

Review of Wairarapa Palliative Care Service November 2009



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“Hospice is not a building; it is a philosophy of care. Our goal is to help people make the most of their lives. We care for the whole person, not just their physical needs, but also their emotional, spiritual and social needs too.”

Hospice NZ, 2009

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1 EXECUTIVE SUMMARY

Wairarapa District Health Board (DHB) implemented a new Palliative Care Service, Kahukura, on 1 September 2008. Wairarapa Community Primary Health Organisation (WCPHO), Wairarapa DHB and Te Omanga Hospice jointly provide the Wairarapa Palliative Care Service and work in partnership to provide a consistent palliative care approach for the population of the Wairarapa district. This community based palliative care service works across primary and secondary health services, so that the palliative care needs of all patients are assessed and their care and support provided in a co-ordinated way as an integral part of primary and secondary health services.

Palliative care is the care of people of all ages with a life limiting illness, with little or no prospect of a cure, and for whom death is the likely outcome – be that hours, days, weeks, months or sometimes years away.

This report is part of a quality improvement process reviewing the service one year after implementation, to provide guidance for service improvement. The report compares current service operation with planned outcomes of the Wairarapa Palliative Care Plan and assesses the extent to which the service is meeting each of the strategic directions in the Palliative Care Plan.

The palliative care service change was initiated to address the significant service issues identified during the plan development including:

- a lack of a palliative care approach in some services
- poor integration and coordination of palliative care services
- lack of standard quality specifications and outcome measures
- lack of workforce planning; and
- variability of funding of palliative care services.

The service in its current form is meeting the majority of the aims of the planned palliative care service, and has addressed some of the identified service issues. The lack of standard quality specifications has been addressed through clear services specifications for providers, but outcome measures have been more difficult to define. Stakeholders interviewed report that after some initial issues, the service is working very well and patients are getting a very good service. The majority of those interviewed were very positive about the palliative care service, and complimentary about the staff involved in the service. While identifying opportunities for improvement, stakeholders believe these issues are consistent with a newly developed service and were very positive about the current and future service. Generally the service model works well and is transferable to other long term conditions.

There has been significant development in primary and residential care and a strong palliative care focus is evident in most services interviewed. Patients and their care givers can access nursing and medical advice/support/personal help 24 hours a day 7 days a week. General Practitioners (GPs) report that primary care has been empowered and reconnected to end of life skills through education. GPs are the lead medical carer in this palliative care service, and this model of care is unique in New Zealand, There is less evidence of a palliative care focus seen in secondary services, with some families and whanau describing inadequate pain management of their family member while in hospital.

Many people reported the staff at Kahukura as being overworked and the service seeing far more people than anticipated. This may be due to the distribution of workloads and work processes as there are actually less patients seen and less community nurse visits than planned for. The actual number of people in the palliative care service from 1 September 2008 to 31 August 2009 was 171 patients, consistent with previous years, and less than the anticipated annual volume of 200 patients. The percentage of Maori clients has increased from 8% to 11% of palliative care patients, and represents a reduction in inequality. While cancer remains the major diagnosis for those accessing the palliative care service, people with other long term conditions have increased significantly.

There are a number of planned elements of the service still to be implemented including:

- Key worker identification and processes which were a key element of the Wairarapa Palliative Care Plan
- Patient held record and/ or communication book
- Identifying community and voluntary resources that will complement funded services
- Stakeholder satisfaction surveys
- Post death reviews are partially implemented
- Strong integration of primary and secondary services for a seamless patient journey.

While significant progress has been made, further development of the service is recommended in a few areas, including multidisciplinary team processes and tools, in linking with other services, and reviewing equipment processes.

The service lacks an identified leader within the multidisciplinary team to be a key point of access for issue identification and resolution, and to pull together the various components of the service and drive changes required. This is a management role and is distinct from clinical leadership. Immediate key tasks for this person include developing linkages to voluntary supports and how these can complement current services, developing relationships with other agencies and the ensuing memorandums of agreement, and the implementation of stakeholder satisfaction surveys.

Although Kahukura did not set out to become a hospice, it fulfils many of the services and functions of a hospice²; the deficits are in the family support and social support services, such as biography writing, that were previously carried out by volunteers. A combination of the current palliative care services and the proposed services of the Wairarapa Hospice Community Trust will provide an excellent palliative care service for Wairarapa residents. It is important that services work together to ensure patients and families receive services that complement each other and do not duplicate services and resources.

² Hospice New Zealand defines hospice as a philosophy of care, not a building. Hospices care for the whole person, including physical, emotional, spiritual and social needs. Further definition can be found in the appendices.

2 BACKGROUND

2.1 Strategic Direction

The Wairarapa Palliative Care Plan set a consistent palliative care approach for the Wairarapa District Health Board population with palliative care delivered across primary and secondary health services. The Wairarapa Palliative Care Plan was approved by the Board of Wairarapa DHB in March 2007. The plan identified seven **strategic directions** to provide a framework for implementing a vision for developing local services, and for coordination with primary secondary, specialist and regional services:

- Provide a clear pathway for entry to the palliative care service
- Provide systematic needs assessment and care coordination
- Provide effective and co-coordinated essential palliative care services; including case management, generalist palliative care and support services, with specialist palliative care services available when required for people with complex needs
- Identify and work with local voluntary and other support services that can provide additional support to people who are dying and their families, whanau and carers
- Provide on-going psychosocial support for carers, family and whanau, including links to welfare and bereavement support
- Ensure culturally appropriate services for Maori and other ethnic groups
- Develop a palliative care approach across all health services through workforce development and training and through the adoption of a recognised pathway for the dying.

In September 2008, the plan was implemented with a new palliative care network of services provided by a range of providers, and is overseen by a management group.

2.2 Frameworks

The following documents provide guidance for the palliative care service design:

- Draft national service specifications – palliative care
- WDHB Palliative Care Plan
- WDHB District Annual Plan
- WDHB Strategic Plan

2.3 Definition and DHB Vision

Palliative care³ is care for people of all ages with a life-limiting illness which aims to⁴:

- Optimise an individual's quality of life until death: to do this, a person's physical as well as psychosocial, spiritual and cultural needs are assessed and addressed.
- Support the individual's family, whānau, and other caregivers where needed, through the illness and after death.

Palliative care is provided according to an individual's need, and may be suitable whether death is hours, days, weeks, months or occasionally, especially in the case of children, even years away. It may be suitable sometimes when treatments are being given aimed at improving quantity of life. It should be available wherever the person may be.

Palliative care should be provided in such a way as to meet the unique palliative needs of individuals from particular communities or groups. These include Māori, Pacific Peoples, Asian, children/

³ NZ Palliative Care: A Working Definition. Palliative Care Working party 2007, MOH

⁴ Specialist Palliative Care Tier Two Service Specification. Final Draft February 2008

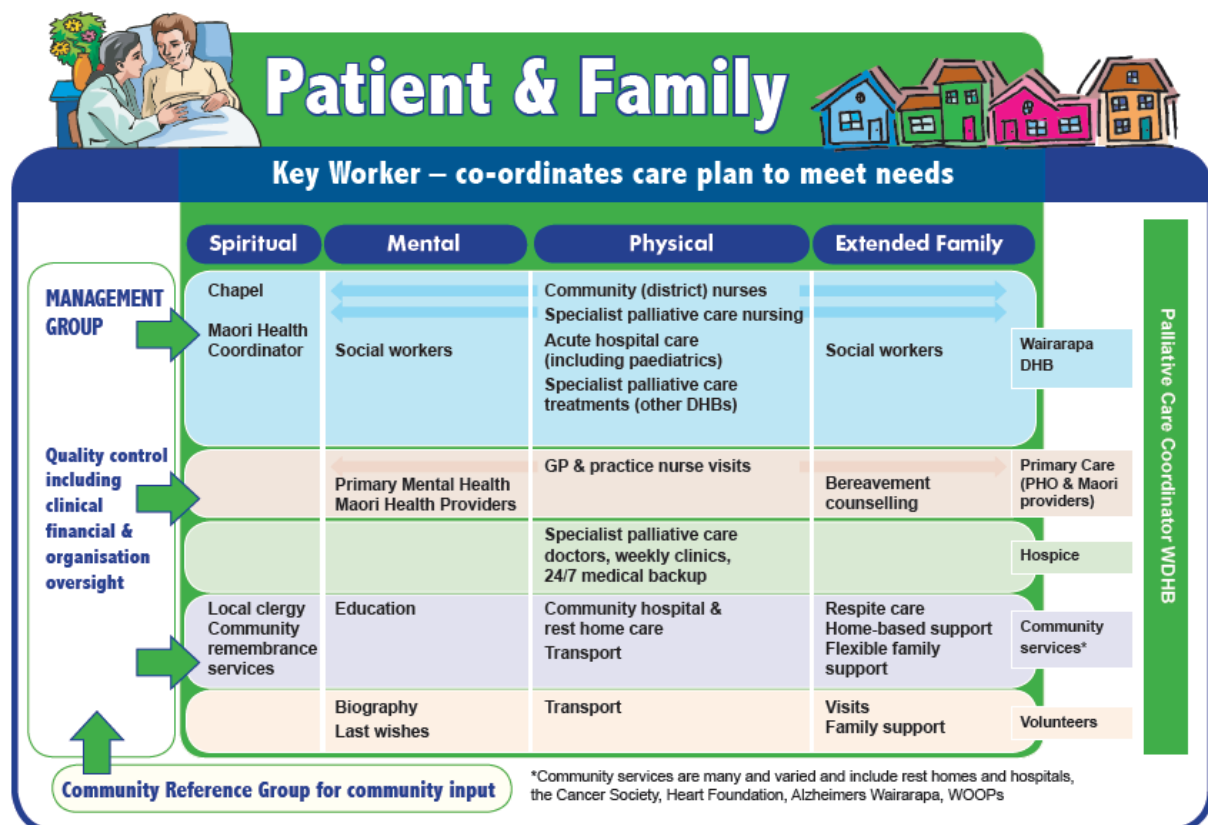
adolescents and their families, immigrants, refugees, persons with disabilities and mental illness, the elderly, and those in rural and remote communities.

The **vision** for Wairarapa palliative care services is:

All people in Wairarapa with a life limiting illness have timely access to palliative care services that are culturally appropriate, are provided in a coordinated way, affirm and encourage the quality of life for each individual and enable them to die comfortably, with dignity and in the place of their choice. Families /whanau, caregivers and close friends receive support and care during the patient's illness and in bereavement.

2.4 Current Service Model

Palliative care services in the Wairarapa DHB region are provided by a local network of providers⁵. The overall approach taken is the provision of high quality generalist palliative care through an integrated network of credentialed health professionals from primary, community, aged residential care and secondary health services. This palliative care service works in partnership with regional specialist palliative care services and is underpinned by palliative care training for all providers, commitment to common palliative care standards and a shared plan of care for each dying person. The integrated network of palliative care services is linked to, and draws on the supports available through family, whanau, community, and voluntary agencies.



The diagram above shows the planned approach to palliative care services and this has been implemented in the following way.

⁵ Network of palliative care providers in appendices.

Wairarapa Community PHO, Wairarapa DHB and Te Omanga Hospice jointly provide the Wairarapa Palliative Care Service and work in partnership to provide a consistent palliative care approach for the population of the Wairarapa district. The service works across primary and secondary health services, so that the palliative care needs of all patients are assessed and their care and support provided in a co-ordinated way as an integral part of primary and secondary health services..

The majority of hands on patient care is provided by community nursing and the patient's primary health care team, supported by specialist nursing and 24/7 medical advice. The plan was for the patient to be supported by a range of other services coordinated by the key worker, and access to services supported by the palliative care coordinator.

The palliative care network is overseen by the management group who provide quality control including clinical, financial and organisation oversight. The spiritual, mental, physical and extended family needs are met with a network of providers working together to provide a coordinated continuum of care.

2.5 Review Objectives

After 12 months of operation, the DHB wishes to determine whether the expected outcomes of the service are being achieved. This review:

- Compares current service operation with planned outcomes of the Wairarapa Palliative Care Plan.
- Assesses the extent to which the service is meeting each of the strategic directions in the Palliative Care Plan and each component of the draft Specialist Palliative Care Service Specification.
- Covers the period from 1st September 2008 to 31st August 2009.
- Is part of the total quality improvement process for palliative care in Wairarapa rather than a 'stand alone' project.

Wairarapa DHB has led the way for an integrated palliative care service and the model which integrates primary and secondary care is likely to be the forerunner of future service design in the Wairarapa. The review aims to strengthen the service design thereby enabling its adoption in other contexts.

2.6 Review Approach

The palliative care management and advisory group sought an independent review of current services, and appointed Marion Thomas to carry out the review.⁶ The review includes all aspects of the generalist and specialist provision of the Wairarapa Palliative Care Service. The review does not include comprehensive analysis of agencies which are part of the palliative care service (e.g. FOCUS, Community Nursing) as many of those are subject to separate reviews. However, it does include review of their role as it relates to provision of the palliative care service.

The reviewer carried out a site visit in October 2009 and met with a wide range of local stakeholders⁷, both in the hospital and community and would like to acknowledge their input into this report. The purpose of the site visit was to seek stakeholder views on areas of excellence in service provision, significant issues and opportunities for improvement in the palliative care service, and the continuum of care patients and families experience. In addition to the site visit, phone interviews were held with people not available during the site visit.

⁶ Reviewer biography in appendices.

⁷ Stakeholders interviewed in appendices.

Information was also provided by Wairarapa DHB and Wairarapa Community PHO on the Wairarapa population, palliative care visits, Emergency Department and hospital admissions, and staff numbers in the palliative care service.

2.7 Linkages

The review has close linkages with the following services and Good to Great projects:

- FOCUS service redesign
- Community Nursing review
- The three strands of the breakthrough collaborative project (ED presentation, system design and change management at practice level, and improved prescribing and medication management)
- Long Term Conditions project

3 REVIEW FINDINGS

The service in its current form is meeting the majority of the documented expectations of the planned palliative care service. Stakeholders interviewed report that after some initial issues, the service is working very well and patients are getting a very good service. The majority of those interviewed were very positive about the palliative care service. While identifying opportunities for improvement, they believe these issues are consistent with a newly developed service and were very positive about the current and future service. Generally the service model works well and with some adjustment is transferable to other long term conditions, as a means of integrating and linking a number of services for enhanced patient care.

The palliative care service change was initiated to provide a comprehensive and coordinated palliative care service to address the significant service issues identified during the plan development including:

- a lack of a palliative care approach in some services
- poor integration and coordination of palliative care services
- lack of standard quality specifications and outcome measures
- lack of workforce planning; and
- variability of funding of palliative care services.

There has been significant development in primary and residential care and a strong palliative care focus is evident in most services interviewed. Patients and their care givers can access nursing and medical advice/support/personal help 24 hours a day 7 days a week. There is less evidence of a palliative care focus seen in secondary services, with some families and whanau describing inadequate pain management of their family member while in hospital.

Integration and coordination of services has improved between specialist palliative care, community nursing and primary care. Further development is required to improve linkages with secondary care and voluntary services.

Quality specifications are in place for all current palliative care services with some outcome measures within these specifications. Trend reporting and monitoring of these and other measures (e.g. such as those used in the Palliative Care Outcome Collaborative⁸) to the management and advisory group needs further development.

At this stage workforce planning has not been a priority with the services focused on patient and family care as its main objective. Future work should include workforce planning.

Funding variability has been addressed with all similar services receiving comparable funding for comparable services.

3.1 Patient Journeys

The three stories below are the experiences of people using the palliative care service and illustrate some of the finding of this review. The first two stories show patients and their families receiving appropriate palliative care.

⁸ <http://chsd.uow.edu.au/pcoc/>

Mrs A, a 72 year old woman living in a rural area, was suffering from cancer of the pancreas and respiratory disease. She had been receiving treatment for her condition and had been visited regularly by the oncology nurse. When her condition deteriorated on October 9 she was referred by her GP to Kahukura for palliative care.

A specialist nurse visited her the same day and assessed her condition as deteriorating rapidly. She arranged for the equipment required to nurse her at home to be delivered. This was done the same day.

Mrs A had a large family, most of whom were living in Australia. On the request of the patient, the nurse rang family in Australia and explained the situation. The family immediately made arrangements to travel to New Zealand.

The GP visited the family at 5.30 in the afternoon and put in place a syringe driver for pain and symptom relief.

Over the next few days Mrs A was cared for at home by her family with regular visits from the Community Nurses and her GP. She was comfortable and calm. Her family had all arrived from Australia to be with her.

Mrs A died peacefully on October 14. After her death her family took her to her home marae for her tangihanga and burial. When they returned home they contacted Kahukura and observed that, although it was a sad time, the experience was extremely spiritual and they had appreciated the support they had received.

Mrs B was a 91 year old woman being cared for by at home her 93 year old husband. She had been visited by the Community Nurses since February when she had surgery for cancer of the bowel, but was not at that point requiring palliative care. On the 6th of August, when her condition deteriorated and she needed a higher level of support, her GP referred her to Kahukura.

With the support of the GP and daily community nurse visits, Mr B was able to care for his wife at home for three months as was their wish. A specialist nurse also visited from time to time to ensure that an appropriate plan of care was in place. Mrs B's daughters dropped in regularly.

In October pain and bowel management became an issue and Mrs B was visited at home by the medical and nurse palliative specialists. The care plan and medications were adjusted and Mrs B remained at home.

On November 9 Mrs B became confused and restless. As she had some unsettled nights Mr B had become very tired. The GP visited the couple at home and arranged for Mrs B to be admitted to a local hospital facility for respite care so Mr B could get some rest.

On November 11 Mrs B's condition deteriorated further. The GP visited her in the facility and arranged for a syringe driver.

Mr B was very happy with the care his wife received in the facility and elected that she remain in the facility for her final days. He visited each day along with other family, but returned home to sleep. The GP continued to monitor her symptoms and medications.

Mrs B died peacefully on the 14th of November.

Some opportunities for improvement can be seen in the story below, particularly to improve the patient journey between primary and secondary care. This and other stories should be used to improve the integration of services and enhance the patient's journey of care.

Mr D was a 61 year old man who lived alone in a rural area 30 minutes out of Martinborough. His only family support was a cousin who lived nearby. Mr D had been diagnosed with cancer of the oesophagus in January 2009.

Mr D was referred by his GP for palliative care in early August. With support from Community Nursing he remained living at home.

On October 15 Mr D became unwell and was visited at home by his GP. His GP referred him to the Emergency Department at 8.30pm, and Mr D was diagnosed with a chest infection and antibiotic treatment commenced. Although ED staff considered he was able to return home that night Mr D declined to phone his cousin at 12.30am and he remained in the hospital until the next morning. A Community Nurse visited him at home later in the morning.

At 5.30pm on October 16 Mr D rang the Community Nurse to seek advice because he was vomiting coffee ground vomit. The Community Nurse phoned ED and was told to send him back to there. As Mr D's cousin was not available, an ambulance was called to get him there. Mr D was assessed in ED and discharged home by taxi at 9.30pm.

On 17 October Mr D was visited at home by the Community Nurse. She found him to be very unwell, scared and not managing on his own. She arranged for him to be admitted to a local facility for respite care and he remained there until November 2nd.

Mr D managed at home with support from his GP and Community Nursing for a further three weeks. On the 23rd of November he became too unwell to be at home and he was readmitted to the facility. Mr D died peacefully on December 1.

3.2 Access to Palliative Care Services

3.2.1 Service Volumes

Many people reported the staff at Kahukura as being overworked and the service seeing far more people than anticipated. This may be due to the distribution of workloads as there are actually less patients seen and less community nurse visits than planned for. The actual number of people in the palliative care service from 1 September 2008 to 31 August 2009 was 171 patients⁹, consistent with previous years, and less than the anticipated annual volume 200 patients.

| Service Volumes | Expected volume | Expected per patient | Actual volume | Actual per patient |
|-------------------------------------|-----------------|----------------------|---------------|--------------------|
| Number of patients | 200 | - | 171 | - |
| Number of PC community nurse visits | 3600 | 18 | 2847 | 16.6 |
| Number GP consults - home | 200 | 1 | 441 | 3 |
| Number GP consults - practice | 600 | 3 | 164 | 1 |
| Phone consultation | 0 | 0 | 114 | 1 |
| Number practice nurse consults | 400 | 2 | 28 | 0 |
| Repeat prescription | 0 | 0 | 540 | 3 |

⁹ The number of palliative care patients differs in the community nursing database, but the FOCUS volumes are consistent with primary care.

Data is from 3 sources: Galen, FOCUS palliative care database and WCPHO database.

The expected number of GP consults was based on experience in Midcentral and the total GP consults is a little lower than the expected number; however there is a far higher proportion of home visits than anticipated.

3.2.2 Ethnicity

In the 2006 census 14% of the Wairarapa population identified themselves as Maori. In 2006/07¹⁰, 8% of palliative clients were Maori and in 2008/09 11% of palliative care clients were Maori. This increase may be the result of increased understanding and knowledge of palliative care, or it may be a result of developing relationships between Whaiora, primary care and the palliative care service. Either way, it represents a reduction of inequalities with regard to accessing palliative care.

| Ethnicity | 2006/07 | % of total 06/07 | 2008/09 | % of total 0809 | |
|--------------------|-----------|------------------|------------|-----------------|-----|
| Maori | 7 | 8% | 19 | 11% | |
| Pacific | 0 | 0% | 1 | 1% | |
| Other (inc blanks) | 81 | 92% | 151 | | 88% |
| Grand Total | 88 | 100% | 171 | 100% | |

3.2.3 Staffing – planned and actual

Staffing of the Kahukura service has been implemented as planned with the exception of the volunteer coordinator. The palliative care facilitator role is now covered by two staff with a total of 1.3 FTE but this role also carries out other tasks and the estimated time for palliative care is 0.6 FTE.

| | Planned FTE | Actual FTE |
|---|-------------|-------------|
| Palliative care facilitator | 1 | 0.6 |
| Specialist medical (.33FTE incl leave cover for 50 wks & oncall 24/7) | 0.33 | 0.33 |
| Palliative care nurse | 1.2 | 1.2 |
| Palliative care educator | 1 | 1 |
| Lead GP | 0.2 | 0.2 |
| Volunteer coordinator | 0.25 | 0 |
| Total | 3.98 | 4.03 |

¹⁰ 2006/07 data includes only Te Omanga patients (not community nursing patients receiving palliative care) – ethnicity, diagnosis and length of time in service.

3.2.4 Access by Diagnosis

While cancer remains the major diagnosis for those accessing the palliative care service, people with other long term conditions have increased significantly. It can be more difficult to judge when those with long term conditions other than cancer are reaching the end of life stage, and consideration to eligibility criteria is important in ensuring appropriate access is maintained.

| Diagnosis | 2006/07 | % of total 06/07 | 2008/09 | % of total 0809 |
|----------------|---------|------------------|---------|-----------------|
| Cancer | 80 | 91% | 120 | 70% |
| Cardiovascular | 2 | 2% | 15 | 9% |
| Other | 4 | 5% | 17 | 10% |
| Renal | 0 | 0% | 5 | 3% |
| Respiratory | 0 | 0% | 9 | 5% |
| Neurological | 2 | 2% | 5 | 3% |
| Grand Total | 88 | 100% | 171 | 100% |

3.2.5 Time in Service

The table below shows the number of people by the length of time from referral to date of exit from service¹¹. There has been an increase in the length of time people receive palliative care services, particularly from 1 - 6 months. Palliative care is particularly aimed at supporting people in the last 6 months of life, but also extends to 12 months.

| Days from referral to date of death | 2006/07 | % of total 06/07 | 2008/09 | % of total 0809 |
|-------------------------------------|---------|------------------|---------|-----------------|
| 1 month or less | 45 | 51% | 61 | 46% |
| 1-3 months | 22 | 25% | 42 | 31% |
| 3 - 6 months | 9 | 10% | 20 | 15% |
| 6 months + | 12 | 14% | 11 | 8% |
| Total | 88 | 100% | 134 | 100% |

3.2.6 Acute Care Admissions

Average attendances per palliative care patient to the emergency department have increased a little since implementation and acute admissions have remained at the same level. The number admitted through ED has decreased slightly, with the increase being for those seen only in ED and not admitted. The increase in ED visits may be due to lack of clarity about the key worker, or new skills being learnt

¹¹ Those still in service have not been included.

and confidence in dealing with acute situations, and thus temporary in nature. However this trend should be monitored, and investigated further if it continues.

| Average visits/admissions per patient | 2007/08 | 2008/09 |
|---------------------------------------|---------|---------|
| Emergency Department | 2.3 | 2.6 |
| Acute admissions | 1.8 | 1.8 |
| ED & Acute Admissions | 4.2 | 4.5 |

3.2.7 Service Utilisation per Patient

Palliative care encompasses a number of services and the table below shows services accessed by patients during this period. Many of these services will be accessed prior to and during the time the patient is part of the palliative care programme. The total number of contacts per clients since implementation for primary and secondary care is 54 per patient. A direct comparison cannot be made to the previous year as we do not have information available on primary care contacts during that period. The data is for a full year and therefore the number of contacts also includes DHB contacts prior to admission into the palliative care programme¹².

| Contacts/patient | 2007/08 | 2008/09 |
|-------------------------------------|-------------|-------------|
| Allied Health | 5.6 | 6.3 |
| Community nursing | 28.7 | 31.5 |
| ED | 2.3 | 2.7 |
| Haematology/blood transfusions | 0.2 | 0.4 |
| Hospital admission | 2.0 | 1.9 |
| Outpatient visit | 2.8 | 3.5 |
| Primary care | 0.0 | 7.5 |
| Procedure | 0.0 | 0.1 |
| Total contacts | 41.7 | 54.0 |
| Total excluding primary care | 41.7 | 46.5 |

¹² Splitting this data into pre palliative and palliative is beyond the scope of this document but may be useful future work.

3.2.8 Financial information

Planned costs of the palliative care service were \$979,213¹³, and actual costs of the service over the review period were \$917,939. The biggest difference between planned and actual costs is community nursing visits, rent and CMI funding. The difference in community nursing visits may be reduction in duplication of nursing visits between Te Omanga and community nursing services, or incorrect coding of palliative care community nursing visits to general community nursing.

| Palliative Care Framework Costs | Planned cost/annum | Actual cost/annum |
|---|--------------------|-------------------|
| Palliative care facilitator | 60,000 | 59,230 |
| Specialist medical including leave cover & oncall | 81,000 | 80,894 |
| Dedicated palliative care nurses | 224,400 | 200,344 |
| Community nursing visits | 230,940 | 195,242 |
| Primary Care - including medical and nursing (practice & home visits) | 60,000 | 60,000 |
| Administration of generalist PC funds | 24,000 | 24,000 |
| Lead GP | 24,000 | 24,000 |
| Volunteer coordinator | 12,000 | 660 |
| Rent | | 28,900 |
| Steering Group | 4,327 | - |
| Ongoing training | 3,617 | 4,524 |
| Ambulance | - | 3,500 |
| CMI Funding | 254,929 | 236,645 |
| Total Cost | 979,213 | 917,939 |

3.2.9 Respite Care

Chronically medically ill (CMI) funding provides services for people who are not eligible to receive long term services. Typically the majority of people accessing this funding pool are those receiving palliative care to provide respite care in residential facilities. In 2006/07 there were 82 people accessing respite services through CMI and Te Omanga at a total cost of \$254,929. From September 2008 to August 2009, 93 people accessed CMI services at a total cost of \$178,757. However there were a number of very low months in that period and more typical costs are shown in the period from December 2008 to November 2009. The average cost of inpatient care has decreased from \$3,109 per person in 2006/07 to \$1715 per person in 2008/09.

| CMI | Jul 06-Jun07 | Sep 08-Aug 09 | Dec 08- Nov 09 |
|-----------------|--------------|---------------|----------------|
| Number patients | 82 | 93 | 138 |
| CMI+TOH respite | \$ 254,929 | \$ 178,757 | \$ 236,645 |
| Average/patient | \$ 3,109 | \$ 1,922 | \$ 1,715 |

¹³ CMI (chronically medically ill) funding was not included in earlier papers but was and still is used predominantly for palliative care patients. It includes all residential care (including patients admitted to Te Omanga Hospice in Lower Hutt) and home support for palliative care patients.

3.3 Strategic Direction Progress

The tables below show progress against the planned strategic directions for palliative care, and the relevant part of the service specifications.

3.3.1 Provide a clear pathway for entry to the palliative care service

| | Palliative Care Plan | Review Finding |
|-----------------------|---|---|
| Referral | <ul style="list-style-type: none"> To access palliative care services all patients must be referred through the single point of entry in FOCUS. Frequently, those who require palliative care are already receiving wider community based health, disability and support services such as home based care. It was intended that, wherever possible, primary, secondary and community health services already involved in a person's care would be the main providers of palliative care. This was to minimise disruption in the care arrangements and relationships that had already been established throughout the course of a person's illness. | <ul style="list-style-type: none"> There is a clear pathway through the single point of entry in FOCUS. Almost all referrals are through FOCUS with a few going through short term community nursing before receiving palliative care by the community nurses. For primary care to receive payment, all palliative care referrals must be assessed to determine their eligibility for palliative care. FOCUS has a standard referral form for palliative care patients. Several stakeholders indicated that the referral form did not cover all the information they wished to provide; <ul style="list-style-type: none"> The transfer of clinical information for handover of clinical care. While the referral form is not designed for clinical handover, processes need developing to clarify clinical handover, particularly from secondary services. Not all types of services are on the referral form, such as volunteer services. |
| Administration | <ul style="list-style-type: none"> A dedicated palliative care administration (PCA) position was to be established to support the various providers in their palliative care roles and support the coordination of care by providing a link between care coordinators and the support services required. The PCA's role included: <ul style="list-style-type: none"> ➤ Notifying and communicating with GP ➤ Identifying who is already involved ➤ Coordinating assessment and case review ➤ Identifying and coordinating with the nominated care | <ul style="list-style-type: none"> During implementation this role shared between two staff became the palliative care facilitator. It is a mix of clinical and administration skills and the role has largely been implemented as planned. However the service reports insufficient administration support. The process for identification of the lead palliative care has yet to be implemented and the service would benefit from progressing this function. <div style="border: 1px solid black; padding: 5px; margin-top: 10px;"> <p>"I had to keep checking to make sure that things happened – it would be useful to have one person who knows everything." Family member</p> </div> |

| | Palliative Care Plan | Review Finding |
|--|--|---|
| | coordinator (Key worker) ➤ Providing administrative support to the key worker in the delivery of the care plan ➤ Arranging support services as required by agreed care plan ➤ Holding and administering equipment | <ul style="list-style-type: none"> • Equipment is not administered by this role but is part of the general DHB equipment pool. • There is opportunity for this role to facilitate and develop linkages with other services. |

There is a lack of clarity about the lead palliative carer role and terminology; the term means different things to different people. In the implementation of the service, the lead palliative carer was renamed the key worker. The key worker may be more appropriate to avoid confusion and the MDT needs to clarify the role and expectations in the development and implementation of key worker processes. Clinical responsibility for the patient rests with the patients GP who could be seen to be the lead carer, but leading the coordination of care (key worker) will probably rest with a community nurse or another health professional that the patient sees on a regular basis.

3.3.2 Provide systematic needs assessment and care coordination

| | Palliative Care Plan | Review Finding |
|-------------------|--|---|
| Assessment | <ul style="list-style-type: none"> • Prior to the assessment the PC coordinator identifies the clinical, nursing, support and voluntary agencies already involved in the care of the person. • Where appropriate, identifies current providers for ongoing case management and care coordination. • A key part of the assessment and planning process is the identification of the individual responsible for the coordination of care and support services (Key worker). • The nominated key worker leads the assessment process in conjunction with locally based specialist palliative nursing staff and key clinical and support agencies. • Wherever possible the assessment should include a palliative care specialist, other clinical staff involved in the care of the patient (for example, oncology and respiratory specialist nurses, Maori health provider, and a social worker). GP teams should have involvement in the assessment and development of a care plan. • A needs assessment tool will be adapted/developed to support the assessment, and that this tool would be used by all providers to ensure a common standard of needs assessment and care planning. • If the assessment determines that palliative care is not needed for any person, alternative support services will be arranged as appropriate. | <ul style="list-style-type: none"> • The PC facilitator identifies those already involved in care of the person. • A process for identifying the key worker has yet to be developed and implemented and thus assessment is not led by the key worker. • Evidence of a multidisciplinary assessment process was not seen. Assessment is provided by only the palliative care specialist nurses. The service specification indicates initial assessment will be carried out by the most appropriate member(s) of a specialist interdisciplinary palliative care team (usually a specialist nurse in conjunction with the generalist providers and palliative care coordinator). • There is now a waiting time of up to two weeks for initial assessment. There was reported evidence of gaps in the assessment process for non-nursing aspects of assessment, such as social work and occupational therapy. However, on many occasions, these services are appropriately referred to. • The assessment tool is reported as long and not adequately picking up the need for other health professionals input. Having moved through implementation it is timely for the MDT to review the assessment process and use an agreed assessment tool that reflects the interdisciplinary nature of the service. Using an agreed and standardised tool will enable a wider group to provide initial assessment and thus reduce waiting time for initial assessment. • The care assessment tool (CAT) tool provides a useful review and is easy to use. • The single point of entry is working well with alternative support services arranged for people not eligible for palliative care services. |

| | Palliative Care Plan | Review Finding |
|-------------------------|--|--|
| Care Planning | <ul style="list-style-type: none"> Following assessment a care plan will be developed covering the goals and priorities of the person and their family and the plan for their care and support. The plan will include all aspects of care, including medical, nursing, physical, spiritual etc. The plan will be a living document, held by the patient, and contributed to and updated by all parties. The key worker, in consultation with a specialist palliative care nurse is responsible for developing the plan in conjunction with the dying person, their family and palliative specialists. The care plan documents the roles and responsibilities of all health care providers, and identifies family, community and voluntary resources which can contribute to the physical, emotional and spiritual care and wellbeing of the person and their family. It will ensure that practical and financial considerations are addressed, including Advance Directives and Enduring Power of Attorney. It will also document the agreed arrangements for accessing after hours and acute care. | <ul style="list-style-type: none"> Care plans are written and updated by health professionals involved in the care of the patient. The care plan is not patient held, and is only available to the nursing group that has written the plan. At this stage primary care does not see the care plan or have input into it. Separate notes are held by each health professional involved; specialist PC nurse, community nurse, GP, Occupational therapist, emergency department, FOCUS, inpatient service, etc. There is no single record available indicating who is involved in the care of this patient. The lack of a key worker in conjunction with no single record creates potential for disjointed care, with duplication and gaps in the care continuum. It is recommended that a patient held record and/ or communication book is established as soon as possible to enable all involved, to be aware of who is involved, any concerns needing to be addressed. The patient held communication book is not intended to replace patient notes, and the patient and family should be encouraged to write in it. Primary care is closely involved in care planning and ongoing care, with the GP being the primary medical carer. |
| Common Standards | <ul style="list-style-type: none"> Both the assessment and planning processes will be to common standards and service specifications irrespective of which provider the key worker is associated with. | <ul style="list-style-type: none"> The assessment process is standard as only the specialist nurses are performing assessment at this stage. The next stage of implementation with a wider group providing assessment will necessitate a MDT approach to confirming the assessment tool and processes to be used. |

| | Palliative Care Plan | Review Finding |
|--------------------------|--|---|
| Care Coordination | <ul style="list-style-type: none"> • Providing effective care co-ordination requires each key worker to have a good understanding of palliative care principles • The key worker does not necessarily provide the care themselves, but is responsible for developing and coordinating the care plan and for facilitating (where appropriate through the palliative care administrator) the services and resources identified in the plan | <ul style="list-style-type: none"> • Most care coordination is undertaken by the community nurses and primary care, but is still largely provided by individual providers with limited knowledge of what other providers are doing. This is mitigated to some extent through the weekly MDT meeting. <div data-bbox="1218 437 2083 584" style="border: 1px solid black; padding: 5px;"> <p>Mum had emphysema – it would have been great to have the respiratory nurse involved right through – she knew Mum and had good respiratory knowledge.</p> <p style="text-align: right;">Family member</p> </div> |

3.3.3 Provide effective and co-coordinated essential palliative care services;

Including case management, generalist palliative care and support services, with specialist palliative care services available when required for people with complex needs.

| | Palliative Care Plan | Review Finding |
|----------------------|--|---|
| Local Network | <ul style="list-style-type: none"> High quality generalist palliative care is provided through an integrated network of credentialed health professionals from primary, community, aged residential care and secondary health services. This network of palliative care providers works in partnership with regional specialist palliative care services and is underpinned by palliative care training for all providers, commitment to common palliative care standards as documented in a manual, common assessment methodology, and a single shared plan of care for each dying person | <ul style="list-style-type: none"> Generally coordinated palliative care services are provided well with specialist input as required for people with complex needs. The major deficit is the lack of an identified key worker. Patients are receiving quality palliative care services through a network of palliative care providers, both specialist and generalist. All providers have access to a comprehensive manual, common palliative care standards and palliative care education. The coordination and provision of palliative care is working particularly well in residential care facilities. The MDT meetings in their current format are reported to provide variable value for members of the multidisciplinary team, and the team need to give thought to how this process can be improved. The addition of practice nurses attending is reported to be effective, and other key providers such as residential facilities should be invited to participate. A process for debriefing post death, including a mortality review¹⁴, has not yet been implemented – this may assist staff and help with identifying clinical and system issues. This could be done in the patient’s primary care practice, or the residential facility to involve those staff involved with care. . Without a service leader, the funding team are often required to provide operational management rather than a pure funding role. |

¹⁴ Mortality reviews are an expectation of all deaths in DHB clinical services to examine the clinical care and determine what improvements should have been made and what recommendations there are for future care.

| | Palliative Care Plan | Review Finding |
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| | <ul style="list-style-type: none"> • | <ul style="list-style-type: none"> • Difficult for GPs to attend MDT meetings given their booked patients and uncertainty of time their patient will be discussed. This is also true for allied health staff. Consideration could be given to booked times for each patient with GPs phoning in for their patients. • When system wide issues arise, there does not appear to be a clear pathway for resolving these. Individually all aspects of the service are working well but the overall system development and problem resolution is missing. The management group provides some of this function but the functions normally carried out by a manager of a team or service are diluted with this structure and things take longer to resolve • The service is working well in individual parts but is not yet functioning as a team |

| | Palliative Care Plan | Review Finding |
|---------------------|---|--|
| Primary Care | <ul style="list-style-type: none"> • Most medical palliative needs are met by a patient's primary medical care provider, while nursing and support needs are met by DHB district nursing, personal care and home support services. • Financial barriers for patients accessing primary care, particularly in the last phases of a terminal illness when home visits are necessary are reduced with funded general practice components of the local palliative service. • GPs can access additional funding for care of patients who are admitted to the palliative service if they undertake regular professional development in palliative medicine, agree to work in partnership with the specialist palliative service, and have an agreed and documented role in the provision of care. • Increase primary health care providers' capacity to meet the health needs of clients • The lead GP provides leadership and guidance to primary health care practices in the delivery of palliative care, and works with all participants in the Wairarapa Palliative Care Service to promote improved palliative care through increased collaboration and best practice, unconstrained by organisational or professional boundaries. | <ul style="list-style-type: none"> • The majority of the patient's medical needs are met by the patients GP, with nursing needs met by practice nurses, community nurses and residential care facilities. The majority of personal care and home support services are organised through FOCUS. • Financial barriers to primary care in the final stages of life are reduced with funded primary care visits, provided by GPs who have undergone training in palliative care. • Primary care has been empowered to take a lead in the care of their dying patients through education, support and the systems developed in the palliative care system. This provides continuity of care for patients right through to the final stages of life, and the bereavement phase for family and whanau. • The multitude of separate notes and lack of access for all to a single care plan means GPs are sometimes not aware of care and support that the patient is receiving. • Primary health care providers have been reconnected to end of life care and their capacity to meet clients needs in this phase has been increased. • The lead GP has provided leadership and guidance to primary care, aged care facilities and those actively involved in the palliative care service. There is an opportunity to work more closely with secondary services, such as through education, secondary care attending MDT meetings, or the lead GP attending some hospital MDT meetings. |

| | Palliative Care Plan | Review Finding |
|----------------------------|---|--|
| Domiciliary nursing | <ul style="list-style-type: none"> • Where domiciliary nursing care is required this is provided by community nursing service. • Where the person's usual residence is a residential care facility, that facility should be supported to provide the additional level of care required. This includes additional GP visits and community nursing. | <ul style="list-style-type: none"> • Community nursing is providing domiciliary nursing for all palliative care patients. Patients and families report that they have had little involvement with palliative care services, and that it is mostly the GP and community nurse they have received care from. • During the review process, changes have been made to community nursing including palliative care nurses starting and ending their day at Kahukura, and identifying themselves to patients as part of the palliative care service. • Residential care facilities are receiving support from primary care and specialist nursing as needed. |
| Inpatient Stay | <ul style="list-style-type: none"> • Palliative care inpatient stays have always been provided in local residential care facilities. • Likewise, patients with complex needs have always been admitted to Te Omanga Hospice in Lower Hutt for short stays while their medication or other needs are sorted out. | <ul style="list-style-type: none"> • Residential facilities are reported as providing an excellent palliative care service throughout the whole palliative stage including bereavement follow up with families and staff. • This is the only part of the palliative service where key workers have been identified. This mostly works well, but as the key worker has not been formally implemented, at times the role of the key worker is overlooked by other palliative care staff. • Facility staff have received additional palliative care education with some nursing staff sitting post graduate palliative care qualifications. • Care workers have also received education and feel empowered to support residents during the palliative stage. • The change has been a positive development for residential care facilities and it has also enabled links to develop with other DHB training sessions. • One facility interviewed proactively ensures after hours medical care is available for their palliative care clients. However, as required, all facilities have the GPs contact details with back up numbers if the GP is not available. • Patients with complex needs have been admitted to Te Omanga Hospice as required. |

| | Palliative Care Plan | Review Finding |
|-------------------------|---|---|
| Support Services | <ul style="list-style-type: none"> Establishing a local palliative service within FOCUS enables the efficient organisation of support services, and ensures that all people are able to access the support they are entitled to. This single point of coordination facilitates links to community and voluntary support services. | <ul style="list-style-type: none"> Patients receive support services they are entitled to regardless of their palliative care status. Links to voluntary support services still require some development. |

| | Palliative Care Plan | Review Finding |
|----------------------------|---|--|
| Specialist Services | <ul style="list-style-type: none"> • The integrated service is a partnership of specialist and generalist providers with specialist services: • Participating in an initial assessment of needs and supporting the nominated key worker in the development of a patient care plan. • Supporting primary and secondary health care providers through patient consultations and advice on complex symptom control issues as required (including telephone advice, clinics and home/hospital visits) • Promoting a palliative approach by providing a planned programme of ongoing education and professional development for all health care professionals and providers (including Wairarapa hospital, Community Nurses, GP teams, Maori providers and aged residential care providers) • Developing and maintaining a manual supporting best clinical practice in palliative care, for use by all health providers involved in palliative care in Wairarapa • Providing ad hoc inpatient beds (at the base hospice) for those with very acute and complex needs who prefer not to be cared for in the community • Developing day care facilities for assessment, symptom control, carer relief and patient support | <ul style="list-style-type: none"> • There is an integrated partnership of specialist and generalist services. • Specialist services are provided by two providers; <ul style="list-style-type: none"> • Te Omanga Hospice providing specialist medical care and • Wairarapa DHB providing specialist palliative care nursing and palliative care education. • Weekly specialist clinics are run by specialist palliative care medical and nursing staff with a patient review meeting at the end of clinic where a number of the multidisciplinary team attend. • Specialist medical advice is available for medical staff on a 24/7 basis, and specialist nursing advice is available Monday to Friday 8-5¹⁵. • While GPs are accessing specialist palliative care advice, few hospital clinicians have taken advantage of this service and there were reported instances of some patients with inadequate pain control while in acute care. • Inpatient beds are available in residential care facilities, and specialist beds are available in Te Omanga Hospice for very complex needs. • Last days of life programmes have not yet been implemented across all providers and this can be developed as time and resources allow. • Day care facilities have not yet been implemented – but Hospice Wairarapa Community Trust plans to develop a day care service in 2010. With Hospice Wairarapa Community Trust joining the Management and Advisory Group, it provides an opportunity for agreeing and coordinating all palliative care services through the Management and Advisory Group to avoid duplication of effort and resources. The terms of reference for this group may need to be revised to reflect these changes. • Client satisfaction surveys have not yet been implemented. • The specialist nurses have been integral to the effective development and functioning of the palliative care service. |

¹⁵ Since the review interviews, specialist nursing advice has been made available through Te Omanga Hospice on a 24/7 basis.

| | Palliative Care Plan | Review Finding |
|-------------------|--|---|
| Acute Care | <ul style="list-style-type: none"> • A reduction in hospitalisations is expected as patients are cared for in the community in a planned and coordinated manner. However it is inevitable that acute, hospital level care will be required by people with terminal illnesses from time to time. • There is a high level of palliative care skill among hospital staff who contribute to the care of palliative patients in a planned and consistent manner. • specialist nursing staff work across community and hospital settings, and clinical expertise is developed within primary or secondary health services to provide a degree of palliative support for hospital services | <ul style="list-style-type: none"> • Hospitalisation rates vary depending on patient needs and management in the community. Concerns raised specific to hospital clinicians were: • The number of palliative care patients admitted to hospital and ED is similar to the number admitted prior to implementation. There has been a small increase in the number visiting ED and this should be monitored to determine if it is an ongoing or an implementation issue. • Lack of information to ED about patients palliative care status, and therefore investigation and treatment paths. • The need for the GP as lead palliative care doctor to be involved prior to any hospital admission. • Medical referral process to palliative care is not captured by the referral form. However referral is intended to provide service entry rather than a clinical handover which is done through the patients GP as with other patients discharged from acute care. • At this stage, education in the hospital setting has still to occur and this will assist with hospital clinicians understanding of the palliative care model and skills. • Families and providers reported instances of patients in hospital with poorly controlled pain and palliative symptoms. • Specialist nurses work across community and hospital settings • Several examples were given of inadequate care for palliative care patients transitioning between primary, community and secondary care. It is recommended that these examples are used to develop improved processes for palliative care patients and increase understanding of palliative care in secondary care services. |

3.3.4 Identify and work with local community support services:

Including families, whanau, voluntary organisations and others that can provide additional support to people who are dying and their families, whanau and carers.

| | Palliative Care Plan | Review Finding |
|----------------------------|---|---|
| Community resources | <ul style="list-style-type: none"> Initial and on-going assessment and care coordination identifies wider family, whanau, voluntary and community resources, empowering and enabling them to support the dying person as appropriate The single point of entry to services will provide equitable and transparent access to funded services, while the palliative care administrator plays an important role in identifying community resources that can complement funded support services through the care planning process. Spiritual | <ul style="list-style-type: none"> Voluntary and community resources have not yet been integrated in the palliative care model or into the assessment process. Community agencies and individuals are seeking involvement with the palliative care service, and developing relationships (and in some cases memorandums of understanding/agreement) with these groups will help avoid duplication of effort, define boundaries and improve the non-funded support available to clients. The single point of entry is providing transparent access to funded services although the variability in patient numbers in different systems may mean not all patients are referred through this access point. Identifying community resources that will complement funded services is still to be developed. Volunteers previously played a major role in the psycho-social and bereavement aspects of the service. Community volunteers stepped away from the service when first implemented, but are now expressing a desire to have involvement. |

3.3.5 Provide on-going psychosocial support for carers, family and whanau, including links to welfare and bereavement support

| | Palliative Care Plan | Review Finding |
|------------------------------|---|---|
| Psycho-social support | <ul style="list-style-type: none"> • Care planning identifies the wider supports available to a dying person and their whanau, and acknowledges their role in providing psychosocial support, including in bereavement. • The key worker remains the key contact with families/whanau in bereavement, and is expected to link them to appropriate services. | <ul style="list-style-type: none"> • Some evidence of psychosocial support was seen. This is done particularly well in the two residential care facilities seen by the reviewer with bereavement support to family after death. • Social work has not closely integrated into the team and is only involved with the consent of clients. • The assessment process is not capturing prior involvement of social work • There is room for increased understanding within the team of the breadth of social work skills and how these can be used to improve the patient journey and support the palliative care staff. • All patients may benefit from initial discussion with the social worker to determine ongoing need and assist with determining prior involvement. • Improved identification of psychosocial needs should be built into the assessment processes in conjunction with the wider team. Bereavement follow-up is limited at this stage with the two residential facilities involved with this review having processes that can be built upon in other parts of the palliative care service. A card is sent to the family 1 month after death and support is offered. • As the key worker role has not been developed, the link with families /whanau in bereavement is limited. • Spiritual care involvement started well and needs to develop further to ensure peoples need for this is appropriately identified in all elements of the service. Specialist nurses are referring to spiritual care where necessary – but gaps have been identified in residential care and secondary care services with people in these services missing out on spiritual care in some instances. |

3.3.6 Ensure culturally appropriate services for Maori and other ethnic groups

| | Palliative Care Plan | Review Finding |
|-----------------|---|--|
| Cultural | <ul style="list-style-type: none"> For Maori, it is often particularly important that care of a dying whanau member is provided by whanau, and within the whanau or home setting. The palliative care plan proposed on-going coordination of care by an acceptable key worker with a good understanding of the needs of the individual and their family/whanau. For Maori this may mean that it is most appropriate that the key worker is Maori and/or is located within a Maori health provider. | <ul style="list-style-type: none"> Whaiora provide cultural support for the service and clients. Good relationships and links have been developed between the palliative care service and Whaiora. These relationships can be further built upon to develop a memorandum of understanding to identify the gaps and remove current duplication in roles between the service. Both groups play a coordination role for clients, and the key worker needs to be clearly identified and therefore the key coordinator of care. This could be either Whaiora or Kahukura staff depending on individual client and whanau preference. |

3.3.7 Develop a palliative care approach across all health services through workforce development and training and through the adoption of a recognised pathway for the dying

| | Palliative Care Plan | Review Finding |
|------------------|---|--|
| Education | <ul style="list-style-type: none"> Ongoing education in palliative care will be required for all health professionals who are closely involved in the care of palliative patients to ensure the provision of a uniformly high standard of care. Training will support the use of a comprehensive palliative care manual by all palliative care providers, and all providers will be required to keep their training up to date. | <ul style="list-style-type: none"> Excellent development of palliative care principles and approach in primary and residential care. Education and professional development is occurring and is highly valued by health professionals and carers receiving it. The education programme has not been as active as anticipated due to patient care demands on the educator but has still made significant progress. Primary care education has been particularly effective with CME sessions well attended and highly valued by those attending. A manual has been developed and is considered valuable. However it needs updating with current information including respiratory and CHF recommendations from CME sessions. |

3.4 Other

Equipment has gone into the general pool and providers report that key equipment is not as accessible as previously. At times, essential equipment such as air mattresses is not available through the pool and has to be hired.

At times there are medication issues at weekends – some nurses on call are still building their knowledge base and don't always pick up mistakes, but this is being addressed. Specific details were not made available and it was not made clear to the interviewer if the medical staff involved were made aware of these issues. The DHB has a reportable events system and any future medication issues should be part of this system.

Families report a seamless service with people working together to get things done. The two comments below are from families who have experienced the palliative care service.

"I'm not sure why you're talking to me as we didn't have much to do with the palliative care service. The early days in Glenwood worked really well and overall people worked together to get things done. The GP did most of the care and was great."

"Overall I was really impressed with the service- I would give it an 8 or 9 out of 10. There were a few glitches but they were relatively minor..... it was reassuring to have the specialists involved now and again, and the information to know that you are doing the right things. Especially near the end, knowing it was okay not to feed her, and that a bit of water was more important.

At times the information was a bit fragmented – nurses and caregivers going into the home have the best of intentions and give advice, but sometimes it varies, and we had to put it all together ourselves – minor stuff though.

Mum had an infection and the doctor was a bit dismissive and wanted to let the infection run its course. She appeared to be suffering and the medication wasn't covering it. In hindsight it was probably the right thing but it was hard at the time."

Family member

Feedback mechanisms have not been implemented yet to enable the service to determine how well it is progressing, where they are doing well and what opportunities for improvement there are. Stakeholder satisfaction surveys need implementation and should include providers as well as patients and families to enable system wide feedback.

4 RECOMMENDATIONS

| | 4.1 Patient Journey | Responsibility | Timeframe |
|-------|---|--|-----------------------------|
| 4.1.1 | Agree and implement processes for formal identification of key worker, and how the key worker will work with the MDT and other providers and agencies. | Team leader | Apr 10 |
| 4.1.2 | <p>Establish a patient communication book as soon as possible to enable all involved, to be aware of who is involved, and any concerns needing to be addressed. This patient held book is not intended to replace patient notes, and the patient and family should be encouraged to write in it and view it as their book rather than the services book. The book will have a summary of simple and relevant is important to the patient and family, and should also include current medications and procedures or interventions.</p> <p>Improve the transfer of clinical information between providers, including the use of patient held records/notes. The patient held notes should include clinical documentation for each visit, and accompany the patient to all services to enable health professionals to have information about the current palliative care journey of the patient.</p> | <p>PC Facilitator</p> <p>Team Leader</p> | <p>Feb 10</p> <p>Apr 10</p> |
| 4.1.3 | Develop, agree and implement stakeholder satisfaction surveys to identify opportunities for improvement and areas of service excellence. This should fit with the mortality review process which addresses family concerns. Broadening the survey to include providers as well as patients and families will enable system wide feedback and development. | PC Facilitator | Mar 10 |
| 4.1.4 | Ensure appropriate pain and symptom management is available for all patients, particularly those transitioning between primary, community and secondary care. Those involved in the provision of care to patients with long term conditions need to understand the principles of palliative care and how their service interacts with the palliative care service. | Lead GP, CMO | Feb 10 |

| | 4.2 Multidisciplinary team | Responsibility | Timeframe |
|-------|--|--------------------------------------|------------------|
| 4.2.1 | Establish (or use part of current meeting) regular forum for identifying and addressing systems and process issues. Initially this may require a longer meeting to work through some of the identified opportunities for change. | Team Leader in consultation with MDT | Apr 10 |

| | | | |
|-------|--|---|-------------------|
| | <ul style="list-style-type: none"> • How to improve value for all team members including the MDT meeting format, phone vs physical attendance for some, booked times for those involved to join the meeting. • Invite other key providers to attend such as residential facilities and secondary care services. | | |
| 4.2.2 | Review and agree the assessment process and tool to reflect the interdisciplinary nature of the service. Improved identification of psychosocial and occupational therapy needs should be built into the assessment processes in conjunction with the wider team | PC Facilitator and team leader | Mar 10 |
| 4.2.3 | Consider a wider group (community nurses) to provide initial assessment using an agreed and standardised tool. This will reduce the workload of specialist nurse and reduce waiting time for initial assessment. | Team leader | Jun10 |
| 4.2.4 | Develop and agree a post death process including: <ul style="list-style-type: none"> • Mortality review following an appropriate DHB process for all deaths (ensuring this process meets the needs of community based services) - this may be part of regular MDT meeting and should include assisting staff involved, any family follow up needed and identifying system issues. • Bereavement phone calls and cards by key worker • Implementation of memorial services | Team Leader in consultation with MDT | Apr 10 |
| 4.2.5 | Incorporate the manual more fully into education processes and maintain the manual to make it a useful reference document, and ensure this is linked into DHB quality resources and processes. | Educator | Mar 10 |
| 4.2.6 | Review equipment processes to ensure adequate equipment is available for palliative care patients | OT Manager | Apr 10 |
| 4.2.7 | Implement Liverpool Care Pathway in: <ul style="list-style-type: none"> • Wairarapa Hospital • Community Services • Residential care as time and resources allow | GM Clinical Services Team leader Educator | Sep 10 June 10 |

| | 4.3 Linkages with other services, agencies and groups | Responsibility | Timeframe |
|-------|---|---|----------------------------|
| 4.3.1 | <p>Further develop linkages with other services and agencies through education, agreed processes and development of memorandum of understanding/agreement where appropriate. This includes hospital clinicians, Whaiora, and the Cancer Society.</p> <ul style="list-style-type: none"> Developing relationships (and in some cases memorandums of understanding/agreement) with these groups will help avoid duplication of effort, define boundaries and improve the non-funded support available to clients. Where these groups play a coordination role for clients, the key worker needs to be clearly identified and therefore the key coordinator of care. | Team Leader | Jun 10 |
| 4.3.2 | <p>Identify community and voluntary resources that will complement funded services, and work with these resources to identify roles and processes that complement the current service, including the development of day programmes.</p> <p>Review Management and Advisory Group terms of reference to ensure recent changes in membership are reflected and that the functions and processes of the group cover all palliative care services to avoid duplication of resources and services.</p> | <p>PC facilitator and Team Leader</p> <p>MAG</p> | <p>Jun10</p> <p>Feb 10</p> |
| 4.3.3 | <p>Improve the integration of primary and secondary services to enhance care for patients transitioning between. Consideration could be given to:</p> <ul style="list-style-type: none"> the palliative care specialist attending hospital MDT meetings on a quarterly basis, with the lead GP attending monthly or weekly MDT meetings. Palliative care training becoming core training for hospital staff | <p>Lead GP & CMO</p> <p>GM clinical services & educator</p> | <p>Mar 10</p> <p>Jun10</p> |
| 4.3.4 | Work with Hospice NZ to formalise hospice status of services in the Wairarapa. | Team Leader | Jun10 |

| | 4.4 Service Management | Responsibility | Timeframe |
|-------|--|-------------------------------|------------------|
| 4.4.1 | Identify a key person within the multidisciplinary team to be the team leader. The service needs a key point of access for issue identification and resolution, and to pull together the various components of the service and drive changes required. This does not necessarily require additional FTE but is a function of a more senior manager with strong relationship skills. | GM clinical services | Mar 10 |
| 4.4.2 | Ensure effective oversight of the palliative care service by the management and advisory group with regular monitoring of key performance indicators including quality and safety indicators to capture. This will include: <ul style="list-style-type: none"> Review and agree KPIs which will be monitored to ensure all relevant parts of the palliative care service are regularly monitored. Review the role of the chair and identify the most appropriate position for the chair of management advisory group | Management and Advisory Group | Mar 10 |
| 4.4.3 | Develop a clinical services group to oversee clinical improvement, peer review and clinical audit. | Lead GP | Jun 10 |

5 APPENDICES

5.1 Palliative Care Network of Providers

The table¹⁶ below outlines service components, the relevant service specification and the provider. All services will work under the national palliative care service specification framework in addition to their specific service specification. For the PHO the sections of the National Palliative Care Service Specification that relate to on ongoing follow up care (excluding day stay), and grief and loss support apply.

| Service Component | Service Specification | Provider |
|---|---|--|
| Specialist Medical including medical clinics, & 24/7 advice | National Palliative Care | Te Omanga Hospice |
| Specialist palliative care nursing | National palliative care | Community Nursing, WDHB |
| General nursing | Specialist community nursing | Community Nursing, WDHB |
| Primary care team (including medical and nursing) | Primary Palliative care | Wairarapa Community PHO |
| Respite Care / Inpatient admission | Aged Residential Care Medical Surgical | Aged residential care facilities Wairarapa Hospital |
| Bereavement Counselling | National palliative care | WDHB social work To be Heard |
| Allied Health (Physio, OT) | | WDHB |
| Social Work | | WDHB Social Work |
| Psychosocial/ pastoral and bereavement support | National palliative care | Community nursing Primary care teams WDHB Social work Ministers |
| Home support | Home Support | Community Nursing & Health Service Access Healthcare NZ |
| Family support Biography writing | | Volunteers |
| Palliative Care Professional Education | National palliative care | Palliative Care Educator Arohanui Hospice |

¹⁶ Table from Palliative Care Manual – note the table does not include all stakeholders such as the Cancer Society or newly established Wairarapa Hospice Community Trust.

5.2 Key Stakeholders

The management group identified the following stakeholders for interviews in the review process: FOCUS, Community Nursing, PHO, Palliative Care GP, Hospital Palliative Care medical lead, Te Omanga, Kahukura specialist Palliative Care nurses, Maori health providers, residential care providers, and Wairarapa hospital.

The table below shows the individuals and services interviewed during the review process.

| | |
|-------------------------------------|---|
| Leanne & Des | Bereaved Family |
| Mary | Community Nurse |
| Rob Lewis | Community Nursing Manager |
| Helene Dore | FOCUS Manager |
| Anna Cardno & Jacinta Buchanan | Cancer Society |
| Annie Lincoln & Nick Crozier | General Practitioners |
| Susan Reeves & Carol Douglas | Medical Surgical Ward & Admission Discharge Coordinator |
| Lisa Burch, Joanne & Simon Everitt | Planning & Funding |
| Anne Savage | Palliative Care Educator |
| Tim Mathews | Physician |
| Lorraine Katterns | Social Work Manager |
| Multi-disciplinary team | |
| Carol Hinton | Specialist Palliative Care Nurse |
| Ian Gwyn-Robson | Specialist Palliative Care Doctor |
| Fred Wheeler | Allied Health Services Manager |
| Franky Spite | Occupational Therapy Manager, WDHB |
| Yvette Grace | Wairarapa Community PHO |
| Sarah, Cherrilyn | Glenwood |
| Norma Hickland, Brenda Gray, Nettie | Palliser |
| Alan Shirley | Chief Medical Officer |
| Maggie Morgan | General Manager Community/Public and Mental Health |
| Fiona Samuels | Whaiora Team Leader |
| Wendy Turton | Palliative Care Facilitator, WDHB |
| Ilana Burt | Project Manager, WDHB |
| John | Family member |
| Joan Ross | Church Minister |

5.3 Palliative care definitions

The following definitions are extracted from a range of palliative care related resources and do not necessarily reflect current practice in the Wairarapa region.

5.3.1 Specialist Palliative Care Service Specification¹⁷

Generalist and specialist services need to be part of an integrated framework of care provision which may be facilitated through local and regional networks, with defined formal linkages to key services including community primary care, local acute hospitals, regional cancer centres, and other regional palliative providers. Depending on the complexity of palliative care need, smaller specialist palliative care services will at times require input from a more comprehensive service with greater specialist resources which may be geographically distant. This must be readily available through defined linkages and processes.

The precise workforce needs for specialist teams will usually be worked out on a specialist palliative care population based needs assessment. Their minimum requirements are:

For a hospice:

- a. Access to an accredited and registered palliative medicine specialist
- b. specialist palliative care nurses with specific training in palliative care
- c. specialist psychosocial and allied health professionals
(with palliative care training where available)
- d. administration support

In a hospital that does not have a specialist palliative care service, there should be formal linkages to external specialist palliative care services. The specialist interdisciplinary team may also include additional medical and nursing staff as well as staff from the following disciplines: physiotherapy, occupational therapy, social work, spiritual care, dietetics, counselling, psychology, pharmacy, speech language therapy, art & music therapy, play therapy and complementary therapies”.

Hospices provide terminally ill people and their families with the services and support they need. In many communities, hospices provide palliative care in the home, as well as at in-patient facilities.

Hospice services include community palliative care, inpatient care, a volunteer support network, day care facilities, family support, bereavement counselling and social work and chaplaincy.

Hospices are partly funded through District Health Boards, with additional funding sourced from community fund raising.

Specialist palliative care:

Specialist palliative care practice builds on the palliative care provided by generalist providers and reflects a higher level of expertise in complex symptom management, spiritual support, psychosocial support, cultural support, and grief and loss support. Specialist palliative care services:

¹⁷ Draft specialist palliative care service specification.

- Provide advice, support, education, liaison and training to other health professionals and volunteers to support their generalist provision of palliative care.
- Provide direct management and support to persons and families and whanau where complex palliative care need exceeds the resources of the generalist provider. Specialist palliative care involvement with any person and their family and whanau can be continuous or episodic depending on their assessed changing need.
- Provide oversight of the palliative care framework.
- Develop and maintain protocols and procedures for palliative care.

| Minimum requirements for a hospice | Wairarapa palliative care service |
|---|--|
| Access to an accredited and registered palliative medicine specialist | Specialist palliative medical care is provided by Te Omanga Hospice with: Weekly patient clinics and multidisciplinary team input. 24/7 specialist palliative care medical advice and liaison education support from Arohanui Hospice |
| Specialist palliative care nurses with specific training in palliative care | Specialist nursing care and education is provided by the team based at Kahukura Some community nurses have had some specific training in palliative care |
| Specialist psychosocial and allied health professionals (with palliative care training where available) | Psychosocial and allied health professionals are part of the team but the need for their input needs better identification at assessment |
| Administration support | Administration support is provided in Te Omanga Hospice, through primary care, and through entry to the service in FOCUS. |

The specialist aspects of the service specification are met by the current service provided. However some areas would benefit from changes in process, such as the assessment process

Generalist palliative care:

Generalist palliative care is provided by primary care, secondary care, community nursing, allied health, whanau ora, residential care and other non specialist palliative care services. Some of these generalist providers have ongoing contact with families throughout the illness and following death e.g. community nursing, GP teams. Others, such as hospital teams have episodic contact, depending on the needs of the person and family. These providers of generalist palliative care need defined links with specialist palliative care team(s) for the purposes of support and advice, or in order to refer persons with complex needs. They also have access to palliative care education and learning to support their practice.

Palliative Care Co-ordination

Care coordination is an intrinsic part of palliative care and is provided by the key worker. The specialist palliative care service will provide education, liaison and support to key workers. Care coordination is complementary to palliative care provision and will:

- enable the person, their family and whanau to remain at the centre of care
- empower the person to maintain control, exercise choice where appropriate, and where resources enable, be looked after in their preferred place of care

- act to link the person, and their family between the different agencies / health professionals involved in the provision of their care

5.3.2 Palliative care: World Health Organisation Definition, 2002

For adults:

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor postpone death
- Integrates the psychological and spiritual aspects of patients' care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness

Is applicable early in the course of the illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

5.3.3 Hospice New Zealand Website Nov 2009

What is hospice?

Hospice is not a building; it is a philosophy of care. Our goal is to help people make the most of their lives. We care for the whole person, not just their physical needs but also their emotional, spiritual, and social needs too. We care for families and friends as well, both before and after a death. Irrespective of where they are, this philosophy of care does not change and everything we provide is free of charge.

We believe that hospice care should be available to anyone who needs it, helping people make the most of every moment, in whatever way works for them.

When support is offered

People may be referred for hospice care even while they are undergoing treatments for their illness, not just at the very end of life - however, usually people are referred at a time when it is acknowledged the illness is incurable.

However, people are living longer with incurable illnesses and in addition to care provided by GP or hospital specialist, hospice staff are able to provide specialist support in other ways e.g. controlling symptoms or providing additional advice and support to family and carers.

Services offered

The services offered will differ from hospice to hospice but are likely to include:

- medical and nursing care
 - pain and symptom control
 - rehabilitation therapies, including physiotherapy and complementary therapies
- spiritual support
- practical and financial advice
 - bereavement care.

What is hospice?

Hospice palliative care can be provided in hospice in-patient facilities, hospital rest homes or in a person's home or place of residence in the community. Hospice is a concept, a philosophy of care. Hospice or palliative care is a special type of care for people whose illness is no longer curable. It enables them to achieve the best possible quality of life and also supports their family and friends.

What services does hospice provide?

Hospice provides services based on the communities need. They may include in-patient and community care, bereavement care, counselling and spiritual care, day-stay care, respite care, equipment hire, as well as education and research.

The services are provided by a multidisciplinary team, which may include: doctors, nurses, counsellors, spiritual counsellors, occupational therapists, physiotherapists, social workers. Many services are provided by volunteers, such as massage therapy, pet therapy and creative therapy.

Is it true that once you go to a hospice you are unlikely to leave?

No. Many patients spend a day or two in hospice for symptom control and pain management. They then return to their homes where their care is continued. Hospice palliative care does not have to be provided in a hospice. It is often provided in a person's own home.

People may choose the supportive environment of a hospice in-patient facility. Whatever is best for them their family and friends is accommodated if possible.

5.4 Primary Care Service Specification

Below are extracts from the Primary Care Service Specification for palliative care

The Primary Health Palliative Care Service is a key part of the integrated palliative care framework operating as the Wairarapa Palliative Care Service and seeks to:

- Improve the health and independence of people with terminal illness
- Reduce the barriers to primary health care experienced by Clients and their families
- Increase primary health care providers' capacity to meet the health needs of Clients
- Co-ordinate and integrate care between primary health care providers and specialist palliative care services
- To improve the quality of services provided to Clients
- Empower decision-making and control by the Client and his or her family/whanau over the health and wellbeing of the Client through prevention, education and self-management
- Enhance the relationships between the Client and their chosen primary health care provider by building on the health education and management instituted by those health care providers
- Improve the Client's access to existing health care services (both primary and secondary) as their need indicates,

Service Components

The focus of the service is the provision of integrated palliative care for clients, particularly primary health care, community nursing and specialist palliative care services.

Service providers will be New Zealand Registered General Practitioners and Nurses who have been approved by the Wairarapa Palliative Care Management Group following participation in training workshops arranged by the WPCMG.

5.4.1 Communication

- All palliative care patients including non-cancer should be easily identifiable by the practice, have an identified GP and lead community nurse (key worker).
- The practice will support proactive rather than reactive care for palliative patients

5.4.2 Coordination

Clinical

- WCPHO will employ a Lead GP for palliative care (Lead GP). This position will provide clinical and service coordination for the primary care service. The Job Description of the Lead GP will be agreed by the WPCMG.
- All palliative care patients will be discussed at the weekly interdisciplinary team meeting that will be convened by the DHB's specialist palliative care nurse. This will provide an opportunity to highlight problems, or potential problems, to enable proactive rather than reactive planning of care
- Each patient will have the following discussed at the meeting: diagnosis, general condition, predicted problems, communication with community nursing service, carer support, symptom control and intended place of care noted. This information will be used in the on-going coordination of the Care Plan.
- The interdisciplinary team will review care following a patient death to identify what did not go well, what could have been done better and what went well. The review should be used to inform practice and identify learning needs for the team and primary care teams.

Co-ordination and integration between services/ palliative care partner organisations

Wairarapa Community PHO will convene regular meetings of the WPCMG. WPCMG ToR will include:

- Monitoring and reporting on performance of the WPCS as a whole
- Facilitation of service linkages and relationships
- Identification of issues and gaps
- Recommendations for service development

5.4.3 Processes

The following service components are included in the contract price for this Service:

| Service Component | Description |
|-------------------|--|
| Provision | <p>General Practice Teams will:</p> <ul style="list-style-type: none"> • Refer patients to the service and provide input into assessment and development of care plans for all patients referred. • Ensure each patient has an identified GP • Work with the Palliative Care Facilitator, Specialist Nurse/s and Key worker (Community Nurse) in development of care plans for patients. • Provide primary health care services to the Client including clinic visits and home visits in line with the Care Plan and/or as appropriate to the needs of the Client. • Services may be provided by either a General Practitioner or a Primary Health Care Nurse. The clinician is to have undertaken the training programme. • Work with specialist palliative care, community nursing and other services as required to meet the needs of the Client • Conduct ongoing assessment of each Client against the Care Plan monitoring the effectiveness, acceptability, and appropriateness of services • Ensure after hours GP cover is available • Ensure patients have timely access to provision of medications and prescriptions, particularly as the patient nears death • Ensure patient held records are maintained when care is provided |

| Service Component | Description |
|---|--|
| | <p>by the primary care team. As soon as it is felt appropriate these will be filled in with anticipated medication for the terminal phase</p> <ul style="list-style-type: none"> Facilitate access to an appropriate team if the Client does not have a general practice team with primary responsibility for their care. |
| Monitoring & Measurement | <p>General Practice teams will:</p> <ul style="list-style-type: none"> Record appropriate clinical notes and ensure that other health professionals providing care to the Client are informed of status and progress WCPHO will maintain statistical records of service including profiles of clients for the purposes of service monitoring All those involved in providing care will participate in service evaluation as required |
| Education for General Practice Teams | <p>General Practice team members must participate in initial and on-going training if they intend participating in this Service. Training will involve 3 two hour sessions.</p> <p>General practice team members must have participated in three initial training sessions by 28 February 2009.</p> <ul style="list-style-type: none"> Introductory courses will be held at period intervals. Refresher courses will be held as needed. |
| Service Management | <p>WCPHO will employ a lead GP who will:</p> <ul style="list-style-type: none"> Provide leadership for primary palliative care in the Wairarapa Be a champion for the palliative care partnership Participate in IDT meetings Participate in further training and development in palliative care <p>The job description for the Lead GP will be developed and agreed by the WPCMG.</p> <p>WCPHO will:</p> <ul style="list-style-type: none"> Provide management services to the WPCS including management of disbursements for services provided by GPs and practice nurses Coordinate and manage the Wairarapa Palliative Care Management Group (WPCMG) – including managing regular meetings, minutes and follow up of actions Manage register of approved palliative care providers. Promote the service to General Practice Teams Facilitate participation in the training programme by General Practice Teams. Monitor and evaluate the Service. Ensure General Practice Teams comply with the terms of the contract and appropriate standards of service. |

5.5 Reviewer Biography

Marion Thomas is health management consultant based in Wellington. She has worked in a range of roles in the health sector, both in clinical and management positions. Marion has extensive experience in strategic planning, stakeholder engagement, relationship management, quality auditing, service development and procurement of new services. While she has held health management positions for 15 years, Marion originally trained as a radiographer, and later graduated with a Bachelor of Business Studies.

Marion has worked with palliative care services over many years, assisting with many innovative service developments. In 2007 Marion worked with key stakeholders in Wairarapa to develop an implementation plan for a new model of palliative care. She then worked with the P&F team to procure and implement the new service model.