multidisciplinary team and services. Patients have access to a seven-day a week specialist nursing on-call service. Hospice Waikato has four community inpatient beds based at Eventhorpe Resthome in Hamilton, for short-term respite care.

A long-term objective is to explore the option of Hospice Waikato community based 24 hour, seven-day week inpatient service to be the single point of entry for out of hour's nurse consultancy service.<sup>1</sup>

### **2. Hospice Tokoroa and Tokoroa District Nursing**

Tokoroa is outside of the palliative collaborative care model. It has its own community based hospice service which supplies equipment and limited volunteer support to patients receiving palliative care and their whānau.

All other palliative care patients needs are meet by the local DNS. When specialist palliative care services are required Tokoroa district nurses contact the regional co-ordinator at PCU.

### **3. Waikato DHB District Nursing Services**

DNS manage the needs of referred patients requiring palliative care services. When specialist palliative care services are required DN's contact the regional co-ordinator at PCU.

### **4. Collaborative Care Model**

Patients receiving palliative care who live in Hamilton, Cambridge and / or Ngaruawahia are not offered collaborative care services. Hospice Waikato usually delivers their palliative care. There are a few patients who live in these areas with complex health needs under the care of DNS.

The collaborative care service delivery model, which commenced in 2003, was put in place to give patients with a palliative diagnosis, living in rural Waikato, the choice to have both DNS and specialist Hospice Waikato services delivered simultaneously. (Hamilton, Cambridge and Ngaruawahia are excluded).

Collaborative care aims to provide a complete service that includes assessment, care co-ordination, clinical care and support that can be accessed through one point of entry.

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<sup>1</sup> During the writing of this document Hospice Waikato have purchased premises that may hasten the meeting of this objective.

Table 2 provides further details of coverage and various service components of community based palliative care nursing models.

**Table 2: Waikato DHB Community Based Palliative Care Nursing Models**

Model	Collaborative Care	Hospice Waikato	Tokoroa	District Nursing
<b>Providers</b>	Hospice Waikato & DNS	Hospice Waikato	DNS & Tokoroa Hospice	DNS
<b>Coverage</b>	Te Kauwhata Huntly Te Awamutu Raglan Thames Ngatea, Paeroa Waihi Matamata Morrinsville Putaruru Tirau Otorohanga Te Kuiti Taumarunui	Hamilton, Cambridge and Ngaruawahia	Tokoroa only	Coromandel town Whitianga, Whangamata Tairua
<b>Assessment</b>	Hospice Waikato & DNS each do own assessment	Hospice Waikato	DNS	DNS
<b>Care Co-ordination</b>	No nominated service. (Usually DNS)	Nominated nurse	DNS	DNS
<b>Clinical Care</b>	DNS	Hospice Waikato (excluding complex patients who are cared for by DNS)	DNS	DNS
<b>Specialist Palliative Care</b>	Hospice Waikato & PCU	Hospice Waikato & PCU	PCU	PCU
<b>Point of entry</b>	RRC DNS PCU	Hospice Waikato	RRC & / Tokoroa Hospice	RRC
<b>Out of Hours</b>	DNS & GP	Hospice Waikato Nursing service & GP	DNS & GP	DNS & GP
<b>Service Specification</b>	PCU- Medical /surgical	COPL 0001 COPL 0002 - with variations <sup>2</sup>	COPL 0001 COPL 0002	DOM 101

The models are either a mixture of specialist palliative care provided by Hospice Waikato, or a combination of generalist and specialist palliative care which is known as collaborative care,<sup>3</sup> or generalist palliative care nursing services delivered by DNS. While the review was cognisant of all four models the focus of this report is the collaborative care model.

<sup>2</sup> A high level overview of the two Hospices variations are summarised in appendix 9.

<sup>3</sup> Refer to Waikato DHB Palliative Care Strategy Plan for definitions of generalist and specialist palliative care providers / services. Development of national definitions is in progress.

### ***WAIKATO COLLABORATIVE CARE MODEL***

In 2003, the Hospice Waikato, and RH&CBS, DNS initiated the current collaborative care model (appendix 7), which was driven to meet the New Zealand Palliative Care Strategy (2001) requirements.

The Memorandum of Understanding (1996) between Community Health, (a division of Health Waikato Limited), and Waikato Community Hospice, provided a platform for the two organisations to consider how they could work more closely (appendix 8) to improve the services provided.

The collaborative care model was developed to introduce Hospice Waikato palliative care service components to the Waikato rural community and was piloted in Te Kauwhata, Huntly, Te Awamutu and Raglan. Collaborative care services have expanded to other Waikato DHB rural areas with varying degrees of success (refer graph 2, data analysis section).

Collaborative care provides patients who have a palliative diagnosis, and live outside of Hamilton, Ngaruawahia, and Cambridge<sup>4</sup> the choice to receive both generalist and specialist multidisciplinary home based palliative care simultaneously.

Collaborative care services involve DNS providing clinical cares and Hospice Waikato providing specialist non-clinical support for the patient and their whānau which include:

- Emotional support through illness dying and bereavement
- Individual support or support groups for bereaved family / whānau members
- Family support volunteers for companionship or family/whānau/carer relief
- Biography volunteers to assist patients with life review<sup>5</sup>

Generally, DNS and Hospice Waikato work closely with Waikato Hospital PCU and the patient's general practice team to deliver a complete package of care.

When service choices are available, the patient is always the decision-maker regarding the services they receive.

At the beginning of this review collaborative care was not available to patients who lived in Coromandel town, Whitianga, Whangamata or Tairua as Hospice Waikato collaborative care services did not extend to these areas. However as of 1<sup>st</sup> July 2006, Hospice Waikato commenced developing services in these rural areas.

As previously indicated in Table 2, the Tokoroa area does not have access to collaborative care services. Tokoroa has its own hospice that offers equipment supply and volunteer services only.

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<sup>4</sup> Patients who live in these areas receive all palliative care services from Hospice Waikato.

<sup>5</sup> Specially trained volunteers record the patient's story on audiotape and then prepare a bound transcript for the patient to keep or share as they choose.

## ***COLLABORATIVE PROVIDERS***

### **Hospice Waikato**

Hospice Waikato is contracted to provide essential<sup>6</sup> palliative care services under a national service specification for people of all ages who have been diagnosed with a terminal illness for which curative treatment is no longer an option and whose death is likely within 12 months<sup>7</sup>.

Initial hospice assessment may be performed over the telephone, via email or during a home visit. Hospice Waikato staff undertake a patient assessment that identifies the patient and family / whānau immediate concerns.

Up to 13 months after the death of a patient Hospice Waikato offer to work with the family / whānau using specific interventions, which have been researched and are evidence based as best practice, to improve mental health outcomes in bereavement.

### **District Nursing**

Waikato community based services consist of six geographical areas. Each area contains a Family Health Team (FHT) of which the DNS is one component.

With the exception of Hamilton, Cambridge and Ngaruawahia, DNS provide all clinical cares for palliative patients. Collaborative care has given patients the opportunity to choose the added input of specialist hospice grief and bereavement services.

On a professional level district nurses work with general practice teams, seek specialist advice about patient care from Waikato Hospital PCU and utilise the skills and knowledge of colleagues who have undertaken specific palliative care education.

### **Palliative Care Unit**

PCU provides specialist palliative care advice and education to patients / DNS / Hospice Waikato (medical) / Hospice Tokoroa / general practice team. PCU patients, who live in the areas of rural Waikato where collaborative care operates, are informed about the availability of collaborative care services.

### **General Practice Team**

General practice teams are essential partners in the collaborative model of care and work in close liaison with DNS and Hospice Waikato. General practice teams link to the regional PCU service for specialist input.

## ***HOURS OF SERVICE***

Collaborative care providers offer the following hours of service:

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<sup>6</sup> Hospice Waikato essential palliative care services are assessment, care co-ordination and clinical care. Essential but not contracted is support care.

<sup>7</sup> As identified in the Strategy Plan, service specification timeframes do not align with the WHO definition.

Hospice Waikato	Normal working hours Monday to Friday 8.30a.m. - 5p.m. Out-side of these hours, rural collaborative care patients and their families are advised to contact their GP or District Nurse for advice.
District Nursing Services	Normal working hours Monday to Friday 8a.m. - 4.30p.m. District nurses work a roster system to cover out of hours and weekends with the exception of Thames-Coromandel district who operate an 'on-call' service.
Palliative Care Unit	Normal working hours Monday to Friday 8.00a.m. - 5p.m. Outside these hours there is a consultant on call to provide telephone advice. Two weeks out of three it is a palliative care specialist, an oncologist covers the third week. The PCU phone is diverted to ward 25 out of hours and the ward co-ordinator confers with the on call house officer whether or not to contact the consultant on call or advice the palliative patient over the phone on who to contact in the community for medical assistance.
General Practice Team	General practice teams who are members of the Waikato Primary Health Organisation (PHO) are given a financial subsidy for up to 12 home visits to palliative care patients in the last two weeks of life. Two of these visits may be surgery visits.

As recommended in the Waikato Palliative Care Strategy Plan (2005), currently there is no direct access to a 24-hour, 7-day specialist palliative care nursing advisory service available to health care providers working in rural Waikato.

In some areas rural areas, where GPs are not available after hours, concern has been voiced by the DNS related to the non-availability of generalist and specialist palliative care advice after hours.

At the present time data is not available around the frequency of providers seeking out of hours support for either generalist or specialist palliative care advice.

### ***DATA ANALYSIS***

The RRC undertakes data collection for Waikato DHB community services (excluding mental health). Information is taken directly from referral request forms and entered into a 'Word Access' database system.

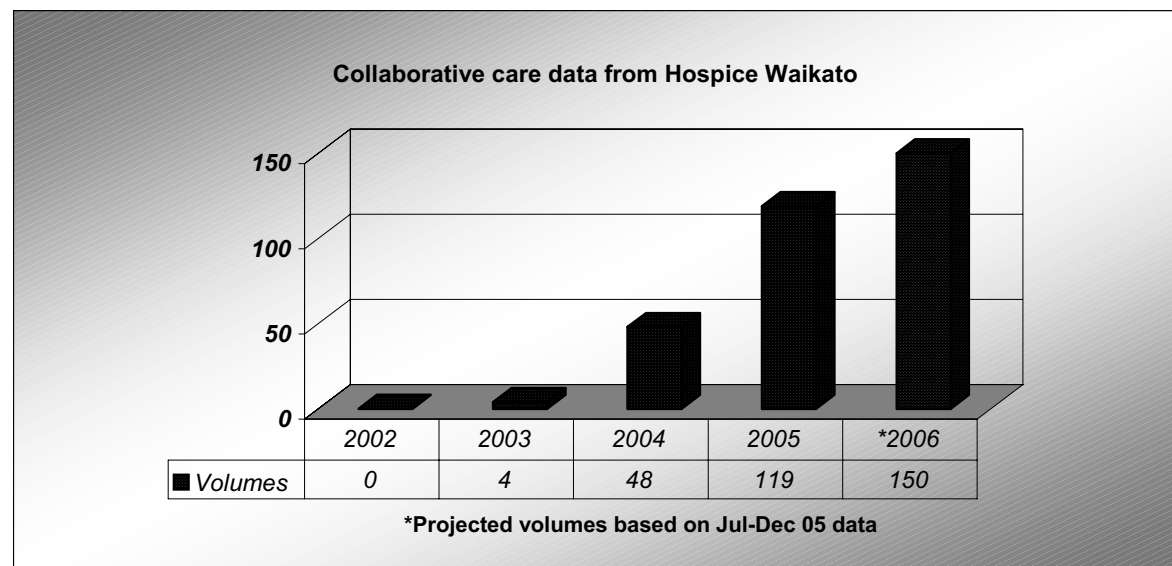
This database identified that from July 2004 to December 2005, 837 palliative care referrals were processed via the RRC. Only three of these referrals could be clearly identified as collaborative care. Waikato DHB baseline data collection does not identify the number of patients receiving collaborative care services throughout the district.

For the purpose of this report Hospice Waikato information has been used to identify volumes, domicile and ethnicity data related to collaborative care services.

## Volumes

Data shows that collaborative care referrals have increased steadily over the past two years. In 2005, there were 105 collaborative care referrals and projected volume for 2006 is approximately 145 (graph 1). This indicates an expected 47% increase in the use of collaborative care services for 2006 (calendar year).

**Graph 1: Hospice Waikato Collaborative Care Volumes 2002-2006**



Source: Hospice Waikato

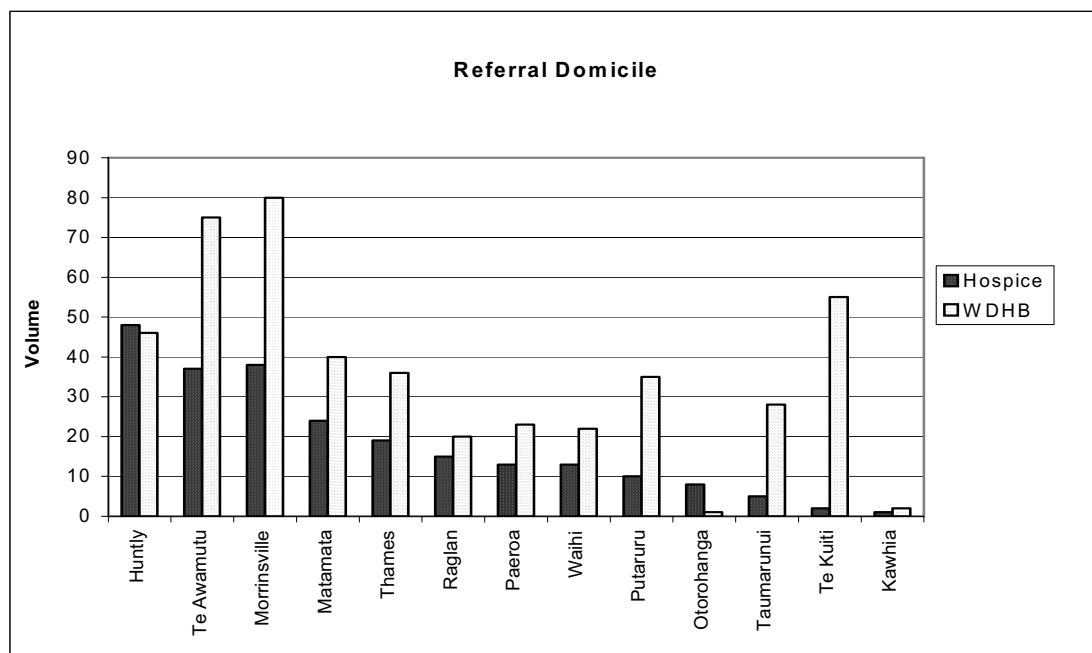
## Domicile

Currently there are large variances among Waikato DHB geographical rural districts (graph 2), in the number of palliative care patients who are receiving collaborative care services. For example 100% of patients requiring palliative care services in the Huntly district have elected collaborative care services whilst in the Te Kuiti district less than 4% of patients have chosen this option. This variation is related to:

- The length of time collaborative care has been operating in a district
- The variation of boundaries between Waikato DHB and Hospice Waikato
- The strength of the working relationship that has been developed between DNS and Hospice Waikato.
- Previously there have been no specialist outreach clinics in Te Kuiti. (In the process of commencing this service since the introduction of the Strategy Plan).



**Graph 2: RRC & Hospice Referrals by Domicile July 2004 – December 2005**



Source: Hospice Waikato and Waikato DHB Regional Referral Centre

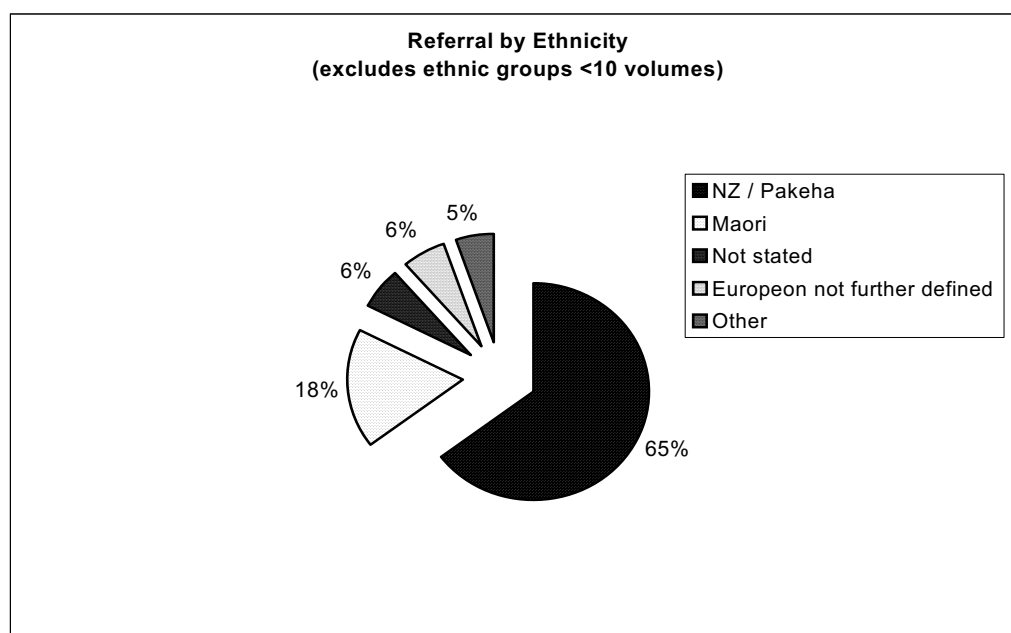
### Ethnicity

The Waikato DHB District Plan states Māori make up 21.7% of the Waikato DHB population. Currently the RRC do not collect accurate ethnicity data. Therefore it is unknown what percentage of Māori access palliative services.

Hospice Waikato ethnicity data (graph 3) indicates 18% of patients accessing collaborative care services are Māori.

**Graph 3: Hospice Referral by Ethnicity July 2004 – December 2005**

Source: Hospice Waikato



## **CURRENT STRENGTHS AND WEAKNESSES**

### ***KEY THEMES OF SWOT ANALYSIS***

Strengths are:

- Collaborative care model support the Strategy Plan intermediate level model of care (Strategy Plan pg 29)
- Providers work collaboratively and aim for a patient centered integrated approach to care in their home
- Collaborative care model provided support systems that reflect the community desire for people to remain in the community and to die at home if this is possible

Weaknesses are:

- Four palliative community based nursing models of care (outside the scope of the project)
- Predicted growth
- Fragmentation and duplication of service
- Lack of clarity around roles and expectations
- No standardised and integrated assessment, care plan, guidelines or tools
- No standardised and integrated package of information for patients and their family / whānau
- Care co-ordinator not clearly identified
- DNS perception of fragmented specialist palliative care services
- Collaborative care not available for small group of patients with complex needs who are under the care of DNS
- Not all specialist palliative care components are available to Tokoroa community
- Collaborative care has only commenced since 1<sup>st</sup> July 06 in Coromandel town and the eastern seaboard areas of Whitianga, Whangamata and Tirua
- Multiply entry points
- Poor inaccurate data, each specialist provider has an incompatible IT system with the other. There is no minimum data set
- No specialist palliative care nursing support available out of hours for health professionals
- No formalised training program for generalist nurses in the community
- DNS concern of some geographical areas having limited general practice / pharmacy out of hours services
- Minimal emergency / out of hours plan (including access and medications) to guide patients and family / whānau

## **LITERATURE REVIEW ANALYSIS**

Some of the key issues raised in the SWOT analysis are not unique to collaborative care nor to the Waikato district. A literature review (appendix 8) revealed that similar issues have been raised in other international palliative care service case studies.

### ***COMPARISON OF THE LITERATURE AND CURRENT MODELS OF CARE***

- This review found that both staff and patients were unclear about the components of service delivered by each provider. According to Abu-Saad (2001), ambiguities related to service provision can be eliminated if staff have clear role delineation and integrated clinical pathways supported by training and education programmes. Palliative care provider training education programmes assist staff working in the primary care arena to obtain the skills and knowledge needed to provide appropriate services to patients in their own homes. Public education programmes and easily accessible information e.g. via the Internet, raise consumer awareness of what palliative care services are available
- Quality information is required to determine whether the needs of the population are being met by the services offered. The need to measure the quality of care being given to patients and the gathering of appropriate data is discussed by many of the authors reviewed (Anderson, Byock, Barriball, Abu-Saad, Hanson, Koeck, and Hearn) as playing a pivotal role in the planning of future needs and wants of service delivery
- It is difficult to accurately assess the amount, type and location of resources being put into collaborative care due to lack of appropriate data collection. Waikato DHBs lack of accurate data makes it difficult to plan future service needs and / or monitor the quality and appropriateness of existing collaborative services
- Prior to the introduction of collaborative care, district nurses working in rural Waikato undertook all patient palliative cares. Luker (2000), recognises the district nurse-patient relationship as something that is very special and complicated due to the relationship being formed in the patients home. Palliative care is one aspect of district nursing work that is universally valued.

District nurses are generalist providers of palliative care and during this review some district nurses voiced their fear of losing valuable skills with the introduction of collaborative care. The collaborative care model offers no threat of decreased skills but offers added value to the services that can be offered to patients and their family / whānau. A challenge for specialist providers is to support primary carers in caring for patients as a team

- As pointed out by O'Neill (1998) common sense solutions need to be found to caring for patients at home. Professional staff involved in collaborative care delivery need better co-ordinated services with improved understanding and communication of roles and responsibilities as the first step in finding improved solutions to caring for patients at home.

Once expected roles and responsibilities for each provider are clearly stated the chances of duplicating services are lowered. It is also a strong basis on which to build formalised staff training and development pathways

- Most literature supported the idea of a care co-ordinator for community areas however, people who responded to the Ministry of Health submissions document (2000) found no clear support for having one provider / position to co-ordinate services

### ***Care Co-ordination***

Care co-ordination is recommended to improve the way in which patients and their family / whānau are supported through the continuum of care of multiple health professionals and / or providers, allowing cultural, physical, spiritual and psychosocial

aspects of patient care to be assessed, together with improved communication that can lead to efficiencies for the delivery of care services involved in collaborative care. The role of a care co-ordinator is to facilitate the delivery of appropriate services by linking general practice teams and specialist providers networks so patients and their family / whānau can be offered the best services available within the community setting.

Factors that may have an effect on the current informal manner in which nursing care is co-ordinated include:

- Lack of best practice standards of care for the delivery of palliative care
- No formalised educational packages for staff working within Waikato DHB palliative care teams
- No clear role delineation among nursing staff
- Each service creates their own set of patient clinical notes which are not shared among the collaborative care team

### *Single Point of Entry*

The Strategy Plan (2005) recommends a single point of entry for community and primary providers. Currently there is more than one point of entry for referrals requesting collaborative care services and for generalist providers seeking assistance or reassurance. Until an official point of entry is established for both the patient and provider, it will remain difficult to monitor accurate demand and supply levels and the quality of the service that is delivered.

The two components of access are referrals and specialist support and advice:

1. The current process of receiving and communication referrals among palliative care providers is diverse and inconsistent. Often the RRC process is being bypassed which creates inconsistencies with tracking the referrals and limits the ability to audit and accurately report the utilisation of collaborative care. With the introduction of a Waikato DHB Central Referral Centre, it is anticipated that within 18 months community referrals will be redirected via this Centre. The implementation of the Central Referral Centre will standardise the manner in which incoming referrals will be processed. This concept needs further scoping.
2. Currently generalist providers of palliative care seek specialist palliative care advice from either PCU and / or Hospice Waikato. This specialist level of nursing care is to be further developed through the implementation of the 24-hour / 7-day week specialist palliative care nurse on-call telephone support service. This service would provide advice and support to generalist providers.

## **RECOMMENDATIONS**

The Waikato DHB palliative care goal is to ensure that all providers of palliative care services in the Waikato DHB district work together with the community to implement the New Zealand Palliative Care Strategy (2001).

The current providers of collaborative care work in an informal manner. There are opportunities to formalise this approach for the future by building on the existing collaborative care model to incorporate better co-ordination and information

exchange, clear role delineation, improved equity of access, and single point of entry for both patient referrals and specialist provider information.

The following recommendations are presented for implementation between 2006 – 2010.

### **Integrated Services**

- Develop a process to ensure all patients receiving collaborative care have an identified care co-ordinator
- Review, standardise and integrate information and documentation between the providers of palliative collaborative care
- Inform the public and providers what to expect from Waikato DHB palliative collaborative care services
- Determine the RRC as the single point of entry for collaborative care services
- Review and update the existing Memorandum of Understanding document held between RH & CBS and Hospice Waikato

### **Improved access of services**

- Explore ways in which Hospice Waikato and RH&CBS can work collaboratively to extend services throughout the entire Waikato DHB district
- Investigate the options and implications of introducing a full range of specialist palliative care services to the Tokoroa community
- Investigate a process for patients with complex health issues who live in the Hamilton, Cambridge or Ngaruawahia, under DNS to enable access to Hospice Waikato specialist services

### **Workforce and resource development**

- Introduce a six month pilot to trial a 24 /7 specialist palliative care nurse on-call telephone service for community providers following review recommendations implementation
- Develop and improved integrated clinical pathways, guidelines and tools for nurses providing palliative care
- Provide specialised educational packages for staff working within palliative care teams

### **Implementation of quality systems**

- The development baseline data that allows accurate reporting and monitoring of collaborative care services

The implementation of the collaborative palliative care recommendations would ensure people with palliative care needs and their family / whānau, who live in rural Waikato, have access to essential palliative care services that are provided in a co-ordinated manner. A detailed action plan of the recommendations is provided

***COLLABORATIVE CARE ACTION PLAN***

<b><i>Integrated Services</i></b>				
<b>Objectives</b>	<b>Specific Tasks</b>	<b>Responsibility/Resources</b>	<b>Timeframe</b>	<b>Performance Measures</b>
1. Develop a process to ensure all patients receiving collaborative care have an identified care co-ordinator	<ul style="list-style-type: none"> <li>Organise a team to develop a framework that identifies who the care co-ordinator is for collaborative care</li> <li>Ensure providers and users of the service know who the nominated co-ordinator is and how they can be contacted</li> </ul>	<p>DNS / Hospice Waikato</p> <p>Resources</p> <ul style="list-style-type: none"> <li>Staff time- no added cost</li> </ul>	<ul style="list-style-type: none"> <li>2006-2007</li> </ul>	<ul style="list-style-type: none"> <li>There is a clear process for identifying the care co-ordinator for each collaborative patient.</li> <li>The co-ordinator role and contact details are written on the care plan</li> </ul>
2. To review, standardise and integrate information and documentation between the providers of palliative collaborative care	<ul style="list-style-type: none"> <li>Undertake a comprehensive stock-take of the current literature handed out to patients and the clinical forms including assessment and care plans</li> <li>Standardise an information package to be given to patients who wish to be enrolled in the collaborative care delivery model</li> <li>Investigate opportunities to develop assessment forms, care plans and clinical records that can be used by all collaborative care providers. Ensure any new forms developed go through the Publication Facilitators committee and the Clinical Records Committee</li> <li>Explore possible opportunities to develop shared clinical notes</li> <li>All clinical care plans will identify an out of hours plan for patients and family / whānau (including access and medication)</li> </ul>	<p>Responsibility</p> <ul style="list-style-type: none"> <li>Collaborative Care Project Group to oversee task</li> </ul> <p>Resources</p> <ul style="list-style-type: none"> <li>Staff time- no added cost</li> </ul>	<ul style="list-style-type: none"> <li>2006-2007</li> <li>2006-2010</li> </ul>	<ul style="list-style-type: none"> <li>Stock-take completed</li> <li>Agreed, updated patient information pack designed for all collaborative patients regardless of which service they enter</li> <li>Standardised                         <ul style="list-style-type: none"> <li>- Assessment form</li> <li>- Care plan</li> <li>- Clinical record</li> </ul> </li> <li>Documentation reviews to be undertaken as per WDHB policy requirements</li> <li>Clinical note options considered and agreed actions implemented</li> </ul>

Objectives	Specific Tasks	Responsibility/Resources	Timeframe	Performance Measures
3. Inform the public and providers on what to expect from Waikato DHB palliative collaborative care services	<ul style="list-style-type: none"> <li>Develop an integrated Waikato DHB palliative care directory to inform both public and professionals of what palliative care services are offered by each provider i.e. proposed updated information for webhealth site</li> </ul>	<p>Responsibility</p> <ul style="list-style-type: none"> <li>Collaborative Care Project Group to oversee actions</li> <li>Nominated person / position to work with webhealth to ensure information is accurate and up to date</li> </ul> <p>Resource</p> <ul style="list-style-type: none"> <li>Staff time- no added cost</li> </ul>	<ul style="list-style-type: none"> <li>2006-2007</li> </ul>	<ul style="list-style-type: none"> <li>Clear explanation of each providers role can be easily accessed by both public and health care professionals</li> </ul>
4. To determine the RRC as the single point of entry for collaborative care services	<ul style="list-style-type: none"> <li>Develop a formalised communication process between providers that ensures all collaborative care referrals are sent via the RRC</li> </ul>	<p>Responsibility</p> <ul style="list-style-type: none"> <li>DNS / PCU / Hospice Waikato</li> </ul> <p>Resource</p> <ul style="list-style-type: none"> <li>Staff time no added cost</li> </ul>	<ul style="list-style-type: none"> <li>2006-2007</li> </ul>	<ul style="list-style-type: none"> <li>100% of collaborative care referrals are channelled via the RRC</li> </ul>
5. A review and update of the Memorandum of Understanding (1996) between RH&CBS and Hospice Waikato will be undertaken	<ul style="list-style-type: none"> <li>Update / replace existing document</li> <li>Check legality and validity of any new documentation with Waikato DHB legal department</li> </ul>	<p>Responsibility</p> <ul style="list-style-type: none"> <li>Hospice Waikato / RH&amp;CBS with support from Legal and Risk</li> </ul> <p>Resource</p> <ul style="list-style-type: none"> <li>Staff time- no added cost</li> </ul>	<ul style="list-style-type: none"> <li>2006-2007</li> </ul>	<ul style="list-style-type: none"> <li>MOU is updated</li> </ul>

<i>Improved Access of Service</i>				
Objectives	Specific Tasks	Responsibility/Resources	Timeframe	Performance Measures
6. Hospice Waikato and RH&CBS work collaboratively to support the extension of the collaborative care model to Coromandel Town, Whitianga, Tairua and Whangamata	<ul style="list-style-type: none"> <li>Hospice Waikato and RH&amp;CBS (Coromandel district FHT) forge relationships to develop collaborative care in Coromandel Town, Whitianga, Tairua and Whangamata</li> <li>Identify issues and service gaps and involve DHB planning and Funding services</li> </ul>	<p>Responsibility</p> <ul style="list-style-type: none"> <li>Hospice Waikato / DNS</li> </ul> <p>Resource</p> <ul style="list-style-type: none"> <li>Staff time-no added cost</li> </ul>	<ul style="list-style-type: none"> <li>2006-2007</li> </ul>	<ul style="list-style-type: none"> <li>Collaborative services are available to patients who live along the eastern seaboard</li> </ul>
7. Consider the options and implications of introducing a full range of specialist palliative care service components to the Tokoroa community	<ul style="list-style-type: none"> <li>Assess what additional specialist palliative care services Tokoroa community would like in their area</li> </ul>	<p>Responsibility</p> <ul style="list-style-type: none"> <li>Waikato DHB Planning and Funding / Tokoroa Community Hospice</li> </ul> <p>Resource</p> <ul style="list-style-type: none"> <li>Staff time-no added cost</li> </ul>	<ul style="list-style-type: none"> <li>2007-2008</li> </ul>	<ul style="list-style-type: none"> <li>Equity of access to all components of specialist palliative care services are available to Tokoroa community if they require them</li> </ul>
8. Develop a formal understanding of when, if ever, collaborative care may be considered within the Hamilton and hinterland areas for complex palliative care patients under the care of DNS	<ul style="list-style-type: none"> <li>Meeting of DNS and Hospice Waikato to determine the need, viability, and cost of offering collaborative care services to complex palliative care patients who live in the Hamilton and hinterland area under the care of DNS</li> </ul>	<p>Responsibility</p> <ul style="list-style-type: none"> <li>DNS / Hospice Waikato / Planning and Funding</li> </ul> <p>Resource</p> <ul style="list-style-type: none"> <li>Staff time – estimated costing to be undertaken if and when required</li> </ul>	<ul style="list-style-type: none"> <li>2007-2010</li> </ul>	<ul style="list-style-type: none"> <li>A decision is made related to offering collaborative care to complex urban patients</li> </ul>



<i>Workforce and Resource Development</i>				
<b>Objectives</b>	<b>Specific Tasks</b>	<b>Responsibility/Resources</b>	<b>Timeframe</b>	<b>Performance Measures</b>
9. Develop within the collaborative care model a 24 hour / 7 day a week specialist palliative care nurse on-call telephone consultancy service for health provider use only	<ul style="list-style-type: none"> <li>Implement a change management process as per Waikato DHB policy</li> <li>Develop a plan that defines the responsibilities of the nursing workforce involved in offering the 24/7 telephone nursing consultancy service</li> <li>Ensure workforce have the skills and educational level to offer such a service</li> <li>Define the role of the on-call consultancy service that is to be offered</li> <li>Pilot on-call service for six month and then review</li> </ul>	<p>Responsibility</p> <ul style="list-style-type: none"> <li>Collaborative Care Project Group in consultation with NZNO / Hospice Waikato / PCU</li> </ul> <p>Resource</p> <ul style="list-style-type: none"> <li>Pilot project staff time – no added cost</li> <li>Rough estimate \$20,000 for Health Waikato (appendix 9)</li> </ul>	<ul style="list-style-type: none"> <li>2006-2007 (dependant on findings)</li> </ul>	<ul style="list-style-type: none"> <li>Plans are either put in place to establish a 24/7 service or the status quo remains</li> <li>Pilot of 24/7 on call nursing consultancy service implemented and reviewed after six months</li> </ul>
10. To improve clinical care through the development and implementation of clinical pathways	<ul style="list-style-type: none"> <li>Develop and standardise clinical pathways / guidelines for palliative care in the community</li> <li>Implement Waikato DHB plan for new clinical pathways</li> </ul>	<p>Responsibility</p> <ul style="list-style-type: none"> <li>Collaborative Care Project Group representative / senior nurse leaders / other appropriate groups</li> </ul> <p>Resource</p> <ul style="list-style-type: none"> <li>Staff time- no added cost</li> </ul>	<ul style="list-style-type: none"> <li>2008-2010</li> </ul>	<ul style="list-style-type: none"> <li>Clinical pathways / guidelines for community nurses working in palliative care</li> </ul>
11. Develop specialised educational packages for staff working within palliative care teams	<ul style="list-style-type: none"> <li>Design a training and development plan for district nurses and allied health staff who work in palliative care</li> <li>Develop an regular in-service training session related to Waikato DHB Palliative Care Strategy Plan</li> </ul>	<p>Responsibility</p> <ul style="list-style-type: none"> <li>Hospice Waikato / DNS / PCU</li> </ul> <p>Resource</p> <ul style="list-style-type: none"> <li>Staff time – no added cost</li> </ul>	<ul style="list-style-type: none"> <li>2007-2010</li> </ul>	<ul style="list-style-type: none"> <li>Training and development programmes for generalist carers are in place and being attended</li> </ul>

<i>Implementation of Quality Systems</i>				
Objectives	Specific Tasks	Responsibility/Resources	Timeframe	Performance Measures
12. Develop and implement a baseline data set that captures relevant data from integrated palliative care services	<ul style="list-style-type: none"> <li>Identify what is required as minimal data-base set</li> <li>Ensure both Waikato DHB and Hospice Waikato are collecting the same data so a comparison can be used to monitor and audit</li> </ul>	Responsibility <ul style="list-style-type: none"> <li>RRC / Hospice Waikato / Manager DNS Resource</li> <li>Staff time- no added cost</li> </ul>	<ul style="list-style-type: none"> <li>2006-2007</li> </ul>	<ul style="list-style-type: none"> <li>The baseline data collected is useful and appropriate for all services including planning and funding and development purposes</li> </ul>
13. Develop a suitable collaborative care reporting and monitoring system, with agreed frequency of auditing.	<ul style="list-style-type: none"> <li>Identify KPIs that can be used to measure and report effectiveness of changes to collaborative care model can be measured</li> </ul>	Responsibility <ul style="list-style-type: none"> <li>RRC / Hospice Waikato Resource</li> <li>Staff time – no added cost</li> </ul>	<ul style="list-style-type: none"> <li>2006-2007</li> </ul>	<ul style="list-style-type: none"> <li>Data collected is accurate and can be used for audit and planning purposes</li> </ul>

## REFERENCES

- DHB, W. (2006). *Memorandum to the Community and Public Health Advisory Committee*. Hamilton: Waikato District Health Board.
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- MOH. (2001). *The New Zealand Palliative Care Strategy*. Wellington: Ministry of Health.
- MOH. (2005). *New Zealand Cancer Control Strategy Action Plan 2005 - 2010*. Wellington: Ministry of Health.
- WHO. (2002). *National cancer control programmes - policies and managerial guidelines* (2nd ed.): World Health Organisation.

## **APPENDIX 1: COLLABORATIVE CARE PROJECT GROUP**

**Sponsor:** Waikato DHB Palliative Care Operations Network

**Steering Group:** Waikato DHB Palliative Care Operations Network

**Project Group:**

Chair - Jan Hewitt, Project Manager, Development and Support Unit, Waikato DHB  
Project Support – Jackie White

Elizabeth Bang, CEO, Hospice Waikato

Janice Osborn, Regional Development Manager, Hospice Waikato

Jill Dibble, Acting Manager Community Services

Helen Smathers, Collaborative Care Nurse, Hospice Waikato

Marg Carey, Manager, Central Family Health Team and continuing care hospital

Lyn Pointon, CNL, DN Northern & Central Family Health Team

Cherry McFarlane, Regional Referral Centre, Community Services

Margaret Stevenson, Regional Co-ordinator, Palliative Care Unit, Health Waikato

## APPENDIX 2: COLLABORATIVE CARE OBJECTIVES AND FINDINGS

**Table 3: Objectives and Findings**

Objective	Finding
To identify the current level of palliative collaborative care service, including strength, weaknesses and opportunities	<ul style="list-style-type: none"> <li>• Waikato rural communities have access to specialist home based palliative care services however there are inconsistencies in the level of access</li> <li>• Patients who live in Hamilton, Cambridge, Ngaruawahia are not eligible for collaborative services. These areas are contracted for hospice care and only complex palliative patients are cared for by the DNS</li> <li>• Tokoroa have their own community based hospice which offers support in the form of loan equipment and co-ordination of some volunteer services</li> <li>• Hospice Waikato services did not cover the eastern seaboard of Coromandel town, Whitianga, Tairua and Whangamata until the 1<sup>st</sup> July 2006</li> <li>• Lack of awareness of the collaborative care approach was found among both the professional and public sector</li> <li>• Users of collaborative care do not clearly understand the role of each home visiting service</li> <li>• The knowledge and understanding by district nurses of the proposed benefits for patients who choose collaborative care is varied. There is a conception by some staff that as generalists DNS are able to provide all patients palliative care needs</li> <li>• Lack of formalised workforce planning. No nominated care co-ordinator exists. It is informally understood to be the DNS</li> <li>• Lack of quality standards / specification and performance indicators</li> <li>• No national or local best practice standards currently exist for the delivery of home based palliative care services. Each provider group works to their own professional standards</li> <li>• There is no formalised referral communication methodology process between providers. Referrals are sent via the Regional Referral Centre (RRC) or directly between providers. When the latter occurs Waikato DHB have no method of accurately tracking the number of patients who are receiving collaborative care</li> </ul>

	<ul style="list-style-type: none"> <li>• There is not always an out of hours / emergency / medication plan</li> <li>• Hospice Waikato and Waikato DHB do not use compatible IT software packages making it difficult to share information and statistical data electronically</li> <li>• There is no standardised baseline data collection set from which formal quality reporting and monitoring of service can be undertaken</li> <li>• Specialist palliative care support is not always available to all palliative care patients and their family / whānau. After hours emergency situations, intravenous therapy and symptom control are initially responded to by either the GP or DNS</li> </ul>
To review other palliative care models both nationally and internationally	<ul style="list-style-type: none"> <li>• International literature indicates that a shared care model of community palliative service delivery known as the Macmillan model is prominent</li> <li>• The national models reviewed during this project were an adaptation of the Macmillan model of care where services shared clinical information and the delivery of skills. Patient care was overseen by specialist hospice services in the districts. Hospice services in the areas visited differed from Waikato in that they offered 24/7 medical and nursing support to patients and their family / whānau and to providers of palliative services</li> </ul>
To recommend the model for the future	<ul style="list-style-type: none"> <li>• To build on the existing collaborative care model by improving patient and professional awareness of the advantages for patients who receive both generalist and specialist services</li> </ul>
To develop a collaborative care action plan. The plan will include implications for resources, contracts, financials, timelines and performance measures required	<ul style="list-style-type: none"> <li>• Refer action plan &amp; assessment of additional funding (appendix 8)</li> </ul>

## APPENDIX 3: HOSPICE SERVICE SPECIFICATIONS

Table 4 details the service specification purchase units and Table 5 summarises what actually is provided by each of the organisations.

**Table 4: Hospice Palliative Care Service Specification Purchase Units (PU)**

PU Code	PU Sub Code	PU Description
COPL 0001 Assessment & care co-ordination	COPL 0001.1	Initial assessment for entry to Palliative care service
	COPL 0001.2	Ongoing assessment
	COPL 0001.3	Case management / care co-ordination
	COPL 0001.2	Advisory & information services
COPL 0002 Clinical Care	COPL 0002.1	Domiciliary care
	COPL 0002.2	Inpatient care
	COPL 0002.3	Night & day carer relief
	COPL 0002.3	Bereavement counselling

**Table 5: Waikato & Tokoroa Hospice Palliative Care Delivery of Purchase Units**

Specialist Hospice Community Palliative Care Providers	Hospice Waikato	Hospice Tokoroa
COPL 0001.1 Initial assessment	✓	✗
COPL 0001.2 Ongoing assessment	✓	✗
COPL 0001.3 Care co-ordination	✓	✗ (limited to volunteer & equipment)
COPL 0001.2 Advisory & information	✓	✓
COPL 0002.1 Domiciliary care	✓	✗
COPL 0002.2 Inpatient care	✓	✗
COPL 0002.3 Night & day carer relief	✓ (limited night)	✓ (limited)
COPL 0002.3 Bereavement	✓	✓

## **APPENDIX 4: SWOT ANALYSIS**

### **Strengths**

1. Collaborative care model supports the intermediate level model of care framework - WDHB Palliative Care Strategy Plan – 2005- 2010 (Page 29)
2. Collegial network support for nurses involved with patient care e.g. informal case review during the time of care and debriefing after patient death
3. Rainbow Place supports the children/grandchildren of dying adult patients or sibling as well as sick children
4. Sharing of information gives added value to patient care
5. The collaborative care team consists of committed and dedicated staff
6. Community based services supported by Palliative Care Unit
7. Collaborative care model has demonstrated improved availability of equipment to patients in the community
8. Support of volunteer groups
9. The model enhances and encourages a network approach where existing services work together
10. Waikato DHB staff have free access to an Employee Assistance Program (refer Waikato DHB HR policies) for emotional and psychological support as and when required

### **Weaknesses**

#### **1. Fragmentation**

- 1.1. There are four palliative community based nursing models of care
- 1.2. Hospice Waikato and District Nursing Service identified examples of fragmentation across all four models of care found across WDHB region:
  - Uncertainty about who provides what, when and where due to lack of clarity around roles or activities to be performed by services involved
  - Lack of clarity around roles and expectations between the organisations. DNS view PCU as the specialist palliative care provider and point of access if support required.
  - Duplication of some tasks e.g. patient assessment – each organisation completes own assessment
  - No standardise / integrated package of information given to patient and family / whānau by the providers. PCU and Hospice Waikato do use the same patient information.
  - Non-integrated clinical notes, all services involved with the patient hold their own notes
- 1.3. New Zealand Palliative Care Strategy recommends that the care co-ordinator is clearly identified to the patient / family / whānau and the health team. Co-ordination of care not always clear defined within the health team
- 1.4. Fragmentation of funding
- 1.5. If a collaborative care patient dies in hospital, sometimes, no notification is sent to either the DNS or Hospice



- 1.6 District nurses perception that there are two separate specialist care services:
  - PCU
  - Hospice Waikato
- 1.7 (Outside scope of project – is captured in Strategic Plan) Difficult to access support in some geographical areas. Issues of:
  - Unregulated workforce lack of availability
  - Poor availability of volunteer support especially in the weekends and at night
  - Access to some GP services at weekends / public holidays and evening / nights
  - Access to pharmacy / medication at weekends / public holidays and evening / nights
- 1.8 (Outside scope of project – is captured in Strategic Plan) Disability or personal care-some staff are unaware of which service to apply to for patient services and equipment
- 1.2 (Outside scope of project – is captured in Strategic Plan) Occupational therapists often cannot get equipment for palliative care patients. Some OT's are unaware that they can apply to hospice for assistance with equipment if the patient is under collaborative care model

Fragmentation can lead to inefficiencies with poor care delivery to the patient and family / whānau, frustration, conflict, 'patch protection' and reduced satisfaction between providers.

## **2. Service Levels**

- 2.1 The collaborative care model is a rural model the collaborative care model does not cover the total Waikato DHB region:
- 2.2 Collaborative care model is not available in Hamilton, Ngaruawahia or Cambridge to those palliative care patients that remain under the care of district nursing services. Hospice Waikato is contracted to provide a full service in Hamilton, Ngaruawahia and Cambridge
- 2.3 Collaborative care is not available in Coromandel town or the eastern seaboard areas of Whitianga, Whangamata and Tairua
- 2.4 Perception by some staff that the General Practice team is not involved in the collaborative care model
- 2.5 Hospice Tokoroa is separate to Hospice Waikato and operates under a different model of care. Tokoroa community does not have access to the full range of specialist palliative care services components i.e. specialist grief / bereavement, specialist palliative social work, biography service, speciality palliative community inpatient Hospice beds. Hospice Tokoroa do access Rainbow Place
- 2.6 Staff at Tokoroa and Thames Hospital's have a perception there are dedicated palliative care inpatient beds (1 – 2) for respite and symptom control. These are actually under the umbrella of medical beds.

### **3. Access to essential services**

Variations in different aspects of care have been identified:

#### **3.1 Referral**

- Multiple entry points, often duplication of referrals, information not always complete. Entry points include RRC and Hospice Waikato, often DNS and PCU refer directly to Hospice Waikato and do not go via RRC. (At the commencement of the collaborative care service there was no expectation to send all referrals via RRC).
- No written integrated referral tool or guidelines

#### **3.2 Assessment**

- Duplication in assessments i.e. Hospice Waikato and District Nurse and Palliative Care Unit
- No integrated standards / guidelines for assessments

#### **3.3 Care co-ordination**

- Lead care co-ordinator not always identified
- Perception that General Practice team has not been identified as a key member of the collaborative care team
- Roles and responsibilities of a care co-ordinator are not defined

#### **3.4 Clinical care**

- No integrated or standardised clinical care pathways, Liverpool End of Life Pathway is not utilised in the community
- District Nursing works to general district nursing best practice standards (2003). They do not have specific palliative care standards.
- Hospice works to Hospice NZ standards dated 1998
- After hours plan is not always formulated

#### **3.5 Support services (Outside scope of project – is captured in Strategic Plan)**

- Variance in amount and type of support services available in rural areas

#### **3.6 Equipment (Outside scope of project – is captured in Strategic Plan)**

- The district nursing and allied health found the process to access equipment was identified as a critical issue / weakness.
- The equipment management system and processes are fragmented
- Possible health and safety and infection control risk, e.g. maintenance and cleaning standards, replacement programmes
- Variability of access across the district
- Equipment owned and managed through multiple providers – Waikato DHB central store, Hospice Waikato and due to difficulties accessing equipment many communities have purchased equipment
- Community purchased equipment not shared across Waikato DHB region as the funding raised by Hospice is always kept within the area which raised the funds.
- No database / asset management system for all equipment throughout the district
- Inadequate level of equipment e.g. electric beds, bed blocks, pillow raisers, wheelchairs, lazyboy's and hoists.
- Incidences where patient and families have accessed equipment outside of the Waikato DHB

#### **4. Lack of awareness of Collaborative Care Approach**

- 4.1 The public are unsure of what palliative care means and services available, such as collaborative care within the Waikato district
- 4.2 Variable understanding of palliative collaborative care services available by Hospice Waikato and District nursing throughout the Waikato DHB
- 4.3 Perception of some people that GP services are not always aware of DNS after hours services availability

#### **5 Forecasted Growth (is also captured in Strategic Plan)**

- 5.1 Expansion of the palliative cares definition and parameters. Hospice Waikato service specifications encompass only the last 12 twelve months of life. Hospice Tokoroa provide community support services only
- 5.2 Increasing and ageing population
- 5.3 Change in the population's ethnicity mix with increasing Māori and Pacific People
- 5.4 Increase in the incidence of cancer
- 5.5 Increase referrals for people with non-malignant diseases due to increased incidence and awareness of other services that recognise the value of palliative care support
- 5.6 Increasing expectations to avoid hospitalisation and / or early discharge promoting management of palliative care in the community
- 5.7 Current funding and resources limit the capacity of Hospice Waikato and District Nursing to expand services

#### **6 Collaborative Care Workforce**

- 6.1 Not all staff within Hospice Waikato and District Nursing are aware of the Waikato DHB Palliative Care Strategy Plan 2005 – 2010 and the role and function of the Waikato DHB Palliative Care Operations Network
- 6.2 'Patch protection' owing to district nurses perception that collaborative care will erode their skill base or take over their jobs
- 6.3 There is no service integrated palliative care workforce plan which is reflected by inadequate formalised education and training programmes for specialist and generalist palliative care nurses
- 6.4 Inadequate levels of nursing staff with recognised post graduate qualifications. June 2005 specialist palliative care nurses and district nurses with recognised palliative care qualifications was <13%
- 6.5 Inadequate levels of Māori and Pacific representation in the palliative care nurse workforce
- 6.6 No formalised support and supervision programme at Waikato DHB. Hospice Waikato provides all staff with monthly supervision
- 6.7 Recruitment and retention of workforce. For Hospice Waikato this could be a risk as the DHB MECA has given a market lead on salaries for nursing staff. Hospice are, along with all other Hospices working with NZNO to try and address this

**7 Lack of quality standards / specification and performance indicators**

- 7.1 Information for patients and family / whānau is variable for each provider and is not integrated
- 7.2 Inadequate and variable data collection
  - Incompatible information systems – Hospice Waikato run File Maker Pro, District Nursing run Access
  - No defined minimal data set and / or performance indicators for collaborative care
  - Waikato DHB retrospective data is incomplete / inaccurate
- 7.3 Poor monitoring and evaluation services, monitoring is not integrated
  - No integrated clinical standards / pathways / guidelines
  - No single referral form supported with guidelines on process
  - Multiple assessments tools that are only verbally shared between providers
  - Clinical plans are not integrated, each provider holds own plans and clinical records
  - No integrated end of life pathway within the community
- 7.4 Increased quality expectations without infrastructure and resources to develop and support

**Opportunities**

1. To develop an integrated specialist palliative care nurse on-call consultancy service utilising staff from Hospice Waikato and PCU
2. To explore the option of a 24 hour / 7 day week specialist palliative care nurse consultancy service provided from Hospice Waikato community inpatient service. It should be noted that this option is probably outside the timeframe of the review. Hospice Waikato have purchased premises in Hamilton City to amalgamate and develop services on one site
3. To develop a collaborative care workforce plan which includes formal development of educational packages for staff working within the palliative care teams
4. To formalise a palliative / collaborative care peer staff support and supervision / debriefing procedure for Waikato DHB staff
5. To develop a Website directory of services to raise public and community awareness regarding collaborative care (as per Strategic Plan). This will include clearly defining the roles and responsibilities of organisations and health professionals working in the collaborative care model
6. To keep staff informed of progress towards the achievement of the Waikato DHB Palliative Care Strategy Plan
7. To develop collaborative care integrated referral, assessment and clinical care plan / notes supported with standardised tools, process guidelines and standards. Continue to explore options to have shared access to clinical information
8. Develop a collaborative care data set and identify IS requirements to integrate the and / or better utilise the current two systems
9. To consider opportunities for improvement of IS systems related to the Service Campus Redevelopment (SCR) Project for the implementation of the all referrals to be logged via the central referral centre
10. Waikato DHB enter into discussions with Hospice Tokoroa regarding opportunities to enhance integration of specialist palliative care service components in the local community

11. To review and update the 1996 Memorandum of Understanding between RH&CBS and Hospice Waikato.

**Threats**

1. New providers entering into palliative care collaborative care may result in duplication of services
2. Bureaucracy/ funding may hold up or limit progress of expected project outcomes

## **APPENDIX 5: NATIONAL MODELS OF CARE**

In New Zealand there is a variety of palliative care delivery models being used. The four models below describe Taranaki, Midcentral, Midland and Capital Coast palliative care delivery.

### **Taranaki**

Taranaki district has four models of care operating:

- In north Taranaki that covers the urban area of New Plymouth, Waitara, Onaero, Oakura to Okato all palliative care is undertaken by hospice nurses
- The Inglewood area palliative care contract operates under a PHO, and is between GPs, Taranaki DHB and hospice
- In Stratford and surrounding coastal areas care is provided by generalist district nurses who have palliative care experience. They are supported by hospice medical staff who run a weekly satellite clinic in the area
- South Taranaki palliative care is delivered by one FTE nursing position funded by Hospice Taranaki. There is a satellite clinic based a Hawera hospital

Communication is maintained between hospice and other regional palliative care providers by regular monthly visits to all outlying areas by the hospice Clinical Nurse Leader. Palliative care patients in the district who use any of the above services have a clinical file held at hospice.

The clinical files held at hospice are not a complete set of notes but consist of a brief weekly report of the condition and medication regime that is sent in by the district nurse. This keeps the medical staff at the hospice up to date with patient progress and they are able to give advice over the telephone when necessary.

### **Midcentral**

Midcentral palliative care covers Manawatu, Horowhenua and Tararua regions including Bulls, Marton, Hunterville, Taihape and surrounding areas. (Some of the area covered is Wanganui DHB).

A specialist team of nurse's work as hospice care co-ordinators. They oversee the care of patients who require palliative care in the community. Their role involves undertaking the initial patient assessment, and in conjunction with district nursing and GPs they maintain and co-ordinate ongoing care for patients. The model is based on shared care and is known as the Macmillan model. All providers use one set of clinical notes which are held by the patient. Hospice offers twenty-four hour medical and nursing advice for community providers.

Community palliative care education is undertaken as a joint venture between the hospice and Manawatu IPA.

### **Midland**

Only the Lakes area of Taupo was investigated. This area has a catchment of 45,000 people. Palliative care is delivered by district nurses under the guidance of a care co-ordinator. This model is very similar to the Midcentral model of shared care.

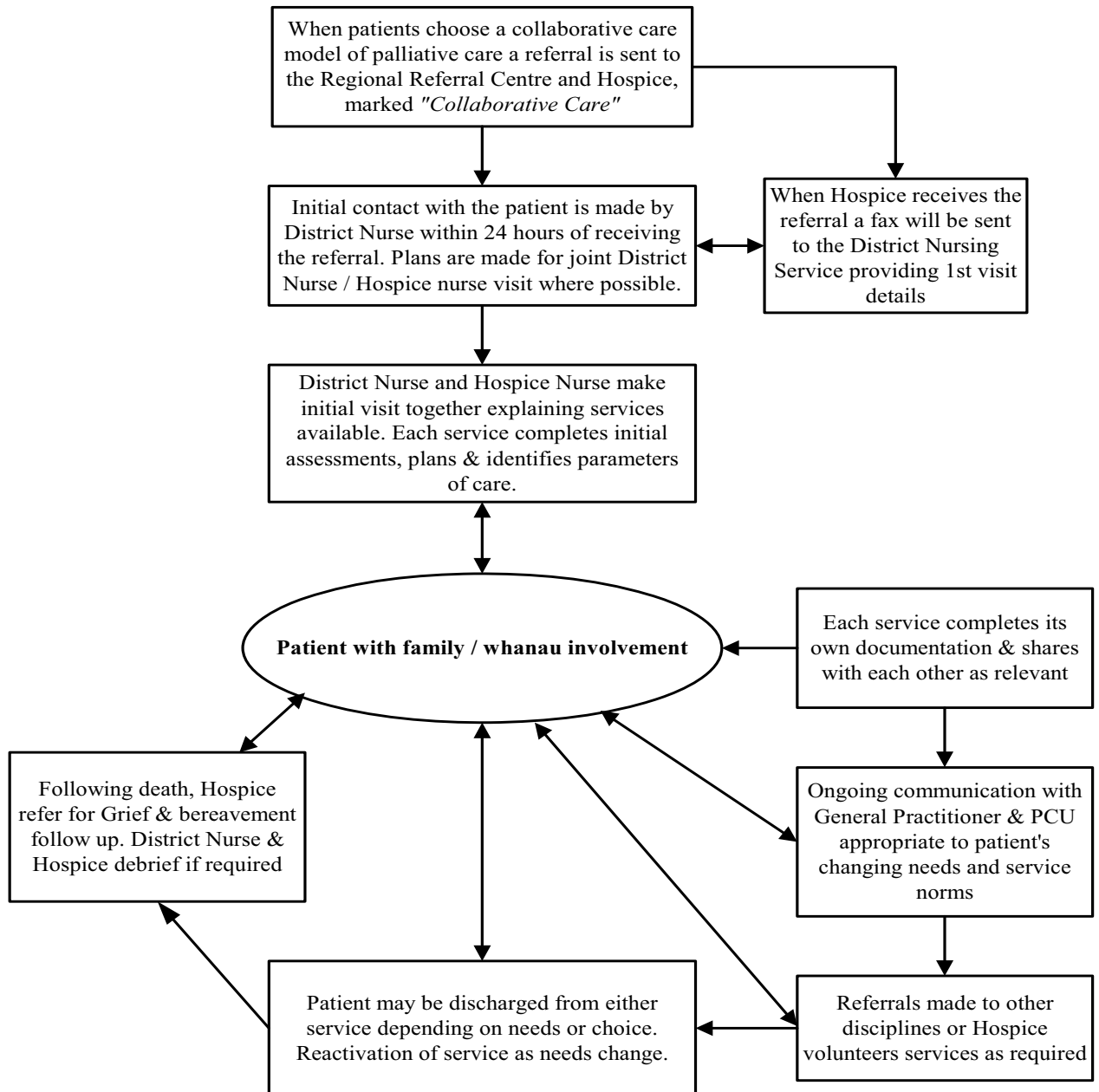
### **Capital Coast**

In the urban areas of Wellington city both Te Omanga and Mary Potter Hospice offer palliative care services. In the outer areas of the district the district nursing service delivers palliative care under the guidance of Te Omanga hospice. District nurses and hospice staff meet every two weeks to discuss patient issues.

This model is in the process of possible change due to Capital and Coast DHB changing to the Nurse Maude agency for community referrals and care co-ordination.

## APPENDIX 6: WAIKATO COLLABORATIVE CARE MODEL

### Collaborative Care Model Between Waikato DHB and Hospice Waikato





## **APPENDIX 7: HISTORICAL OVERVIEW OF PALLIATIVE COLLABORATIVE CARE MODEL**

Hospice Waikato has provided services to patients requiring palliative care and their families for twenty-five years. In 1991 Hospice implemented a full nursing service providing care to patients receiving palliative care in Hamilton, Cambridge and Ngaruawahia with Hospice nurses available as required over 24 hours x 7 days per week. Services outside this main service area consisted of family support volunteer groups in some, but not all, of the Waikato communities. Hospice took referrals from district nurses as required.

Increasingly Hospice Waikato was being asked by rural families, particularly those who had experienced hospice care in Hamilton or other parts of New Zealand, why they could not access total hospice care in their communities. Hospice Waikato nurses received some referrals in an ad hoc manner to work with District Nursing but there was no formal structure or process to enable this to occur.

The model of care at this time did not provide equity of service across the Waikato district which was recommended in the New Zealand Palliative Care Strategy (MOH, 2001). It was for this reason that Hospice Waikato employed an outreach co-ordinator to assist in developing a model of care which could be used across the Waikato DHB district in the areas outside of Hamilton, Cambridge and Ngaruawahia.

A working party was formed with representatives from:

- Northern and Central Family Health Team represented Waikato District Nursing service
- Waikato Hospital Palliative Care Unit
- Hospice Waikato nurses

The challenge was to ensure that services were enhanced and not merely duplicated. The strength of the process was that the nurses themselves were given the opportunity to work together, recognising the issues both historical and current and find solutions, which they believed, were relevant to the Waikato district.

Once an agreed model was developed, the Acting Manager of Health Waikato Community Services and the Chief Executive Officer (CEO) of Hospice signed off the proposal. In November 2003 a pilot scheme between Hospice Waikato and District Nurses was implemented in Te Kauwhata, Huntly, Te Awamutu and Raglan.

Both DNS and hospice nurses worked hard to establish the relationships and trust required to work effectively together. The GPs involvement is essential.

Where appropriate hospice counsellors and / or Rainbow Place therapists along with other professionals were added to the team as required. PCU remains the tertiary specialist service for patients who require palliative care.

Since 2003, the palliative collaborative care service has extended, with varying success, from the original geographical area to include Thames, Ngatea, Paeroa, Waihi, Matamata, Morrinsville, Putaruru, Otorohanga and Te Kuiti and Taumarunui.

## **APPENDIX 8: LITERATURE REVIEW**

The literature review confirmed much of what has already been identified during the period of this project. Key themes from the literature were unity of purpose, staff and public education, and clarity about who provides what service.

Palliative care providers need to develop a unity of purpose for which education is the key. According to Abu-Saad (2001) ambiguities related to service provision can be eliminated if staff have clear role delineation and integrated clinical pathways supported by training and education programmes.

Palliative care provider training education programmes assist primary staff in obtaining the skills and knowledge needed to provide appropriate services to patients in their own homes. Public education programmes raise awareness of what palliative care services are available.

Many authors focused on the need to measure the quality of care being given to patients who require palliative care. Donabedian's quality framework involving input, process and output appeared to be the tool of choice. This multi-systems framework generates quality indicators across all the dimensions of care. For example access to services, formal support services, organisation of care, technical clinical interventions, provision of information and communication. (Anderson, Byock, Barriball, Abu-Saad, Hanson, Koeck, and Hearn).

When the Macmillan model of palliative care was introduced in the United Kingdom they experienced similar issues to those occurring with the collaborative care model. There was role conflict between district nursing services and Macmillan nurses and although a lot of effort has been put in to rectifying this, three years post introduction of the model there is still some hostility evident between the two services.

MacLennan (2004) noted some hospices offer a level of care that is intermediary between primary and specialist palliative care. The Hospice Waikato services could be described as an intermediary service as they do not have dedicated medical staff. Hospice staff seek medical advice from either the patients GP or a specialist from the Waikato Hospital PCU. Whilst Hospice Waikato do have nursing staff on call 24/7 this service operates for use in the urban area of Hamilton, Cambridge and Ngaruawahia only.

District nurses are not seen as specialists in palliative care but rather they are generalists. However Luker (2000), discusses the district nurse-patient relationship as something that is very special and complicated due to the relationship being formed in the patient home. These issues coupled with palliative care as one aspect of district nursing work that is universally valued, as an exemplar of excellence for realising the ideals of nursing practice, are reasons for patch protection among the nursing groups.

As pointed out by O'Neill (1998) there needs to be common sense solutions found to caring for patients at home. Many of the solutions will result from better co-ordination of the professionals involved in collaborative care e.g. PCU, Hospice Waikato, District Nursing Services, GP's etc.

Whilst most literature supports the role of a care co-ordinator for community areas, the Ministry of Health submissions document (2000) found no clear support for having one provider to co-ordinate services.

## APPENDIX 9: ASSESSMENT OF ADDITIONAL FUNDING

Assessment of additional funding required for the implementation of a 24/7 on-call nursing telephone service is extremely difficult. Specialist providers are unable to estimate the number of out of hours telephone calls they receive from generalist providers seeking advice. Therefore the cost is an indicative amount only and monies to operate such a service would come out of the operating budget.

(The estimates used for costing the implementation of a 24/7 service have been taken from the Home Service haemodialysis area who currently operate a 24/7 telephone nursing advisory service for both patients and providers).

	Estimated Additional Funding			
Workforce	Hours per week on call	Estimated on call allowance	Overtime rate of 1.5 times usual hourly rate per call with minimum payment of 15 minutes	
	125.5	\$2.50 per hour	10 hours per week	
Equipment	Cost of phone purchase is nil with a \$30.00 per month mobile connection fee			
	Cost of running a cell phone with a 0800 on call phone number:			
	Free2call casual	Free2call 75	Free2call 250	Free2 call 1000
Set up fee	\$13.33	-	-	-
Monthly access fee	-	\$19.50	\$45.00	\$100.00
Included Minutes	-	75	250	1000
Additional minutes	39c per minute	30c per minute	20c per minute	15c per minute

### Notes and assumptions

- A grade 3 senior nursing salary of \$66,153 per annum has been used to estimate a per week cost of \$790.75 comprising of \$477.00 for 10 hours at overtime rates plus \$313.75 call out rate for on call service rates. These figures have been taken from the NZNO MECA. This equates to an approximate salary cost of \$41,119 per annum.
- The cost of operating a mobile phone varies as shown on the above table. Calls could either come through the hospital operator or a 0800 telephone number could be assigned for this purpose.