



PALLIATIVE CARE

STRATEGY PLAN 2005-2010

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

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

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Ngā Peehitanga Tāngata o te ao Hurihuri, ngā whakaritenga mo te tika me te ora morimori atawhai.

The trials people face in a challenging world, can be overcome by caring for and loving one another.

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Executive Summary

The aim of this plan is to provide strategic direction for an integrated and co-ordinated Waikato District Health Board (DHB) palliative care service. The plan will guide service delivery and development between the years 2005 and 2010. The plan builds on the achievements and findings of the Waikato DHB Palliative Care Strategic Project and should be read in conjunction with the Waikato DHB Palliative Care Strategic Steering Group Report (2005) and the New Zealand Palliative Care Strategy (2001). The project objectives were to:

- To develop a Waikato DHB Palliative Care strategic blueprint that reflects the views and expectations of the district, and attain best practice standards and outcomes for patients and their families / whānau
- To have an integrated and planned service delivery model approach for future development of palliative care services for the Waikato district.
- To ensure there are good linkages with and between palliative care providers and that people are aware of palliative care services that are available in their communities.

“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” (World Health Organisation, 2002). A fundamental shift has been the recognition that the provision of palliative care is applicable at any stage after diagnosis of a life-threatening illness, and not at the very end of life (terminal phase).

Palliative care for children represents a special, albeit closely related field to adult palliative care. This plan considers and recognises the needs of Waikato people for all ages.

Current Issues

As the Waikato DHB population grows and ages, with an increasing incidence of cancer and growth in chronic life-threatening diseases, there will be increasing demands on the health system. Palliative care services tend to be associated with the needs of people with cancer. Large proportions of the population, however, have chronic illnesses, which over significant periods of time may include symptoms requiring palliative care. The number of referrals to palliative care for non-malignant conditions is increasing. Delivering palliative care services is a challenge in the Waikato. The Waikato DHB spans a large geographical area and encompasses a diverse mix of rural, remote and urban areas.

The key weaknesses in the current system are:

- The fragmentation of providers and co-ordination of care and services
- Service gaps and access issues to essential palliative care services across the Waikato
- The urgent need for workforce development, including building teams and staff levels
- Lack of palliative care approach awareness within both public and private health care providers

This plan expounds a gold standard of evidence based best practice, however, health resources are scarce and limited. The Waikato DHB has dedicated staff who are committed to working towards meeting the needs of the Waikato DHB population and the achievement of the New Zealand Palliative Care Strategy. The majority of the people in the Waikato DHB district preference is to die at home. The current Waikato DHB palliative providers currently are unable to meet the objectives outlined in the New Zealand Palliative Care Strategy (2001). The plan provides an ongoing opportunity to prioritise the different strategic initiatives and allocation of scarce resources. Waikato DHB palliative services infrastructure and resources need to be developed long term, along with the community, to meet the required needs and expectations of the population.

Waikato DHB Palliative Care Strategy

The Waikato DHB palliative care goal is to ensure that all providers of palliative care in the Waikato DHB work together with the community to ensure that the New Zealand Palliative Care Strategy is implemented in the most optimal way for the Waikato district. This is to ensure that all people with palliative care needs and their family / whānau have access to essential palliative care services, provided in a co-ordinated and culturally appropriate way.

The goal encompasses four key result areas:

1. Integrated and collaborative care
2. Patient focus on improved access and equity to palliative care services based on identified needs and informed choices
3. Workforce development to ensure a skilled and competent workforce committed to the palliative care approach
4. Quality systems

Each of the key results areas have supporting objectives and strategic initiatives recommended for implementation over the next five years. The supporting objectives are:

Integrated and Collaborative Care

- 1.1. To establish the Waikato DHB Palliative Care Network
- 1.2. To promote the palliative care approach and inform the public and providers
- 1.3. To establish formal links between the various service levels and providers
- 1.4. To ensure there is palliative care clinical leadership

Patient Focus on Improved Access and Equity of Services

- 2.1. To provide access to culturally appropriate palliative care services
- 2.2. To continue to improve palliative care services through review, analysis and improvement to the patient journey and parallel processes
- 2.3. Waikato rural communities to have improved access to palliative care services
- 2.4. To strengthen the palliative care links and partnership with general practice
- 2.5. To provide specialist palliative care advice and support to palliative care patients in resthomes and continuing care organisations
- 2.6. To establish assessment single point of entry
- 2.7. To improve clinical care through the development and implementation of clinical pathways
- 2.8. To maximise scarce specialist palliative care resource and reduce duplication

Workforce and Resource Development

- 3.1. To ensure all palliative care service providers practice within the palliative care approach
- 3.2. To ensure there are adequate levels of appropriate trained palliative care staff
- 3.3. To ensure there are adequate Hospice community inpatient beds for respite and symptom control
- 3.4. To ensure there is adequate, safe and appropriate equipment to support people in the community

Quality Systems

- 4.1. To foster a culture of continuous quality improvement that enhances best practice and improves quality of care and services provided
- 4.2. To develop and implement a transition pathway and process between child and youth services to adult services
- 4.3. To establish adult and child and youth baseline data, appropriate performance indicators, benchmarks and reporting mechanisms to ensure achievement of the Palliative Care Strategy
- 4.4. Participate in national initiatives to improve the quality palliative care and establish benchmarking
- 4.5. Waikato DHB planning and funding service should review the Disability Support Link palliative care administrative function for night relief and respite care to resthomes / continuing care organisations
- 4.6. Waikato DHB planning and funding service should review all palliative care service specifications, rationalise, integrate and establish reporting and monitoring systems

To meet the challenges, integrated service delivery models have been developed to meet the palliative care needs of both adult and child and youth Waikato population.

Adult Model of Care

The adult integrated service delivery model is based on patients receiving different levels and types of services depending on their needs. The patient and family / whānau are the focus point with the general practice team supporting the patient and family / whānau. The primary care providers are integral players in this model. Wrapped around the patient and family / whānau is the concept of care co-ordination. Patient's episodes of care will move between different levels of care over time as the needs of the patient change. The three levels of care are:

1. Generalist – primary and community based palliative care services
2. Intermediate – integration of generalist and specialist palliative care community based services
3. Specialist – specialist palliative care services

The adult model of care builds on what we have and formalises the development of the intermediate level of care where there are stronger links and integration of services within the community. A number of initiatives are required to support the development of community based palliative care services.

Child and Youth Model of Care

The needs of children are different to adults. Key principle's underpinning the model are:

- Child and family / whānau focus that take into account the rights of the child
- Home is the centre of caring
- Recognise that parents are the experts and primary carers
- Open and honest partnership approach with the family / whānau and health professionals
- An approach that intertwine palliative care with curative care is essential

Starship Hospital, Auckland DHB is the acknowledged tertiary provider and offers paediatric palliative care advice. Paediatricians remain involved in the child's care throughout their lives and work alongside other providers of service. The child's general practice team provides care in the community and is kept informed throughout the continuum.

The child and youth palliative care strategic initiatives have been integrated into the overall Waikato DHB palliative care strategy objectives. The strategic initiatives are:

- A system and local structure for leadership in child and youth palliative care services will be developed
- Access to and need for child and youth palliative care will be appropriately monitored. Develop and implement minimum dataset for paediatric palliative care
- Develop and implement a system for informing providers and public about the availability of palliative care services in place in the Waikato DHB
- To complete a review of the various packages of respite care / support available from different intersect providers
- Develop and implement a transition pathway and process between child and youth services to adult services

The New Zealand Palliative Care Strategy and the New Zealand Cancer Control Action Plan recommend establishment of a palliative care network for each DHB and priority focus on two essential elements of palliative care, assessment and care co-ordination. For long term success priority investment should be directed to these three critical initiatives.

Waikato DHB Palliative Care Network

The proposed network approach is the mechanism that pulls together providers to work towards achievement of the Waikato DHB Palliative Care Strategy. There are two groups that form the Waikato DHB Palliative Care Network:

1. Waikato DHB Palliative Care Operations Network (generalist and specialist stakeholders)
2. Waikato DHB Palliative Care Advisory Group (community stakeholders)

The network requires strong leadership and facilitation skills. It is recommended that a chair and project manager be appointed for the first twelve months.

Assessment Single Point of Entry

Primary services and the community require entry points to access specialist palliative care services. Primary services require access for advice and support. Key recommendations are:

- A formal review of the adult collaborative care model is completed with recommendations for the future
- Implementation of a 24 hour / 7 day week medical palliative care specialist on-call consultancy service is implemented. This is dependent on appointment of a specialist palliative care physician, to ensure roster compliance
- Enhancement of the 24 hour / 7 day week specialist palliative care nurse on-call consultancy service

Care Co-ordination

Care co-ordination is needed to ensure patients are supported through the continuum of care. Care co-ordinators at each of the three levels of the adult palliative care service facilitate the delivery of culturally appropriate services by linking providers within the clinical network. Key recommendations are that the:

- Waikato DHB Palliative Care Network and resthomes / continuing care organisations jointly develop and agree the link nurse pilot project supported through the employment of specialist palliative care nurse educators 1.0 FTE
- Waikato DHB Palliative Care Network, the Palliative Care Unit and the district hospitals jointly develop and agree link person, with supporting portfolio and training programme
- Formal review and evaluation of the collaborative care model is undertaken to identify options to support the development of clinical nurse specialists as care co-ordinators within this framework

- Hospice Waikato support a clinical nurse specialist care co-ordination role within existing resources for palliative care services based in Hamilton City, Cambridge and Ngaruawahia
- A training and development programme is developed for community services including supporting staff to achieve recognised palliative care qualifications
- A training and development programme is developed for Hospice Waikato staff to achieve target of 80% of staff with recognised palliative care qualification
- To promote and develop a career pathway for care co-ordinators to achieve clinical nurse specialist status
- To promote and develop a career pathway for a clinical nurse specialist to achieve nurse practitioner status

The Waikato DHB Palliative Care Strategy Plan has taken a common sense approach to build on what we have. The real risk is in ensuring that the 'new' Waikato DHB Palliative Care Strategy Plan and supporting model of care and operating framework actually delivers on expectations and is an improvement on what we currently have. Planning was based on best practice the rate of implementation will be contingent upon available funding. Investment and support is required to ensure long term success.

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Introduction

Waikato District Health Board (Waikato DHB) is responsible for assessing the health and disability needs of its community and managing resources and service delivery to best meet those needs for its population¹. Whilst this occurs in a variety of ways throughout the DHB services, it requires Waikato DHB to develop a comprehensive palliative care plan. The purpose is to ensure that all people who have palliative care needs and their family / whānau have timely access to quality palliative care services that are culturally appropriate and provided in a co-ordinated way.

The aim of this document is strategic. It provides a basis for planning the delivery of Waikato DHB palliative care services over the next five years.

How the Plan was Developed

A Palliative Care Strategic Project Steering Group (appendix 1) was established to oversee the review and development of the plan. The Waikato DHB Palliative Care Strategy Plan was developed through a process of consultation, review and needs assessment.

Methodology

The following approaches were taken to develop the plan:

- A stocktake of Waikato DHB palliative care services, provider profiles and contracts (for summary refer to appendix 2)
- A health needs assessment and analysis of Waikato DHB population in relation to palliative care (refer to Waikato DHB Palliative Care Strategic Steering Group Report)
- A high level mapping of the patient journey (adult and paediatric)
- A critical analysis of the current Waikato DHB palliative care service provision in comparison to the national palliative care strategies²
- A SWOT (Strengths, Weaknesses, Opportunities, Threats) analysis (refer appendix 3)
- Site visits to:
 - Royal Perth Hospital Palliative Care Service, Perth, Australia
 - Silver Chain Community Hospice Service, Perth, Australia
 - St Joseph's Mercy Hospice, Auckland
 - Auckland Hospital Palliative Care Service, Auckland
- General Practitioner Peer Group consultation meetings (11 in Waikato DHB region)
- Consultation session with Area Managers from the Waikato DHB district hospitals³
- A Paediatric Focus Group held with specialist paediatric palliative care team from Starship and Waikato paediatric staff
- Literature review (internal and external)
- Review and consultation with other New Zealand DHB palliative care services
- Review of the Hospice Waikato Research Programme Results⁴ for Waikato residents and customer surveys
- External expert advisory review and critique.

¹ The New Zealand Public Health and Disability Act 2000

² Ministry of Health (2001). The New Zealand Palliative Care Strategy. Wellington : Ministry of Health

³ District Hospitals refer to Waikato DHB Thames, Te Kuiti, Tokoroa and Taumarunui Hospitals

⁴ Pistoll & Associates / Leuthart (2004). Hospice Waikato Research Programme Results for Hospice Waikato Development Strategy

The consultations and reviews allowed the Steering Group to clarify the current service delivery arrangements, establish the strengths and weaknesses of the current service and discuss service options and strategies for the future. Further details of the Steering Group findings are available in the Waikato DHB Palliative Care Strategic Project Steering Group Report (2005). The Waikato DHB Palliative Care Strategy Plan focuses on the way forward.

The Structure

The structure of the document is:

Part One sets out the strategic context against the background of global, national and local levels of concern and provides definitions based on emerging best practice palliative care trends.

Part Two builds on the strengths of what we have and outlines the Waikato DHB Palliative Care Strategy objectives and strategic initiatives for the next five years.

Part Three describes the Waikato DHB palliative care model of care and operating framework for investment to achieve the Waikato DHB Palliative Care Strategy objectives and strategic initiatives.

Part Four outlines the implementation of the strategic initiatives, including detailed discussion on three critical initiatives:

- Waikato DHB Palliative Care Network
- Assessment the single point of entry
- Care co-ordination

Part One - Strategic Context

The New Zealand Palliative Care Strategy⁵ has formed the foundation for developing the Waikato DHB Palliative Care Strategy.

The following national key documents were considered alongside the New Zealand Palliative Care Strategy:

- Paediatric Review, 1999
- The New Zealand Health Strategy, December 2000
- The New Zealand Disability Strategy, April 2001
- Primary Health Care Strategy, February 2001
- He Korowai Oranga Māori Health Strategy, April 2001
- Improving Non-Surgical Cancer Treatment Services in New Zealand, July 2001
- Health of Older Persons Strategy, April 2002
- Waikato District Health Board Strategic Plan 2002 – 2011
- New Zealand Cancer Control Strategy, 2003
- Progress Towards Implementing the New Zealand Cancer Control Strategy – Interim Action Plan, August 2004
- Waikato District Health Board Models of Care – Palliative Care & Child and Adolescent, 2004
- Waikato District Health Board Health Needs Assessment & Analysis, 2005
- The New Zealand Cancer Control Strategy, Action Plan 2005 – 2010, March 2005.

The Waikato DHB vision is ‘Building Healthy Communities, Te Hanga Whairanga Mo Te Iwi’. The Waikato DHB will improve the health, independence and quality of life for the communities it services by addressing the needs of the population and reducing inequalities.

The Waikato population in 2004 was 337,290 and the population is predicted to grow by 8.6% between 2004 – 2026. Hamilton City is contributing the most to the population growth. The Waikato DHB population is ageing.

22% of the Waikato DHB population is Māori. The Treaty of Waitangi is the founding document of New Zealand. The Waikato DHB operates from the premise that Te Tiriti o Waitangi defines the relationship between Māori and the Crown. It is predicted that the Māori will have a growth rate of 24% from 2004 – 2026 and will represent a greater proportion of the Waikato DHB total population. Māori has the poorest health status of any ethnic group in New Zealand. There are a number of issues⁶ affecting access and provision of palliative care services for Māori. The Waikato DHB Palliative Care Strategy Plan places emphasis on the need to have policies in place that recognise the specific palliative care needs of Māori, strengthen linkages between providers and that the Waikato DHB builds capacity and capability of Māori health providers.

⁵ Ministry of Health. (2001). The New Zealand Palliative Care Strategy. Wellington : Ministry of Health.

⁶ Examples of issues include: lack of awareness of existing palliative care services, lack of Māori palliative care providers and lack of education amongst current Māori providers, lack of understanding by mainstream providers of the whānau model of health and illness.

The Waikato DHB district is made up of ten distinct areas referred to as Territorial Local Authorities (TLA's). These territorial local areas are within the geographical boundaries for Tainui waka, Ko Mokau ki runga, Ko Tamaki ki raro, Ko Mangatoatoa ki waenganui, Pare Hauraki, Pare Waikato.

Delivering health services is a challenge in the Waikato. The map demonstrates that the Waikato DHB spans a large geographical area and encompasses a diverse mix of rural, remote and urban areas.

Map 1: Waikato District Health Board Region



Vision

All people with a life threatening illness and their family / whanau who could benefit from palliative care services have timely access to quality palliative care services that are culturally appropriate and are provided in a co-ordinated way. Underpinning this vision is a community-based model of palliative care services.

Definition

The World Health Organisation⁷ has redefined palliative care since the launch of the New Zealand Palliative Care Strategy - ‘An approach that improves the quality of life of individuals and their families facing the problem 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 approach:

- 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 patient care
- Offers a support system to help 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 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.

The WHO definition reflects a fundamental shift internationally in recognising that the provision of palliative care is applicable at any stage after diagnosis of an life limiting illness⁸, wherever there is a need and wherever the patient is, and not just at the very end of life (terminal phase). This definition is reflected in the recently published New Zealand Cancer Control Strategy: Action Plan 2005 – 2010: “there is now widespread recognition that the principles of palliative care should be applied as early as possible in the course of any chronic, ultimately fatal illness” (page 80).

Health professionals and the public need assistance to understand this shift in palliative care philosophy and provision of service to ensure that those people with a need can access appropriate resources. There is a need to have a strong foundation and infrastructure to support expansion of palliative care services to meet the increasing demand on health services.

⁷ World Health Organisation. (2002). National Cancer Control Programmes - policies and managerial guidelines. 2nd Ed. Geneva : WHO.

⁸ Life limiting illness is used to describe ‘illnesses that can be reasonably expected to cause the death of the patient within the foreseeable future. This is inclusive of malignant and non-malignant illness. This differs from chronic illnesses where, even though there may be significant impact on the patients abilities and quality of life, there is less likely to be a less direct relationship between the illness and the persons death’. Palliative Care Australia. (2005). A Guide to Palliative Care Service Development – a population based approach. Australia

Definition for Child and Youth

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders⁹:

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited
- It can be provided in tertiary care facilities, in community health centres and in children's homes.

Strategies

The New Zealand Palliative Care Strategy (2001) is a document with a 5 – 10 year vision. To support this vision, nine strategies have been developed with the aim to build a palliative care culture. The strategies are:

1. Ensure access to essential palliative care services
2. Each DHB to have at least one local palliative care service
3. Develop specialist palliative care services
4. Implement hospital palliative care teams
5. Develop quality requirements for palliative care services
6. Inform the public about palliative care services
7. Develop the palliative care workforce and training
8. Ensure that recommendations from the Paediatric Review are implemented
9. Address issues of income support.

Essential Services

Palliative care incorporates a wide range of different services and providers. Care is provided in a variety of settings and requires a case management approach to enable an appropriate combination of interventions by the right providers in the right place, at the right time and based on the needs for each individual and their family / whānau. A full range of essential services ensures access for people to choose the option of dying at home and having access to a range of community based services and access to specialist services when required.

Essential services include:

- Assessment – initial and ongoing multidisciplinary team assessment to identify needs early and establish an individualised care plan. General practice services must be included in the multidisciplinary team to ensure continuity of care to the person.

⁹ World Health Organisation. (1998a). Cancer pain relief and palliative care in children. Geneva :WHO.

- Care co-ordination – each person should be allocated a care co-ordinator. This co-ordinator is responsible for appropriate information regarding options and services available to the person and family / whānau. Patients need to experience a seamless service with smooth and timely transition from one service to another. Timely referral to palliative care service is essential (preferably not in crisis) with smooth access to inpatient care (respite, symptom control) when required. Rapid and straight forward discharge planning and transfer from acute care to palliative care services is also required.
- Clinical care – access to medical services, nursing services and equipment, 24 hours a day, seven days per week. Access to allied health services, inpatient care for respite and / or control of symptoms (if required or preferred), bereavement counselling and spiritual care before and after death.
- Support care – includes support in the home and / or long term residential care in an appropriate setting for people who are unable to be cared for in the home. Access to Government long-term residential care is through a needs assessment by a Needs Assessment and Service Co-ordination agency¹⁰.
- The development of a framework around a palliative care network comprising two inter-linked levels of care. The two levels of palliative care services will be generalist and specialist. A well co-ordinated service network with flexible service arrangements to ensure that the needs of all population groupings can be met.

Generalist Palliative Care

A generalist palliative care provider is any health professional involved in the care of someone with a life-threatening or life-limiting illness, with no / limited formal training in palliative care and / or where palliative care is not their primary role / function.

Generalist palliative care providers include general practitioners and staff within the practice, residential / continuing care staff, community nurses and allied health staff, district hospital staff. It also includes other Waikato Hospital specialist services and staff i.e. oncology, cardiology, renal. These groups provide significant palliative care input along the patient's continuum of care and will continue to do so.

Primary health practitioners (usually GP's, practice nurses and district nurses) appropriately care for many patients with palliative care needs. These practitioners need to be able to refer and / or seek advice from specialist palliative care services when necessary. For the majority of patients this will be for assessment or periodic review, with the responsibility for ongoing care remaining with the primary health care provider. For patients with more complex care needs, care will involve a specialist palliative care service in conjunction with the primary health care service. 24 hour / 7 day access to specialist palliative care advice, support and consultation is essential to ensure quality care and to build skills and confidence of the primary health services.

Specialist Palliative Care

Specialist palliative care providers are health professionals trained specifically in palliative care who are involved in the care of someone with a life-threatening or life-limiting illness, working within a multidisciplinary specialist palliative care team. The health professionals will have completed recognised training programmes for specialist medical or nursing staff.

¹⁰ Determination of eligibility for DHB subsidy is through a financial means assessment. This Plan does not propose changes to funding to residential care services.

A specialist palliative care service is a service provided by a cohesive interdisciplinary network of specialist palliative care providers¹¹. Waikato specialist palliative care providers are the Waikato DHB Palliative Care Unit based at Waikato Hospital, and the Waikato District Community Hospice Trust. The Palliative Care Unit also provides the tertiary level hospital palliative care team functions. The Palliative Care Unit and Waikato Community Hospice Trust hold regular forums to communicate and manage patient care. Both the Palliative Care Unit and the Waikato Community Hospice Trust provide local services to the community.

There is a critical responsibility to value, educate and support the generalist palliative care providers. WHO¹² states it is unrealistic to expect the wider emerging needs for palliative care to be met by expanding the workforce of specialists in palliative care. It is more likely that a solution will be found by expanding the knowledge and skills of health professionals generally.

Additional specialist palliative care provider responsibilities include:

- Providing evidence based specialist advice, support and consultation, including 24 hour / 7 day on call service
- Facilitating quality improvement among local palliative care providers
- Providing specialist education and training for all staff involved in palliative care
- Working at a national level on quality improvement activities / developments.

Current Service Issues

A critical analysis of the patient flow and current model of care (Strength, Weakness, Opportunities and Threats Analysis, appendix 3) highlighted strengths and issues that require addressing. The key strengths of the current model are:

- The commitment and skills of the staff and providers
- Philosophy of home based care and support
- Links and integration with primary services i.e. Community Services, Hospice Waikato and Palliative Care Unit
- PHO Palliative Care Home Visit programme in rural Waikato
- Collaborative care model¹³ to address the needs of rural population
- Paediatric Shared Care model
- Palliative Care Unit model of providing specialist services across the range of settings. Medical consultants provide outreach clinics and home visits (if required) in partnership with the GP
- Palliative Care Unit access to acute inpatient beds for complex symptom control

Summaries of the key weaknesses are:

- Fragmentation of services with and between providers resulting in variation in standards of practice
- Service level gaps

¹¹ Palliative Care Australia (2005). A guide to palliative care service development : a population based approach. Australia : PCA.

¹² World Health Organisation (2004). The Solid Facts. Geneva : WHO.

¹³ There are 2 primary palliative care nursing service delivery models. Collaborative care model - Waikato DHB district nursing service provides the primary nursing care across the Waikato district with the exception of Hamilton, Cambridge and Ngauruawhia. When a patient chooses the collaborative care model specialist multidisciplinary palliative care input is provided through Hospice Waikato. The model was established to meet the needs of those living in rural areas and is based on a multidisciplinary partnership approach between the two services in conjunction with the general practice team and working with the Palliative Care Unit, Iwi providers, community groups and resthomes and continuing care organisations. Hospice Waikato provides a package of home based palliative care services for Hamilton, Cambridge and Ngauruawhia. Hospice Waikato delivers the primary palliative nursing functions as well as access to the multidisciplinary team and services. Hospice Waikato has four community inpatient beds based in Hamilton for short-term respite and symptom control.

- The PHO Palliative Care Home Visit programme does not cover Hamilton City as the local management group in this region is not operating yet
- There are gaps in accessing out of hours primary care support throughout the district
- Fragmentation and difficulty accessing night relief support throughout the district
- Difficulties accessing medication especially out of hours and / or pharmacy not having medication in stock
- The collaborative care model has not been implemented across the whole of the Waikato DHB
- No single point of contact for referral, assessment, co-ordination, crisis advice and management
- There are shortages in essential equipment and the management of equipment is fragmented across the Waikato DHB
- Access to essential services is fragmented resulting in service gaps and variations in different aspects of care. There are no guidelines and tools for assessment, which can often be duplicated. Care co-ordination is not always clearly identified with supporting treatment plans, including out of hours backup support. There is fragmentation regarding the quality of clinical care along the continuum of care. Support care packages do not always meet the needs of the patient and family / whānau
- Lack of palliative care approach, both public and private health care providers are unsure of services available often resulting in late referrals
- Forecasted growth in referrals due to population growth and change in population characteristics, the expansion of palliative care definition and parameters, increasing incidence in cancer and non-malignant diseases / conditions. There is no planned approach to address predicted growth in demand with limited resources. Waikato palliative care services and providers need to develop the infrastructure and resources to support achievement of the New Zealand Palliative Care definition of care of the dying before meeting the needs of all patient's and family / whanau with life-threatening illnesses from diagnosis
- Workforce development and education is viewed as a critical area requiring urgent attention. There are inadequate levels of staff including gaps in allied health professionals that should be part of the multidisciplinary team. There are recruitment and retention issues. Due to limited resources education and training is adhoc. There is insufficient specialist nursing staff with postgraduate qualifications in palliative care. There is under representation of Māori and Pacific health workforce within palliative care
- Investment in service development historically has been adhoc with limited resources and funding. Hospice Waikato subcontracts community hospice inpatient beds and does not have its own purpose built facility. Waikato region has inadequate level of community hospice inpatient beds
- Lack of quality standards / specification, performance indicators and poor data systems
- Cultural barriers resulting in access issues, as cultures are unaware of existence of palliative care services.
 - There is a lack of education and development with Māori and Pacific providers
 - Lack of knowledge and understanding about Māori and Pacific Peoples cultural beliefs in the area of providing care for those dying
 - Long term planning and consideration is required for other minority ethnic groups
- Paediatric issues are predominately related to the small numbers of patients and issues with economy of scale for service provision across the district, especially of rural areas. There are issues of equitable access to packages of respite / support care available from multiple providers. There is no clear approach for transition of adolescent to adult specialist palliative care services.

The Waikato DHB has dedicated and committed staff that have developed the current model of care who are working towards meeting the needs of the Waikato DHB population and the achievement of the New Zealand Palliative Care strategies. There are gaps and issues that require ongoing attention and it is recognised that the development of palliative care services within the Waikato DHB will take time.

Part Two - Waikato DHB Palliative Care Strategic Direction

The Waikato DHB palliative care goal is to ensure that all providers of palliative care in the Waikato DHB work together with the community to ensure that the New Zealand Palliative Care Strategy is implemented in the most optimal way for the Waikato district. This is to ensure that all people with palliative care needs and their family / whānau have access to essential palliative care services, provided in a co-ordinated and culturally appropriate way.

The goal encompasses four key results areas:

1. Integrated and collaborative service

Continuity of care requires the collaboration of all service providers and the community. Integration of services is essential to ensure seamless transition through providers and services. This will enable people with life-threatening illness and their family / whānau access to a flexible service model to ensure a holistic continuum of care.

2. Patient focus on improved access and equity to palliative care services based on identified needs and informed choices

The Waikato DHB population will have an improved awareness and understanding of palliative care through a health promoting framework that incorporates education, advice and support. Waikato DHB population will have improved access to palliative care services on basis of identified care needs and informed choices. Gaps identified in service provision are addressed.

3. Workforce development to ensure a skilled and competent workforce committed to the palliative care approach

Opportunities are provided for specialist and generalist palliative care staff, volunteers, carer's and the general community to raise awareness, upskill and train. The public and health professionals / providers have ongoing access to relevant information.

4. Quality Systems

Develop palliative care data collection and reporting across the Waikato DHB. Mechanisms are in place to monitor outcomes / outputs and quality of care to ensure continuous evaluation and evidence base practice is developed to inform service delivery and development.

Each of key results areas has supporting objectives and strategic initiatives. These are detailed.

Integrated and Collaborative Service

Objectives:

1.1 To establish the Waikato DHB Palliative Care Network

Strategies:

- (a) Establish the Waikato DHB Palliative Care Operations Network
 - Employ a project manager to assist in leadership and facilitation of the Network
 - Elect a chair
 - Develop and agree terms of reference
 - Prioritise Waikato DHB Palliative Care Strategy Plan's recommendations
 - Develop an implementation plan and commence implementation
- (b) Establish the Waikato DHB Palliative Care Advisory Group
 - Elect a Chair
 - Develop and agree terms of reference
- (c) Ensure a system and local structure for leadership in child and youth palliative care is supported in the Waikato DHB palliative care network

1.2 To promote the palliative care approach and inform the public and providers

Strategies:

- (a) Develop an integrated Waikato DHB palliative care directory to inform the public on:
 - The palliative care services offered by each provider
 - Information on what to expect from a palliative care service
 - Outline the public's rights / entitlements from Waikato DHB palliative care services
- (b) Develop and promote the palliative care approach in other specialist services
- (c) Review and standardise palliative care patient and family / whānau information, clinical guidelines, protocols and pathways between providers
- (d) Palliative care approach is developed for all ages

1.3 To establish formal links between the various services levels and providers

Strategies:

- (a) To develop a Waikato DHB role delineation model that describes the various levels of service, delineates expected resources and capability of generalist and specialist services
 - To develop an urban role delineation for Hamilton City
 - To develop rural role delineation for each of the district areas
- (b) To develop and implement a transition pathway and process between child and youth services to adult services

1.4 To ensure there is palliative care clinical leadership

Strategies:

- (a) On appointment of third palliative care specialist expressions of interest should be sought to appoint, from within existing resources, the appointment of a Clinical Director 0.2 FTE.
- (b) The purpose of this position is to provide clinical leadership across the Waikato DHB and ensure development of:

- A consultancy service to General Practice teams and other specialties 24hr / 7 day
- Support and supervision (as required) of the interdisciplinary team
- Medical specialist integration with Hospice Waikato
- Education and training of workforce
- Research and quality activities
- Structure and system that also recognises child and youth palliative care services

Patient Focus on Improved Access and Equity of Services

Objectives:

2.1 To provide access to culturally appropriate palliative care services

Strategies:

- (a) Māori and Pacific People workforce and provider development to build capacity and capability
- (b) Apply the Health Equity Assessment Tool (HEAT) to policy and funding decisions regarding palliative care strategic initiatives

2.2 To continue to improve palliative care services through review, analysis and improvement to the patient journey and parallel processes

Strategies:

- (a) Adopt the patient mapping and model for improvement methodology and guidelines from the Midland Region Non Surgical Cancer Treatment Implementation Project (2005)
- (b) Further develop work commenced on the palliative care patient mapping and processes
- (c) Link the palliative care patient mapping within the Midland Region Non-Surgical Cancer Treatment tumour group mapping process
- (d) In partnership with other Clinical Streams consider mapping of patient journeys

2.3 Waikato rural communities to have improved access to palliative care services

Strategies:

- (a) Commence formal review and evaluation of the current collaborative care service and recommendations for the future
- (b) Waikato DHB district hospitals included in the collaborative care service review

2.4 To strengthen the palliative care links and partnership with general practice

Strategies:

- (a) Primary health providers actively participate and contribute in the network
- (b) As the model of care and care co-ordination service develops, the roles and responsibilities are more clearly defined including interaction and links between the various levels of service. Each palliative care patient has a nominated care co-ordinator. There is a plan for continuity of care for out of hours
- (c) An educational programme for general practice teams is developed, an option is utilising the UK Gold Standards framework. Supporting this is the directory and manual of services / resources available

- (d) To explore strategies / options with the aim to increase coverage of the palliative care home visiting programme concept to all GP's
- (e) Waikato PHO Hamilton Local Management Group to consider implementation of the Palliative Care Home Visit Programme
- (f) Develop sustainable solutions to address the issue of out of hours cover and access to pharmacy / medication

2.5 To provide specialist palliative care advice and support to palliative care patients in resthomes and continuing care organisations

Strategies:

- (a) Employ specialist palliative care nurse educators to the level of 1.0 FTE to facilitate a pilot project. The educators would be expected to maintain a clinical practice role in palliative care
- (b) Conduct a baseline assessment, including training needs analysis of current palliative care provision in resthomes and continuing care facilities in the Waikato DHB
- (c) Raise profile of specialist palliative care services including directory of services and develop resource file that can be accessed by all home care staff
- (d) Work collaboratively with other education providers to develop educational palliative care programme for staff in resthomes and continuing care facilities, including orientation processes
- (e) Establish a 'link' nurse system for palliative care information delivery in each resthome
- (f) Establishment of clear referral and communication channels
- (g) Introduce integrated care pathway for the dying (i.e. Liverpool End of Life pathway)
- (h) Complete an evaluation of the pilot project

2.6 To establish assessment single point of entry

Strategies:

- (a) To explore options and implement preferred solution
- (b) To implement 24 hour / 7 day week medical specialist on-call consultancy service. Note: this recommendation is reliant on recruitment of third palliative care specialist
- (c) To develop the 24 hour / 7 day week on-call nursing service to integrate senior nurses from the two specialist palliative care providers; Hospice Waikato and Palliative Care Unit
- (d) Develop standardised referral and assessment tools and guidelines

2.7 To improve clinical care through the development and implementation of clinical pathways

Strategies:

- (a) End of Life Liverpool pathway is implemented. Initially pilot in one or more of the following settings:
 - Hospice Waikato community inpatient facility (as required)
 - Hospice Waikato home based care
 - Waikato Hospital specialty services
 - Resthomes / continuing care organisations
- (b) Employ dedicated resource initially to lead and facilitate development of the clinical pathways. It is recognised that there are numerous barriers to the implementation of the

Liverpool pathway. Resource is required for training and ongoing continuous improvement

- (c) Development of standardised bereavement risk assessment tool to ensure those families / whānau with the highest risk have support and follow-up plans

2.8 To maximise scarce specialist palliative care resource and reduce duplication

Strategies:

- (a) To define the specialist palliative care roles and additional responsibilities between the two specialist palliative care providers; Hospice Waikato and Palliative Care Unit
 - advice and consultation
 - quality improvements local and national
 - education and training
- b) To review the various child and youth respite / support packages, to ensure that there is equity of access and flexibility to suit the individual needs of the child and family / whānau

Workforce and Resource Development

Objectives:

3.1 To ensure all palliative care service providers practice within the palliative care approach

Strategies:

- (a) Educate providers in the palliative care approach through development of a suite of education packages for:
 - General Practice teams
 - Resthomes and continuing care organisations
 - Māori and Pacific providers
 - Other NGO's and / or support groups
 - Specialist clinical services based at Waikato Hospital, i.e. renal, cardiology, neurology
 - District hospitals
 - Community services
 - Specialist palliative care services
 - Volunteers
- (b) Ensure all providers have policies and protocols reflecting the palliative care approach
- (c) To build Māori and Pacific health workforce capacity and capability

3.2 To ensure there are adequate levels of appropriate trained palliative care staff

Strategies:

- (a) Actively contribute to the national development of guidelines on workforce requirements. Findings should contribute to determining the appropriate level of Waikato DHB multidisciplinary staff required for palliative care services. In the interim Waikato DHB palliative care services should focus on the following strategic initiatives related to each health professional group.

Specialist Palliative Care Physicians

- (b) Employ a third palliative care specialist
- (c) Appoint a Clinical Director 0.2 FTE

- (d) Implement a 24 hour / 7 day week on-call consultancy roster and service
- (e) Specialist palliative care physician to have sessional time in Hospice Waikato service
- (f) Promote and support GP's in palliative care
- (g) Promote and develop medical staff education and training programmes in palliative care
- (h) As required increase support to district hospitals and communities in terms of outreach clinics
- (i) Development of the palliative care approach with other specialties and district hospitals

Registrars

- (j) Submit business case to the Clinical Training Agency to increase the number of registrar training positions (and associate funding)

Medical Staff for Intermediate Level Palliative Care

- (k) Develop a pilot project business plan to establish GP's, with an interest in palliative care, to provide medical support at the intermediate level of generalist / specialist community based palliative care. This is predominately providing a service in partnership with Hospice Waikato.
- (l) Recruit GP's across the district at an estimated 0.1 – 0.2 FTE with a total of 0.5 – 1.0 FTE
- (m) Implement project and evaluate

General Practitioners

- (n) Education programme to support GP teams, including education / training option other than the Donny Fellow programme to allow GP's to remain in practice
- (o) Continued promotion and support of the Donny Fellow programme

Nursing

- (p) Enhance the 24 hour / 7 day week on-call nurse consultancy service through integration of specialist resources from both specialist palliative care providers
- (q) Training and development plan is developed for all specialist palliative care nurses. The target is to attain 80% of the workforce with or working towards a post graduate palliative care qualification
- (r) Training and development plan be developed for all groups of generalist nurses
- (s) Appoint specialist palliative care nurse educators for resthomes / continuing care organisations to develop a focused training and development plan, enhance integration and service provision through the establishment of 'link' nurses
- (t) To work with national agents to define clinical nurse specialist and associated training and development pathway for palliative care. Support specialist palliative care nurses to attain this level of competency
- (u) Promote nurse practitioner pathway and programme for Waikato DHB palliative care

Allied Health

- (v) Waikato DHB consider how allied health are aligned with the proposed Clinical Streams Model of Care
- (w) Review the level of allied health within palliative care and the need for allied health staff to be designated within palliative care teams

Volunteers

- (x) Review to ensure that all volunteers are adequately supported and co-ordinated
- (y) Consider the need for development of the palliative care co-ordinator role for volunteers for the following functions:
 - Recruitment and retention
 - Training and development

- Provision of psychological support
- Practical co-ordination and communication
- Supervision
- Compliance with health and safety standards
- Addressing quality service issues

3.3 To ensure there are adequate Hospice community inpatient beds for respite and symptom control

Strategies:

- (a) Waikato DHB and Hospice Waikato need to consider and address the current level of community Hospice inpatient beds, 4 is inadequate and strategies to increase to 10 should be explored as the Waikato DHB model of care is developed
- (b) Explore long term facility / management options for community inpatient respite and symptom control beds for the Waikato district
- (c) Develop and strengthen Hospice community inpatient respite and symptom control services to ensure best practice and excellence in standards
- (d) Training and development plan for the staff providing care to patients admitted to the Hospice community inpatient beds to ensure that the Hospice philosophy and standards of clinical care are achieved
- (e) Reporting and evaluation systems are implemented to monitor performance against standards
- (f) Implementation of the Liverpool End of Life pathway for patients admitted (if appropriate) to Waikato Hospice community inpatient respite and symptom control beds

3.4 To ensure there is adequate, safe and appropriate equipment to maintain people in the community

Strategies:

- (a) Complete a formal review of palliative care equipment management processes and systems and consider long term strategies
- (b) Stocktake of equipment available and identification of provider responsible for management of the equipment. Develop methodology of an integrated asset register
- (c) Identification of inadequate levels of equipment and strategy to address
- (d) Process guidelines on accessing and returning palliative care equipment
- (e) Review of assessment for appropriate equipment allocation
- (f) Standards established for maintenance and cleaning of all equipment used

Quality Systems

4.1 To foster a culture of continuous quality improvement that enhances best practice and improves quality of care and services provided

Strategies:

- (a) Adopt the patient journey mapping and parallel process methodology and model for improvement developed as part of the Midland Region Non-Surgical Cancer Treatment Implementation Project (2005)
- (b) Research and evidence based standards should be developed

- (c) An audit programme should be implemented, including satisfaction surveys, to measure performance against the standards and quality improvement programmes implemented as required

4.2 To develop and implement a transition pathway and process between child and youth services to adult services

4.3 To establish adult and child baseline data, appropriate performance indicators, benchmarks and reporting mechanisms to ensure achievement of the Palliative Care Strategy

Strategies:

- (a) Develop minimum palliative care data set
- (b) Develop Waikato DHB integrated palliative care reporting and monitoring system

4.4 Participate in national initiatives to improve the quality of palliative care and establish benchmarking

4.5 Waikato DHB planning and funding service should review the Disability Support Link (DSL) palliative care administration function for night relief and respite care to resthomes / continuing care

Strategies:

- (a) Identify if current funding level is adequate and identify the appropriate organisation to administer funds
- (b) Ensure improved access and integrated approach to night relief throughout the Waikato district
- (c) Develop access criteria and guidelines to access the two service components
- (d) Develop data set for reporting and monitoring

4.6 Waikato DHB planning and funding should review all palliative care service specifications, rationalise, integrate and establish reporting and monitoring systems

Strategies:

- (a) Participate in national development of service specifications
- (b) Waikato DHB planning and funding should negotiate with the Ministry of Health / DHBNZ to consider the development of separate purchase units for hospital palliative care units first specialist attendance, subsequent attendance and home visit.

Part Three - Model of Care and Operating Framework

This section describes the Waikato DHB palliative care model of care and operating framework to support the achievement of the Waikato DHB Palliative Care Strategy objectives and strategic initiatives over the next five years.

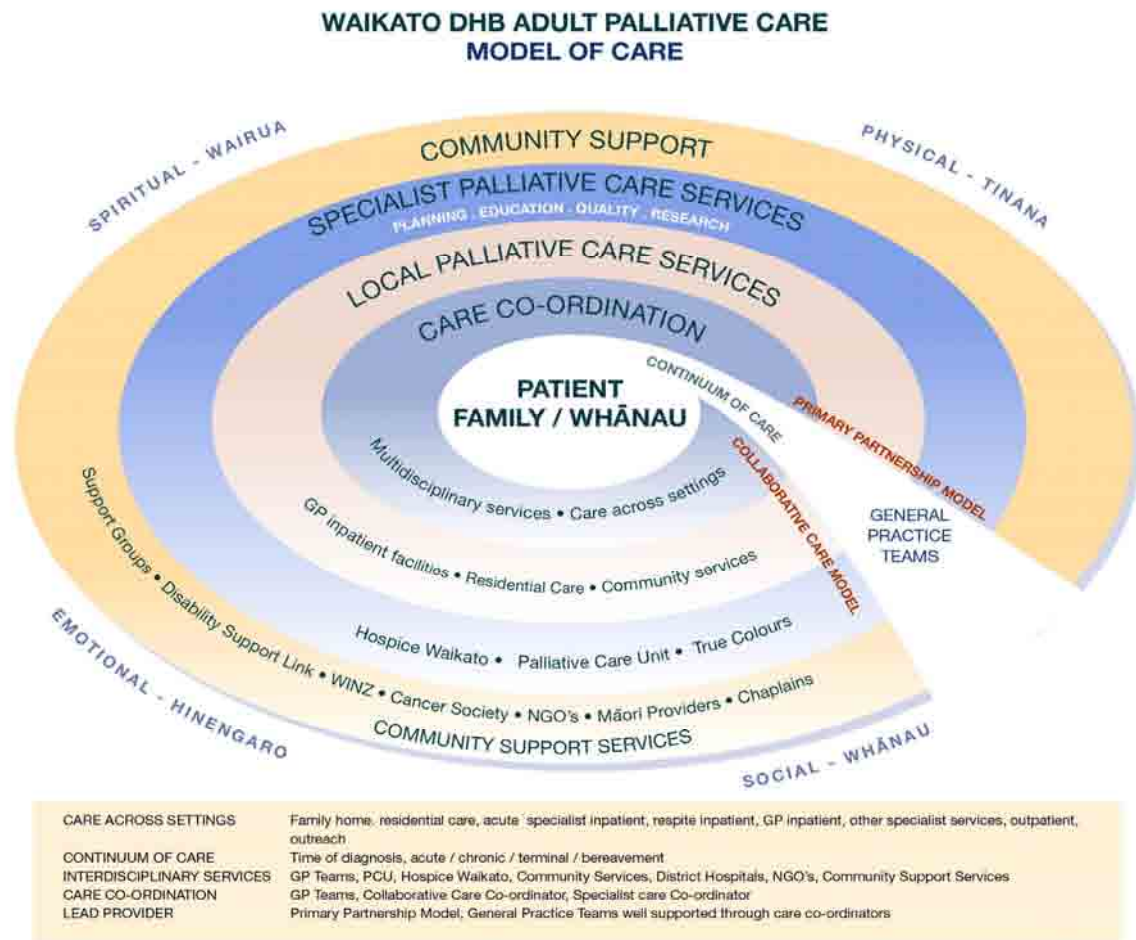
Part three considers both the adult and child and youth models of care.

Model of Care Framework

To meet the challenges, an integrated service delivery model has been developed to meet the palliative care needs of the adult Waikato population. The integrated service delivery model is based on patients receiving different levels and types of services depending on their needs.

Seven key principles were used to develop the Waikato DHB Palliative Care Model these are:

- Patient and family / whānau focused
- Local community based action
- Responsive and flexible model
- Culturally appropriate
- Building on what we have
- Integration and co-ordination
- Workforce development



The model of care is a visual demonstration that the patient and family / whānau are the focus point with the general practice team supporting the patient and family / whānau along the continuum of care. Wrapped around the patient and family / whānau is the concept of care co-ordination. Care co-ordination ensures that the patient and family / whānau are supported through the various services along the continuum of care. The concept of care co-ordination is further described in part four.

The target palliative care population is grouped into three broad sub groups based on complexity of need. Patient's episodes of care will move between different levels of care over time as the needs of the patient change. Access to palliative care will be based on complexity of need through a single point of entry based on established assessment and referral protocols. A number of pathways need to be developed that delineates formalised links and define expected capabilities of providers at all levels allowing seamless patient flow.

The three levels of service are:

1. Generalist – primary and community based palliative care services
2. Intermediate – generalist and specialist palliative care community based services
3. Specialist – specialist palliative care services

The primary care providers are integral players in this model. Every patient has an identified primary medical carer and the primary care providers are involved with the patient's care throughout the continuum of care.

A fundamental prerequisite for this model is that skills and expertise of mainstream primary care providers are strengthened to allow them to deliver quality palliative care services. This will require strengthening the role of the specialist palliative care services in education, professional development and consultancy services. Furthermore, a strong health promotion role is essential to provide education and support to the community.

The model is based on formalised partnerships and role delineation between the different levels and providers of palliative care. The formation of a palliative care network will assist in the implementation of the integrated model. The strategic network initiative is further discussed in the next section.

The three levels of service are described.

Generalist Palliative Care Service

Generalist palliative care services are provided by general practice teams, community services, resthomes and home based support. Primary services over time will expand the range of services both in home based support and complementary general practice i.e. primary nurse practitioners, allied health attached to general practice, case management of people with chronic illnesses and / or complex needs.

Patients receiving primary care usually have an established relationship. For these patients a palliative care approach will be introduced as part of ongoing and comprehensive care along the continuum of care. Access to primary care providers is generally through normal referral and relationship mechanisms. Most people with palliative care needs will be met by generalist palliative care services.

Intermediate Palliative Care Service

What is new in the model of care is the formalised intermediate level of care that bridges the gap between generalist palliative care services and specialist palliative care services across the different settings and along the continuum of care. Intermediate level of service is an integration of generalist palliative care and specialist community based palliative care providers and services.

Some patients' episodes of care will move in and out of generalist and specialist palliative care services and different settings (i.e. community based, hospice inpatient, acute secondary hospital) based on complexity and level of need. In this intermediate level of care patients and family / whānau can continue to receive care from their primary care provider. Specialist palliative care services will provide episodic consultation and advice.

Specialist Palliative Care Service

From time to time a patient and family / whānau may have increased palliative care needs that are complex. Access to specialist services is based on complexity or intensity of need and access to specialist palliative care will ideally be through referral from a primary care provider, however there needs to be mechanisms in place to respond to self or family / carer referrals. The policy guidelines for self / family / carer referral must be supported with robust communication criteria to ensure continued involvement of the general practice team. Established assessment and referral protocols should be in place.

Benefits of the Framework Model

The model of care aims to achieve the following:

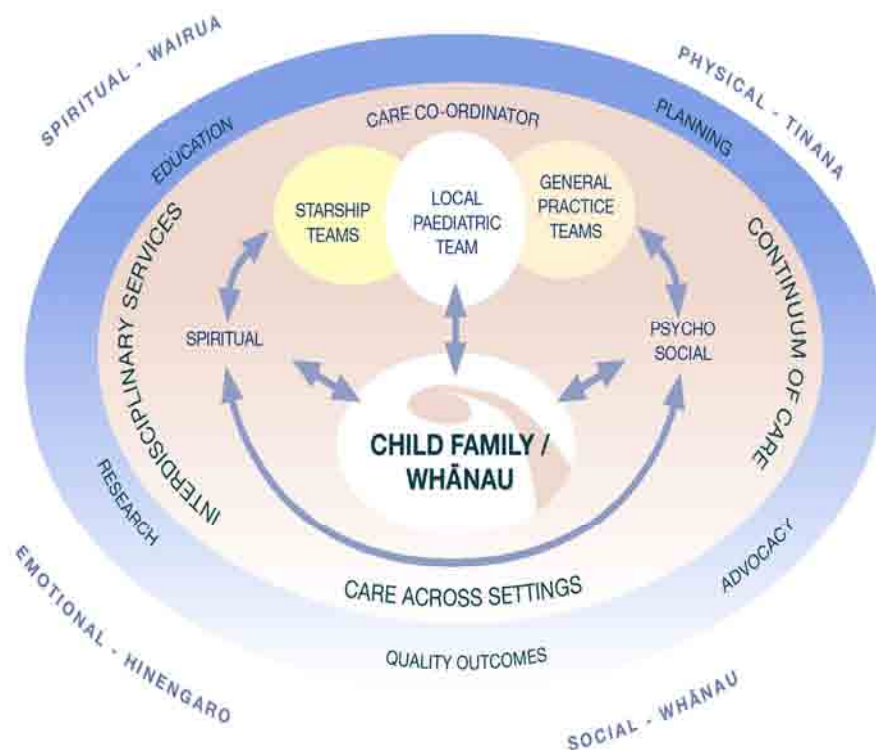
- Enable people with palliative care needs to remain living in the place of their choice with adequate support
- Improve access to all essential palliative care services
- Improve the patient journey through improved co-ordination
- Improve the interface of generalist and specialist palliative care services
- Ensure smooth transition between components of the care continuum
- Reduce avoidable hospital admissions
- Planned and informed approach to development of palliative care services
- Build capability and capacity within the community
- Address local issues identified in the Waikato DHB SWOT analysis
- The model enables a shared operating framework that enables Waikato DHB to work towards achievement of the New Zealand Palliative Care Strategy guiding principles and nine strategies.

Child and Youth Model of Care

The needs of children are different to adults and the subsequent model demonstrates this. Principles underpinning and promoting the holistic child and youth palliative care model are:

- Child and family / whānau focus that take into account children's rights
- Home is the centre of caring
- Recognise that parents are the experts and primary carers
- Open and honest partnership approach with the family / whānau (family / whānau empowerment and understand the needs of all members of the family / whānau). The expertise of families / whānau and professionals is of equal importance. One cannot operate without the other if the quality of care for the child is to be optimised
- Culturally appropriate
- Multidisciplinary best practice care components encompass symptom management, emotional and practical support, spiritual needs and bereavement support for the total family
- Service delivery is based on assessment of needs and can start as soon as possible after diagnosis. Care plans are flexible to accommodate changing needs
- Well co-ordinated services (integrated providers) and an emphasis on continuity of services.

WAIKATO DHB CHILD AND YOUTH PALLIATIVE CARE MODEL OF CARE



CARE ACROSS SETTINGS	Family home, acute inpatient care, respite inpatient care
CONTINUUM OF CARE	Time of diagnosis, acute / chronic / terminal / bereavement care
INTERDISCIPLINARY SERVICES	Starship, CRN's / Ward, Rainbow Place, True Colours, DSL, Community Services
CARE CO-ORDINATION	Starship, CRN's / Ward
LEAD PROVIDER	Starship, Paediatrician supported through GP Teams

Current literature on support for family / whānau with a dying child indicates home is considered the most appropriate and desired place of care. The child and youth palliative care model of care supports the philosophy and principles of The Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT) and the Royal College of Paediatrics and Child Health (RCPCH) Guide 1997¹⁴.

Key themes of the model include:

- Child - family focus
- Philosophy of home based care wherever possible
- Multidisciplinary team approach
- Seamless patient flow continuum
- Collaborative and integrated model with and between service providers
- An approach that intertwine palliative care with curative care is essential in paediatrics, as there is often uncertainty with prognosis with some cases

Starship Hospital, Auckland DHB is the acknowledged tertiary provider for child health, including palliative care. Starship Hospital cares for specialist paediatric care needs and works in a partnership model with the local Waikato paediatric services including liaison with support services. The Starship palliative care team provides specialist palliative care for Auckland region and offers advice on palliative care nationally.

Children's palliative care services are not organised the same way as adults. Paediatricians tend to remain involved in the child's care throughout their lives and work alongside other health providers of services. All Waikato children that have or are expected to have palliative care needs are under a Waikato paediatrician who is the designated lead provider team. The Starship specialist palliative care team supports the paediatric team as required. A network of health providers delivers support and paediatric palliative care services.

The child's general practice team provides care in the community and is kept informed throughout the continuum from specialist services.

Waikato DHB Child and Youth Palliative Care Co-ordination Service

The care co-ordination process is described for children with malignant and non-malignant conditions.

Specialist Paediatric Oncology care is provided by Starship Paediatric Oncology team. Local paediatric oncology care is co-ordinated by designated paediatrician with an interest in oncology. Both teams are multidisciplinary and communicate regularly to ensure seamless support to the child, family / whānau and general practice team. At a Waikato DHB level there are two nurses based at Waikato Hospital (Ward 52) that assist with co-ordination by communicating with the family / whānau and arranging treatments and follow-up as required. Support services, including community support are implemented early in the process, often from Starship, i.e. Child Cancer Foundation, CanTEEN. Support services are provided where and when required, i.e. Rainbow Place or True Colours may provide services while a child is in hospital or in the community.

¹⁴ Association for Children with Life-Threatening or Terminal Conditions and their Families / Royal College of Paediatrics and Child Health. (1997). A guide to the development of children's palliative care services. United Kingdom : ACT/RCPCH.

Children with life limiting conditions that are non-malignant have care co-ordinated by a lead paediatrician. Paediatric community resource nurses (CRN's) assist the paediatrician with care co-ordination. There are two groups of CRN's:

1. neonatal children <1 year
2. children >1 year

All children have open admission status and support is available 24 hour / 7 day a week via Waikato Hospital paediatric inpatient nursing staff who have access to oncall paediatric registrar and / or paediatrician. When a palliative care child is admitted to hospital a specific primary care team is formed to provide care and support to the child and family / whānau as often care required is complex and intensive.

In 2004 the Waikato DHB established a working party (Respite Services Group) to develop a service for short-term home care for medically fragile children¹⁵. The aim of the service is to support families / whānau to promote quality of life, community participation and maximum independence for the child (0 - 14 years). Short-term respite care must be flexible, responsive and needs based and be delivered by well trained service providers. There are packages of care that can consist of; specialist nursing support / advice, personal care, household management and home based support.

¹⁵ Medically fragile has been defined as a child with a medical condition who is under the care of a paediatric specialist and requires daily nursing care and / or has significant risk of a life-threatening event in the next year and is either:

- Technology dependent in terms of a medical device to compensate for loss of bodily function or
- Requiring substantial daily skilled nursing care to avoid death or permanent disability and/or
- Families / whānau who face extraordinary demands in caring for their special needs child(ren) related to the complex and combining effects of a chronic illness, that is a family whose coping skills and family functioning are being eroded to an extreme degree causing repeated crisis.

Part Four – Implementation

Part two detailed the key result areas, objectives and strategic initiatives recommended for implementation over the next five years. For long term success there are three critical initiatives that should be given priority. The three critical strategic initiatives are:

1. The establishment of a Waikato DHB Palliative Care Network
2. Assessment the single point of entry
3. Development of care co-ordination

The New Zealand Cancer Control Action Plan 2005 – 2010 emphasised the need for each DHB to establish a palliative care network. The Waikato DHB Palliative Care Network is critical, as this is the mechanism to bring all providers together to work on implementation of the recommendations. The New Zealand Palliative Care Strategy (2001) gave priority to the development of the first two essential services, assessment and care co-ordination. These three initiatives are discussed in more detail.

Palliative Care Network Strategy

It is recommended the first priority is the establishment of a formal Waikato DHB Palliative Care Network for the care of people with palliative care needs. The model of care requires a common sense approach to build on existing skills, services and providers. The proposed network approach is the mechanism that pulls together providers to work towards achievement of the New Zealand Palliative Care strategic goals through implementation of the Waikato DHB Palliative Care Strategy Plan.

The Network formalises relationships with generalist and specialist palliative care providers as well as the community. Nationally, it has been determined that palliative care will sit under the umbrella of Cancer Control. The National Cancer Control Action Plan 2005-2010 has determined that each DHB will have a palliative care network in place. Specific actions of the Cancer Control Action Plan will be for the Network to implement the New Zealand Palliative Care Strategy through development of:

- A clear palliative care plan
- Referral system guidance
- Agreements regarding a local system of care co-ordination
- Agreed communication systems
- A local service directory
- Local audit and monitoring activities
- A co-ordinated workforce strategy

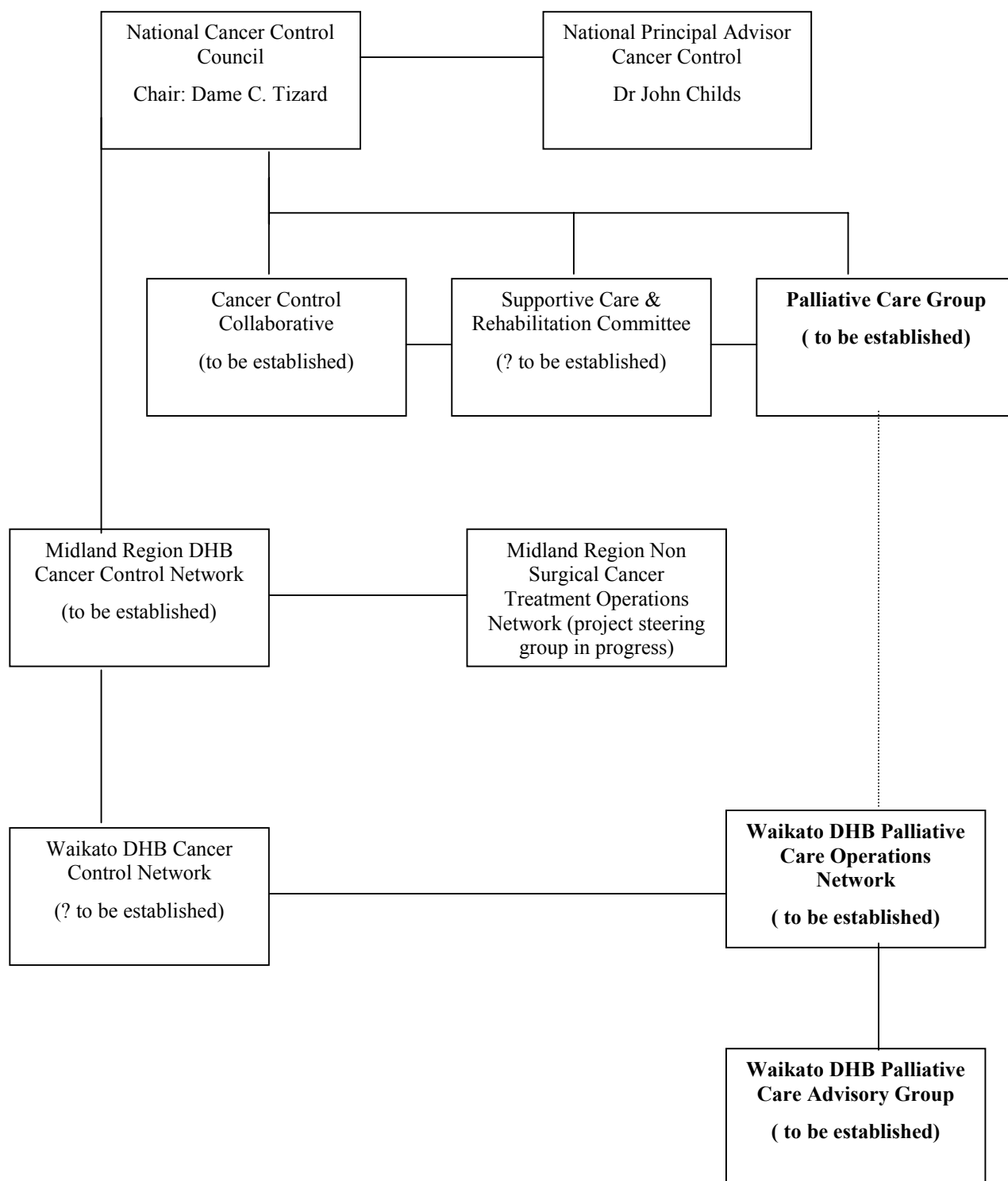
There are two groups that will form the Waikato DHB Palliative Care Network, they are:

1. Waikato DHB Palliative Care Operations Network (generalist and specialist stakeholders)
2. Waikato DHB Palliative Care Advisory Group (community stakeholders)

The network will ensure operational responsibility of service development and provision. Strong leadership and facilitation skills are required to ensure the success of bringing together different cultures from a range of providers and health professionals.

It is recommended that a Chair and a Project Manager be appointed to the Network to co-ordinate the establishment of the Network and the Advisory Group. The Network supported by the project manager will prioritise recommendations, facilitate implementation of the strategic objectives and initiatives in partnership with line management. The proposed Waikato DHB Palliative Care Network structure with roles and responsibilities are outlined in more detail.

Figure 3: Waikato DHB Palliative Care Network



Purpose of the Waikato DHB Palliative Care Operations Network

A group of health professionals from generalist and specialist palliative care providers will work in a collaborative and co-ordinated manner to ensure equitable provision of high quality, clinically effective, culturally appropriate palliative care service throughout the Waikato DHB.

A philosophy of broad-based community service is the optimal way to accommodate and address the projected increased demand in palliative care needs.

It is recommended that all stakeholders participate in the Network and that an Advisory Group is complementary to the Operations Group. The purpose of the Advisory Group is to ensure participation of all community stakeholders which takes account of views and expectations, communication on progress towards the strategic plan, identify issues and develop joint action plans to resolve. Further details of the Network's principles and responsibilities along with the benefits of establishing a Network are briefly outlined in appendix 4.

Palliative Care Operation's Network Group representation

- PHO
- Palliative Care Unit
- Waikato District Community Hospice
- Community Services
- Waikato DHB Planning and Funding
- Paediatric Services
- Māori health
- Palliative Care Advisory Group Representative

Palliative Care Advisory Group representatives:

- NGO's
- Māori providers
- Pacific People providers
- Cancer Society
- Child Cancer Foundation
- Starship Specialist palliative care service
- Residential / continuing care providers
- Community Support Groups
- Other specialist services that refer to palliative care i.e. renal, cardiology, surgery
- Older Persons service

Assessment Single Point of Entry Strategy

This strategy refers to the point of entry being the request for an initial palliative care assessment whether this is in the community or acute hospital setting. An initial multidisciplinary assessment identifies the patient and family / whānau physical, social, spiritual and emotional needs. The assessment determines the level of services and referral to appropriate services. Single point of entry refers to the process of assessment.

Primary services and the community require entry points to access palliative care services. Primary services require access to specialist palliative care advice and support.

The single point of entry concept also aims improved equitable access for all patients and family / whānau. Waikato DHB Agewise has a single point of entry strategy, and is in the process of implementation. Palliative care can learn from this process. Robust evaluation of this concept is required to whether this strategy addresses equity of access and addresses inequalities as a result of improved access to appropriate and timely services.

The adult and child and youth assessment single point of entry needs to be developed, initial recommendations are:

- Generalist provider access to the intermediate level of care is to be further developed. Currently single point of entry occurs through the Hospice Waikato and Community Services collaborative care model.
- Generalist provider access to the specialist level of care is to be further developed through the implementation of the 24 hour / 7 day week medical palliative care specialist and specialist palliative care nurses on-call consultancy services. These services will be able to provide advice and support to generalist providers and triage referrals for assessment as required.
- Specialist secondary / tertiary level palliative care is via the Palliative Care Unit reception either via written or verbal referral.
- To develop standardised assessment and referral tools with guidelines that can be used by all providers.

It is envisaged that this will evolve over time and a variety of options need to be explored and evaluated. There needs to be a strong link with the care co-ordination strategy.

Palliative Care Co-ordination Strategy

Care co-ordination is needed to ensure patients are supported through the continuum of care, ensuring cultural, physical, spiritual and psychosocial aspects of care are addressed, together with improvement of efficiencies for services. Care co-ordinators facilitate the delivery of culturally appropriate services by linking general practices and other providers within the clinical network.

The Waikato DHB Palliative Care Strategy Plan proposes to formalise and develop the palliative care co-ordinator role to strengthen the links within the clinical network. Care co-ordinators can be a GP, practice nurse, district nurse or specialist palliative care nurse. The long-term aim is to strengthen the role of co-ordinators. Palliative care co-ordinators can be expert specialist palliative care nurses, with a case management component to the role and there would be the potential to develop this role into a nurse practitioner position in the future.

Levels of care co-ordination

As described in the Waikato DHB palliative care model, co-ordination can occur at various levels:

- Generalist palliative care

- Intermediate palliative care
- Specialist secondary / tertiary palliative care

The Waikato DHB Palliative Care Strategy Plan has recognised the need to clarify roles and responsibilities and the interaction at / and between each level.

Generalist Palliative Care Co-ordination

General practice teams, community services and resthomes largely provide generalist palliative care services. A large proportion of people with palliative care needs are provided by general practice teams and often supported by community nursing service, and co-ordination of care and services will continue.

Resthomes and continuing care facilities require significant attention and recommend a focused training and development plan for staff and enhanced integration and service provision through the establishment of 'link' nurses. A link nurse in an aged care facility is defined as a nurse with a portfolio who has developed an interest, received training and will promote palliative care approach and standards within the facility. The link nurse maintains regular contact with the clinical network, general practice team and specialist palliative care providers. Aims of this concept are:

- To promote the palliative care philosophy and approach
- Improve quality of life for older people through evidence based standards
- Minimise avoidable hospital admissions
- Improve standard of care during the terminal phase of the patients continuum

It is recommended that the:

- Waikato DHB Palliative Care Network and resthomes / continuing care facilities jointly develop and agree link nurse pilot project supported with link nurse portfolio description, competencies and training programme.

Intermediate Palliative Care Co-ordination

Care co-ordination for adults currently occurs through the collaborative care model (community services and Hospice Waikato) for rural Waikato and through Hospice Waikato for Hamilton City, Cambridge and Ngaruawahia. This level integrates generalist and specialist palliative care providers.

At present any staff that works within community nursing or Hospice Waikato can provide a co-ordination function. Care co-ordination provided through Hospice Waikato for Hamilton City, Cambridge and Ngaruawahia is delegated to a Hospice Waikato nurse.

The strategic initiative is to support and promote clinical nurse specialists within the Waikato DHB. Clinical nurse specialists will provide much of the advanced practice in palliative care. To support the development of care co-ordination at the intermediate level it is recommended that:

- A formal review and evaluation of the collaborative care model is undertaken to identify options to support the development of clinical nurse specialists as care co-ordinators within this framework
- Hospice Waikato support a clinical nurse specialist care co-ordination role within existing resources for palliative care services based in Hamilton City, Cambridge and Ngaruawahia
- A training and development programme is developed for community services including supporting staff to achieve recognised palliative care qualifications

- A training and development programme is developed for Hospice Waikato staff to achieve target of 80% of staff with recognised palliative care qualification
- To promote and develop a career pathway for care co-ordinators to achieve clinical nurse specialists status
- To promote and develop a career pathway for a clinical nurse specialist to achieve nurse practitioner status

Specialist Hospital Palliative Care Co-ordination

This level of care co-ordination for patients and family / whānau with complex needs is provided by the Palliative Care Unit in a hub and spoke model based at Waikato Hospital. The Palliative Care Unit has a specialist nurse co-ordinator.

The district hospitals require attention and it is recommended a focused training and development plan for staff and enhanced integration and service provision through the establishment of 'link' person (nurse and / or medical staff) with an interest in palliative care. The link people for the district hospitals would have an interest in palliative care, receive training and will promote palliative care approach and standards within the facilities. The link person maintains regular contact with the Palliative Care Unit and the clinical network, general practice team, community services, Hospice Waikato, resthomes and continuing care facilities.

Aims of this concept are:

- To promote the palliative care philosophy and community based approach
- To improve the quality of life for people with palliative care needs through evidence based standards
- To minimise hospital admissions and length of stay when appropriate
- To improve the standard of care during the terminal phase of the patients continuum
- To improved discharge planning

It is recommended that the:

- Waikato DHB Palliative Care Network along with the Palliative Care Unit and district hospitals jointly develop and agree link person portfolio and training programme.

Care Co-ordinator Role and Responsibilities

- Promote evidence based advanced palliative care nursing within the clinical network
- Provide specialist palliative care nursing advice and support to patients and family / whānau
- Co-ordinate the care of patients in active partnership with the local palliative care team and other relevant local providers and health professionals
- Ensure the general practice team is kept informed
- Ensure initial and ongoing assessments are completed as appropriate
- Care co-ordinator is identified in partnership with the patient, family / whānau and GP
- Relevant information to ensure patient and family / whānau are aware of options, enhance patient choice and involved in all aspects of care
- In partnership with the patient, family / whānau and GP a treatment plan is developed. Included in the plan is management plan for out of hours and when and who to contact when assistance is required
- Referrals made to other health professionals within the palliative care team or other agencies as appropriate. Equipment and resources obtained.

Funding the Implementation Phase

When the work of the Steering Group was peer reviewed it was identified that that Waikato DHB Palliative Care Strategy Plan direction was appropriate, however the objectives and strategic initiatives while achievable, were ambitious. There are numerous providers and stakeholders involved in palliative care, however the number of people with a primary focus in palliative care to bring about change are small.

The growth and demand for palliative care in the Waikato DHB cannot be ignored. The Waikato DHB Palliative Care Strategy Plan gives direction. The planning is based on best practice and the rate of implementation will be contingent upon access to scarce available funding. As indicated previously the three critical initiatives should be given priority. This does not preclude development of other recommended strategic initiatives at the same time.

It is recommended that current project management resource funding from the Waikato DHB Development and Support Unit continues.

In addition it is recommended in year one if resources are available, that funding priority should be given to the two essential service components: assessment and care co-ordination.

Assessment requires the investment of a third palliative care specialist to commence a 24-hour / 7-day week consultant on-call service to General Practice teams, and also will be a resource to the specialist palliative care nurses. A minimum of three consultants is required to develop a compliant on-call roster. In addition, a specialist palliative care nurse on-call service will be enhanced to support generalist palliative care providers.

Care co-ordination priority is the investment in:

- 1.0 FTE Nurse Educators for pilot project with resthomes and continuing care organisations
- 1.0 FTE General Practitioners for pilot project to establish intermediate level palliative care services throughout the Waikato DHB

To facilitate success of the three critical initiatives development, working in parallel is development of the workforce. As previously mentioned this is urgently required. A palliative care workforce development plan needs to be developed and further investment will be required for funding:

- Adequate levels and disciplines of staff
- Education and training for generalist and specialist staff groups
- Career development for clinical nurse specialists and nurse practitioner
- Supervision and support
- Promotion of cultural learning
- Adequate levels of Māori and Pacific People in the palliative care workforce
- Training for non-regulated care givers

Challenges and Risks

A number of challenges and risks exist when proposing development changes to the organisation of health services. The key challenge relates to getting stakeholder buy-in to strive to achieve the required changes in a resource constraint environment. Waikato DHB palliative care services is made up of different providers with different cultures and different agendas and priorities. The Waikato DHB Palliative Care Strategy Plan has taken a common sense approach to build on what we have. The real risk is in ensuring that the 'new' Waikato DHB Palliative Care Strategy Plan and supporting structure actually delivers on expectations and is an improvement on what we currently have. Many of the mitigation strategies are built into the plan.

Outlined below are the key risks and mitigation strategies

Risks	Mitigation Strategy
1. Inability to fund implementation phase	<ul style="list-style-type: none"> • Funding for initiatives should be sought from several different sources • Focus on maximising existing funding and reorganise as appropriate
2. Culture change in relation to working in a new model of care and operating framework	<ul style="list-style-type: none"> • Strong leadership • Senior and skilled Operations Network group • Senior project manager to seek early implementation of recommendations to indicate the value of Waikato DHB Palliative Care Strategy Plan and supporting Network • Robust communication and consultation strategy with Waikato DHB Palliative Care Advisory Group
3. Culture change and risk of passive resistance, patch protection and cynicism	<ul style="list-style-type: none"> • Clear responsibilities and a high level of accountability of the Operations Network members • Robust communication and consultation strategy and management of stakeholders expectations • Principle based approach to service developments
4. Strategy 'too big' for the size of the service and number of resources able to contribute to moving forward. Expectations ahead of anticipated deliverables	<ul style="list-style-type: none"> • Sound project management approach to implementation of Waikato DHB Palliative Care Strategy Plan • Robust and regular reporting, monitoring and evaluation of progress • Phased approach, which allows priorities to be reconsidered at various stages, design and deliver what we can within resources
5. Large geographical area and actual capacity to deliver services	<ul style="list-style-type: none"> • Continue existing specialist outreach services • Improve communication networks and access to required advice and support from specialist services when required • Develop role delineation model for rural and urban areas • Look to develop innovative solutions to delivering services in rural and urban communities in conjunction with DHB rural health and PHO pilots
6. Palliative care does not meet the needs of Māori	<ul style="list-style-type: none"> • Māori involvement at onset of strategy implementation • Seek support from DHB Māori Development Unit and supporting DHB and community infrastructure • Build on existing work • Recruitment of Māori staff and build capability of Māori providers • Apply the HEAT tool to policy and funding decisions
7. Inability to maintain community based model due to primary and community based issues	<ul style="list-style-type: none"> • Ensure community based health promotion approach taken with increasing palliative care approach • DHB, PHO and community continue to work in partnership to resolve gaps in service delivery, especially out of hours services • Specialist services develop consult advice service to primary services

Appendix 1 – Waikato DHB Palliative Care Strategic Project Steering Group

A number of individuals have provided support and assistance in the development of this document. In particular the support and input of the following individuals is acknowledged:

Project Sponsor

Dr Jan White Waikato District Health Board Chief Executive Officer

Project Steering Group

Jan Hewitt	Project Manager, Waikato DHB Development & Support Unit
Mary Bonner	General Manager, Health Services
Jan Adams	Manager, Waikato & District Hospitals
Dr Jeremy Long	Clinical Director, Oncology Services
Dr Des Swanevelder	Specialist Palliative Care Physician
Dr Alan Farnell	Specialist Palliative Care Physician (end part of project)
Dr Dave Newman	Paediatrician
Neil McKelvie	Service Manager, Oncology services
Margaret Stevenson	Regional Co-ordinator, Palliative Care Unit
Dr Mike Harris	Donny Fellow
Dr Margaret Parle	Donny Fellow
Dr Linda Rademaker	Waikato GP Liaison
Elizabeth Bang	General Manager, Waikato Community Hospice Trust
Michelle Bayley	Waikato PHO
Lynne Benefield	Maniapoto Marae Pact
Tureiti Moxon	Chief Executive Officer, Te Kohao Health
Brett Paradine	General Manager, Waikato DHB Planning & Funding
Ditre Tamatea	Strategic Leader, Māori Health
Moria Gawith	Kaiwhiriwhiri, Māori Health
Janice White	Manager, Disability Support Link
Diana Bowen	Community Development, Waikato / BOP Cancer Society
Jill Dibble	Acting Manager, Community Services
Jeff Bennett	Manager, Older Persons Service
Jean Botting	Nurse, Rural Representative Taumarunui
Lisa Horlor	Field Officer, Motor Neurone Disease Association
Annie Schenkel	Healthcare NZ (end part of project)
Sue Hadington Hight	Portfolio Manager, Waikato DHB Planning & Funding
Judy Hindrup	Resthome / Residential Care Provider Representative
Sandra Darbyshire	Resthome / Residential Care Provider Representative
Cathy Holland	Chair, ChildWatch
Allan Leadley	Chaplain Service, Health Waikato
Louise Dobson	Child Cancer Foundation
Anna Steele	Pacific People representative
Cynthia Ward	Clinical Nurse Specialist, True Colours

Appendix 2 – Stocktake of Providers and Contracts

Waikato DHB Summary Stocktake of Providers

Provider	Type of Services
Waikato PHO	Primary funded initiative through Services to Improve Access funding
Network of General Practitioners (formerly First Health) who now belong to Waikato PHO	Primary funded initiative through Conserved Resources funding
Primary Care Inpatient Services	Community GP acute inpatient care
Waikato District Community Hospice Trust	Collaborative care (with Community Services) Children and family focused service Inpatient beds x 4 Hamilton (sub contracted) Day Hospice All services are multidisciplinary
Tokoroa District & Community Hospice Trust	Family support volunteers
Disability Support Link	Administration financial function for night relief and access to continuing care facilities for respite care
True Colours	Paediatric community support
Continuing (residential) care facilities	Private hospital and resthome care (non-specialist respite care)
Waikato / Bay of Plenty Division Cancer Society of New Zealand Inc.	Community Support – support services, health promotion, research, advocacy and information services
Child Cancer Foundation	Community Support
Motor Neurone Disease Association of New Zealand	Community Support
Waikato Hospital	Specialist Palliative Care Unit – inpatient care, specialist consultation service, outpatient clinics, outreach services, home visits (limited) Other specialist services – inpatient and outpatient
Thames Hospital	Palliative Care specialist visiting service
Tokoroa Hospital	Palliative Care specialist visiting service
Te Kuiti Hospital	-
Taumarunui Hospital	Palliative Care specialist visiting service
Health Waikato Community Services	Community nursing and allied health care (including collaborative model with Waikato Community Hospice). Acute home support

The following identifies Waikato DHB palliative care contracts and non DHB investment into palliative care.

Provider	Contract 2004-05	Price	Volume (CWD)	Total Revenue
Primary Care Inpatient Services ^{Note 1}	M-179			
Waikato Community Hospice Trust	COPL0002	\$3,285	343.47	\$1,128,299
Tokoroa District & Community Hospice Trust	COPL0002	\$834	28.78	\$24,003
Waikato Acute Inpatient	M80001	\$2,887.74	347.00	1,002,046
Waikato Inter District Flow acute	M80001c	\$2,855.02	23	65,665
Waikato Outpatient Attendance FSA	M80004N	\$172.76	200	34,552
Waikato Outpatient Attendance Sub	M80004R	\$172.76	1000	172,760
Disability Support Link				\$445,307
Non Waikato DHB Contracts				
PHO	2004-05	Price	Volume (CWD)	Total Revenue
Waikato PHO	Palliative Care Free Home Visits			\$126,000
Network of General Practitioners (formerly First Health) who now belong to Waikato PHO				\$111,704
TOTAL				\$3,110,336

Data Source: Waikato DHB Planning and Funding service.

Note 1: total volumes and costs of primary inpatient palliative care services are unknown, an estimation of 5% has been used in planning.

Appendix 3 – S.W.O.T. Analysis

Strengths

- Committed and dedicated staff
- Overall good provider relationships
- Providers involved in national developments and initiatives, also links with Cancer Control Strategy taskforce
- Good infrastructure in urban areas
- Specialist Palliative Care Unit and hospital palliative care team established
- Specialist Palliative Care Unit provide outreach and when necessary home visits. The Palliative Care Physician works with the General Practitioner
- Collaborative Care model working well and expanding. Integration with Community services and Hospice Waikato
- The General Practice Palliative Care Home Visit Allowance Programme, positive support on evaluation
- Community willingness to donate funds
- Volunteers and community support
- Community donated equipment
- Waikato residents (98%) believe hospice palliative care services are good for the community and high support for home care (Hospice Waikato Research Programme Results, 2004)
- Hospices three top services rated in customer satisfaction were: home care, inpatient unit and 24 hour call service
- Access to specialist Palliative Care Physicians and Palliative Care Unit
- Paediatric Shared Care Model in place with Starship
- Establishment of the Paediatric medically fragile service
- Agewise Strategy

Weaknesses

Fragmentation

Providers and health professionals identified fragmentation of services as a key issue. Examples of fragmentation identified were:

- Uncertainty about services available by the various providers in the Waikato DHB
- Several different providers involved in palliative care, with no clear co-ordination resulting in fragmented care
- Lack of clarity around roles and expectations
- Poor planning and minimal integration between providers for service development
- Fragmentation of funding
- No clear co-ordination of care between providers
- Duplication of services
- Diverse patient information provided by the different providers
- Variations to the definition of palliative care between the providers
- People with palliative care needs do not fit neatly into either personal health or disability services. The current demarcation causes fragmentation along the patient continuum
- Other Clinical Streams Models of Care do not clearly identify palliative care as part of the patient continuum, or if it has, how the service integrates and co-ordinates patient and family / whānau care with palliative care services

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

Service Levels

- The collaborative care model does not cover the total Waikato DHB
- General Practice Palliative Care Visit model is not provided by all GP’s and is not available in Hamilton City
- Lack of health and support services in rural areas
 - out of hours GP team access
 - short term respite care
- Variability of access to GP community based beds across the Waikato DHB
- Variation in community care and support services across the Waikato DHB
- Insufficient community based hospice beds, currently have 4 beds
 - In 2004 require 10.35 palliative care beds¹⁶ and forecast 11 beds by 2011
 - Waikato DHB has 1.5 hospice community beds per 100,000 the recommended level is 4 per 100,000
 - if the scenario included the current 2 acute secondary palliative care beds based at Waikato Hospital were included then Waikato DHB would have 2.3 beds per 100,000
 - Health professionals and public view the need for a stand alone purpose built hospice with community inpatient beds. There are economy of scale inefficiencies with the projected bed requirements for a stand alone facility

Access to essential services

Service gaps and variations in different aspects of care have been identified through analysis of the essential components of service.

- Assessment
 - Multiple entry points, often duplication of referrals, information not always complete
 - Late referrals, often in crisis situation
 - Duplication in assessments
 - No standards / guidelines / tools
- Care co-ordination
 - Not identified
 - Roles and responsibilities not defined
 - Poor co-ordination links with and between palliative care services and non-malignant services
- Access to Specialist Palliative Care
 - Access to specialist palliative care services is limited due to the number of medical and nursing resources. Waikato DHB does not have a full team who can provide advice on a 24 hour, 7 day a week basis.
 - Waikato Hospital provides 24 hour, 7-day week medical on call acute service via the Oncology roster. In the future the current scenario of Oncologists covering palliative care service out of hours maybe seen as inadequate and inappropriate as Oncologists are not trained in palliative care. This service should continue until recruitment of adequate number of palliative care physicians that could sustain an acute on call roster, or

¹⁶Assumption: Waikato DHB 2004 population >15 years is 258,840. New Zealand Palliative Care Strategy recommend 4:100,000 (United Kingdom Palliative Care benchmarking recommend 5.1:100,000, Australian Palliative Care Planning Guide recommend 6.7:100,000)

development and training of GP's with an interest in palliative care that could contribute to a specialist / generalist medical palliative roster.

- Clinical care

Resthomes and continuing care facilities have a long history in providing generalist palliative care.

There are concerns that the delivery of quality palliative care may be impeded due to:

- Recruitment and retention of registered nurses, due to both supply and pay rates
- Physician and staff training, particularly in palliative care
- Client mix – the needs of the frail elderly and the palliative care client and their families. The use of an unqualified workforce in this industry means that supervision of staff may be compromised. The high care levels of some palliative care clients could lead to compromised care for the frail elderly
- Variable symptom management, due to availability/skill of medical support (usually GP)
- Variability of out of hours support by General Practice
- Lack of psychosocial support for patients, staff, and families
- Some resthomes and/or continuing care facilities may not have an appropriate palliative care focus, or the equipment required
- Funding for palliative care is currently at the contracted aged care rate. This funding is deemed inadequate to provide the level of care required by palliative care clients which is often more complex
- People under the age of 65 in this region are often admitted to an aged care facility for respite care. This is not always the most appropriate environment for this group of people.

Recognition of the palliative care requirements of people living in rural areas.

- Support services

- Difficulty accessing night relief support throughout the District. There is confusion and duplication of services, Hospice Waikato fund 4 days total (flexible on case by case basis) and DSL fund 2 days per week.
- Home care agencies with unregulated caregivers contribute to respite and support services by providing personal cares for patients and home help. There are national shortages of caregivers with associated issues regarding salary levels, recruitment and retention.

- Equipment

- The equipment management system and processes are fragmented
- Possible health and safety risk, e.g. maintenance and cleaning standards, replacement programmes
- Variability of access across the district
- Equipment owned and managed through multiple providers – Waikato DHB central store, Waikato Hospice and due to difficulties accessing equipment many communities have purchased equipment
- No database / asset management system for all equipment throughout the district
- Inadequate level of equipment e.g. electric beds, bed blocks, pillow raisers, wheelchairs, lazyboy's and hoists
- Incidences where patient and families have accessed equipment outside of the DHB

Lack of awareness of Palliative Care Approach

- The public are unsure of what palliative care means and services available within the Waikato DHB
- Variable understanding of services available by providers throughout the Waikato DHB
- Not all Waikato DHB Clinical Streams Models of Care include the development of a palliative care approach and integration along the continuum of care for patients and family / whānau. The Models of Care also need to consider the multidisciplinary team and consider how allied health will contribute to that team.

Forecasted growth

- Expansion of the palliative care definition and parameters
- Increasing and ageing population
- Change in the population's ethnicity mix with increasing Māori and Pacific Peoples
- Increase in the incidence of cancer
- Increase referrals for people with non-malignant diseases due to increased incidence and awareness of other services that recognise the value of palliative care support
- Increasing demand for inpatient consultation service

Workforce

- Some health professionals lack understanding about palliative care approach
- Inadequate levels of staff when benchmarked against the Australian Palliative Care Planning Guide, especially medical staff and allied health staff. Due to inadequate levels of staff identified there are gaps in the multidisciplinary team
- Recruitment and retention issues with staff, especially medical staff, nursing and allied health staff
- Inadequate levels of nursing staff with recognised post graduate qualifications. June 2005 specialist palliative care nurses with recognised palliative care qualifications was 53%. Specialist palliative care nurses and district nurses with recognised palliative care qualifications was 13%
- Inadequate GP training in palliative care
- Inadequate formalised education and training programmes for specialist and generalist palliative care providers
- Inadequate levels of Māori and Pacific representation in the palliative care workforce
- Unsure of training programmes for non-regulated care givers
- Some health professionals in rural Waikato feel isolated and lack support
- No formalised supervision programme
- Lack of audit and research due to demand on current resources.

Improving the quality of health services depends on adequate levels and availability of appropriate trained workforce. This includes an important group of volunteer workers. The national Cancer Control Taskforce (2003) has identified that there is a need to develop national guidelines on palliative care workforce requirements, to determine the appropriate number of multidisciplinary staff required for palliative care services. This needs to include workforce planning for Māori and Pacific as

there is a shortage within these provider groups. Māori health practitioners are 5% of the national health workforce (HWAC 2001).

Key issues for development of a sustainable workforce include:

- Staff levels to address the growing demand
- Staff recruitment and retention
- Underdevelopment of the multidisciplinary team approach
- Role of care co-ordination
- Training and development for undergraduate, graduate and post graduate health professionals, health care assistants, volunteers, carers and families / whānau
- Promotion of palliative care approach and services to general health professionals and providers
- Promotion of cultural learning
- Needs of palliative care workforce in rural areas
- Support and supervision

Investment into Service Development

- Scarce health financial resource to meet expectations of best practice
- Historically there has been limited access to funding to develop the palliative care service, which highlights the lack of focus in this area in the past. Most providers identified good working relationships between individuals rather than between providers, however this has also been tested at times
- Funding and planning needs to recognise and address increasing demand and requirements to work towards achievement of the New Zealand Palliative Care Strategy
- Multiple funding streams / sectors required to be used to access support services
- DSL currently manages the administration of funds to authorise payment for night carers and access to reshome facilities for respite care. This role is by default.
 - There are no guidelines and criteria for accessing this fund
 - DSL have expressed a preference not to administer this service
 - There is methodology to identify if the level of funding is appropriate
 - Perception that the level of funding is inadequate
 - Poor data collection, monitoring and evaluating of the service
- Waikato Community Hospice Trust level of funding from the DHB is approximately 50% and is seen as inadequate to meet needs and develop services
- Specialist Palliative Care Outpatient purchase units for first specialist attendance and follow-up need to be split. New purchase unit needs to be established for medical home visit.

Lack of quality standards / specification and performance indicators

- Information for patients and family / whānau is variable for each provider and is not integrated
- Inadequate and variable data collection
- Poor monitoring and evaluation of contract and services, monitoring is not integrated
- No integrated clinical standards / pathways / guidelines
 - No referral guidelines
 - Multiple assessments tools that are not shared between providers
 - Clinical plans are not integrated
 - No integrated end of life pathway
 - No criteria guidelines for access to support services

- No defined minimal data set and / or performance indicators

Cultural barriers

- Māori and Pacific People may not access palliative care services due to lack awareness of the existence of these services
- Lack of education and development with Māori and Pacific providers to raise awareness of the palliative care approach
- Lack of knowledge and understanding about Māori and Pacific Peoples culture among health professionals including beliefs in the area of providing care for those dying
- Acceptability of services, attitudes to services, cost to access services
- Under representation of Māori and Pacific health workforce within palliative care services

Paediatric

- Small patient numbers and issues with economy of scale for service provision across the Waikato DHB especially in rural areas
- Ability to recognise new entrants and the perception of competing community providers – Waikato Community Hospice Trust – Rainbow Place and True Colours
- Feedback that the various packages of respite care / support available from different intersect providers is not always equitable in terms of access across the District and the current packages are at times inflexible to meet the individual needs of the child and family
- No clear approach for transition of adolescents to adult specialist palliative care services

Opportunities

- Leadership
- Establish a Waikato DHB Palliative Care Network
- Appoint a Clinical Director, Specialist Palliative Care
- Medical staff within and / or integrated with Hospice Waikato
- Website directory of services to raise public and community awareness
- Promotion of palliative care philosophy with primary health teams, residential resthomes and specialist health services
- Single point of entry 24 hour 7 day access to support and advice
- More effective night relief and flexible support packages
- Continued development of care co-ordination role and responsibilities
- Workforce development and education
- Increase medical training positions, e.g. CTA funded FRACP positions
- Develop a suite of educational programmes for health professionals / providers
- Integrated clinical guidelines, standards, referrals, pathways and tools
- Development of Liverpool End of Life Pathway
- Build capacity and capability of Iwi and Pacific providers
- Education, support and increased integration with Resthomes
- Expand collaborative care model into cover the total rural Waikato – formal review and evaluation
- Improved data collection, establishment of minimal data set and key performance indicators
- More efficient equipment management systems

- Develop the role of Nurse Practitioner
- Technology as an enabler, i.e. integration of systems between primary – Hospice Waikato and Palliative Care Unit, electronic referral guidelines and tools, assessment tools, treatment plans, diagnostic results
- Improve contracting, specifications and monitoring and evaluation process

Threats

- New entrants resulting in duplication of services
- Increased quality expectations without infrastructure and resources to develop and support
- Frustration of health professionals due to competing health service demands and limited access to resources to develop palliative care services
- Recruitment and retention of workforce

Appendix 4 – Palliative Care Operations Network

Essential principles

- A formal collaborative arrangement using agreed terms of reference
- Goal orientated objectives and processes that leads to equity of access and improved quality of life outcomes of people covered by the palliative care framework
- Focus on the needs of patients and their families / whānau, as well as ensuring active involvement of all stakeholders
- Enhance relationships between providers through a partnership model, which enhances effectiveness through mutually beneficial relations, built on trust and complementary capacities. A partnership model between primary and community health care generalists and specialist palliative care teams will better meet the needs of patients and family / whanau
- Integration – combining systems and services previously segregated into one uniform system / identity
- Leadership that fosters an environment of clarity and unity of purpose, promotes participation and team building, ownership of the process, continuous learning, mutual recognition of efforts and contribution
- Working collaboratively to produce an environment for creating and sharing improvement ideas, to be innovative and test new models of delivering care and create learning for service improvement
- Systematic and integrated approach allowing the framework to build a comprehensive service with interrelated essential service components at different levels of care, sharing the same goals as well as providing transparency for service providers on decisions made
- Palliative care service planning will be incorporated into the wider Cancer Control planning process as well as Clinical Streams Models of Care.

Responsibilities

- To deliver on the goals of the Waikato DHB Palliative Care Strategy Plan which aims to achieve the national palliative care and cancer control strategies
- Implementation of the WDHB Palliative Care Strategy Plan strategic objectives/initiatives
- To focus on local service co-ordination and ensure provision of required specialist support
- Development of annual service delivery plans to include planning priorities which reduce inequities, promote service quality improvement, workforce development and education and training
- To monitor the implementation of the annual service delivery action plans
- To monitor and evaluate service provision including reporting of data to inform and shape future service development
- To ensure participation of all key stakeholders through a reference advisory group which takes account of the views of patients, families / whānau and / or carers
- To promote the development of collaboration and integration, including intersectoral linkages between services
- Effective and efficient communication links among health professionals / providers and with patients and carers
- To participate in national initiatives, and communicate developments.

Benefits of the Network

- Patient and family / whanau centric focused with a needs led approach, rather than a service orientated approach
- Improved patient family / whānau care and support – shared assessment and management plan, working to common standards
- Discontinue fragmentation of services and / or between providers
- Acknowledges multiple providers and multidisciplinary teams, maximises use of existing resources and builds on what we already have
- Defines local and specialist palliative care roles
- Integrated partnership approach at and between generalist and specialist palliative care teams
- Strengthen co-operation and collaboration between the partnership network with key roles in care co-ordination
- Efficiencies through managing through a systems approach (planning, evaluating and monitoring)
- Long term planning and co-ordinated service development – all providers working towards common strategic plan
- Build workforce capability and provider capacity and capability