He moana pukepuke, e ekengia e te waka
I know who to go to for support and information

Ma te huruhuru ka rere te manu
I am supported to stay independent and in charge of my care

He oranga ngākau, he pikinga waiora
I am treated with dignity and respect

Ko tōu reo, ko tōku reo, te tuakiri tangata. Tihei uriuri, tihei nakonako
I am confident that I will receive quality care and my wishes will be respected

Waiho i te toipoto, kaua i te toiroa
The people that I care about are supported now and after I am gone

MidCentral District Health Board

Palliative Care Strategic Plan

2012 – 2017

“How people die remains in the memory of those who live on”
Dame Cicely Saunders, founder of the Modern Hospice Movement
Mihi Maioha

E nga mana, e nga reo, e nga karangaranga maha o nga maata waka katoa,
Tēna koutou tēna koutou tēna tātou katoa.

Ko te mea tuatahi me mihi atu ki te kaihanga o ngā mea katoa.

E tangi tonu ana ki nga mate kua wheturangitia,
Hei tohu maumahara ki o rātou wawata, ki o rātou moemoea,
Kei te tangi tonu te ngakau mō ngā kanohi
Kua riro ki tua o Paerau haere,
Haere, haere! haere ki te po uriuri, te po tangotango, te po i kaore i otinga
Kaati! rātou ki a rātou; tātou ki a tātou!

He mihi nui ki te kaupapa nei i ahu mai o ngā matua tipuna
Kia poupou ko nga tikanga Māori ki roto i te ao kikokiko nei,
Hei awhina, hei tautoko, hei manaaki hei arataki ki tatu.

Ka mihi nui ki a koutou i kawe tēnei take kei runga i to pokohiwi
Koutou i tākoha mai ko ngā pitopito kōrero, ko ngā whakaaro rangatira,
Ko ngā wheako, ko ngā wawata tēna rawa koutou,
Ko te tumanako kia whakamanu tēnei tuhinga i o koutou mahi
Kia tu tangata, kia tu motuhaki, kia tu rangatira, kia whai mana
Kia pai te wairua me te mauri o nga whānau katoa o te ao kikokiko nei

Mauri tau, mauri tu, mauri ora
The Korowai represents the fundamental values of this Palliative Care Strategic Plan
Foreword

This Palliative Care Strategy, developed by the Arohanui Hospice for and on behalf of MidCentral District Health Board, provides clear direction for developing and improving palliative care and end of life care for our people. It builds on the success of the Palliative Care Partnership which has been operating in our district for several years, and extends that model of collaborative integration to include a broader scope of health care providers.

At the core of the Strategy is caring – care for our people when cure is no longer the prevailing focus, and care for their loved ones who are with them on this journey. This is symbolised by the korowai (as pictured on the front cover and page 3 of the document), the cloak of caring that should enfold our people at this time.

Our thanks go to Whaea Rawinia Cousins of Ngāti Toa Rangatira and Ngāti Raukawa who has generously gifted Te Korowai o Rongo (the cloak of Rongo, the guardian of peace and tranquillity) to MidCentral District Health Board as a gesture of faith in those who will carry this Strategy forward. Te Korowai o Rongo (featured on the front cover) embodies the caring and protection that is fundamental to a palliative approach. It also serves as a symbol of the harmony between and among MidCentral’s manawhenua (Ngāti Raukawa, Ngāti Kahungunu, Rangitaane, Muaūpoko) and the various providers of palliative care in our district.

The centrepiece of the Strategy is Korowai Care – a new service model that will mean more people can access palliative care in a wider variety of settings. This new service model will be supported by a network of service providers, all focused on ensuring that every aspect of care is ‘joined up’ so that patients and their families and whānau experience a seamless service.

The focus on improved integration is timely. The Minister of Health signalled early in 2012 that he expects District Health Boards to focus more strongly on service integration, ensuring the scope of activity is broadened and the pace significantly stepped up. This Strategy is one of the ways in which MidCentral is responding to that call to action.

There is still a great deal of work to be done to ensure that all people in our district face death surrounded by those they love, feeling safe, comfortable, and cared for, but this Strategy, and the work that flows from it will carry us a long way forward towards the attainment of that goal.

Murray Georgel
CEO MidCentral District Health Board

Clare Randall
CE Arohanui Hospice
“He aha te mea nui o te ao? māku e kī atu, he tangata, he tangata, he tangata”
“What is the most important thing in this world? and I will say to you, ‘tis people, ‘tis people, ‘tis people”
The strategy in summary

Overview

This MidCentral District Health Board (MDHB) Palliative Care Strategic Plan 2012-2017 is the first Strategic Framework for Palliative and End of Life Care for the MidCentral District. It provides a clear direction for developing and improving palliative care and end of life care services across the MidCentral district during the next five years 2012 – 2017.

Palliative care (from the Latin palliare, to cloak) is an area of healthcare that focuses on relieving and preventing the suffering of patients and has a fundamental place in the Treaty of Waitangi and the principles of Partnership, Participation and Protection. The name “Te Korowai O Rongo”, which has been taken to symbolise the Palliative Care Strategy and future integrated service model, refers to the concept of a cloak for protection, love, peace and harmony and is representative of the role and services provided by the organisations in partnership with Iwi.

He Korowai O Rongo translated:

“the cloak of Rongo the guardian of peace and tranquility”.

This Palliative Care Strategic Plan symbolises the protective cloak and mana o te tangata – the cloak that embraces, develops and nurtures the people physically and spiritually. In the weaving, or raranga, of a korowai there are strands called whenu or aho. In the strategy these represent all the different people who work together to support people with end of life and palliative care needs – including whānau, hapū and iwi, the health professionals, community workers, providers and hospitals.

Vision

Our vision for the District is:

“All people with life limiting conditions live well and die well irrespective of their condition or care setting”

The vision and goals presented to achieve this vision are grounded in the priorities of the Ministry of Health regarding improving patient experience through Better, Sooner, More Convenient (palliative) care in our district. The plan is evidence-based to lead and validate the planning and delivery of palliative care services including paediatric palliative care services.

The table below shows, in broad-brush terms, some of the differences between the current arrangements and the future vision.

<table>
<thead>
<tr>
<th>Current</th>
<th>New</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative care services have developed in an ad hoc nature driven by local need</td>
<td>Services designed and developed in an integrated model with a district wide and best practice focus</td>
</tr>
<tr>
<td>Access to services varies across the district</td>
<td>District wide consistency of service</td>
</tr>
<tr>
<td>Health sector focus</td>
<td>Patient, family and whānau focus</td>
</tr>
<tr>
<td>Individual provider focus</td>
<td>Integrated service focus</td>
</tr>
<tr>
<td>Isolated pockets of information and technology</td>
<td>Integrated technology and information where it is needed</td>
</tr>
<tr>
<td>Activities such as research and education driven by local need and funding</td>
<td>Funding model that supports the strategy’s goal of an integrative model of care</td>
</tr>
<tr>
<td>Workforce lacking formal coordination</td>
<td>Coordinated and effective workforce</td>
</tr>
</tbody>
</table>
**Strategic Goals**

The following core goals, developed during the extensive engagement process, were identified as priorities that would inform the future Palliative Care services model.

1. The patient experience will be at the centre of service design.
2. Support will be available and accessible for family and whānau.
3. An integrated model of palliative care, Korowai Care, will be developed for all people in the district.
4. The workforce (paid and unpaid) will be developed and sustained with the required competencies, resource and flexibility to respond to service and health care demand.
5. A sustainable system of clinical governance and leadership will be implemented.

Each of the goals will be achieved adhering to the following principles:

- Ngā kaupapa tuku iho
- Family/whānau opportunity
- Best family/whānau outcomes
- Coherent service delivery
- Whānau integrity
- Effective resourcing
- Empowerment
- Competent and innovative service provision

Vision must be partnered by action and the following two key objectives (expanded in the next section) have been identified to move forwards:

- Development of a Palliative Care Network to provide clinical governance and leadership
- Development and implementation of an integrated model of Palliative Care – ‘Korowai Care’

**Development of a Palliative Care Network to Provide Clinical Governance and Leadership**

To ensure the plan commences with appropriate oversight and resources a Palliative Care Network (PCN) based on the combined strengths of Arohanui Hospice, the Hospital Palliative Care Team, the Cancer and Palliative Care District Group, Central PHO and the Integrated Palliative Care Governance Group will be formed.

PCN will deliver the leadership to drive activity that:

- Steers the development of the Palliative Care Strategy implementation plan across the sector that is aligned with the MDHB Palliative Care Strategic Plan.
- Ensures all Palliative Care Clinical Governance Groups/Networks be merged into one or have formal links established via memorandum of understanding.

Representation will be sourced from within:

- Specialist Palliative Care
- Child Health
- Primary Care

The following diagram was developed to pictorially demonstrate the strategy and pathway to achieving the future vision.
Aged Care including Residential Care
Māori Health
District Nursing
Central Primary Care Organisation (CPHO)
Planning and Support (MDHB)
Pharmacy
Education and Research
Consumer representative/s

The PCN will be resourced to effectively drive the initiatives outlined in the plan by the following positions. It is expected that adequate resourcing will be given.

- **Project Manager** 0.5 FTE
- **Programme Clinician** 0.4 FTE

The Project Manager will:

- Drive the development of the implementation plan across the sector.
- Work on models and clinical pathways to support an integrated *Framework* and key action plans.
- Support a review of palliative care clinical tools/pathways and outcome measures linked to the Strategic Plan outcomes.
- Engage with Māori Health and Kaumātua towards the development of the Korowai Model for Palliative Care aligning with Whānau Ora.
- Develop clinical tools across the district including referral, needs assessment, triage, access pathways to 24/7 support/emergency and specialist palliative care.
- Develop a feasibility study to develop a Patient Experience Programme for palliative care.
- Support and integrate ACP and GSF and LCP into new service models.

The Programme Clinician/s will:

- Undertake relationship building and partnership across key provider groups including consumers.
- Develop intersectoral liaison and alignment of palliative care services.

- Lead the development and evaluation of the strategic and implementation plans.

### Next steps | Timeframe
--- | ---
Establish the PCN through an appropriate representational process. This includes establishing a terms of reference for the PCN | Q2 2012/13
Identify and secure funding for the two identified positions. Recruitment process to be part of the strategy development tasks | Q2 2012/13

**Development and Implementation of an Integrated Model of Palliative Care – ‘Korowai Care’**

In the context of Health Care and more specifically Palliative Care, what in fact is integration?

‘Integration is a coherent set of methods and models on the funding, administrative, organisational, service delivery and clinical levels designed to create connectivity, alignment and collaboration within and between the cure and care sectors. The goal of these methods and models is to enhance quality of care and quality of life, consumer satisfaction and system efficiency for patients with complex, long term problems cutting across multiple services, providers and settings. The result of such multipronged efforts to promote integration for the benefit of these special client groups is called ‘integrated care’.  

*Kodner and Spreeuwenberg (2002)*

Through integration, improved patient outcomes will be a key priority of the Korowai Care model. Through the incorporation of the principles of Whānau Ora in each integrative process, whānau-centred initiatives will be fully integrated and supported. With the patient and whānau-centred focus, the Korowai Care service design will model excellence in terms of partnership between services and delivering services that promote a seamless continuum of palliative care.

The Korowai Care integration model identifies six types of integration. Each type of integration is enabled through a range of integrative processes, some of which focus on systems and structures; others on less tangible aspects such as professional behaviour and teamwork.
The functions of services to support an integrated palliative care approach will be determined and will be informed by a focus on understanding the patient experience in palliative care. The existing Palliative Care Partnership model has enabled integration between primary care and palliative care services across the district and building on this model and expanding it across services will achieve further integration – which practically may be achieved through better collaboration and formalising agreed ways of doing things.

Further integration through the PCN will:

- create a drive for clinical governance which is in touch with District wide sector activities
- reduce the chance of specialist bias
- maximise opportunities to deploy the MDHB Palliative Care Strategy
- create shared leadership in palliative care across the District
- oversee the funding model for palliative care District wide

Next steps

<table>
<thead>
<tr>
<th>Timeframe</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1 2012/13</td>
<td>Develop a project terms of reference and secure the appropriate resources to build on the existing work and create an integrated model of palliative care</td>
</tr>
<tr>
<td>On-going</td>
<td>During the project ensure a focus is maintained on identifying and implementing quick wins</td>
</tr>
</tbody>
</table>

Implementing the Strategy

The achievement of the future vision for Palliative Care will clearly involve a period of change over the next five years. In implementing the strategy there are a number of important principles for ensuring a stable and constructive transition:

- In the first instance, protect the gains already made and relationships developed during the development of the strategy. The future vision will only be able to be delivered if the district acts as a coordinated whole.
- During the development of the Korowai model involve, discuss and collaborate with the Palliative Care sector, providers and communities.
- Focus on stepwise, evolutionary, change which is progressively consistent with national, regional and local solutions.

The two key objectives outlined in this summary provide a focus for activity in the coming months and in particular the development of the Integrated Model for Palliative Care – Korowai Care is the key aspect for delivering the future vision this strategy is focused on. The Korowai Care model, once accepted, will direct resources and investment and so its importance cannot be stressed enough. It provides the district with an opportunity to significantly improve Palliative Care services over both the short and long term.
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“All people with life limiting conditions live well and die well irrespective of their condition or care setting”.

The District Vision
1 Introduction

1.1 The Facts

- New Zealand continues to be a death-denying society. Although people are more aware of hospice and palliative care services, they still do not see dying as an integral part of life. The focus of the health care system continues to be on keeping people alive, rather than on the quality of their living and dying.

- There is still a great deal of work to be done – at the local and regional levels – to ensure that all people in the District “face death surrounded by those [they] love, feeling safe, comfortable and cared for”.

- To ensure that all people in the District have access to quality palliative care we must work to change attitudes towards death and dying. This strategic plan will address this issue.

- Evidence on the impact and cost effectiveness of palliative care is lacking in the MidCentral District. Work needs to occur to measure the impact, outcomes and cost-effectiveness of palliative care services – including bereavement services – across the District.

1.2 Defining Palliative Care

“Palliative Care is taking the bumps out of an uncomfortable journey. It is more than just the end of life…..”

Hospice Patient and Consumer, 2012

The term ‘palliative care’ comes from the Latin word ‘palliare’, to cloak. It is any form of medical care or treatment that concentrates on reducing the severity of disease symptoms, rather than striving to halt, delay, or reverse progression of the disease itself or provide a cure.

The World Health Organisation defines palliative care as...

...an approach that improves the quality of life of patients and their families facing the problems associated with life limiting or life threatening conditions, 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 implies both a philosophy of caring for a patient and his or her family and the provision of palliative care services as such. It spans the period from the diagnosis of advanced disease until the end of bereavement. Palliative care should be offered as needs develop and before they become unmanageable and not seen as something that only specialised palliative care teams or hospices offer when other treatment has been withdrawn. It is an integral part of care and should take place in a variety of settings.

1.3 Methodology

This Palliative Care Strategy was developed using a participatory process including workshops and hui with stakeholders using the Health Co-design Framework. The engagement process focused on a shared understanding and improving patients’ experiences of services as well as the services themselves.

The data for informing this strategic plan were derived from a variety of sources including document review, a survey of stakeholders, focus groups with service providers across district areas, focus groups with consumers, a Māori hui, and key-informant interviews with the Ministry of Health, the Palliative Care Council, Hospice New Zealand, Hospital Palliative Care New Zealand and Palliative Care Nurses New Zealand.

This process enabled patients, family members, kaumātua, volunteers, allied health, spiritual care and pastoral services, administrators, nurses, physicians and community leaders to play a significant role in the creation of priorities for the Strategy. The results (reproduced in Appendix 1) show that stakeholders share a similar set of goals directed towards the improvement of palliative care in MidCentral’s district.

The process used means that this strategy’s key objectives have been informed from the core grass roots (bottom up approach), yet informed also by a strong steering group (top down approach)
which leads to a realistic and achievable Framework for the district.

The core values critical to the development of this Strategy were:

- Transparency and openness
- A focus on outcomes
- A focus on the patient experience to promote empowerment, choice and equity
- Clinical effectiveness and quality
- Acknowledgement of the distinctive values and roles of all service providers
- A focus on increased integration and cross-sectoral workings to enable services to consider how they can respond to the complex palliative care needs of the district, which often cannot be compartmentalised
- Sustainable development that meets the needs of patients and family or whānau without compromising the ability of future services

A Project Manager (independent consultant) was employed over a four month period to develop this Strategy. Oversight was provided by the MidCentral Palliative Care Strategic Steering Group, chaired by Arohanui Hospice.

The group’s representation included General Practitioners, Paediatric Services, the District Nursing Service, Pharmacy, Aged Residential Care, Māori Health, MidCentral Health Funding and Planning, Compass Health, Hospital Palliative Care, Arohanui Hospice and importantly, consumer representation. All have committed to the delivery of the Framework. A full list of stakeholders can be found in Appendix 2.

1.4 Our Vision – Te Aho

‘All people with life limiting conditions live well and die well irrespective of their condition or care setting’

The vision articulated above was developed during the stakeholder engagement process and the wording used was agreed by the consumers’ engagement group.

Our Mission Drivers

- To increase the understanding of palliative and end of life care in our community
- To ensure that all palliative and end of life care is planned around the specific needs of the individual and/or whānau and is responsive to their expressed preferences
- To ensure that best and appropriate care is supported by responsive and competent palliative care services
- To ensure that timely information and choice are available for individuals and their whānau
- To ensure that patients and whānau receive coordinated care, support and continuity
2 Population profile and expected demand for services

MidCentral District Health Board has responsibility for the populations of Palmerston North City, Manawatu District, Tararua District, Horowhenua District, and the Otaki Ward of the Kapiti District.

The main causes of mortality for the population of MidCentral are diseases of the circulatory system, cancers, respiratory disease, injuries and accidents and metabolic causes (which includes diabetes). Within this general picture, deaths due to cancer are rising, while deaths due to ischaemic heart disease and stroke are declining. This is in keeping with the trends in mortality data for the population of New Zealand4.

MidCentral's population is slowly increasing, and its structure is aging – with each passing year an increasing proportion of the population accumulates in the older adult groupings. The distribution of people aged 65 and over is not uniform across the district. It is higher in Horowhenua and Otaki. The percentages at the 2006 Census were: Horowhenua, 20.0%; MidCentral portion of Kapiti (Otaki and surrounds ), 20.2%; MidCentral overall, 14.1%; and New Zealand, 12.3%5.

MidCentral has a greater proportion of people living in areas with higher scores for socio-economic deprivation compared to New Zealand. Within MidCentral, Horowhenua and Otaki have greater proportions of their populations living in areas with higher NZDep 2006 scores (areas with greater socio-economic deprivation) compared to other areas within MidCentral’s catchment. There is some evidence showing that providing palliative care for people in deprived areas required greater resources than in more affluent areas6.

MidCentral District Health Board has a higher proportion of Māori residents compared to New Zealand (MidCentral 17.3%; New Zealand 14.7% at the 2006 census). Mortality data is used as a general marker of health status – as health status improves, mortality rates fall. The age adjusted mortality rates for Māori in MidCentral are consistently higher than for non Māori7.

Health Workforce New Zealand has developed a model for projecting the number of potential palliative care patients in future years. The model assumes that 90% of people with cancer and 40% of people with chronic disease will require some level of palliative care. Applying the model to MidCentral's population yields an estimate of 758 adult deaths in 2016 and 798 adult deaths in 2026 for which palliative care is likely to be needed. These projections for MidCentral are compared to projections for the New Zealand population in Table 1, below.

### Table 1. Number of Adults Likely to Benefit from Palliative Care

<table>
<thead>
<tr>
<th></th>
<th>2006</th>
<th>2016</th>
<th>2026</th>
<th>% increase between 2006 and 2026</th>
</tr>
</thead>
<tbody>
<tr>
<td>MidCentral DHB</td>
<td>691</td>
<td>758</td>
<td>798</td>
<td>15.5%</td>
</tr>
<tr>
<td>New Zealand</td>
<td>15,452</td>
<td>17,550</td>
<td>19,076</td>
<td>23.5%</td>
</tr>
</tbody>
</table>


---

The plan provides a clear direction for developing and improving palliative care and end of life services across the districts of Horowhenua, Tararua and Manawatu, during the five years 2012 to 2017.

The number of deaths across New Zealand is projected to increase steadily up until 2025, but thereafter to increase rapidly until 2045, and then start to slow down. This is mainly due to the effect of the aging baby boomers (those born during 1945-1965).

MidCentral DHB can expect steady growth in demand for palliative care services up until 2025, followed by a rapid expansion in demand for the years between 2025 and 2045. Particular care should be taken to ensure the needs of Horowhenua and Otaki are adequately catered for, given the higher proportion of older adults and the higher proportion of areas with high deprivation in these locations.

---

8 Ministry of Health. Palliative Care Workforce Service Review.
3 Health sector context

This Palliative Care Strategy needs to deliver within the wider health sector context. The guiding context provided by key organisations, documents, and concepts is summarised in the sections below.

3.1 The World Health Organisation

The World Health Organisation (WHO) proposes that all countries, rich or poor, that implement palliative care with a public health approach, need to integrate the services at all levels of care in order to ensure accessibility to the whole target population9.

3.2 The Ministry of Health

The New Zealand Palliative Care Strategy has a five to ten year vision. To support this vision, nine further sub-strategies were developed with the aim of building a palliative care culture.

These are:

- Ensure access to essential palliative care services
- Each District Health Board to have at least one local palliative care service
- Develop specialist palliative care services
- Implement hospital palliative care teams
- Develop quality requirements for palliative care services
- Inform the public about palliative care services
- Develop the palliative care workforce and training
- Ensure that recommendations from the Paediatric Review are implemented
- Address issues of income support

3.3 System Wide Government Objectives

In his Letter of Expectations to District Health Boards10 2012/2013, the Minister of Health outlines the priorities that the Government expects to achieve to deliver better, sooner, more convenient care, to lift health outcomes for patients. District Health Boards have been urged to focus more strongly on service integration particularly within primary care; ensuring the scope of activity is broadened and the pace significantly stepped up.

The Government objectives include:

- Improved patient experience – Better, Sooner, More Convenient
- Shifting services from hospital settings to primary care, delivering more care within existing resources
- Reducing demand for hospital capital investment

3.4 Regional Service Plan

The six District Health Boards in the central region (MidCentral, Capital & Coast, Hawke’s Bay, Hutt Valley, Wairarapa, and Whanganui) have developed a Regional Service Plan which will achieve the Government’s goals for their communities. The collective aim is outlined below.

There will be a regionally co-ordinated system of health service planning and delivery that will lead to ongoing improvements in the sustainability, quality, and accessibility of clinical services11.

The Regional Service Plan proposes a new model, which recognises home and community as the preferred place for the provision of most clinical care. It argues for stronger community-based services and primary care that meets a wide range of health needs without resorting to hospital care. Hospitals will then be freed up to focus on the provision of more complex care.

---


11 Central Region District Health Boards (2011) Regional Clinical Services Plan: working together for our region’s future health. Central Region District Health Boards.
3.5 Resource and Capability Framework for Integrated Adult Palliative Care Services

The Resource and Capability Framework for Adult Integrated Adult Palliative Care Services (The Framework) 2012 (consultation draft) produced by the Ministry of Health is intended to inform the completion of the final specialist palliative care service specifications. The Framework was commissioned to provide planners and funders, and providers, with guidance on the resource and capability requirements of palliative care services in New Zealand.

The Framework describes the levels of care and staffing resources appropriate for New Zealand and supports the delivery of accessible, equitable, and high quality palliative care services for all New Zealanders. It describes a structured approach to integrated palliative care services that differentiates levels of service to support more consistent access to and purchasing of palliative care services across the country. The Framework makes the following recommendations:

That the palliative care sector:

- adopts the Framework
- adopts a national standards and accreditation programme for palliative care across settings and providers
- adopts national guidelines for evidence-based symptom management to reduce duplication and resources required for review

That District Health Boards:

- take into account population palliative care need during regional clinical service planning
- use the Framework to inform planning and strategic development of palliative care services
- implement care pathways (e.g., Liverpool Care of the Dying Pathway)

The Framework supports an episodic need for specialist palliative care, based on the concept that, for many people, the need for palliative care can be appropriately met by their existing primary palliative care provider. Research on levels of patient need identifies three groups of patients, as illustrated in Figure 1, below.

Group A, the largest group, comprises patients whose needs are met through the support of primary palliative care providers and who do not need access to specialist care. Patients in Group B may require episodic access to specialist services, but will continue to have their care managed by their primary palliative care provider. The smallest group is Group C. The needs of these patients are complex and do not respond to standard palliative clinical practice guidelines. Group C patients are likely to require ongoing care by specialist services.

Figure 1. Levels of Need for Palliative Care

Source: Palliative Care Australia by the Ministry of Health

3.6 Specialist Palliative Care Service Specification

The current service specification for palliative care is not considered relevant for those District Health Board areas where all the components of the services described in the specification are provided by the local hospice under a separate contract.

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A review of palliative care service specifications was a key component of the continued implementation of the New Zealand Palliative Care Strategy\textsuperscript{14}, which specifically directs that a specialist palliative care service specification (tier two) be developed (Strategy 3). The recently published Resource and Capability Framework for Integrated Palliative Care, outlined in the section above, is intended to inform the completion of the final specialist palliative care service specification.

### 3.7 Palliative Care Council of New Zealand’s Service Model

The Palliative Care Council was established in 2008 by Cancer Control New Zealand (CCNZ) to provide independent and expert advice to the Minister of Health, and to report on New Zealand’s performance in providing palliative and end of life care. CCNZ recognises that palliative care is an essential part of the cancer continuum, and that it encompasses people with a non-cancer as well as a cancer diagnosis. The Palliative Care Council promotes a patient centred, integrated model of care delivery, as outlined in Figure 2, below.

**Figure 2.** The Palliative Care System as Outlined by the Palliative Care Council of New Zealand.

### 3.8 Primary Palliative Care Services

The New Zealand Palliative Care Glossary (2012)\textsuperscript{15} promotes the use of the term ‘primary palliative care’ as a replacement for ‘generalist palliative care’. The Glossary’s definition of ‘primary palliative care services’ is reproduced below.

Primary palliative care is provided by all individuals and organisations that deliver palliative care as a component of their service, but their substantive work is not in the care of people who are dying. It is palliative care provided for those affected by a life-limiting or life-threatening condition as an integral part of standard clinical practice by any healthcare professional who is not part of a specialist palliative care team.

In the context of end of life care, a primary palliative care provider is the principal medical, nursing or allied health professional who undertakes an ongoing role in the care of patients with a life-limiting or life-threatening condition. A primary palliative care provider may have a broad health focus or be specialised in a particular field of medicine. Care is provided in the community by general practice teams, Māori health providers, allied health teams, district nurses, and residential care staff etc. Care is provided in hospitals by general ward staff, as well as disease specific teams – for instance oncology, respiratory, renal and cardiac teams.

Primary palliative care providers assess and refer patients to specialist palliative care services when the patient’s needs exceed their service’s capability.

Quality care at the end of life is realised when strong networks exist between specialist palliative care providers, primary palliative care providers, support care providers and the community – working together to meet the needs of all people.

### 3.9 The Liverpool Care Pathway

The Liverpool Care Pathway (LCP) is an evidence-based, integrated care pathway developed in the UK to transfer the hospice model of care into other care settings. The LCP guides health care professionals to deliver best practice care to dying patients and their families/whānau in the last days and hours of life, irrespective of diagnosis or care setting. This programme has been implemented into hospitals, residential care facilities, in the individual’s own home and into hospices in New Zealand. The LCP


\textsuperscript{15} Palliative Care Council of New Zealand, Hospice New Zealand & Ministry of Health. (2012). New Zealand Palliative Care Glossary.
is recognised by the Ministry of Health as a best practice model for care of the dying. A recent report published in the *Journal of Palliative Medicine*\(^\text{16}\) suggests that within acute settings staff perceive that the LCP improves end of life care overall, assists interdisciplinary communication around death and dying, and is a useful tool to positively influence decision making and care delivery. Further research into aspects of staff communication, diagnosing dying, changing direction of care, and the physical environment is warranted.

A further recent publication\(^\text{17}\) affirms that LCP supports and improves the overall framework of care in the aged residential care (ARC) setting and that it promotes consistent, proactive care. The study noted that implementation of the LCP facilitates teamwork and communication and that it can help overcome some of the obstacles to providing timely and informed end of life care to ARC residents. It recommends that the ARC sector should be supported by specialist palliative care in meeting the needs of people dying in their ‘home’.

### 3.10 The Changing Model of Palliative Care for Adults

In New Zealand, the vision of The New Zealand Palliative Care Strategy\(^\text{18}\) is that “All people who are dying and their family/whānau who could benefit from palliative care services have timely access to quality palliative care”.

Traditionally, palliative care has focused on the needs of patients and their families at the end of life, but it has mostly been offered to cancer patients during the last few weeks of life — when no other treatments are beneficial — and can be delivered only by specialist services. In fact, people and their families experience many problems throughout the many years of an illness and need help at the time and not at an easily definable point just before death. The concept of offering palliative care only at the end of life clearly not does fit many common situations, whereby people need palliative care after diagnosis and continue to benefit from treatments that alter the progress of disease until the end of life. New concepts of palliative care try to match the service more closely to what is understood about the course of the illness, as shown in Figure 3, below.

*Figure 3. Appropriate care near the end of life from disease modifying to active palliation*\(^\text{19}\)

![Figure 3](image)

This new model of care starts at diagnosis of a life-limiting illness and gradually increases while disease-modifying care may decrease. The model can be applied to all people with a progressive illness including organ failure and frailty. As illness progresses people can be considered for a palliative approach. The concept of palliative care as an intervention that can be offered alongside potentially curative treatment requires development to meet the needs of ageing populations.

Provision of palliative care should be triggered not by diagnosis, or even prognosis, but according to need, as it complements specific approaches aimed at influencing the course of the main illness. As an illness progresses, the importance of specific approaches diminishes, while palliative care becomes increasingly important.

Emerging needs over the last decade of people living with serious chronic illnesses, together with new evidence for the effectiveness of palliative care, mean it must now be offered more widely and integrated more broadly across health care services\(^\text{20}\).

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\(\text{17} \) Clark J.B., Sheward K., Marshall B., and Allan S.G. (2012). Staff Perceptions of the impact of the Liverpool Care Pathway in the aged residential care in New Zealand. *International Journal of Palliative Nursing* 2012 Vol 18 No 4


3.11 Palliative Care for Children

Palliative care for children is considered a similar but separate area of practice, as children and young people with life-limiting conditions present different challenges, and their families may have different needs. The New Zealand Paediatric Palliative Care Group endorses the definition of palliative care appropriate for children and their families developed by the UK based Association for Children's Palliative Care. This definition is reproduced below. (Note: The Association for Children's Palliative Care has recently merged with Children's Hospices UK to form a new organisation: Together for Short Lives.)

Palliative care for children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of quality of life for the child/young person and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

Principles of palliative care for children include:

- Beginning when illness is diagnosed and continuing regardless of whether or not a child receives treatment directed at the disease
- Evaluating and alleviating a child’s physical, psychological and social distress
- 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
- Being provided in tertiary care facilities, in community health centres and in children’s homes

Guidance for Integrated Paediatric Palliative Care Services in New Zealand was released by the Ministry of Health in November 2011. This work was commissioned by the Ministry of Health in response to the national review of paediatric sub-specialty programmes (Ministry of Health 2010). The review noted, outside of the Auckland region, paediatric palliative care services are not fully coordinated or sufficiently specialised and generally provide no access to specialist care. Many families of children with palliative care needs have no access to specialist care services, and rely on local primary health care, community services and non-government organisations (NGOs).

This Guidance document proposes a service delivery system that is implemented at minimal extra cost, builds on existing resources and utilises clinical networks and collaborative approaches to create a coherent structure that is nationally led and coordinated, but enables local District Health Board development and ownership.

Further, the document proposes a national Framework with the Starship Paediatric Palliative Care Team as the national specialist service. In each DHB, nurse coordinators and lead paediatricians would lead service development, and link local providers with the national specialist service.

3.12 Palliative Care for Māori

Whakatauaki – He toa taumata rau
‘Bravery has many resting places’

The Māori view of health emphasises the multiple contributing elements which influence health and well-being. For example, Sir Mason Durie’s Te Whare Tapa Whā model symbolises four dimensions of health that are important to Māori: taha wairua (the spiritual elements), taha hinengaro (thoughts and feelings), taha tinana (the physical elements) and taha whānau (the family).

The importance of whānau as a contributing influence to health and well-being was a driver for the introduction of a new approach to service delivery, Whānau Ora, to a number of sites throughout New Zealand in 2010. Whānau Ora is a whānau-centric model of service integration. It empowers whānau as a whole rather than focusing separately on individual whānau members. Typically, a kaiarahi, or navigator will work with whānau to identify the aspirations and outcomes they seek, develop an outcomes focused plan to achieve them, and broker their access to a range of services. There are six navigators employed by Māori /iwi providers across MidCentral’s district (three in Palmerston North, two in Horowhenua/Otaki, and one in Dannevirke).

The Whānau Ora model of integration has relevance to palliative care for Māori as it focuses on the whole whānau (the main support structure for many Māori at who are dying), and brings
together services that whānau may have had difficulty accessing without the aid of a navigator.

Many Māori prefer to die at home nursed and cared for by their whānau. The Ministry of Health Palliative Care Strategy identifies providing palliative care at home as a key feature of palliative care services for Māori. It follows that general practice has an important role to play in meeting Māori palliative care needs. The preference for dying at home (shared by both Māori and non Māori) is often overlooked in service design.

The following issues affecting access to palliative care services for Māori have been identified by the Māori Palliative Care Strategy Working Party and the National Health Committee:

1. Māori may not access palliative care services because they are not aware of the existence of these services.
2. There is a lack of Māori palliative care providers and a lack of palliative care education amongst current Māori providers.
3. There is a lack of understanding by mainstream providers of the whānau model of health and illness. Clinicians in both hospices and hospitals do not always work with the wider whānau or Māori providers when coordinating care, yet the whānau is the main support for the Māori person who is dying.
4. Some Māori choose to use traditional healing practices during the palliative phase of illness.
5. There may be limited connections to whānau support or marae for some urban Māori.

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Minister of Health (2001); National Health Committee (1999).
4 Current palliative care services in MidCentral DHB

4.1 The Palliative Care Partnership

The Palliative Care Partnership is a model developed and pioneered by MidCentral District Health Board in 2004 where funding was provided (a three year pilot) to enhance and promote integration of palliative care in the primary sector. The initiative at the time was ground-breaking and was led through quality coordinated health care services, using both specialist services (Arohanui Hospice) and generalist services, with support from the management services organisation Compass Health Ltd. Care is delivered by a partnership between palliative care coordinators (augmented by specialist hospice clinicians), general practitioners, practice nurses, and supported by community district nurses.

The aims of the Palliative Care Partnership are:

- To enhance access to palliative care for patients and families.
- To increase knowledge of palliative care within General Practice Teams.
- To build a supportive partnership between Community Palliative Care and Arohanui Hospice.
- To maximise the use of Specialist Palliative Care.
- To reduce cost as a barrier to access to Community Palliative Care.

Mandatory clinician induction, education using clinical pathways plus a written reference manual are prerequisite elements of the Palliative Care Partnership, in addition to a community reference group and a joint management team representing Arohanui Hospice, Central PHO and MidCentral District Health Board. Currently, 95% of medical practices in the district are registered on the programme with 85% of GPs registered as members of the programme. This ensured 393 patients were registered on the programme, almost 70% of the Arohanui Hospice patients, during 2011.

The core values of the Palliative Care Partnership are about the relationships. The trust, respect and mutual understanding created in the District through the Palliative Care Partnership will be the flagship moving forward.

An external evaluation of the Palliative Care Partnership occurred in 2006. The study used a mixed method approach including in-depth, semi-structured interviews with a purposeful sample of stakeholders and analysis of routinely collected data. All stakeholders reported favourably on the model of care.

The study concluded that the Palliative Care Partnership is an effective model of funded palliative care in primary care. It utilises the enhanced skills of primary and specialist clinicians to provide cost effective palliative care and is a model worthy of replication nationally and internationally.

4.2 Arohanui Hospice

Arohanui Hospice began as the Palmerston North Christian Home Trust in the mid seventies, and developed into the Palmerston North Hospice Service Trust in 1985. Arohanui Hospice opened in 1991 and now has overall responsibility to provide specialist palliative care services to people throughout the Manawatu, Tararua, Horowhenua and Rangitikei. The Hospice is governed by a Board of Trustees, which is made up of 10 community representatives.

The services provided by Arohanui Hospice include support of the patient in the community, inpatient care, respite care, a 24-hour telephone advice service seven days a week, outpatient clinics, medical and nursing services, clinical pharmacy services, day procedures, an activities-based day programme, social work services, family support, pastoral support and bereavement support. Service data are provided in Appendix 3.

Arohanui Hospice aims, where possible, to enable patients to continue to live at home. The team of specialist palliative

Emergency Department, Ambulatory Care, Medical Oncology Day Ward, and Radiation Oncology outpatients.

Referral patterns for the last decade have shown that 70% of referrals are for malignant diagnosis, with the majority received from general medicine. A relatively small proportion of people referred die in hospital, with the majority referred to the Arohanui Hospice service. A small number of people are seen as inpatients from partner DHBs in the Regional Cancer Treatment Service per annum. Data on referrals to the Hospital Palliative Care Team are provided in Appendix 4.

In addition to an advisory clinical service to the principal care team, the Hospital Palliative Care Team provides informal and targeted education for nursing and medical staff, participates in policy development, engages in relevant audit/research related activities, and provides a continuum of care with Arohanui Hospice.

Arohanui Hospice services support the delivery of palliative care in the community and hospital through the Palliative Care Partnership Programme. The Hospice provides education, training, specialist advice, and support. This includes doctors in training, junior doctors, general practitioners, rest home and aged residential care staff, undergraduate and post graduate nurses as well as district nurses working in the community, social workers and therapists.

Future service development using an integrated model of care will be a key enabler, increasing access to palliative care wider than Primary Care to include Aged Residential Care and Hospital Services and widening the scope of palliative care in the sector.

Arohanui Hospice leads the development of core manuals and systems to support a consistent approach based on evidenced based practice. The Education and Research unit at Arohanui Hospice has a sustainability programme in place for the Liverpool Care Pathway now that their three year implementation programme is complete. The service is actively involved in leading the integration of Hospice New Zealand Fundamentals of Palliative Care education programme in aged residential care and the development of Advance Care Planning and the Gold Standards Framework models of care in the District.

4.3 The Hospital Palliative Care Team

Hospital Palliative Care is an established and valued component of the MidCentral Health spectrum of services. The Hospital Palliative Care Team (HPCT), based in the Regional Cancer Treatment Service, supports generalist colleagues to address specialist palliative care need within Palmerston North Hospital. The service is demand driven, receiving clinical referrals for adult inpatients from adult services, including Intensive Care Unit, Coronary Care Unit, medical services, surgical services, elder health, Regional Cancer Treatment Service, and occasionally Emergency Department, Ambulatory Care, Medical Oncology Day Ward, and Radiation Oncology outpatients.

Referral patterns for the last decade have shown that 70% of referrals are for malignant diagnosis, with the majority received from general medicine. A relatively small proportion of people referred die in hospital, with the majority referred to the Arohanui Hospice service. A small number of people are seen as inpatients from partner DHBs in the Regional Cancer Treatment Service per annum. Data on referrals to the Hospital Palliative Care Team are provided in Appendix 4.

In addition to an advisory clinical service to the principal care team, the Hospital Palliative Care Team provides informal and targeted education for nursing and medical staff, participates in policy development, engages in relevant audit/research related activities, and provides a continuum of care with Arohanui Hospice.

The specialist services work collaboratively within a Memorandum of Understanding to meet clinical need, and progress palliative care initiatives (e.g. Liverpool Care Pathway). The Hospital Palliative Care Team networks with hospital teams nationally through Hospital Palliative Care New Zealand, and other national palliative care bodies.

4.4 Paediatric Palliative Care

Paediatric palliative care is demand driven and managed through MidCentral Health’s Child Health services. The Child Health service aims to enable the child and family, wherever possible, to remain at home or in the location of their choice.

The service provides a lead paediatrician, key nursing coordination, home visiting and 24/7 telephone advice and support, inpatient care as needed, social work support, and some limited bereavement support. Access to and advice from the Starship Palliative Care Team and MidCentral Health and Hospice palliative care service are readily available.

There is the opportunity to develop paediatric palliative care services in the district in accordance with the National Guidelines for Paediatric Palliative Care (2011) to ensure that:
In accordance with the national paediatric palliative care framework, MidCentral DHB is committed to developing and implementing services so that all children with palliative care needs and their families/whānau have timely access to high-quality palliative care services.

1. The service framework utilises a paediatric palliative care network and links levels of care.
2. Services are coordinated and flexible.
3. Services are equitable and needs-based.
4. Services are of high quality.
5. Services are culturally anchored.
6. Services are fiscally responsible and appropriately resourced.
5 Initiatives under development

5.1 Gold Standards Framework

MidCentral District Health Board is working towards implementation of the Gold Standards Framework in General Practice teams and Aged Care Facilities. The Gold Standards Framework provides an educational framework at ‘best practice’ level for end of life care. The framework enables ‘generalists’ to deliver high quality end of life care, so that quality end of life care becomes standard for every patient. For many, the place of death is by default rather than by choice, due to lack of planning or service provision, problems with symptom control or carer support.

Providing care closer to home is now both a preference for patients and an economic necessity. Discussions on end of life care are sometimes sensitive and difficult. Staff may feel the need to develop their confidence in holding such discussions. The Gold Standards Framework provides tools to support the wider clinical community. Services tend to be provided in silos with little regard to a wider support mechanism that links all initiatives under one consistent and sustainable vehicle. The Gold Standards products are seen as being able to provide this stability, leadership, and an enduring framework that the wider clinical community can be sure is based on international best practice.

5.2 Advance Care Planning

Advance Care Planning is a key focus nationally, regionally and locally. Currently a network of local clinicians linked to the National Cooperative Group are advocating and planning how a rollout may occur.

Advance Care Planning is a process of discussion and shared learning for future health care, focusing on the individual and involving both the person and the health care professionals responsible for their care. The planning process assists the individual to identify their personal beliefs and values and incorporate them into plans for their future health care, providing individuals with the opportunity to develop and express their preferences for care informed not only by their personal beliefs and values but also by an understanding of their current and anticipated future health status and the treatment and care options available.

Both Advance Care Planning and Gold Standards Framework align appropriately within the wider MDHB Palliative Care Strategy at the present time as tools and frameworks to support the wider clinical community, collegially.
6 Service integration key to improved outcomes

6.1 Call for Improved Integration from Health Sector Leaders

In palliative care, it is common for patients to receive care from a range of providers including general practitioners, district nurses, occupational therapists, physiotherapists, support services, oncologists, oncology nurses, radiotherapists, pharmacists, the acute pain team, and hospice/hospital palliative care nurses and doctors.

New Zealand’s Health and Disability Commissioner, writing for New Zealand Doctor in 2011, stressed the need for seamless, consumer-centred services for patients with complex needs:

Patients will often move from one part of the health care system to another, and back again, as they access the various services they need and it is common for patients to have more than one issue or diagnosis. For example, a patient who is an older person may have co-morbidities which are not related specifically to age but require specialist advice from a range of providers.

In order for patients with complex needs to receive appropriate services there must be a series of systems, including skilled people, all working together to deliver a seamless service to that patient. Where any one or more of these safeguards does not operate optimally there is the potential for delivery of appropriate services to be compromised.24

The Minister of Health called for a significant lift in the pace and scope of service integration in his 2012 Letter of Expectations for District Health Boards:

International evidence shows that integrating primary care with other parts of the health service is vital to better management of long-term conditions, an ageing population, and patients in general. This is achieved through better co-ordinated health and social services and the development of care pathways designed and supported by community and hospital clinicians.

DHBS must focus more strongly on service integration particularly with primary care; ensuring the scope of activity is broadened and the pace significantly stepped up25.

6.2 Defining Integration

To assist our understanding of what service integration means for palliative care, it is helpful, first of all to consider Grone and Garcia-Barbero’s26 (2001) commentary on the generic concept of integration:

Every organisational activity – from the making of pots to placing a man on the moon – gives rise to two fundamental and opposing requirements: the division of labour into various tasks to be performed, and the coordination of these tasks to accomplish the activity. The structure of an organisation [or a system] can be defined simply as the sum total of the ways in which it divides labour into distinct tasks and then achieves coordination among them.

Kodner and Spreeuwenberg (2002) offer the following definition of integration within the context of health care delivery:

Integration is a coherent set of methods and models on the funding, administrative, organisational, service delivery and clinical levels designed to create connectivity, alignment and collaboration within and between the cure and care sectors. The goal of these methods and models is to enhance quality of care and quality of life, consumer satisfaction and system efficiency for patients with complex, long term problems cutting across multiple services, providers and settings. The result of such multi-pronged efforts to promote integration for the benefit of these special client groups is called ‘integrated care’.27

The ‘connectivity’ referred to by Kodner and Spreeuwenberg above can be further explored by distinguishing between the levels of linkage, co-ordination, and full integration:

**Linkage** involves organisations agreeing to collaborate to improve outcomes, referring clients to the right service at the right time, and facilitating communication between professionals in order to promote continuity of care. Responsibilities are clearly aligned to different groups with no cost shifting.

**Coordination** entails organisations putting in place defined structures and processes to overcome fragmentation. It includes coordinating different services, sharing clinical information and managing transition of clients between different services.

**Full integration** involves establishing new programmes and services in which resources are pooled and information shared.

Achieving integrated care requires those involved in planning, funding and providing services to have a shared vision, employ a combination of processes and mechanisms and ensure that the patient’s perspective remains a central organising principle throughout.
7 The way forward

7.1 Strategic Goals

Five strategic goals emerged from the process of engagement with consumers and service providers and consumers across the district:

**Goal 1**
The patient experience will be at the centre of service design.

**Goal 2**
Support will be available and accessible for family and whānau.

**Goal 3**
An integrated model of palliative care, Korowai Care, will be developed for all people in the district.

**Goal 4**
The workforce (paid and unpaid) will be developed and sustained with the required competencies, resource and flexibility to respond to service and health care demand.

**Goal 5**
A sustainable system of clinical governance and leadership will be implemented.

The scenarios below describe the future state when each of these goals has been attained.

**Goal 1: The patient experience will be at the centre of service design**

An understanding of palliative care in the MidCentral district is increased through public awareness activities. This could include community forums around death and dying, increased online information regarding palliative care and publications/brochures in local health centres and hospitals. Furthermore, patients and their families have access to palliative care earlier in the journey of their illness through Advance Care Planning and Gold Standards Framework implementation. There is an increased presence of patient and family representatives on local and palliative care district service initiatives and increased consultation regarding changes in services that will impact patient care. There is a reduction in admissions to Hospital from aged residential care services due to proactive planning in the community that includes Advance Care Planning and the Gold Standards Framework. Patients and families have the opportunity to be involved in the development of local guidelines and policies via Arohanui Hospice.

**Goal 2: Support will be available and accessible for family and whānau**

Mary is a 51 year old woman with advanced chronic obstructive pulmonary disease. Mary has two adult children from her first marriage and three children age 14, 12 and 10 years from her current relationship with Paul. Mary is admitted acutely to hospital for the third time this year, where she undergoes two weeks of intensive care to treat her acute exacerbation. Discharge home is complicated by conflicting views of where she should be discharged to, and there are family tensions. She is reviewed by the Hospital Palliative Care Team, with her family present, and a rapport is struck. It is now more evident that with better support for her symptoms and the wrap around care of the community based Hospice team (now accepted by the patient) that she can be managed at home with appropriate support. Her children receive counselling from the Hospice Social Worker and in particular the 10 year old adjusts to the transition in Mum’s condition through art therapy. Mary continues to be at home with District Nursing Service and Home Help with no further Hospital admissions. One five day Hospice respite admission occurs. She dies at home surrounded by family some seven months after her last Hospital admission and bereavement support is accessed over the next year especially by the children.
Goal 3: An integrated model of palliative care, Korowai Care, will be developed for all people in the district

Tipene, a 68 year old man, with a diagnosis of renal failure, recently died at home. Tipene’s wife and his two sons were pleased that they were able to manage his care with the help of daily visits from the local district nurse. The decision to withdraw from haemodialysis had been hard but was greatly helped by a joint discussion between Tipene’s whānau, the renal nurse, and the palliative care coordinator. Tipene’s’s general practitioner had a long term relationship with the family and felt confident to manage Tipene’s medical care. He visited Tipene regularly at home and was willing to allow Tipene’s wife to ring him after hours. The local hospice were also able to access Tipene’s health records online in real time which ensured that all staff were up to date with recent treatment options, support services and practitioners involved in his care. Tipene had few problems with symptoms, apart from joint pains, that responded well to regular opioid analgesics. Tipene’s whānau were well prepared for his death which happened peacefully in his own home. They were supported by their whānau through their bereavement and received a follow up visit from their GP.

Goal 4: The workforce (paid and unpaid) will be developed and sustained with the required competencies, resource and flexibility to respond to service and health care demand

- All health workers practising in Aged Residential Care, Chronic Health and Hospital services have an understanding of the common principles related to Advance Care Planning, Gold Standards Framework and Liverpool Care Pathway.
- There is an increased percentage of non specialist health workers participating in study of palliative care and/or participating in research and local palliative care projects.
- A high level of competency among specialist palliative care nurses enables them to support, and in some cases to lead, interdisciplinary teams in primary care settings.
- The extended clinical role of palliative care nurse practitioner and clinical nurse specialist is well integrated in local health centres through clinics.
- The multidisciplinary Hospital Palliative Care service is developed and has the resource and flexibility to respond to service and healthcare demands.
- The palliative care medical service supports all areas of palliative care across the district in an integrated way and assists with service and individual patient management reviews.
- Physiotherapy, occupational therapy and pastoral support across the district are appropriately aligned to integrate aspects of care to patients and education to empower patients, families and staff.
- Residential care staff have appropriate and accessible training and support. They are also able to access district nursing and specialist support and advice out of hours. They have confidence that they are providing quality end of life care for dying patients in their facility.
- GPs are further supported in developing their lead/ coordination/collaborative roles in working with primary care and specialist interdisciplinary teams.
- There is an increased recognition of specific health workforce needs from all ethnicities and in particular the need to raise the profile and skills of Māori and Pacific health workers in supporting palliative care as part of the community mainstream health services.
- Grief and loss services are available in a coordinated and systematic way across the district.

Goal 5: A sustainable system of clinical governance and leadership will be implemented

The GP Chair of the Palliative Care Clinical Network and Governance Group reports good progress in achieving reasonably equitable 24/7 cover in the district and how the specialist on call service has now been formally extended to Palmerston North Hospital. He/she is impressed with the report from the Nurse Practitioner listing the successful triage of patients in aged residential care over the last quarter and the aged residential care staff training sessions which have been delivered. The Korowai
model of palliative care is strongly supported by district nursing, Māori health, aged residential care, and primary care.

7.2 Korowai Care: An Integrated Model of Palliative Care for MidCentral

This Strategy proposes that the Integrated Family Health Centre model currently being implemented in MidCentral is adapted for palliative care. The resulting service model, Korowai Care, will have two distinctive features:

1. the patient will be enfolded by a seamless system of service delivery, achieved by productive relationships between and among the various providers of palliative care
2. the Whānau Ora approach will be used to build on the strengths and resilience of families/whānau and ensure there is respect for their beliefs and values
3. that the Korowai model of care actively supports vulnerable population groups.

Achieving integrated care requires those involved in planning, funding and providing services to have a shared vision, employ a combination of processes and mechanisms and ensure that the patient’s perspective remains a central organising principle throughout. To that end, specific planning and leadership that ensures a true integrated approach is sought from all involved and will be the foundation for service delivery.

Whatever the degree of integration, the primary purpose should be to accomplish the three critical objectives of the ‘Triple Aim’ referred to by the New Zealand Health & Safety Quality Commission which are to:

- Improve the quality, safety and experience of care
- Improve health and equity for all populations; and
- Gain the best value from the resources made available to the public health system.

Through integration, improved patient outcomes will be a key priority of the Korowai Care model. Through the incorporation of the principles of Whānau Ora in each integrative process, whānau-centred initiatives will be fully integrated and supported. With the patient and whānau-centred focus, the Korowai Care service design will model excellence in terms of partnership between services and delivering services that promote a seamless continuum of palliative care.

The diagram below was developed to pictorially demonstrate the strategy and pathway to achieving the future vision.

7.2.2 A Seamless System of Service Delivery

In the weaving, or raranga, of a korowai there are strands called whenu or aho.

In the Strategy these represent all the different people who work together to support people with end of life and palliative care needs – including whānau, hapū and iwi, the health professionals, community workers, providers and hospitals.

The Korowai Care integration model identifies six types of integration (outlined in Figure 3). Each type of integration is enabled through a range of processes, some of which focus on systems and structures; others on less tangible aspects such as professional behaviour and teamwork.
Figure 3 Multi-faceted Integration in Health Care

- Organisational integration will create high-trust low-bureaucracy outcome-based contractual arrangements with aligned management and business structures.
- Functional integration will align back-office functions, IT, budgets and financial systems, and create a single entry point to IFHC services including outpatients, inpatients and community-based care.
- Service integration drives interdisciplinary health care teams to deliver connected health and disability services across primary and secondary care.
- Clinical integration will create patient-focused models of care that are supported by well-established clinical governance, clinical networks and collaborative clinical pathways with integrated performance accountability and shared outcomes measures with a particular focus on Māori outcomes.
- Normative integration will drive the development of shared values, culture, vision, mindsets and behaviour across the IFHC.
- Systemic integration will be underpinned by the principles of Māori health and Whānau Ora, and engagement of front-line clinicians and patients in designing services. Aligned incentives and accountability will drive service improvement activities.

Source: Adapted from Fulop et al (2005)
The functions of services supporting an integrated palliative care approach will be developed with the patient experience at the centre of service design. The existing Palliative Care Partnership model has enabled integration between primary care and palliative care services across the district and building on this model and expanding it across services will achieve further integration – which practically may be achieved through better collaboration and formalising agreed ways of doing things. Proposed arrangements for key linkages between Korowai Care and existing services and initiatives are outlined in Appendix 5.

Advances in integration will be supported by a newly formed MDHB Palliative Care Clinical Governance Group which will:

- create one drive for clinical governance activity which is in touch with district wide sector activities
- support a distributed model of care (more emphasis on non-specialist services)
- maximise opportunities to implement the MDHB Palliative Care Strategy
- create shared leadership for all palliative care initiatives across the district

7.2.3 The Whānau Ora approach

A Whānau Ora approach to palliative care means co-ordinating care on behalf of patients and ensuring care plans and Whānau Ora plans comprehensively address client needs. It embraces a whānau-centric model of service integration.

Underlying a whānau-centred approach to service provision are seven principles. These principles, identified by the Whānau Ora Taskforce are reproduced below, and are fundamental to the strategic model for palliative care advocated for in this Strategy. The strategic model “Palliative Care for All” is illustrated in Figure 4.

The Principles

- Ngā kaupapa tuku iho
- Family/whānau opportunity
- Best family/whānau outcomes
- Coherent service delivery
- Whānau integrity
- Effective resourcing
- Competent and innovative service provision

---

Figure 4: Palliative care for all

PALLIATIVE CARE FOR ALL
Our Vision: ‘All people with life limiting conditions lives well and die well irrespective of their condition or care setting’

- What do I need to understand?
- What questions do I ask?
- How can I get the best care?
- What can I expect?
- Who do I go to?
- Who can I rely on and trust?
- Quality Care
- Public Awareness
- Timely Access

Our Principles: Nga kaupapa tuku iho • Family/whānau opportunity • Best family/whānau outcomes • Coherent service delivery • Whānau integrity • Effective resourcing • Empowerment

How? We will put the Patient Experience at the centre of service design.

How? We will develop an Integrated Model of Palliative Care – Korowai Care

How? We will develop a responsive competent workforce

How? Support will be available and accessible for family or whānau

How? A sustainable system of clinical governance and leadership will be implemented.
7.3 Plan of Action for Each Strategic Goal

Goal 1: The patient experience will be at the centre of service design

Opportunity to

Use the patient experience across services to drive improvement and development of services continuously to:

- capture the experience.
- understand the experience.
- improve the experience.
- measure the improvement.

Initiatives

- SWOT analysis mid-2012 to identify and plan organisational readiness for change and any barriers/obstacles to that at local and district levels.
- Identify the different patient groups with palliative care needs (cancer and non cancer life limiting conditions) across all cultural groups.
- Engage with patient groups using current approved design tools/methodology to capture experiences.
- Develop a district wide policy aimed at improving the patient experience in palliative care that is aligned with systems to continuously capture, understand, improve and measure the improvements made.
- Stakeholder engagement plan (see Appendix 10.1).

Benefits to patient and whānau

- Services will develop a deep understanding of my expectations and those of my family or whānau.
- Services are patient focused as the views of service users will be sought.
- I will feel involved in the shaping and developing of health services.
- I will be informed.
- I will learn more about palliative care services available. I will understand what options I have.

Outcomes measured by

- Consumer presence on the Clinical Governance and Leadership Group.
- Consumers able to access their own health record in real time by July 2013.
- Consumers able to contribute to their case management through accessing records.
- Consumers receive copies of all referral letters and patient notes/letters and communication by December 2013.
- Number of quality action points evolving from patients’ contributing to the patient groups/forums.
- Degree of involvement in service design and planning.
- Patient and family satisfaction surveys.
- Evaluation of the patient experience influence on service design.
Goal 2: Support is available and accessible for family and whānau

Opportunity to

- Put in place formal mechanisms to ensure that the patient and their family and whānau have access to bereavement care, information and support services.\(^{29}\)
- Support the development of whānau ora in the district with specific focus on end of life care needs and ‘Korowai Care’ model.
- Identify the supportive care needs of family or whānau.
- Improve the experience for family or whānau caring for their loved ones.
- Support Māori whānau to take charge to ensure access to quality palliative care.
- Incorporate the Supportive Care Guidelines into district wide policy and service models.

Initiatives

- Development of the Korowai Care model includes key implementation goals for supportive care for whānau.
- Develop a coordinated pathway across a service that enables timely referral and access to bereavement support for family or whānau and is not limited to hospice palliative care patients.
- Stakeholder forums with family and carers inform service design.
- Increase the knowledge to enable whānau to support their loved ones to die in preferred place for care through information and education.
- Develop a shared care model for family support services across the district that links to the Supportive Care Guidelines and includes support groups, coordinated education and collaboration with other support groups/agencies. This will allow family caregivers to continue to work if required.
- Evaluation of family/whānau needs including monitoring the impact of caregiving on families.

Benefits to patient and whānau

- I feel confident that I can care for my loved one if I choose.
- I will feel in control.
- I will be supported through loss and grief and post bereavement.
- I will know who to go to in an emergency or out of hours.
- I will not feel alone.

Outcomes measured by

- Guidelines that support whānau/family/group-centred general practice services in place by December 2013.
- Stakeholder forums influence on work plans.
- Publication of data related to Quality of Death and Dying tool (QODD) by December 2013.
- Carer groups designed and commenced in IFHC by June 2013.
- Alignment with Paediatric Palliative Care Network.

Goal 3: An integrated model of palliative care, Korowai Care, will be developed for all people in the district

Opportunity to

- Widen the PCP model across all services of the care continuum to enable providers (including all members of the health care teams) both within and across settings to collaborate to reliably deliver high-quality coordinated care with clear lines of accountability.
- Improve communication and between services to ensure that the appropriate levels of information are available to all providers at the point of care and to patients and whānau.
- Improve systems to enable timely needs assessment, referral, care planning and discharge.
- Integrate research opportunities with tertiary providers.

Initiatives

Creation of a Clinical Governance and Leadership group for palliative care building on the existing PCP model that will:

- Ensure strategic plan is evolved into all implementation and annual plans with providers.
- Use the ‘patient experience’ outcomes to inform service design.
- Align current plan with ‘whānau ora’ and the IFHC model to develop an improved palliative care model ‘Korowai care’.
- Include paediatric palliative care.
- Develop an integrated care pathway that incorporates GSF, ACP and LCP standards and practices.
- Facilitate systems to support documented EOLC discussions with patients (ACP).
- Develop targets aimed at improving service access and early palliative care intervention for areas of the district in most need/at risk.
- Develop outcome measures for services including PCP admission and attendance to ED data analysis.
- Strengthen home based support services.
- Increase access to specialist palliative care services for those with non-malignant conditions.
- That a redeveloped service design and funding model supports the Korowai model of care

Benefits to patient and whānau

- I will receive timely access to quality service and care.
- I will know that services are talking to each other.
- I will receive care before it is too late so that I have time to consider my options, make choices, receive support and enjoy quality of life.
- I will feel in control as I know who to go to and what to do.
- I have access to information regarding my entitlements, access and service providers.
- I know that support will be there out of hours in an emergency if I need it.
- I have confidence and trust in my health service.

Outcomes measured by

- Clinical Governance and Leadership Network formed and annual plan developed
- Redeveloped funding model for palliative care will be in place
- Implementation Plan finalised
- Nurse led clinics established and nursing utilisation data increased
- Clear referral processes are established and reviewed.
- Increased referrals to PCP by 10% per annum.
- Palliative Care Patients presenting inappropriately to ED decreased by 30% by July 2013.
- Percentage of General Practice Teams implementing the Korowai Care Model by November 2013.
- Percentage of patients identified earlier with potentially deteriorating chronic conditions requiring palliative care management.
- Percentage of patients with moderate-to-high complexity chronic illness receive case management services through palliative care providers.
- Percentage of patients who die in preferred place for care.
- Medication audit shows reduction in prescription burden for palliative care patients by 10% by June 2013.
- Number of increased MoUs with other health and social services.
- Strategies and actions that reduce cost as a barrier for high needs population in place by March 2013.
- 20% increase in the number of staff trained in culturally responsive palliative care by June 2014.
- 50% of deaths in the district are registered on an end of life care pathway.
Goal 4: The workforce (paid and unpaid) will be developed and sustained with the required competencies, resource and flexibility to respond to service and health care demand

Opportunity to

Be supported by a culture of continuous innovation, quality improvement and learning that is embedded in the service design

- Develop and train the volunteer workforce.
- Develop sufficient capacity with primary and specialist palliative care.
- Develop a funding programme for palliative care specialists
- Develop nurse leadership in palliative care to support an integrated model of care and workforce development.
- Promote best practice through education and research.
- Build and grow the non-regulated workforce with a particular focus on Māori.
- Support current scholarship initiatives regarding Māori scholarship uptake to support palliative care related study pathways.

Initiatives

- Attract and retain required volunteer capacity.
- Develop and support advanced nursing positions to support the delivery of palliative care in IFHC and aged residential care.
- Support the implementation of the Performance and Service Improvement Framework.
- Embed the integrated model of care through education delivered by Arohanui Hospice informed by research.
- Provide and fund opportunities for education to develop palliative care nursing knowledge and skills. This education will include Gold Standards Framework (GSF), Advance Care Planning (ACP), and Liverpool Care Pathway (LCP) and spiritual care and communication skills.
- Establish and support new entry to practice (NETP) in palliative care with a focus on the Māori workforce.
- Develop a culturally diverse palliative care workforce to reflect society.
- Determine the best model for allied health deployment in palliative care (therapy based vs equipment providers).

Benefits to patient and whānau

- I have confidence and trust that I am receiving high quality palliative care.
- I have confidence and trust that what matters to me, matters to services and that my psychological and psychosocial needs will be addressed.
- I have confidence and trust that I can receive the same level of care regardless of my place of care.
- I will be able to plan ahead through future planning as health professionals will talk to me carefully about my options and my values and wishes for end of life care.

Outcomes measured by

- Gold Standards Framework and implementation pilot completed by July 2013. This includes evaluation of ACP.
- Percentage staff actively participation at collaborative education sessions.
- Workforce survey to identify learning needs of health providers in the district completed by March 2013.
- Annual workforce development plan established which reflect the identified staff learning needs by March 2013.
- A decision tool that determines best fit service for the IFHC from a palliative care perspective is established by April 2013.
- Interdisciplinary Knowledge and Skills Framework underpins staff development as part of the workforce development plan.
- Annual CPD calendar linked to palliative care sessions available to all IFHC staff by April 2013.
- 50% of general practice team and other relevant providers within the IFHC are engaged in a 1 palliative care programme session per year by 2013.
Goal 5: A sustainable system of clinical governance and leadership will be implemented.

Opportunity to

Integrate clinical governance and leadership, paving the way to
- Governance and clinical leadership to all palliative care clinicians and non clinicians.
- Drive service improvements.
- Leverage off joint strategic leadership decisions.
- Align regional initiatives.
- Provide horizon scanning to the district.
- Align to national, regional and district strategies.
- Develop a funding management model for palliative care that allows alignment and flexibility with funding.

Initiatives

- Integrate and strengthen combined leadership and governance groups to single group leading and initiating change.
- Develop terms of reference for the PCN.
- Identify change management values and activity required to achieve the opportunity.
- Identification of agreement to shared risks and mitigation thereof.
- Development of integrative data modelling.
- Obtaining data to support ongoing IT requirements.
- Proactive implementation of IT and IS systems where this is practical and adds value to the end goals.
- Recruit and retain people with the skills and commitment to implement the five-year strategy.
- Work with its partners to plan for the future.
- Develop indicators and KPIs as a quality framework for evaluating the strategy.

Benefits to patient and whānau

- Reduced bureaucracy provides for more streamlined and efficient decision making and work plan.
- Staff will feel supported under simple structures.
- The system is evident in supporting patients and whānau.

Outcomes measured by

- Evidence of single and simple structures supporting all.
- Regular governance or clinical network links to all palliative care services.
- Engagement plan demonstrates and illustrates clinical governance structure and this is communicated to all.
- Integration is able to illustrate and role model degree of involvement from wider sector in service design and planning of initiatives.
### 7.4 Current and Future View of Palliative Care in MidCentral

<table>
<thead>
<tr>
<th>Current state</th>
<th>Future state</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1</strong> Service design and development driven by the health sector</td>
<td>Service design and development driven by the patient experience</td>
</tr>
<tr>
<td><strong>2</strong> Palliative Care features ad hoc in independent service plans across providers in the district or not at all</td>
<td>A common system wide shared vision and principles for palliative care in the region</td>
</tr>
<tr>
<td><strong>3</strong> Access to services and 24/7 coverage varies across the DHB. Horowhenua is experiencing delays in service due to lack of GP cover and after hours support</td>
<td>Integrated access across the care continuum through 24/7 coverage and quick/rapid response services</td>
</tr>
<tr>
<td><strong>4</strong> Lack of a defined model of palliative care for Māori resulting in reduced access to services for Māori</td>
<td>Korowai Care model of care integrates the principles of the Korowai and whānau ora into the palliative care model of care delivery</td>
</tr>
<tr>
<td><strong>5</strong> Independent access systems and processes vary across the district causing delays in referrals and timely access to information and services</td>
<td>Coordinated access and a central registry of palliative care patient records</td>
</tr>
<tr>
<td><strong>6</strong> Acute ED admissions of patients on the PCP programme are not recorded and reported on. There is a lack of quantitative data regarding access to palliative care between and across services</td>
<td>Access to quality palliative care in the community and data that validates reductions in acute ED attendances /hospital admissions, enhancing appropriate discharges</td>
</tr>
<tr>
<td><strong>7</strong> Aspects of leadership and governance by Palliative Care Teams are based on relationships and individual contracts, projects/plans and there is no governing Framework or succession planning</td>
<td>Leadership/Governance oversight and accountability for palliative care district-wide, with sustainable Frameworks of care</td>
</tr>
<tr>
<td><strong>8</strong> Qualitative data (Stakeholder forums) validate that consumers and stakeholders experience delays in transition of referrals, communication and information regarding care and treatment</td>
<td>Improved transitions between care settings</td>
</tr>
<tr>
<td><strong>9</strong> Education is delivered primarily to Registered Nurses and GPs with limited access by other Health professionals or services</td>
<td>Consistent and continuous learning opportunities for staff (interdisciplinary)</td>
</tr>
<tr>
<td><strong>10</strong> Access to bereavement services is inconsistent, available for Arohanui Hospice patients only</td>
<td>Extended access to multi-disciplinary care across all sites and services including post bereavement care district-wide</td>
</tr>
<tr>
<td><strong>11</strong> The Palliative Care Partnership programme is specific to primary care providers only</td>
<td>Expand the Palliative Care Partnership model across all services – Korowai Care</td>
</tr>
<tr>
<td><strong>12</strong> Common decision tools available by the Palliative Care Partnership programme. Referral Pathways not in place</td>
<td>Common needs assessment tools, referral pathways and management tools increase the quality of palliative care in the district</td>
</tr>
<tr>
<td>No.</td>
<td>Statement</td>
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<tr>
<td>13</td>
<td>Care Pathways are restricted to the Liverpool Care Pathway programme which addresses the last days of life only, limiting a proactive approach and access to quality palliative care earlier in the disease trajectory.</td>
</tr>
<tr>
<td>14</td>
<td>Limited support is available to whānau through the Arohanui Hospice programme only.</td>
</tr>
<tr>
<td>15</td>
<td>Qualitative data (Stakeholder forums) validates that consumers and stakeholders experience delays in symptom management through lack of skill base and palliative care support in the community especially after hours.</td>
</tr>
<tr>
<td>16</td>
<td>Lack of a quality Framework specific to palliative and end of life care.</td>
</tr>
<tr>
<td>17</td>
<td>Qualitative data (Stakeholder forums) reports delays in transition of referrals, communication and information regarding care and treatment.</td>
</tr>
<tr>
<td>18</td>
<td>Gaps in specialist and primary care palliative care workforce. Resource depleted environment with gaps at all levels.</td>
</tr>
<tr>
<td>19</td>
<td>Lack of mandate through the service infrastructure to support development of KPIs and outcomes for palliative care. Lack of IT capability and resources to support timely analysis and measurement of services.</td>
</tr>
<tr>
<td>20</td>
<td>The mixed funding model encourages silo activity and impedes full integration of services.</td>
</tr>
<tr>
<td>21</td>
<td>Education programmes promoted by specialist palliative care.</td>
</tr>
<tr>
<td>22</td>
<td>Research in palliative care is ad hoc and opportunistic.</td>
</tr>
</tbody>
</table>

**7.5 Risks and Controls for Strategy Implementation**

See appendix 6.
Summary of key initiatives

The Plan of Action for Each Strategic Goal outlined in Section 7.3, above, provides a detailed list of initiatives which will be implemented as part of the work programme supported by this Strategy. The risks and controls associated with this work programme are outlined in Appendix 6. The section below highlights, in summary form, the key initiatives advanced by this Strategy.

1. Establish a Palliative Care Network based on the combined strengths of Specialist Palliative Care, the Cancer and Palliative Care District Group, Central PHO, and the Integrated Palliative Care Governance Group. Ensure all existing palliative care clinical governance groups/networks are merged into one, or have formal links established through memorandum of understanding.

The Palliative Care Network will provide the leadership to drive the implementation of the remaining initiatives.

Representation will be sourced from:
- Specialist Palliative Care
- Child Health
- Primary Care
- Aged Care including Residential Care
- Māori Health
- Central Primary Care Organisation (CPHO)
- Planning and Support (MDHB)
- Pharmacy
- Education and Research
- Consumer representative/s
- District Nursing

The Palliative Care Network will be supported to drive the initiatives outlined in this Strategy by:
- Project Manager 0.5 FTE
- Programme Clinican/s 0.4 FTE (this part time allocation could be a single position or be distributed among a number of clinicians)

The Project Manager will:
- Drive the development of the implementation plan across the sector.
- Work on models and clinical pathways to support an integrated framework and key action plans.
- Support a review of palliative care clinical tools/pathways and outcome measures linked to the Strategic Plan outcomes.
- Engage with Māori Health and Kaumātua towards the development of the Korowai Model for Palliative Care aligning with Whānau Ora.
- Develop a Patient Experience Programme for palliative care.
- Support and integrate Advance Care Planning and Gold Standards Framework and the Liverpool Care Pathway into new service models.

The Programme Clinican/s will:
- Undertake relationship and partnership building and across key provider and consumer groups.
- Develop intersectoral liaison and alignment of palliative care services.
- Provide leadership for the implementation and evaluation of this Strategy’s initiatives.

2. Commission a study to improve understanding of the ‘patient experience’ and ‘family and whānau experience’ of palliative care services in MidCentral. Develop and establish a formal programme to a) continuously capture data on the patient and family/whānau experience of palliative care services, and b) measure the improvements made as a result.

3. Develop and implement the Korowai Care Model for palliative care. Evaluate in partnership with local Māori.

4. Develop clinical tools across the district including referral, needs assessment, triage, access pathways to 24/7 support/ emergency response, and specialist palliative care.
5. Develop key performance indicators and outcomes for all services contributing to Korowai Care, and embed these as appropriate in relevant local and regional plans.

6. Integrate the Gold Standards Framework (GSF), Advance Care Planning (ACP) and the Liverpool Care Pathway (LCP) for the Dying into MidCentral’s new service model for palliative care (Korowai Care).

7. Develop and implement clinical pathways for primary palliative care services that meet the mandates of Better, Sooner, More Convenient care and the priorities of Māori as expressed in Whānau Ora and via local hui.

8. Develop a district wide bereavement support framework and guidelines for palliative care services.

9. Implement key recommendations of the National Paediatric Palliative Care Guidelines within MidCentral.

10. Undertake a review of workforce competencies and resource, including the exploration of advanced nursing roles. This should be informed by the Resource and Capability framework for Integrated Adult Palliative Care30.

11. Reconfigure Specialist Palliative Care funding into one revenue stream.

12. Establish common data collection for palliative care across the district with a focus on IT connectivity and shared records.

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9 Conclusion

The importance of strengthening and integrating palliative care services to deliver more effective, efficient and sustainable care cannot be over-emphasised. With an ageing population, increasing multi-morbidities and complexities of care, the population needs to be able to access quality palliative care wherever they may be. The challenge of doing so should not be underestimated.

The achievement of the future vision for Palliative Care will clearly involve a period of change over the next five years. In implementing the strategy there are a number of important principles for ensuring a stable and constructive transition:

- In the first instance, protect the gains already made and relationships developed during the development of the strategy. The future vision will only be able to be delivered if the district acts as a coordinated whole.
- During the development of the Korowai model involve, discuss and collaborate with the Palliative Care sector, providers and communities.
- Focus on stepwise, evolutionary, change which is progressively consistent with national, regional and local solutions.

This Strategic Plan represents a call to action through a united District plan. The goals under the plan will evolve and optimise future service delivery of palliative care in the District through an integrated approach. It provides the district with an opportunity to significantly improve Palliative Care services over both the short and long term. The plan will be driven from the patient perspective. This is a strength. It is about the people. What matters to them is what matters to us.
Appendix 1: Stakeholder engagement methodology and results

Developing the Strategic Plan

The data for informing the Strategic Plan were derived from a variety of sources including: document review, a survey of Stakeholders, focus groups with service providers across district areas, focus groups with Consumers, a Māori hui and key-informant interviews with the Ministry of Health, Palliative Care Council and Hospice New Zealand. Stakeholders also had the opportunity to feedback via a questionnaire. Posters were also circulated advertising the local forums and a newspaper advertisement was placed highlighting the Consumer forum.

These process enabled patients, family members, kaumātua, volunteers, allied health, spiritual care and pastoral services, administrators, nurses, physicians and community leaders to play a significant role in the creation of priorities for the Strategic Plan. The results (Appendix 1) show that Stakeholders have universal similar key themes and goals to improve palliative care in the district.

Aims of the Stakeholder Forums

- To promote a regional conversation on dying, death and bereavement in the district.
- To ascertain the key issues at the end of life – to understand the patient and carers experience at the end of life, specifically:
  - What mattered most to them personally?
  - What services made a difference?
  - Were there any gaps?
- To explore the views and concerns of the public and varying health partners and providers
- To ensure a wide range of views are heard
- To prepare the ground for a district Strategic Plan to advance the views emerging from the Forums.

Key Themes from Consumer Forums (of which there were three including a Māori hui)

a) Information
- Need to ‘define palliative care at a laymans level – what does it actually mean?’
- To enable choices and some empowerment, control or influence of the situation.
- Access to care options and ‘how to’.
- We want more information - a better informed public will reduce patient concerns/anxiety.
- ‘How health workers talk to patients is really important. Communication by some clinicians can be a barrier’. We do not want to feel dumb, be belittled or judged.
- Links to navigator co-ordination key worker – information and facilitation of access to support.

b) Access to support
- It is about ‘the people’ with no boundaries.
- Services should not be just at the ‘hospice end’ but available when people are told that they cannot be cured.
- Linked to integrated service provision and navigator co-ordination key worker.
- Home support for people under 65 with palliative care needs.
- Transport and other support services (e.g. on-line shopping)
- 24 hour access to advice and support even if we are not under hospice.
- Assessment, systems, processes and criteria need to be in place to enable early access to services.

c) Equality
- No stereotyping
- No favouritism (especially for age)
- Patient rights and advocacy should be upheld.
Patient and provider views on ‘What the patient wants and needs’

The top three Key priorities from service providers:

- Information
- Access to Support
- Integrated Services
Appendix 2: Stakeholder list

Table 11.5 (a) Attendees at stakeholder forums, hui and written submissions

<table>
<thead>
<tr>
<th>Name</th>
<th>Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alan Jones</td>
<td>Te Whānau, Bupa</td>
</tr>
<tr>
<td>Amanda Gill</td>
<td>Ranfurly Rest Home</td>
</tr>
<tr>
<td>Anna Blackwell</td>
<td>Arohanui Hospice</td>
</tr>
<tr>
<td>Ann Fowler</td>
<td>Peppertree Rest Home</td>
</tr>
<tr>
<td>Andrea Thompson</td>
<td>Compass Health</td>
</tr>
<tr>
<td>Angela Pullen</td>
<td>MidCentral Health</td>
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<tr>
<td>Angela Verhoeven</td>
<td>Compass Health</td>
</tr>
<tr>
<td>Barry Keane</td>
<td>Pathway</td>
</tr>
<tr>
<td>Belinda Ray-Johnson</td>
<td>Consumer</td>
</tr>
<tr>
<td>Bonnie Simmons</td>
<td>Compass Health</td>
</tr>
<tr>
<td>Brad Grimmer</td>
<td>Te Waka Hui</td>
</tr>
<tr>
<td>Brenda Boyd</td>
<td>Arohanui Hospice</td>
</tr>
<tr>
<td>Bridget Marshall</td>
<td>Waireka Oceania</td>
</tr>
<tr>
<td>Bruce Toulon</td>
<td>Levin</td>
</tr>
<tr>
<td>Chiquita Hansen</td>
<td>GP</td>
</tr>
<tr>
<td>Chrissy Paul</td>
<td>Hospital Palliative Care New Zealand</td>
</tr>
<tr>
<td>Clare Randall</td>
<td>GP</td>
</tr>
<tr>
<td>Deirdre McNicholl</td>
<td>GP</td>
</tr>
<tr>
<td>Denise Hewitt</td>
<td>GP</td>
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<tr>
<td>Diane Welch</td>
<td>GP</td>
</tr>
<tr>
<td>Dorothy Moore</td>
<td>GP</td>
</tr>
<tr>
<td>Dr Bruce Stewart</td>
<td>GP</td>
</tr>
<tr>
<td>Dr Carol McAllum</td>
<td>GP</td>
</tr>
<tr>
<td>Dr Delamy Keall</td>
<td>GP, Tararua Health Group</td>
</tr>
<tr>
<td>Dr Fred Hirst</td>
<td>GP</td>
</tr>
<tr>
<td>Dr Jane Laver</td>
<td>GP</td>
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<tr>
<td>Dr John Drake</td>
<td>GP</td>
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<tr>
<td>Dr Joy Percy</td>
<td>GP</td>
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<tr>
<td>Dr Pauline Blackmore</td>
<td>GP</td>
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</table>
Appendix 3: Service data for Arohanui Hospice

Total Community Contacts by Month 2010/11 Year

Referrals/Deaths 2010/11 Year
Admissions/Discharges/Occupancy 2010/11 Year

New Referrals to Hospice per annum
The graph above demonstrates increased service activity in the Community, with a marked 135% increase in activity during 2004. This coincides with the Palliative Care Partnership pilot which commenced in 2004 (4868 PCC visits to 11426 PCC visits in 2006). This validates the success of the PCP. Limitations are related to the number of medical centres enrolled on the PCP - which in 2012 is at 95%. This reduces the scope for further enrolment.

Since 2006, the number of PCC visits has increased by 3.6% and the number of referrals to specialist palliative care by 15%. The occupied bed days have remained static indicating capability of specialist services to care for palliative care patients in the community.

Future service development using an integrated model of care will be a key enabler increasing access to palliative care wider than Primary Care to include Aged Residential Care and Hospital Services and widening the scope of palliative care in the sector.
Appendix 4: Referrals to hospital palliative care team

Table 1. All referrals by month from June 2002 – April 2012
### Appendix 5: Linkages with other services

<table>
<thead>
<tr>
<th>MidCentral Business Case: Programme of Work</th>
<th>Palliative Care Integrated Programme</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Paediatric Palliative Care Clinical Network</strong></td>
<td>Care Coordination of paediatric palliative care in the district. Membership of core palliative care working parties/groups.</td>
</tr>
<tr>
<td><strong>Arohanui Hospice Strategic Plan</strong></td>
<td>The Arohanui Hospice Strategic Plan will be aligned with MDHB Palliative Care Strategic Plan.</td>
</tr>
<tr>
<td><strong>Chronic Care Model roll-out</strong></td>
<td>Arohanui Hospice delivers core education programmes for GPs (palliative care partnership), RNs, ENs and non-regulated staff. AH will expand this programme in 2012/2013 to support the roll out of the Gold Standards Framework and Advance Care Planning initiatives. Specialist Palliative Care nurse specialists/NP will provide more effective integration between chronic care management services and palliative care services to their enrolled population eg through nurse clinics.</td>
</tr>
<tr>
<td><strong>Nurse Led Clinics</strong></td>
<td>Palliative Care Nurse-led (Nurse Practitioner) clinics will be implemented within agreed priority areas where the medical workforce is limited.</td>
</tr>
<tr>
<td><strong>EnhancedCare+</strong></td>
<td>The revised Palliative Care Partnership model ‘Korowai Care’ working with General Practice Teams will support the delivery of EnhancedCare+ programme which is inclusive of electronic Comprehensive Health Assessment and Client Care Plan to ensure that palliative care quality standards are met.</td>
</tr>
<tr>
<td><strong>Case Management</strong></td>
<td>Arohanui Hospice NP will work in partnership with General Practice Teams to stratify the enrolled population and provide targeted case management for complex patients or whānau. This will build on the GSF model.</td>
</tr>
<tr>
<td><strong>Self management programmes</strong></td>
<td>Arohanui Hospice will support the provision of Client Self Management programmes using the wider multidisciplinary team (Wellness clinics, Carer groups)</td>
</tr>
<tr>
<td><strong>Recovery at Home</strong></td>
<td>PCCs will follow up all hospital patients discharged to the community within 24 hours. The NP will assist with complex discharge management to promote patient choice and timely discharge to preferred place for care. 24/7 telephone advice will be expanded.</td>
</tr>
<tr>
<td><strong>Urgent Community Care Project (UCC)</strong></td>
<td>Dependant on outcome of the Horowhenua pilot. Arohanui Hospice is working with St John’s Ambulance with the aim of reducing acute demand and presentations of palliative care patients through Advance Care Planning and improved communication ensuring that an alert system and training is in place for St John Ambulance team.</td>
</tr>
<tr>
<td><strong>Improved Care for Older People</strong></td>
<td>The introduction of Advance Care Planning and the Gold Standards Framework will be supported by education from Arohanui Hospice and collaboration with Care of the Older people team. A Shared Model of care will be developed between disciplines.</td>
</tr>
<tr>
<td><strong>InterRAI electronic Needs Assessment tools</strong></td>
<td>Electronic Needs Assessment tools used for assessment of older adults provide an opportunity to use aggregated data and specifically identify the most pressing issues facing the older person with Level 4 and Level 5 need who may benefit from proactive palliative care assessment. The data gathered can specifically lead to maximising a person’s health deficits thereby enhancing a person’s health status. There is an opportunity later in 2012 to pilot the palliative care InterRai tool.</td>
</tr>
<tr>
<td><strong>Whānau Ora</strong></td>
<td>The principles of Whānau Ora will be woven across all services and integrated as an underlying principle of these services. Whānau Ora Navigator roles will be grown and current relationships will be strengthened as part of the Korowai Care model. Implementation of cultural training will occur through the Interdisciplinary Knowledge and Skills programme.</td>
</tr>
<tr>
<td><strong>Information Management</strong></td>
<td>Information Management will be utilised effectively across the MDHB district to improve the client journey by streamlining and supporting integrated service delivery.</td>
</tr>
<tr>
<td><strong>Workforce Development</strong></td>
<td>Linkages through the delivery of consistent workforce development programmes based on the Interdisciplinary Knowledge and Skills Framework.</td>
</tr>
<tr>
<td><strong>Other CPHO services such as Pharmacy facilitation</strong></td>
<td>Palliative Care linkages through pharmacy expertise involved with community pharmacy practices. Assistance towards out of hours support, reduction in inappropriate prescriptions and greater understanding of Palliative Care is anticipated.</td>
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## Appendix 6: Strategy implementation risks and controls

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<th>Number</th>
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<th>Description</th>
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<th>Owner</th>
<th>Accept Ctrl Risk</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>The Patient Experience is at the centre of Service Design</td>
<td>Lack of buy in from key stakeholders and difficulties in recruitment of patients due to complex palliative care needs.</td>
<td>Moderate</td>
<td>PCN</td>
<td>Yes</td>
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</table>

- Embed Clinical Governance and Leadership Group
- Regular communication with stakeholders
- Linkages identified
- Sharing of plans
- Communicate way forward
- Cultural guidance from Māori Health Group
- Consumer involvement at governance level
- Leadership input from Director Palliative Care Arohanui Hospice
- Embed into staff PDPs and orientation discussions

<table>
<thead>
<tr>
<th>Number</th>
<th>Reference</th>
<th>Name</th>
<th>Description</th>
<th>Res Risk Level</th>
<th>Owner</th>
<th>Accept Ctrl Risk</th>
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</thead>
<tbody>
<tr>
<td>2</td>
<td>Strategic Plan</td>
<td>Failure to develop Implementation plan and progress a district wide palliative care plan.</td>
<td>Moderate</td>
<td>PCN</td>
<td>Yes</td>
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</table>

- MidCentral DHB has ownership of the Palliative Care Plan and can exercise some influence at Board level
- Development of a Clinical Governance and Leadership group drives the implementation and raises awareness of the need for palliative care in the district to become more integrated
- Project lead to assist key integration strategies

<table>
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<th>Number</th>
<th>Reference</th>
<th>Name</th>
<th>Description</th>
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<th>Owner</th>
<th>Accept Ctrl Risk</th>
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<tbody>
<tr>
<td>3</td>
<td>Support is available for whānau</td>
<td>Failure to implement the multi-disciplinary care model in the community and progress increased availability of specialist palliative care support services for whānau.</td>
<td>Moderate</td>
<td>PCN</td>
<td>Yes</td>
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</table>

- MidCentral DHB has ownership of the Palliative Care Plan and can exercise some influence at Board level
- Development of a Clinical Governance and Leadership group drives the implementation and raises awareness of the need for palliative care in the district to become more integrated
- Embed Whānau Ora Strategies
- Stakeholder survey post bereavement will be used to guide level of need
- Ensure alignment with Arohanui Hospice Strategic Plan.
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<th>Number</th>
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<th>Name</th>
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<th>Owner</th>
<th>Accept Ctrl Risk</th>
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<tr>
<td>4</td>
<td>Integrated model of care</td>
<td>Inability to develop a systemic approach that integrates both health and social service systems</td>
<td>Moderate</td>
<td>PCN</td>
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<td></td>
<td></td>
<td></td>
<td>An outcomes based <em>Framework</em> is embedded in implementation plan</td>
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<td></td>
<td></td>
<td></td>
<td>Role and support of a single clinical governance group is key</td>
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<td></td>
<td>Consider KPIs and incentives for all staff driving the integrated model</td>
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<tr>
<td>5</td>
<td>Integrated model of care</td>
<td>Lack of engagement with consumers and whānau in experienced based design methodology</td>
<td>Moderate</td>
<td>PCN</td>
<td>No</td>
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<td></td>
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<td></td>
<td>Build on similar work within the MDHB Network Groups</td>
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<td>Seek advice from CPHO or get outside expertise to facilitate</td>
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<td>Build on other similar work undertaken within the PHO, Compass Health or nationally</td>
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Appendix 7: Glossary

Advance Care Planning (ACP): Advance Care Planning (ACP) is a process of discussion and shared planning for future health care. It is focused on the individual and involves both the person and the health care professionals responsible for their care. It may also involve the person’s family/whānau and/or carers if that is the person’s wish. ACP provides individuals with the opportunity to develop and express their preferences for care informed not only by their personal beliefs and values but also by an understanding of their current and anticipated future health status and the treatment and care options available.

Bereavement: The period after a loss during which grief is experienced and mourning occurs. Although there are similarities in people’s responses, there are also marked differences. Each person will grieve and recover in their own way and in their own time.

Care Pathway: A care pathway is a complex intervention for the mutual decision making and organisation of care processes for a well-defined group of patients during a well-defined period. Defining characteristics of care pathways include:

i. An explicit statement of the goals and key elements of care based on evidence, best practice, and patients’ expectations and their characteristics;

ii. the facilitation of the communication among the team members and with patients and families;

iii. the coordination of the care process by coordinating the roles and sequencing the activities of the multidisciplinary care team, patients and their relatives;

iv. the documentation, monitoring, and evaluation of variances and outcomes; and

v. the identification of the appropriate resources. The aim of a care pathway is to enhance the quality of care across the continuum by improving risk-adjusted patient outcomes, promoting patient safety, increasing patient satisfaction, and optimising the use of resources.

Chronic Condition: A biological or physical condition where the natural evolution of the condition can significantly impact on a person’s overall quality of life, including an irreversible inability to perform basic physical and social functions. Serious and persistent chronic conditions are multidimensional, interdependent, complex and ongoing. Chronic conditions are characterised by persistent and recurring health consequences lasting for three months or more.

[Note: this Glossary proposes to not use the term ‘illness’, as it implies a more narrow scope of health issues that impact on a person’s quality of life.]

Death: The cessation of all vital functions of the body, including the heartbeat, breathing and brain activity (including the brainstem).

Dying: A person is considered to be dying when they are in the process of passing from life to death. It is characterised by a gradual failing of vital functions including the cardiac, respiratory and central nervous systems, followed by an absence of criteria that define life (spontaneous heartbeat, breathing and brain function). The dying phase is generally considered to be minutes to hours in duration, but can occasionally be just seconds.

End of Life: The end of life phase begins when a judgment is made that death is imminent. It may be the judgment of the health/social care professional or team responsible for the care of the patient, but it is often the patient or family who first recognises its beginning.

End of Life Care: End-of-life care is the provision of supportive and palliative care in response to the assessed needs of the patient and family/whānau during the end of life phase. It focuses on preparing for an anticipated death and managing the end stage of a life-limiting or life-threatening condition. This includes care during and around the time of death, and immediately afterwards. It enables the supportive and palliative care needs of both the person and the family/whānau to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support and support for the family.

Family: A family is defined as those who are closest to the patient in knowledge, care and affection. The family may include the biological family, the family of acquisition (related by marriage/contract), and the family of choice and friends (including pets). See also Whānau.

Generalist Palliative Care: Refer to ‘Primary Palliative Care’. [Note: this Glossary proposes not to use the term ‘Generalist Palliative Care’, as it does not adequately describe the nature of
palliative care provided by health services that are not specialist palliative care services.

**Gold Standards Framework (GSF) (from UK GSF website):** The Gold Standards Framework (GSF) is a systematic evidence based approach to optimising the care for patients nearing the end of life delivered by generalist providers. It is concerned with helping people to live well until the end of life and includes care in the final years of life for people with any end stage illness in any setting. Several DHBs in New Zealand are now looking at implementing the programme in primary and aged residential care settings.

The National GSF Centre in the UK is the national training and coordinating centre for all programmes in the UK, enabling generalist frontline staff to provide quality care for people nearing the end of life, whatever their illness, wherever the setting. It aims to support best implementation of GSF in all settings, using a common framework and toolkit of resources.

GSF improves the quality, coordination and organisation of care in primary care, care homes and acute hospitals. This enables more patients to receive the type of care they want, in their preferred place, with greater cost efficiency through reduced hospitalisation.

**Holistic:** A system of comprehensive or total patient care that considers the physical, emotional, social, economic, and spiritual needs of the person; their response to illness or life-limiting/life-threatening condition; and the effect of the illness or condition on the ability to meet self-care needs. The principles of palliative care are framed around holistic care and the interdependent physical, social, emotional, cultural and spiritual aspects.

**Hospice:** Hospice is not only a building; it is a philosophy of care. The goal of hospice care is to help people with life-limiting and life-threatening conditions make the most of their lives by providing high quality palliative and supportive care.

Hospices provide care for the whole person, not just their physical needs but also their emotional, spiritual, and social needs. They also care for families and friends, both before and after a death. Irrespective of where a hospice service is, this philosophy of care does not change. In New Zealand all aspects of hospice care are provided free of charge.

**Interdisciplinary Team:** A group of individuals with diverse training and backgrounds who work together as an identified unit or system. Team members consistently collaborate to solve patient problems that are too complex to be solved by one discipline or many disciplines in sequence.

Membership varies depending on the services required to identify and address the expectations and needs of the patient, caregiver and family. A palliative care interdisciplinary team typically includes one or more doctors, nurses, social workers, spiritual advisers, pharmacists, and personal care workers. Other disciplines will be part of the team as resources permit.

**Life-Limiting Condition:** A life-limiting condition is one for which there is no reasonable hope of cure and from which the person will die. Some of these conditions cause progressive deterioration rendering the person increasingly dependent on family and carers. Also refer to ‘Life-threatening condition’ and ‘Terminal condition’. [Note: this Glossary proposes to not use the term ‘illness’, as it implies a more narrow scope of health issues that impact on a person’s quality of life.]

**Liverpool Care Pathway (LCP):** The LCP is an evidence-based, integrated care pathway that was developed to transfer the hospice model of care into other care settings. The LCP guides health care professionals to deliver best practice care to dying patients and their families/whānau in the last days and hours of life, irrespective of diagnosis or care setting.

**Multidisciplinary Team:** A multidisciplinary team consists of a team of professionals, including representatives of different disciplines, who coordinate the contributions of each profession, which are not considered to overlap, in order to improve patient care.

Members of a multidisciplinary team might include GPs, surgeons, medical or radiation oncologists, palliative care specialists, pastoral care workers, nurses, social workers, occupational therapists, physiotherapists, dieticians, volunteers, pharmacists or care assistants.

**Paediatric Palliative Care (PPC):** The World Health Organisation (WHO) definition of palliative care for children defines paediatric palliative care as “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 also apply to other paediatric chronic disorders):

- Palliative care for children is the active total care of the child’s body, mind and spirit, and also involves support for 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, psychosocial, 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 even in children’s homes.

Palliative Approach: A palliative approach embraces the World Health Organization definition of palliative care. It incorporates a positive and open attitude toward death and dying by all service providers working with patients and their families, and respects the wishes of patients in relation to their treatment and care.

Palliative Care: The World Health Organization defines palliative care as: an approach that improves the quality of life of patients and their families facing the problems associated with life-limiting or life-threatening conditions, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care: provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten nor postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patient’s illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of 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.

A New Zealand specific definition of palliative care is: Care for people of all ages with a life-limiting or life-threatening condition which aims to:

1. Optimise an individual’s quality of life until death by addressing the person’s physical, psychosocial, spiritual and cultural needs.
2. Support the individual’s family, whānau, and other caregivers where needed, through the illness and after death.

Palliative care is provided according to an individual’s need, and may be suitable whether death is days, weeks, months or occasionally even years away. It may be suitable sometimes when treatments are being given aimed at improving quantity of life. It should be available wherever the person may be. It should be provided by all health care professionals, supported, where necessary, by specialist palliative care services. Palliative care should be provided in such a way as to meet the unique needs of individuals from particular communities or groups. These include Māori, children and young people, immigrants, refugees, and those in isolated communities.

Palliative Care Network: To ensure the plan commences with appropriate oversight and resources a Palliative Care Network (PCN) based on the combined strengths of Arohanui Hospice, the Hospital Palliative Care Team, the Cancer and Palliative Care District Group, Central PHO and the Integrated Palliative Care Governance Group will be formed.

PCN will deliver the leadership to drive activity that:

- Steers the development of the Palliative Care Strategy implementation plan across the sector that is aligned with the MDHB Palliative Care Strategic Plan.
- Ensures all Palliative Care Clinical Governance Groups/Networks be merged into one or have formal links established via memoranda of understanding.

Palliative Care Partnership: The Palliative Care Partnership is a model developed and pioneered by Arohanui Hospice and Primary Care with the support funding from MidCentral DHB (a three year pilot) to enhance and promote integration of palliative care in the primary sector. The initiative at the time was ground-breaking and was led through quality coordinated health
care services, using both specialist services (Arohanui Hospice) and generalist services, with support from the management services organisation Compass Health Ltd. Care is delivered by a partnership between palliative care coordinators (augmented by specialist hospice clinicians), general practitioners, practice nurses, and supported by community district nurses.

The aims of the Palliative Care Partnership are:
  • To enhance access to palliative care for patients and families.
  • To increase knowledge of palliative care within General Practice Teams.
  • To build a supportive partnership between Community Palliative Care and Arohanui Hospice.
  • To maximise the use of Specialist Palliative Care.
  • To reduce cost as a barrier to access to Community Palliative Care.

Palliative Care Services: This term refers to any individual, team or organisation whose core work focuses on delivering palliative care, for example a hospice or hospital palliative care team.

Palliative Care System: This refers to palliative care services, primary palliative care providers and the other factors that enable them to deliver palliative care, such as communication and coordination between providers. Without these ‘other factors’ palliative care providers cannot function as part of a ‘system’. It is not simply the existence of primary palliative care providers and palliative care services that comprises the palliative care system; it is the links that exist between them that tie together ‘a system’. An Interdisciplinary Team approach to palliative care is one example of how such links can be developed and maintained.

Patient: A patient is the primary recipient of care. In the practice of palliative care, the patient together with their family and carers are the focus of care.

Primary Carer: The primary carer is generally in the close kin network of the patient and is usually self identified. The primary carer can be the patient’s spouse, child, another relative, family member or friend. They may be supported by other carers, but generally will take a primary role in the co-ordination and delivery of care and support to the patient. This person provides for the practical needs of the patient and takes on additional tasks that may be of a technical nature, to provide ongoing care for the patient, e.g. the administration of medications. They provide the primary support role for the patient at all levels of need.

Primary Palliative Care: Primary palliative care is provided by all individuals and organisations that deliver palliative care as a component of their service, but their substantive work is not in the care of people who are dying. It is palliative care provided for those affected by a life-limiting or life-threatening condition as an integral part of standard clinical practice by any healthcare professional who is not part of a specialist palliative care team.

In the context of end of life care, a primary palliative care provider is the principal medical, nursing or allied health professional who undertakes an ongoing role in the care of patients with a life-limiting or life-threatening condition. A primary palliative care provider may have a broad health focus or be specialised in a particular field of medicine. It is provided in the community by general practice teams, Māori health providers, allied health teams, district nurses, and residential care staff etc. It is provided in hospitals by general ward staff, as well as disease specific teams – for instance oncology, respiratory, renal and cardiac teams.

Primary palliative care providers assess and refer patients to specialist palliative care services when the patient’s needs exceed their services capability.

Quality care at the end of life is realised when strong networks exist between specialist palliative care providers, primary palliative care providers, support care providers and the community – working together to meet the needs of all people.

Specialist Palliative Care: Specialist palliative care is palliative care provided by those who have undergone specific training and/or accreditation in palliative care/medicine, working in the context of an expert interdisciplinary team of palliative care health professionals. Specialist palliative care may be provided by hospice or hospital based palliative care services where patients have access to at least medical and nursing palliative care specialists.

Specialist palliative care is delivered in two key ways in accordance with New Zealand Definition of Palliative Care.
  • Directly – to provide direct management and support of patients and families/whānau where more complex palliative care need exceeds the resources of the generalist provider. Specialist palliative care involvement with any patient and the family/whānau can be continuous or episodic depending on the changing need.
need in this context is defined as a level of need that exceeds the resources of the generalist team – this may be in any of the domains of care – physical, psychological, spiritual, etc.

- Indirectly – to provide advice, support, education and training of other health professionals and volunteers to support the generalist provision of palliative care provision.

Standards: A standard is something established as a measure or model to which other similar things should conform. There are three types of standards in health care: structure, process, and outcome standards. Structure refers to evaluation of the setting in which care is rendered and the resources that are available. Process refers to evaluation of the actual activities carried out by the care giver. Outcome refers to evaluation of the results of activities in which the nurse has been involved (what the result is for the patient). For example: the Hospice New Zealand Standards set out best practice in relation to the provision of end of life care in hospices. They identify the essential elements that need to be in place to ensure consistent quality end of life care across the hospice sector.

Supportive Care: Supportive care helps the patient and their family / whānau to cope with their condition and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease.

When the underlying disease has been identified as incurable, ‘Supportive Care’ would be best substituted with ‘Palliative Care’.

Terminal Condition: A progressive condition that has no cure and that can be reasonably expected to cause the death of a person within a foreseeable future. The definition is inclusive of both malignant and non-malignant conditions and ageing. Also refer to ‘Life-limiting condition’ and ‘Life-threatening condition’.

Whānau: Whānau means the extended family, family group, a familiar term of address to a number of people - in the modern context the term is sometimes used to include friends who may not have any kinship ties to other members.

Appendix 8: Acknowledgements

Acknowledgement and thanks to the many people across the MidCentral District Health Board and lower North Island who have attended the stakeholder and consumer workshops, the Māori hui, submitted questionnaires and been interviewed. These valued contributions have been instrumental in the process of developing the vision and goals for the MidCentral District Health Board Strategic Palliative Care Planning.

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- Dr Bruce Stewart, General Practitioner, Aorangi Health Centre and member of the Palliative Care Partnership Group
- Dr John Drake, General Practitioner, Cook Street Health Centre and Secretary (Manawatu) Royal College GPs
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• **Dr Joy Christison,** Executive Project Manager, Planning and Support, MidCentral District Health Board.

Disclaimers: While this document has been developed after consultation with many people, consideration should be given to the changing nature of the health environment. **Neither MDHB nor any other person associated with the preparation of this plan accepts responsibility for the results of any actions taken, or not taken, by any person as a result of anything contained in or omitted from this publication.**
We will seek to develop and maintain palliative and end of life care services of consistent high quality that reflect the vision and priorities of the people that we serve.