

# LIVING WELL, DYING WELL

A Strategy for a  
Palliative Care Approach

2017 – 2020



*In partnership with*

LOWER NORTH ISLAND  
**Palliative Care Managed Clinical Network**



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**Palliative Care Managed Clinical Network**

# Foreword

Many people have been involved in the development of this strategy document, which represents the passion of the people, whānau, consumers and community leaders who have given it the highest level of importance for the future provision of palliative care services. It is a result of the collaborative effort of the Lower North Island Palliative Care Managed Clinical Network engaging with many stakeholders, including consumers, across Wellington, Hutt Valley and Wairarapa districts. There is no single author – we are all contributors and accountable to advancing a common vision through our individual and collective actions.

It sets the direction of palliative care in the sub-region to improve the experience for people, whānau and their communities. The document focuses on a palliative care approach and how to better understand and respond to people's needs.

This strategic plan is specifically aimed at meeting the needs of all people who would benefit from a palliative approach. Over the next couple of decades New Zealand will see a dramatic change in the patterns of life, disease, dying and death. There will be more people dying each year; people will be dying at older ages and with a range of more chronic conditions and frailty. This increasing and changing demand has wide reaching implications for our wider society and health system, but especially our palliative care system.

Services do an excellent job of providing specialist palliative care – and this plan supports sustaining specialist palliative care – but we need to do a much better job of providing coordinated and individualised care for the large and growing number of patients for whom a palliative approach would be beneficial. This groups of patients, which is projected to increase by 60% in 2036, have not been in the forefront of our minds in planning palliative care services – and it is this group of patients whose needs this plan is principally intended to address.

The themes of the refreshed NZ Health Strategy (April 2016) were used to inform this strategy and are embedded in this document. People powered, care closer to home, value and high performance, one team and smart systems are all key drivers.

The ultimate goal of this palliative care strategy is for greater system integration that puts the patient and their whānau at the core of every decision that is made.

It represents a common consensus on a vision for palliative care across the sub-region and outlines the steps we need to take together to make that vision a reality. Members of the network will all use this document as a framework to engage more broadly with our colleagues and stakeholders to inform and implement change.

## **Adri Isbister**

Project Sponsor,  
*Chief Executive, Wairarapa DHB*



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# Section 1: Background and Context

## INTRODUCTION

There are a number of challenges facing our health care system, and in particular palliative care services across our sub-region. Evidence indicates there will be more people dying each year and more people dying in older age. Therefore the needs of the dying population will change as this older population becomes increasingly frail and with the presence of multiple comorbidities including dementia. As more patients identify their preferences for palliative care (with developments in Advanced Care Planning) it is likely that palliative patients will increasingly indicate a preference to die at home (currently this figure is two thirds of the palliative patient population). This will mean that future demand will increasingly be driven into community settings, primary care and aged residential care.

Our current health care system is primarily focused upon keeping people alive; however, more focus is needed on the quality of patients' living and dying. Although people are becoming more aware of hospice and palliative care services, health professionals do not always see dying as an integral part of the health system. In order to ensure that all people have access to a palliative approach in our sub-region, we must work to change attitudes towards death and dying. Recent Kings Fund research found health professionals must be able to talk about death and dying if we are to improve end of life care throughout our regions (Rachael Addicott, 2010).

There is overwhelming evidence indicating the need for a considerable shift in the way palliative care is organised and delivered at a sub-regional level. Carers, whānau and health care staff report that there is currently large variability in the range of services and supports for those nearing the end of life and those services are not always responsive to the needs of patients and their whānau. For some, particularly those that enter a hospice pathway, the experience for the most part is a positive one. However, for others, patients and their whānau are left to navigate the myriad of options available on their own, with often sub optimal outcomes. Our inability to support the needs of all those requiring such care must be addressed into the future.

We must also address the extent to which separate services are currently set up to work towards their own organisational priorities, and shift the dominance of vertical silos. Our funding and commissioning models are outdated, and support an insular approach to service delivery. It is essential to develop effective working partnerships between primary and specialist palliative care, whereby a sufficient specialist workforce can provide the support, advice and education to those providing primary palliative care so that a palliative approach to end of life care becomes 'everyone's business'.

Consequently, work is needed at both the sub-regional and district levels to ensure that all people in the Lower North Island "face death surrounded by those (they) love, feeling safe, comfortable and cared for" (Canadian Hospice Palliative Care Association, 2009). This strategy details a comprehensive integrated model of palliative care to align treatment with a patient/whānau's goals and preferences for care as they near the end of their lives. It seeks to improve the quality of palliative care services for adults in our sub-region, irrespective of their ethnicity, age, gender, locality or socio-economic status, and ensure that they have every opportunity to access services to meet their needs. This includes but is not limited to: Māori, members of the Pacific and Asian community, prisoners, immigrants, refugees, mental health patients as well as those with physical or intellectual disabilities.

The Lower North Island Palliative Care Managed Clinical Network (Network) was established in 2014 following a successful submission for funding from Health Workforce New Zealand (HWNZ) to address the probable gaps in palliative care service delivery across the sub-region. The network's vision is of palliative care services working in a seamless, integrated, cost effective way across all levels of primary, secondary and tertiary care to improve equitable access and care for patients and their whānau. In February 2016, the Network agreed its work programme to develop a Palliative Care Strategy for the sub-region, and include a future way of working.

## METHODOLOGY

This strategy was developed using a participatory process of engagement with key stakeholders (Appendix 2) and builds on earlier work carried out by the Network, as well as the programme of work to develop service proposals as part of the new initiatives funding to hospices for community focused palliative care services.

The results (summarized in Appendix 3) from focus groups with service providers across district areas; focus groups with carers/consumers; and interviews with the many stakeholders across the sub-region who interact with patients with palliative care needs and their whānau, were used to inform the strategic direction and the goals for this plan. Data was also derived from a variety of other sources including a comprehensive review and analysis of national and international literature, as well as a stock take analysis.

## WHAT IS PALLIATIVE CARE?

Palliative care is the care of people of all ages who have a life-limiting or life-threatening condition and aims to:

- Optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual and cultural needs.
- 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 and should be available wherever the person may be located. 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, prisoners, homeless and those in isolated communities. (Ministry of Health, 2015)

Palliative care can be provided to patients at any point on their journey irrespective of whether the goal of treatment is cure or palliation of symptoms. They can be provided by primary palliative care providers or specialist palliative care providers. Many individuals and health professionals do not differentiate between a palliative approach and the palliative care provided by specialist palliative care. Indeed, palliative care can occur at the same time as curative or life-prolonging treatment. Palliative care programs include psychosocial and spiritual care for patient and family; management of symptoms such as pain, fatigue, shortness of breath, depression, constipation, and nausea; support for complex decisions, such as discussions of goals, do not resuscitate (DNR) orders, and requests for treatment; and coordination of care across various health care settings (Kate Rowland, Dec 2010).

Throughout this document, we use the words palliative care and palliative approach to describe the above.

The diagram below (Figure 1) illustrates the different journeys that palliative care patients may take as they transition between primary and specialist palliative care, according to their needs or service expertise/experience.

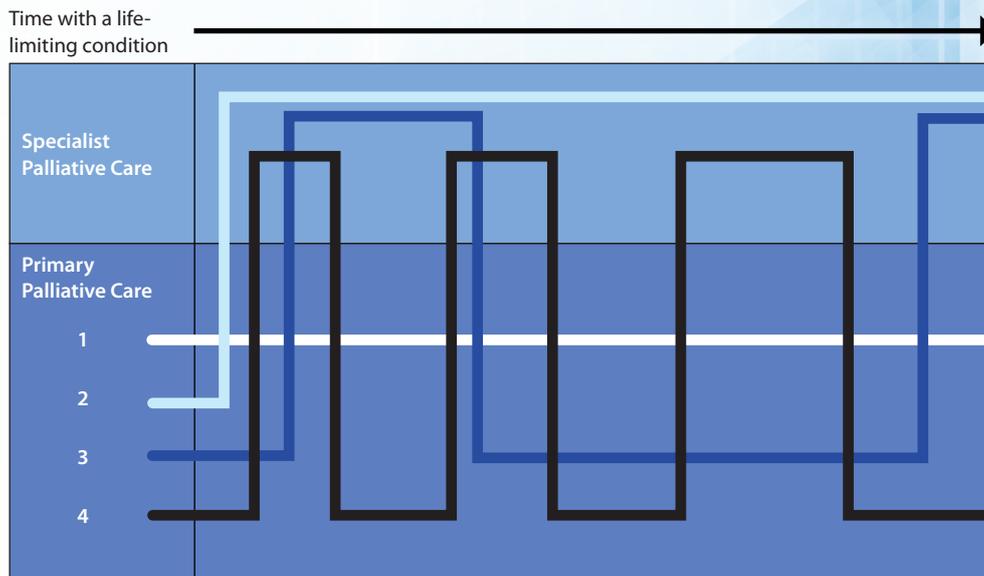


Figure 1: The relationships between primary palliative care and specialist palliative care

Source: Ministry of Health (2015a)

Four examples of patient journeys are illustrated:

- 1) All care is provided by the primary palliative care providers with no input required from specialist palliative care services.
- 2) Care is provided by specialist palliative care for the duration of the illness with little or no input from primary palliative care providers.
- 3) Initial involvement from specialist palliative care to guide a plan of care with 're-referral' during the deteriorating phase or during the last days of life.
- 4) Multiple episodes of specialist palliative care involvement during times of increased need/complexity, not necessarily during the last days of life.

## SUPPORTING AN INTEGRATED MODEL OF PALLIATIVE CARE

In 2014, the first ever global resolution on palliative care, World Health Assembly resolution WHA67.19, called upon WHO and Member States to improve access to palliative care as a core component of health systems, with an emphasis on primary health care and community/home-based care.

The Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand (Ministry of Health, 2012) provides a good framework for the composition and requirements of palliative care services that are appropriate for the New Zealand context. The Framework (see Figure 2) places the family and their whānau at the centre with primary care (the main providers of palliative care) providing the first level of care. Primary care providers work in an integrated (hub and spoke) way with secondary care providers, specialist palliative care providers and other providers. The family/whānau is critical in coordinating care and supporting the person requiring palliative care. This means that for many people, the need for palliative care can be met by their existing primary care provider (e.g. their general practitioner). The need for specialist palliative care services may be episodic or shared rather than required on an intensive basis.

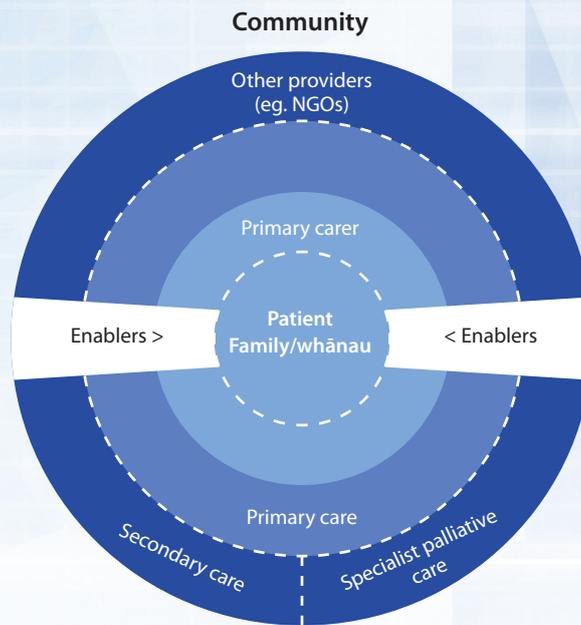


Figure 2: Framework for Integrated Adult Palliative Care Services

The underlying intent of the Framework is equity of access and quality care at the appropriate level of care. Patients and their whānau are not necessarily concerned if the care they receive is delivered by primary or specialist providers, but more that the right services are delivered by the right people, at the right time, in the place that is right for the patient and their whānau. The Framework emphasises the importance of partnership and integration where primary palliative care providers work in collaboration with specialist palliative care providers and other providers to provide the palliative care services that are required for the DHB population in a seamless way.

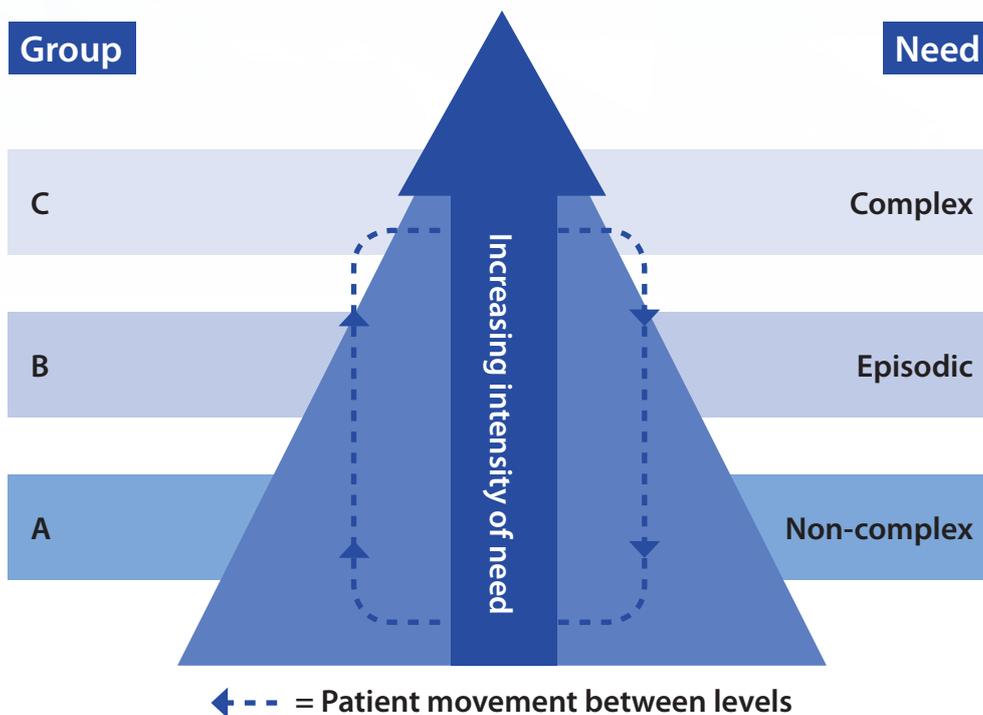


Figure 3: Levels of Need for Palliative Care (Ministry of Health, 2012)

Figure 3 represents the differing needs of the palliative care population. The majority of people requiring palliative or end of life care have non-complex needs and are managed successfully by their existing primary palliative care providers (Group A) and do not need to access specialist palliative care. Patients in Group B require episodic access to specialist services, although continued to be managed by their primary palliative care provider in a shared care model. As complexity and need increases, standard palliative care clinical practice guidelines may not meet the needs of Group C and this small group of patients are likely to require on-going care by specialist palliative services. This strategy addresses the needs of all those within these levels (Figure 3).

Palliative care services have traditionally been offered once all the options for active treatment have been exhausted and patients have come to the end stage of their disease (usually cancer). There are a number of patients who would benefit from a palliative approach much sooner than they currently experience, with early conversations providing guidance and support on the range of services available as the patient moves through various stages of dying.

The traditional model of palliative care is shown in the first diagram in Figure 4. The second diagram illustrates how an integrated curative and palliative approach differs. New evidence for the effectiveness of palliative care together with the emerging needs of people living with serious chronic illness, have shown a palliative care conversation and options should start earlier than previously thought. Many patients can benefit from receiving life prolonging or disease modifying treatments while simultaneously having their palliative care needs addressed.

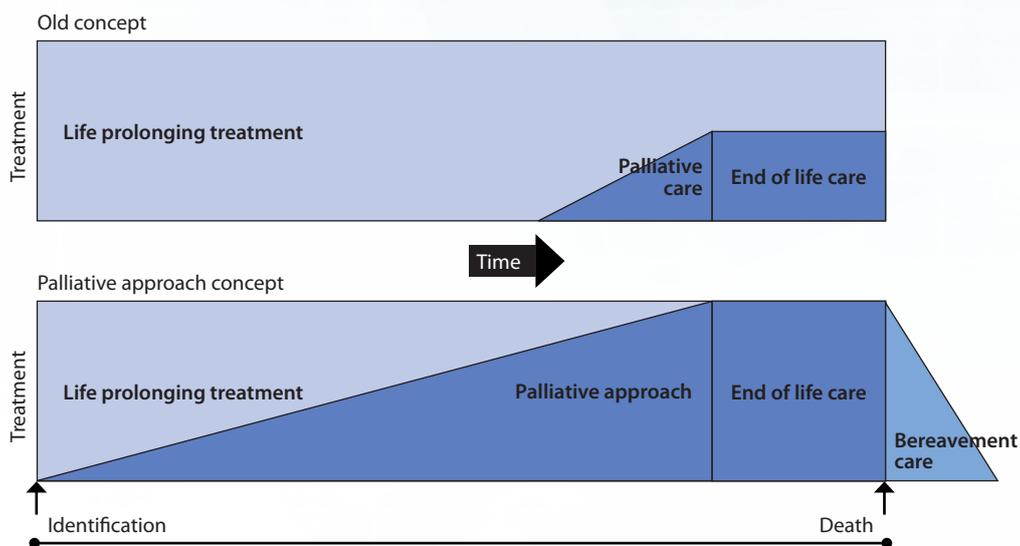


Figure 4: Palliative Care Models

Historically palliative care has been linked to cancer services, however, it is now recognised that, as New Zealanders live with chronic disease, patients dying from other conditions (e.g. renal failure, motor neurone disease, respiratory conditions) will all benefit from high quality palliative care services.

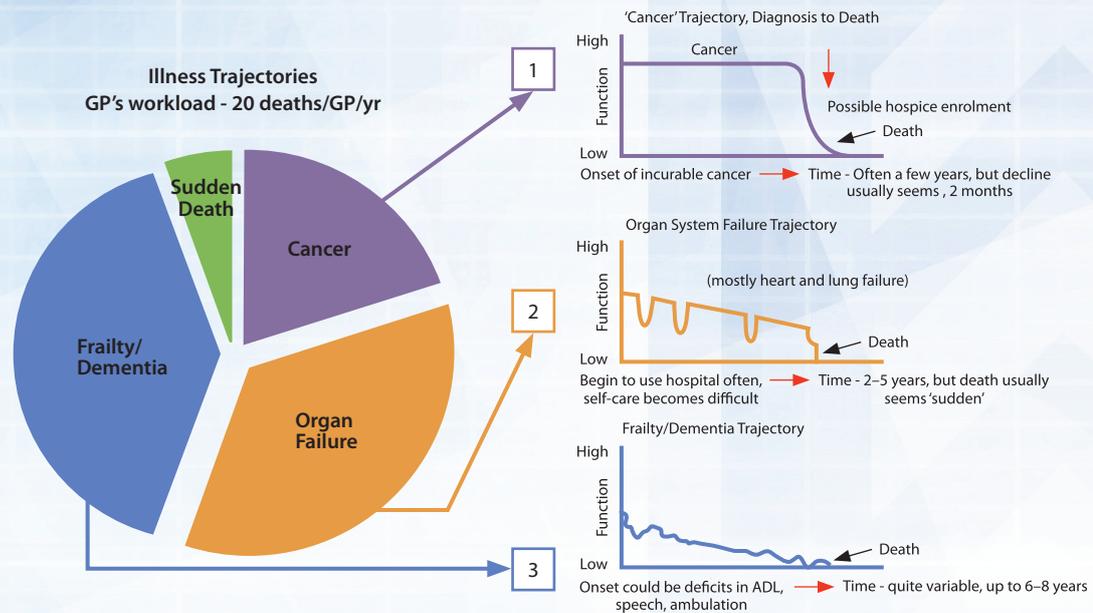


Figure 5: Disease Profile of Chronic Terminal Disease in Older People  
Source: Lynn et al, Edited Higginson, 2004

Figure 5 outlines the various trajectories of chronic illness with the first showing the typical profile for cancer patients with rapid progress from diagnosis to treatment to dying. The second trajectory shapes the profile for organ failure with a more erratic decline. This might occur with renal disease, heart disease, chronic obstructive pulmonary disease (COPD), liver disease, or general neurological diseases such as motor neurone disease, Parkinson's disease or multiple sclerosis. Palliative care services may become involved after a 'serious episode' and then remain involved for the remainder of the illness.

The final trajectory shows gradual decline with 'prolonged dwindling' over time; these include frailty, dementia or cerebral vascular accident (CVA/stroke). It is vital that discussions with individuals living with dementia are started as early as possible to ensure that whilst they still have mental capacity they can discuss how they would like the later stages managed. This would ensure that these patients receive the right information about their disease necessary to make advance decisions about prioritising their resources, including time, psychological energy and financial resources. This can cause issues for those funding and delivering palliative care services, as for many patients it is very difficult to define when a patient becomes 'palliative'.

Finally, it is important to note that palliative symptoms in patients with chronic terminal illness can often go unrecognised or under treated i.e. patients with dementia who experience pain are often not recognised. This strategy extends a palliative approach to include all those that would benefit. That is, a palliative approach should be available to everyone over the course of their terminal illness regardless of who is the principal provider of their health care.

## FUTURE DEMAND FOR PALLIATIVE CARE

It is estimated that across the 3DHB sub-region there will be approximately 3,050 deaths in 2016, this number is projected to increase to 4,190 deaths in 2036 (see Figure 6). It is projected that although there will be minimal growth in those deaths where specialist palliative care services will be involved, the biggest increase will be amongst those patients involved with primary palliative care services (1337 to 2146).

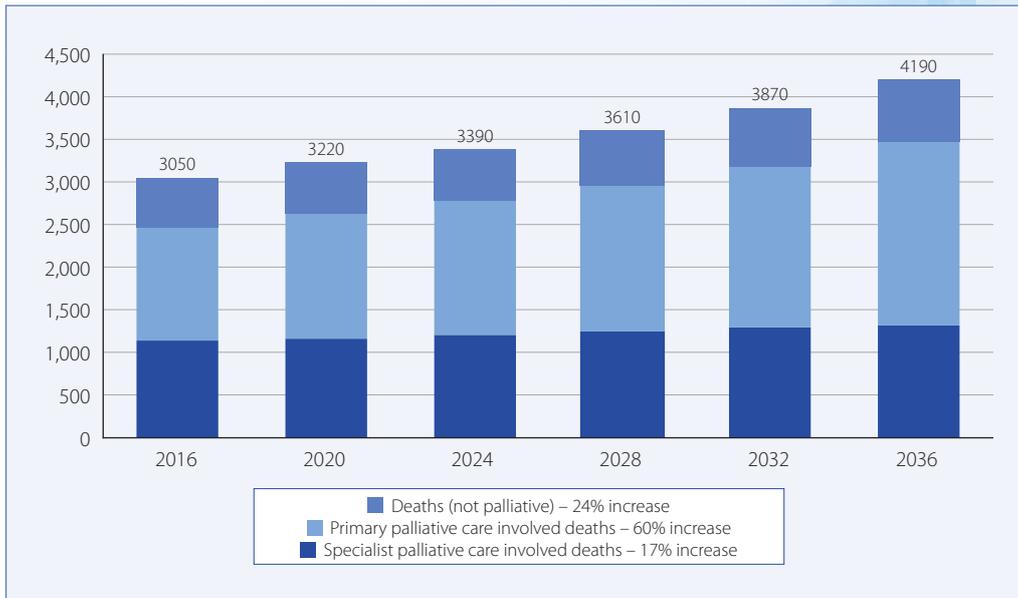


Figure 6: Projected deaths in the 3 DHB region – 2016 to 2036

Patients who do not receive specialist palliative care (denoted as primary palliative care in Figure 6) are already in a healthcare environment where many of their needs are being proactively managed by the primary healthcare team (check-ups, tests, reminders etc). In a wider context than palliative care, patients who are at risk of deterioration might already have a plan of care developed with their primary palliative care provider to meet this need. Figures 7 (a, b and c) below illustrate this growth for each district.

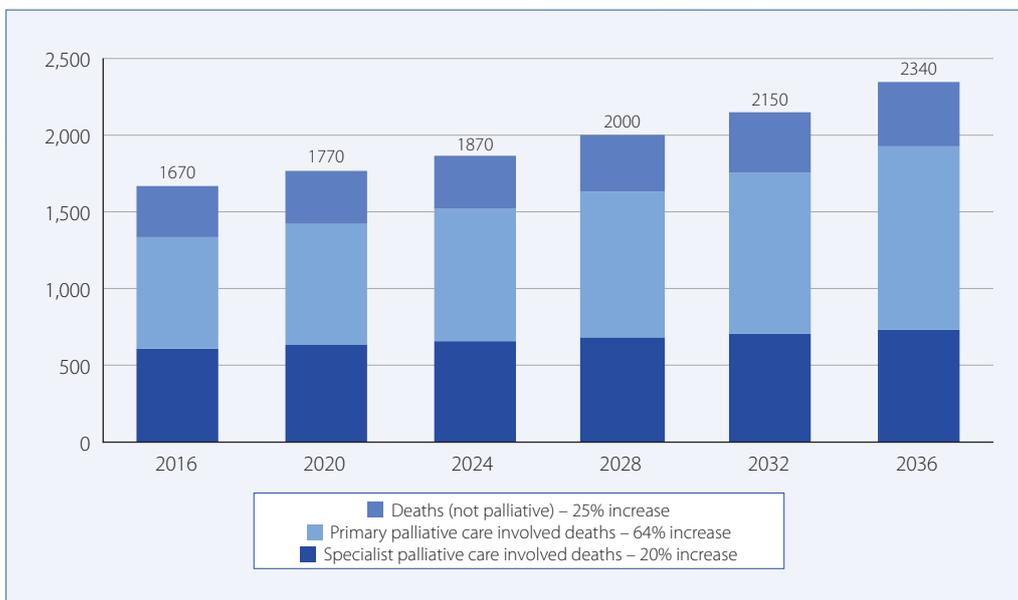


Figure 7a: Projected deaths in Capital & Coast DHB

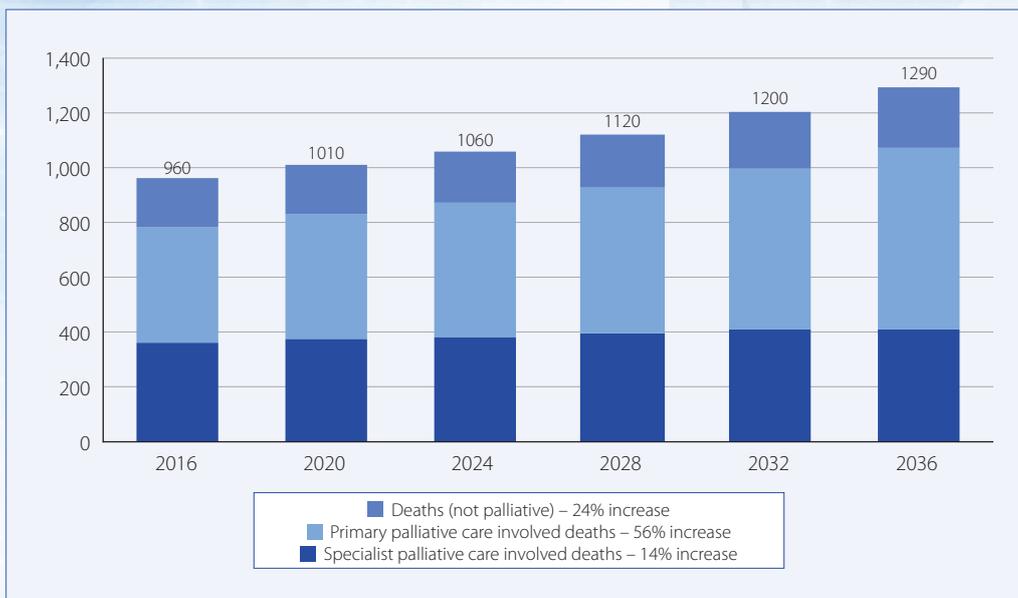


Figure 7b: Projected deaths in Hutt DHB

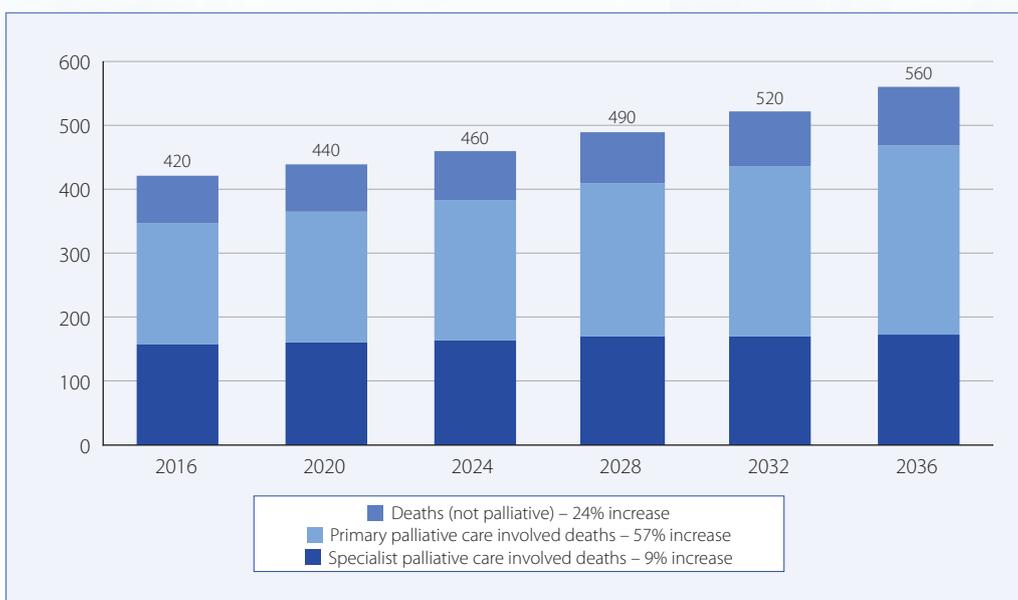


Figure 7c: Projected deaths in Wairarapa DHB

## Ageing population and increased need

As our population ages so demand for palliative care increases, as does the nature of that demand (See Appendix 4).

By 2038 there will be approximately 3624 people per annum needing a palliative approach in this sub-region, with approximately one third likely to be receiving support from specialist palliative care services. It is projected that the number of older people 75+ years needing palliative care will almost double by 2038 – from an estimated 1,632 in 2016 to 3,069 in 2038. The number of people under 74 years needing palliative care is expected to decrease, from an estimated 836 in 2016 to 555 in 2038 (McLeod, June 2016).

Wairarapa DHB has the oldest population of the three DHBs, with 9,000 people (20% of the population) aged over 65 years. This distribution is roughly the same across all three of Wairarapa's territorial authorities. The proportion of Wairarapa DHB's population who are 65+ years is projected to increase from 19% in 2013 to 32% in 2038. The largest increases in people aged 65+ years are expected to be in the Asian and Other ethnic groups.

In Hutt Valley DHB, 21,000 people (14%) are aged over 65 years. This distribution is roughly the same across Lower and Upper Hutt. The proportion of Hutt Valley DHB's population who are 65+ years is projected to increase from 13% in 2013 to 25% in 2038. The largest increases in people aged 65+ years are expected to be in the Other and Asian ethnic groups.

In Capital and Coast DHB, 39,400 people (12%) are aged over 65 years. The Kapiti Coast has the highest proportion of older people of the territorial authorities in the CCDHB region, with one in four people (11,100) aged over 65 years. In Wellington and Porirua, approximately one in ten people (5,800 and 19,700, respectively) are aged over 65 years. The proportion of CCDHB's population who are 65+ years is projected to increase from 12% in 2013 to 22% in 2038. The largest increases in people aged 65+ years are expected to be in the Other and Asian ethnic groups.

## Palliative Care for Māori

There is anecdotal evidence that Māori do not receive the benefits of a palliative approach early enough, and do not equitably access palliative care services that are available. The reasons for this are complex, and likely to be in part due to the fact that current palliative care models of care do not specifically address Māori needs, or the differing views on death and dying by Māori.

Maori (and Pacific people) experience a higher incidence of chronic and degenerative disease and die at an earlier age than those of other ethnicities. This higher incidence combined with "palliative care treatments that prolong life mean whānau are increasingly being called upon to provide end of life care for months or years. Caring requires families to balance their paid work, their caring responsibilities and other aspects of their lives. When carers have their own health issues, or face financial or housing challenges, caring for whānau at the end of life requires resilience. Whakapapa, shared cultural and familial values, and a commitment to the process of caring for a loved person and their whānau as a whole both strengthen and encourage a way forward." (Tess Moeke- Maxwell, 2014)

The Ministry of Health publication *Palliative Care and Māori from a Health Literacy Perspective* (2014) identified approaches to enhance Māori health literacy and access to palliative care. This publication identified health system, organisational, and patient and whānau level factors that have the potential to influence the achievement of health literacy and access to palliative care for Māori patients and their whānau. Key measures to improve Māori health literacy in palliative care and service delivery relate to strengthening a Māori focus and presence, and a whānau orientation within the palliative care system. This should be reflected in:

- the constitution of the workforce (i.e., Māori representation)
- increased coordination between providers, including Māori community organisations
- the availability of quality palliative care information that is tailored to Māori
- quality ethnicity data that is routinely analysed and reported to inform palliative care planning and decision-making
- health professionals who engage in health literacy and cultural competence training that enables them to communicate effectively with Māori and support the integration of Māori culture into palliative care
- specific Māori navigator roles
- palliative care services that reflect the values and preferences of Māori
- high health literacy among Māori in palliative care.

Health literacy for Māori in the palliative care context is a complex topic. This plan contributes to achieving health literacy within palliative care systems, organisations and health professionals in order to realise the potential of palliative care for Māori. That is, palliative care that supports whānau, optimises quality of life for patients including the maintenance of their mana, and enables preferred death experiences that give free expression to cultural values and practices relating to death and dying.

Te Ara Whakapiri (MoH, 2015) provides principles and guidance specifically related to the care of the person in their last days of life. It defines what all New Zealanders can expect as they come to the end of their life and is based upon the Te Whare Tapa Whā model of care.

### Palliative Care for Diverse Cultural Groups

The experiences outlined for Māori are also relevant to other diverse cultural groups in the Lower North Island sub-region, including the many different Pacific and Asian communities. It is well documented that the health outcomes of Pacific and Asian peoples are worse when compared with the general population in New Zealand and are often the result of poor utilisation and access to palliative care.

While each Pacific and Asian culture within New Zealand has its own experiences of death and dying, there are some similarities between cultures. These experiences are similar to those outlined for Māori above and approaches to enhance health literacy and improve access to palliative care will have benefits for the wider population.

## OUR CURRENT PALLIATIVE CARE SERVICES

The 3 DHBs within our sub-region currently spend just under \$13 million per annum on a range of specific palliative care services. In Capital and Coast DHB, the level of funding is \$7.2m, for Hutt DHB it is \$4.4m and for Wairarapa DHB it is \$1.4m. However, there are other services which are provided to palliative care patients that are not included in these figures such as Home Based Support Services, who provide personal cares and household management to palliative patients. It also excludes the majority of services provided to such patients in public hospitals, ARC facilities and general practice teams (except in Wairarapa) as palliative care patients are not as distinctly identified as such. The range of services currently provided across the sub-region are summarised in Table 1 on the next page.

Table 1: Summary of palliative care services in the 3DHB region

Level of Care	Provider	Type of care
Primary Palliative Care Providers	General practice teams – General practitioners (GP) and practice nurses	Primary care in the community
	Aged residential care facilities	Continuing care and rest home care
	District nursing services	Community (home based) nursing care
	General ward staff at public hospital, as well as disease specific teams for instance respiratory, renal, cardiology, oncology teams)	Inpatient and outpatient palliative care (non-specialist)
	DHB allied health staff (e.g. occupational therapists, physiotherapists, social workers, dietician etc.)	Assessment for equipment, therapy, access to support services
	NGOs and volunteer organisations, carer support agencies	Support care
Specialist Palliative Care Providers	Kahukura & Te Omanga Hospice <sup>1</sup>	Each region has available: Community care Day care Inpatient care <sup>2</sup> Hospital teams <sup>3</sup>
	Te Omanga Hospice – HVDHB	
	Mary Potter Hospice – CCDHB	
	CCDHB	
	HVDHB	
Hospice Wairarapa	Bereavement support, counselling, massage, podiatry, wellness therapies, biographies, art table, day respite programme, caregiver programme.	

**Specialist community nursing care** for specialist palliative care patients in CCDHB is provided by the district nursing teams with support from specialist palliative care nurses. Wairarapa DHB has a dedicated palliative care team. Te Omanga Hospice provides 24/7 nursing support to patients under the care of the hospice in the HVDHB district.

**Inpatient care for palliative patients** is provided by both Mary Potter Hospice and Te Omanga Hospice for hospice patients. These inpatient units also provide respite care. Wairarapa district does not have a dedicated inpatient unit but patients that have complex symptom management that need to be addressed in a specialist inpatient unit, can be admitted to the Te Omanga Hospice inpatient unit.

**Specialist hospital palliative care teams** are based in both Hutt Hospital and Wellington Regional Hospital and support primary palliative care colleagues to address palliative care need within the hospital setting. Wairarapa Palliative care team provide a daily in reach service to the hospital wards and a visiting consultant from Te Omanga will do weekly inpatient domiciliary visits. Kenepuru Hospital, CCDHB does not have access to a specialist palliative care team.

**General practice team** involvement varies across the sub-region. For patients living in Wairarapa and Capital and Coast DHBs, the General Practitioner (GP) remains the lead physician throughout the journey. In Wairarapa, the GP provides all medical care for all but a few patients who need specialist medical support on an ad hoc basis.

1 Specialist palliative care assessment, advice and education only in Wairarapa DHB district

2 Wairarapa does not have an inpatient unit.

3 Hutt and Wellington Regional Hospital only.

For CCDHB patients, the hospice physicians work closely with the primary care team, and only take over medical care where the GP requests this. In the Hutt Valley district, patients remain under the care of their GP until they reach the final stages of life, at which stage some are transferred to specialist palliative care. More recently, GPs in the Hutt Valley have been supported to remain the lead carer for patients with non-complex palliative care needs although this development is still in the early stages.

**ARC facilities** across the sub-region manage the majority of patients with palliative care needs, either in a residential care or a respite care capacity.

**Home based support** for palliative patients to assist with personal cares is provided by various home based support providers. Eligibility for access to these and aged residential care (for either residential or respite care) is through an assessment by Needs Assessment and Service Coordination (NASC) services within each respective DHB.

Recent funding for new initiatives (Service Development Proposal, Palliative Care Innovative Funding, 2016) will see the implementation of a number of initiatives to support closer linkages between specialist and primary palliative care providers. One initiative that is being introduced across CCDHB and HVDHB is free visits for palliative care patients and their whānau to meet with their GP to develop an individualised palliative care plan. This initiative is currently being trialed and will be modified as opportunities for improvements arise.

## Advance Care Planning

Advance Care Planning (ACP) is a key focus nationally and regionally. ACP is a process of discussion and shared planning for future health care. The planning process assists the individual to identify their personal beliefs and values and incorporate them into plans for their future health care. 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. The ACP process may result in the person choosing to write an advance care plan and/or an advance directive and/or to appoint an enduring power of attorney (EPA).

The 3DHB sub-regional Advance Care Planning (ACP) Steering Group has approved a plan to forward the ACP project with two tiers of activity. Tier one builds on the work in the sub-region over the last few years to increase awareness through educating and engaging both public and health professionals about what ACP is and what the benefits are. Tier two will focus on more intensive ACP work with specific services and practices in the sub-region. The goal with these providers will be to embed ACP into models of practice by developing workforce competence and confidence as well as the systems, processes and measures that are needed for discussing and recording ACP conversations.

## A FUTURE MODEL OF PALLIATIVE CARE - A NEW WAY OF WORKING

Based on the inequity of access across the sub-region as well as increasing future demand with limited resources, we need to move towards a consistent, coordinated and integrated model of palliative care in the Lower North Island. The future way of working will facilitate a coherent and seamless patient journey through the palliative care system. There will be improved collaboration and sharing of knowledge, expertise and resources across the system to create opportunities for operational efficiency and collective wisdom.

A future model of care will ensure that a palliative approach is made available to palliative care patients and their whānau from the time it is first identified end of life is approaching. There will be earlier identification and recognition by health professionals about curative treatment moving to palliative care and earlier conversations to enable patients and their whānau to make informed life choices. These honest conversations will enable earlier planning, with multiple disciplines if necessary, to ensure patients' palliative care needs are met 24 hours, seven days a week.

This new way of working will be characterized by seamless patient care delivered efficiently and effectively by one integrated team; service provision will be based upon needs and; a palliative care approach will be firmly embedded in and led by primary care with support from specialists; as well as clearly defined roles and responsibilities for those involved along the patients journey.<sup>4</sup>

## Seamless and holistic patient care

There is overwhelming evidence that good palliative care has the same elements as good chronic disease management and care. A future palliative care system should be integrated with care and support right from the time when it is first identified that end of life is approaching, through the last days of life and into bereavement. Partnerships and integration between all service providers, volunteers, patients and whānau will create a seamless journey for patients. Communication, collaboration and sharing of resources are fundamental to addressing patient need and achieving efficiency.

Palliative care provided in a holistic way embraces the elements of wairua (spiritual), hinengaro (thoughts and feelings), tinana (physical) and whānau (family) (Durie, 1985) and ensures that these work together in harmony. Holistic care will include a range of allied health and psychosocial supports such as counselling, social work, spiritual care and bereavement support.

## Service provision is based on need

The majority of patients in need of palliative care are non-complex to moderately complex and their needs can, and will be adequately managed by their primary palliative care provider. This may include indirect or direct (generally episodic) involvement of specialist providers. The relatively small proportion of patients with highly complex needs might receive direct specialist involvement, similar to what occurs in most other health care specialties and subspecialties.

## One integrated care team

To enable shared care, each patient will have one virtual integrated inter-disciplinary care team who will ensure that the needs of the patient and their whānau are identified and met. The patient, whānau and any informal carers are crucial elements of this team. Each patient will have an individualised palliative care plan which will encompass all settings in which the patient receives care. This care plan will clearly identify all the key members that are directly involved in caring for the patient, as well as a designated lead palliative carer (LPC) and a palliative care facilitator (PCF). The LPC is responsible for clinical/medical oversight and the PCF is responsible for facilitating services to meet need.

Additional membership of this team will vary depending on other services that might be required to identify and address the expectations and needs of the patient, whānau or informal carers. The team may typically include one or more doctors, nurses, social workers, spiritual advisers, pharmacists, and personal care workers with other disciplines from voluntary and NGO sector becoming part of the team as resources permit (Ministry of Health, 2015). Team members may transition in and out of the caring team as they are needed i.e. locality palliative care specialists (see below) may be called upon to undertake assessment and/or provide episodic support/care during an acute phase.

<sup>4</sup> Example of patient experience along future palliative care continuum is outlined in Appendix 6.

## Led by primary care

The general practice team will drive a palliative approach, and be well supported by the specialists within the Locality Palliative Care team, as well as responsive nursing, home based support and allied health services. A member of the general practice team will usually be the designated 'lead palliative carer' if the patient lives at home, and will be the first point of contact for patients and their whānau throughout their journey. They will ensure, in partnership with the palliative care facilitator, that the individualised palliative care plan details the arrangements for medical care and support 24 hours/ 7 days a week. After hours care may be provided by a coordinated suite of professionals whose core role includes a 24 hours /7 days a week service.

The Lead Palliative Carer (LPC) may change as the patients' needs change, and when this change occurs there will be clear transfer of care, i.e. initially the GP may be the LPC but as needs increase this may change episodically to a community nurse or specialist palliative care nurse, although the GP should always remain involved through the journey. If the patient lives in an ARC facility, the LPC may still be a member from the general practice team or alternatively can be the registered nurse from the facility.

## Supported by specialists in palliative care

Primary care providers will have access to expert consultation and advice from Palliative Care Specialists. These specialists will work together to support a cluster of GP practices, ARC facilities, and other health care providers like District Nursing, depending on the population within the locality. These teams will potentially include a gerontologist, a practice nurse with a special interest in palliative care, a gerontology nurse, social worker /allied health representative, nurse practitioner and nurse prescriber, specialist pharmacist, a palliative medicine specialist and nurse from the hospice community team. Their main role will be to make sure specialist knowledge is available for frontline workers. They will build and strengthen relationships and over time develop trust and confidence. This will improve the coordination between services and enhance the seamless experience of care for patients. These specialists will indirectly, and at times directly, support primary providers in their locality with facilitating interdisciplinary review of palliative care patients, case reviews and educational support. Certain specialists within this locality support team i.e. palliative medicine specialist will be contactable 24 hours/7 days a week.

Assessments and planning for patients with complex needs and multiple comorbidities may be undertaken in collaboration with this group of specialists and facilitated by the palliative care facilitator. They will be well equipped to offer advice and support in improving the patients experience across all settings, and especially where the patient has unresolved complex needs that cannot be met by the caring team – these needs may be physical, psychological, social and /or spiritual (Association for Palliative Medicine , December 2012).

## Clearly defined roles and responsibilities

The new model of care will clearly define and agree the roles and responsibilities of the various providers including the roles of the lead carer and lead facilitator. In our current models, assessment, coordination and service delivery are often carried out by different people or different organisations. Under the new model, these functions will be pulled together into one agreed assessment and planning process which will be synchronized by the same person to maximize the connectivity between services for patients. This will help facilitate improved communication, collaboration and sharing of resources to address need and achieve efficiency.

# Section 2: Vision, principles and goals

## OUR VISION - TE AHO

*'All people who require a palliative approach live well and die well irrespective of their condition or care setting'.*

## PRINCIPLES

The following principles will guide the implementation of the strategy:

- Patient and their families/whānau are at the centre of all care
- Patients and family/whānau can expect and receive high quality care wherever they may be
- Patients and family/whānau will be supported so they can die well

## GOALS

The following outlines each step, and respective goal, of the pathway for the patient nearing the end of their life from the identification of their palliative care needs through to care after death (Rachael Addicott, 2010)



- 1. Patients and their whānau have timely identification that end of life is approaching, and early discussions to ensure they make informed choices about what, where and how they receive care and support (Self Management)**
- 2. Patients and their whānau receive coordinated assessment, care planning and review throughout their illness (Planning)**
- 3. Patients and their whānau experience equitable and seamless care through coordinated service provision (Integration)**
- 4. Patients and their whānau experience high quality services in different settings (Quality)**
- 5. Care in the last days of life is comprehensive, with good symptom control, is in the most appropriate setting in the company of whānau and/or friends (Last days of life)**
- 6. Whanau experience high quality care after death (After death support)**

For each of these goals, there are a number of desired outcomes, actions to achieve these goals as well as measures to determine if the goals have been achieved. Where relevant, statements attained from whānau and stakeholders through the consultation process are included to support each goal.

### **Goal 1: Patients and their whānau have timely identification that end of life is approaching, and early discussions to ensure they make informed choices about what, where and how they receive care and support (Self Management)**

To enable self management patients and their whānau need early discussions and information to enable early involvement of a palliative approach.

#### **Timely identification**

Many health professionals struggle with the dilemma of when to inform patients that their condition is life limiting and recognising that a palliative approach might be beneficial alongside their treatment. For many people this discussion is left until they are in the final months or weeks of life. There is new evidence that early involvement of a palliative approach improves quality of life and allows patients and whānau to better adjust. The traditional care model is to aggressively treat to both prolong patients' lives and ameliorate their symptom burden. Three recent studies in Boston showed early integration of a palliative approach for oncology patients with a poor prognosis showed improvements in outcomes, ranging from quality of life, mood, patient satisfaction, prognostic understanding, health service use, and possible length of survival. "Despite the barriers to the involvement of palliative care in the care of patients with advanced cancer, strong evidence now supports integrated palliative and oncology care." (Temel, 2014)

***"I realise now that hospice is more than just dying and that they could have supported us earlier. It is not just the end of the road."***

An open conversation about palliative approaches to support patients and whānau from the time when it is first identified that end of life is approaching is crucial.

***"It's the transition that is the issue - pre planning is important. No one has had the discussion with the patient and family."***

These early, timely conversations not only allow patients and whānau to adjust, but they allow patients to make informed life choices, as well as helping to identify any psychosocial needs that may need addressing.

***"What we experienced with our father was not palliative care as it could and should have been. Our family was robbed of what might have been a very different experience of our father's last days. We appreciate that human grief is a different experience for every person and we knew he was at the end of his life. This should have been a moment of grace and of family experiencing love and support at his end. Instead we felt exhausted, empty and alone."***

## Early discussions as end of life approaches

There is ambivalence amongst some healthcare professionals to discuss dying, end of life care and death. Clinicians are often ill equipped and possibly reluctant to undertake these difficult conversations. All clinicians should be confident and competent in raising the issues as they arise and responding to questions from patients and whānau about prognosis, care preferences and options for the future. Training to improve the definition of diagnosis and to undertake conversations about planning as end of life approaches need to occur.

## Information

Families experience frustration through lack of knowledge about what is available and often feel disempowered until they are referred to specialist palliative care services. The aim is not to stop curative treatment upon diagnosis of a terminal disease, but to have early conversations about what patients and their whānau might experience over the course of the illness.

***“We now believe palliative care not to be what it could be. This should have been a moment of grace at the end... 1 ½ years on our family is still fractured, and we are not sure when treatment became palliative care.”***

***“Early information about what to expect would have been more helpful.”***

***“You can do the whole thing yourself... My wife and I were in control – we just need you to support us.”***

The public and health professional understanding about palliative care has to change to allow the palliative care journey to begin much earlier (Kate Rowland, Dec 2010). By providing information and education to the public and promoting community resilience and self-management of care, we raise the profile of palliative and end-of-life care.

Patients and whānau need early information about their condition; what they can expect to occur over the coming weeks and months; the services and supports available to them; as well as information about how they can access them. This aligns with the future direction for the NZ Health Strategy to develop a ‘smart system – He atamai te whakaraupapa’ whereby services can make use of technologies such as shared care plans, e-referrals, and telehealth to ensure people have access to the information they need to enhance empowerment. The Health Navigator website<sup>5</sup> provides patient information and self care resources on hundreds of health conditions, and palliative care resources for patients should be placed here, with health professionals directing people to this website.

<sup>5</sup> <http://www.healthnavigator.org.nz/>

***“We were surprised to hear the term palliative care being used by a doctor as if the family were all aware that this was the stage things were at.”***

***“No one knew what was going on – and if they did, they didn’t communicate this to us – not being clear when the treatment became palliative care and not receiving guidance on how best to manage this.”***

As a patient's condition changes, whānau may be told their whānau member cannot remain in their current environment i.e. in hospital, and that they need to urgently find an alternative i.e. seek a residential care facility or increase level of support. Frequently they are not given the context of why and what level of care they need to find.

***“We were waiting for tests and spaces to become available in rehab, then we were later told these were ‘pointless’ as it would not change anything in his care, and it was unlikely he would return home.”***

### Desired Outcomes

- Health professionals involved in palliative care are skilled in identifying people entering the end stage of their life and are well prepared at having early discussions with patients and their whānau about the choices they have.
- Health professionals, patients and whānau are aware of all palliative care services and supports for people and their families.
- Patients and their whānau are better prepared for their palliative care journey and have increased control and self-management over aspects of this journey.

### Actions

1. Develop a method/pathway to support identification of people as their end of life approaches and implementation of lead palliative care model.
2. Implement individualised palliative care planning in primary care as a mechanism to identify and access services
3. Promote the Health Navigator website as the basis for information to support patients, whānau throughout the journey including after death support.

### Measuring success

- Increase in competence, capability and comfort of health professionals having early conversations with people and their whānau requiring palliative care
- Palliative patients and their whānau will have recorded early conversations about a palliative care approach to enable adjustment and planning of their lives, advanced care plan and goals of care.
- Patients and their whānau will have accessed information and support in relation to palliative care and satisfaction with journey start and choices.

## Goal 2: Patients and their whānau receive coordinated assessment, care planning and review throughout their palliative care journey (Planning)

People nearing their end of life should have their needs assessed by an appropriate individual. Those needs should be recorded in the form of a care plan and reviewed as their condition changes. The care plan should identify patient's preferences about care delivery and place of death. These records should be accessible by multiple health professionals from across the palliative care system, so the plan can be followed irrespective of where the patient is. An identified lead palliative carer (LPC) should be identified as part of the care plan. Patients and their whānau should be involved in this process as well as in all decisions that involve planning and provision of care.

Advance care planning can also be a component of this process, so that patients can express their preference for end of life care. It should be noted that advance care plans should be updated continually as the needs of patients change.

### Assessment & Care Planning

Providing for initial and ongoing assessment of needs is an important part of care planning. Currently there are multiple assessment processes that patients are required to undergo and work is required to refine the assessment and care planning processes to reduce duplication. This will require shared information technology to ensure access to shared records.

Individualised palliative care planning is being introduced in primary care for patients that would benefit from a palliative approach. Patients and their whānau receive a free consultation(s) with their primary care team to consider all aspects of care over the next 12 months, including medical, nursing, physical, spiritual, psychosocial care. This is an opportunity to begin the early conversation for patients and their whānau. This process will identify the lead palliative carer (LPC) and trigger the engagement of a palliative care facilitator (PCF).

As the patient experiences diminishing health, the palliative care facilitator will initiate a palliative care assessment. This will be undertaken by an appropriately skilled health professional and include those already involved in the care of the patient (for example, oncology and respiratory specialists, Māori health provider, social worker, dietician, OT). This comprehensive assessment will evaluate the needs, strengths and preferences of the palliative patient and their whānau and build upon the individualised care plan.

Planning tools such as the Gold Standards Framework, (National Gold Standards Framework Centre 2011) the Supportive and Palliative Care Indicators Tool (SPICCT™) or the interRAI Palliative Care assessment (interRAI 2014) can assist the PCF to identify those people who need a transition of care whether this is the place of care, the levels of care and/or the goals of care.

The nominated LPC will always be involved in the assessment and care planning. This LPC is most likely to be a member of the general practice team (GP or practice nurse), but might be a specialty nurse (eg oncology, respiratory, cardiac), Māori health provider nurse or health worker, or aged residential care provider, if this is more appropriate, but the GP will remain lead medical carer. The LPC identified to undertake this coordination role, will not necessarily provide the care themselves, but will be responsible for developing and coordinating the care plan and for facilitating (where appropriate through the palliative care facilitator) the services and resources identified in the plan.

Specifically the LPC will be responsible for ensuring that medical, social and spiritual needs are met, this might include domiciliary nursing, GP visits, social work input, hospice or other specialist assessment and advice and support services as required. They might also link patients/whānau to income/financial support, respite care and community and voluntary services.

## Discharge planning and service transitions

The shift to providing more end of life care in the community and home requires health professionals to work in a different way. Ward staff for instance, require support to ensure patients are appropriately discharged to their preferred place of care, and that the necessary supports are in place in a timely manner to allow for this. Enhanced discharge planning for complex cases will support ward staff to conduct assessments in more instances and allow planning for end of life care to be delivered in the individual's preferred location.

Transition between health services such as public hospital and aged residential care facilities present challenges for patients. Hospital-based care teams, aged residential care teams and primary care teams have different health care systems that are geographically separated and use isolated health information systems. Generally patients and whanau experience excellent patient care within the services they access. However, if and when patients do transfer, the transition between services is interspersed with inconsistent information. Information that is provided is often provided by those who do not have good enough knowledge and end up providing inaccurate information. A fundamental change is required for transitioning between services. Discharge from hospital is a particular concern for family and almost all stakeholders we interviewed would like to see improvement. Examples included:

***“Unfortunately no care plan or notes were transferred from the hospital to the rest home. We were asked several times by staff if we knew what medications Dad had been on, which we did not. The rest home doctor did not visit until the following day so it was 24 hours before any pain relief or sedation could be provided for Dad who seemed to have worsened with the move.”***

***“Mum was sent home alone after 3 days instead of the planned week after 8 hour surgery - I'm home alone with her and I've got no medication.”***

While the information systems are improving and shared care platforms edge closer, this separation creates significant obstacles to communication, resulting in poor handover of the care plan. Additionally there can be a lack of understanding of the capacity and capability of the service that the patient is being discharged to, resulting in essential medication not being available, or inadequate supports such as equipment being available. Consequently, patient care suffers, and often, patients recently discharged return to the hospital for further care.

***“It's the transition that is the issue - pre planning is important. No one has had the discussion with the patient and family.”***

It is important that patients at discharge have access and availability of their medications in a timely manner.

## Desired Outcomes

- An individualised palliative care plan is developed in conjunction with the person and their whānau and is available to them and their health and care teams with an Identified lead palliative carer and linked to a palliative care facilitator to support the co-ordination of the person's care
- Suitably experienced health professionals carry out comprehensive assessment of the palliative care needs of a person. The integrated care team can further contribute and develop this as needed.
- Review of a patient's health and care needs occur in a timely manner whenever the patient's condition changes, and the care plan is then updated
- Duplication of assessment and service provision is avoided and transition between services is safe and easy for the patient and whanau

## Actions

4. Consolidate current assessment tools and processes across multiple providers into one agreed assessment tool that allows access to a full complement of services.
5. Implement a consistent palliative care pathway across all services within a district that supports service transitions and transfer of patients between services.

## Measuring success

- Patients identified as palliative will have one comprehensive palliative care assessment/care plan/goals of care with an identified lead palliative carer and palliative care facilitator for their palliative care
- The patients care team of interdisciplinary health professionals will have access to and be able to contribute to the assessment/care plan/goals of care and subsequent reviews
- Patients do not have assessment duplicated by different services but different services contribute to one assessment and transitions between services feels seamless to the patient and their whānau

## Goal 3: Patients and their whānau experience equitable and seamless care through coordinated service provision (Integration)

Once a care plan has been developed and communicated, the provision of care under the care plan requires strong collaboration and coordination across the range of local providers. Poor coordination of care is the largest obstacle to achieving the care preferences of patients and their whānau.

Coordination needs to occur at various levels – within teams, across teams, within organisations and across organisations. This strategy proposes a single point of facilitation through which services can be coordinated that has a dedicated helpline for people nearing the end of their lives.

Seamless care for patients requires those involved in planning, funding and the provision of services to have a shared vision, employ a combination of processes and mechanisms and ensure that the patient's perspective remains a central principle throughout. Our palliative care services will feature:

- the patient enfolded by a seamless system of service delivery, achieved by productive relationships between and among the various providers of palliative care
- a Whānau Ora approach to build on the strengths and resilience of families/whānau and ensure there is respect for their beliefs and values
- active support for vulnerable population groups.

### Single point of entry

For patients to experience seamless care, once it has been identified that a patient would benefit from a palliative care approach, a single point of entry for service facilitation and access is required. This will need to be well documented and understood by all health professionals and the wider community. This single point of service facilitation will enable access to all domiciliary nursing, support services, family/care support, and primary and specialist palliative care services. Referral to this single point can be made by referrers and patients/whānau at any stage of the patient's journey. In the early stages of the patient's journey, this may be as simple as sharing the individualised palliative care plan as a means of communicating the patient's status and preparing for support to move quickly as and when need arises. Where referral is not made by the GP, the PCF will contact the primary care team to include them in the process. This approach is working successfully in Wairarapa for most patients, and should be expanded to both HVDHB and CCDHB districts. This could be locality based and be part of the local delivery alliance arrangements.

This strategic plan seeks to embed a palliative approach throughout health services, so that primary care clinicians can provide continuity of care throughout a person's illness, with the support of specialist palliative care services. It is possible that services and funding streams for palliative care could be accessed through the same channels as other health and disability services.

The palliative care facilitator (PCF) will facilitate access to a range of services including equipment, end of life packages of care, nursing services, allied health, home and community support services, ARC facilities, respite, 24/7 support, prescribing services, specialist doctors and nurses, informal carers/Kaiawhina and volunteers.

To support the various providers in providing end of life care and support, it is proposed that this function is responsible for:

- Receiving referrals
- Notifying and communicating with the GP
- Identifying who is already involved
- Facilitating assessment and ongoing case review
- Identifying and closely liaising with the lead palliative carer (LPC)
- Providing administrative support to the LPC in the delivery of the care plan
- Arranging a range of packages of care and support services as required by agreed care plan
- Holding and administering equipment

Most importantly, the PCF function will support the coordination of care by providing a link between lead palliative carer and the necessary support services.

### After hours care and support

After hours care and support is problematic. The needs of palliative care patients and their whānau continue 24 hours, 7 days a week, through weekends and statutory holidays. Individualised palliative care plans will detail the arrangements for medical care and support 24 hours/ 7 days a week. After hours care could be provided by a coordinated suite of professionals whose core role includes a 24 hours /7 days a week service. This planning and coordination of care is particularly vital to avoid unnecessary hospitalisation at the end of life as these services play a critical role in managing the care of patients in the community outside of normal working hours. These services can provide emergency and planned visits to patients homes (including a prescriber), as well as emotional support and guidance to patients and carers over the telephone during after hour periods.

Care planning will formalise a coordination and case management role that is at present frequently undertaken by community based health professionals. However, there is likely to be some impact on workloads, with

consequent resource considerations. Additional resources may also be required to provide culturally appropriate coordination of services for Māori. Detailed service specifications and an implementation plan will be developed as part of the configuration of services. Clinical pathways, including after hours care, will be available on the 3DHB Health Pathways website to support care planning for those involved in the patients care.

The different technology platforms across the sub-region are of concern and awareness about the importance and value of shared care platforms is increasing, and Manage my Health is now becoming available to some health professionals. Shared care planning utilising Manage my Health needs to be available to all those involved in the patient's care, both to view and to contribute. Patients, whānau and providers want to be able to check who is visiting the home and work together to minimise visits and maximise care.

### Desired Outcomes

- Palliative care provision that is equitable across the whole of the population that the health systems serve
- Palliative care professionals and services that are aware of and address service access disparities for their local population
- Palliative care services that collaborate between primary, secondary and specialist services with a named lead palliative care professional co-ordinating service provision
- Palliative care that is well co-ordinated and seamless for the patient and their whānau
- Māori and Pacific services that are integrated with other services

### Actions

6. Implement a local single point of service facilitation to access a wide range of comprehensive wrap-around palliative care services
7. Establish and implement locality palliative care specialists and case collaboration models to create a clear and formalised way of working across the palliative care system
8. Implement shared care planning across the 3 districts and enable access to all relevant health providers

### Measuring success

- Single point of service facilitation in each district is implemented
- Patients have equal access to palliative care services across all parts of the community, whatever their ethnicities and socio economic situations
- Palliative care system is responsive to different cultural need across the population
- Palliative care services and provision is coordinated and seamless for patients and their whānau
- Providers of palliative care have integrated systems and processes with robust communication

## Goal 4: High quality sustainable services are delivered (Quality)

People nearing the end of their lives might need to access a complex combination of different services from a range of different providers. These services need to be provided across a range of different care settings (hospital, aged care, hospices, and community) but also prisons, hostels for the homeless and homes for those with disabilities.

Providing high quality care in these various settings requires the implementation of quality tools (e.g. Hospice NZ Standards for Palliative Care (Hospice New Zealand, 2012) and the Gold Standards Framework (The Gold Standards Framework National Central Team , v25)), coordinated 24/7 responsive community services, and robust

and consistent workforce training and education including identification of patient's needs, communication skills, and the physical management of patients nearing the end of their lives.

### Enabling care at home

*"I'm dying and I want to go home."*

Many people want to die at home but this will always be dependant on the person's and whānau circumstances, capacity and capability. For most this is not possible without supports that are currently difficult to organise. To enable dying at home, we need to provide responsive coordination and palliative care planning, access to respite care, home based support and whānau support. Service delivery requires a lead carer that can respond quickly to rapidly changing end of life needs by coordinating patient requirements such as equipment, carers, and domiciliary health providers – district nursing, hospice nursing and home support carers. Enabling this change may require a reallocation of current resources.

Developing and implementing system wide training for whānau and informal carers is necessary to empower care and self care. Those caring for patients can be trained to give injections and administer medication. The processes and support to enable this will need to be improved so that, when issues arise they can be managed safely. Concerted efforts to supporting carers to minimise carer fatigue will need to be made.

Medication protocols are also required to support patients and carers managing these in the home and for surplus medications to be safely managed. All health professionals involved in their care have responsibility to ask questions about and manage surplus medications.

### Hospitals

Although it is acknowledged that, given the choice, most people would choose to die in their own homes, it may be appropriate for some patients approaching end of life to be treated and to die in acute settings. Data projections indicate that 28% of deaths, in 2016 of people needing palliative care will die in a public hospital and it is likely that this figure will remain the same in 2038 (MacLeod, 2016). It is crucial to ensure that care delivered in these settings is both compassionate and patient centred. Hospital palliative care teams already play a key role to develop and support the primary palliative care skills of hospital teams. In the future model, this will continue and they will provide essential advice and support to the LPC and PCF roles.

### Aged Residential Care Facilities

Many aged residential care facilities are committed to enabling their residents to remain in this setting as they near the end of their lives, if that was their expressed preference. This could include sourcing additional specialist equipment, liaising with health and social care professionals, ensuring that there was sufficient staff capacity to provide particular attention to those residents very close to death.

### Hospice

Patients and whānau experience of using hospice services is very good across the sub region. The role of hospice in the inpatient support and management of people with complex palliative care needs will continue to remain an essential component of palliative care in the future.

Specialist palliative care services already play an important role in supporting the primary palliative care service, (including assessment and development of care plans) providing advice and education, episodic specialist consults, respite, management of patients with complex palliative care needs and end-of-life care. With the growing trajectory of people who will require palliative care support as people age, the role of hospice will also likely change to increase their support of the primary care and aged residential care teams to better manage patients in the home through changes in their model of care.

*“Instead of a Park Royal for some, we need a Holiday Inn for all”*

### Workforce approach

Patients with similar needs currently experience varying service levels depending on which service they are accessing. This plan puts emphasis on the provision of high quality primary palliative care, provided through an integrated network of carers, volunteers, and health professionals from primary care, community services, aged residential care, secondary health services and specialist palliative care services. This network of palliative care providers will work in partnership and be underpinned by palliative care training for all providers, commitment to common palliative care standards, common assessment methodology, and a single shared plan of care for each dying person.

The palliative care workforce (medical specialists, nurses, allied health practitioners, and home and personal care workers) is a vulnerable sector as this is a maturing and ageing group. Although this is a concern for the whole of health, it is particularly relevant to palliative care. There is also a shortage of palliative medicine specialists and a forecast shortage of specialist nurses, GPs and Māori health workers.

There is considerable potential to better utilise the skills of the allied health and pharmacy workforce in palliative care. The carer and support workforce, including volunteers and those working in ‘compassionate communities’, are a fundamental component of current specialist palliative care services, and a workforce development approach needs to recognise the role of volunteers and ensure they are adequately prepared and supported.

A renewed workforce approach is needed to ensure the provision of a consistent high standard of care. We will develop a palliative care approach across all health services through workforce development and training, and through the adoption of a recognised care pathway for the dying. On-going education in palliative care will be required for all health professionals who are closely involved in the care of patients with end of life needs.

We need to build capability and capacity in primary palliative care services to enable all those who would benefit from a palliative approach to receive high quality services appropriate to their needs. Simultaneously a concerted effort to maintain sufficient capacity in the specialist workforce is needed in order to provide the necessary support, advice and education. A sub-regional stocktake to ascertain workforce capacity would inform a workforce development programme that will:

- actively advance expertise amongst providers of primary palliative care services (European Association for Palliative Care, 2016);
- explore rotating of nurses through specialist palliative care services, district nursing service and primary care;
- mentoring or secondment programmes for nursing and medical graduates;
- ensure a culturally competent workforce to accommodate diverse personal, cultural and spiritual customs and values;
- build and grow the non-regulated workforce with a particular focus on Māori;

- develop, train and support the informal carer and volunteer workforces;
- support sub-regional approaches to workforce development including e-learning, face to face mentoring and support, resource development, training of medical and nursing staff in primary and specialist services;
- enable supportive work practices such as mentoring, case collaboration, specialist partnership staff working alongside primary providers; and
- enhance the utilisation of the skills of allied health professionals, pharmacists and specialist palliative care nurses.

Specialist palliative care nurses offer a range of skills, from assessment and care planning and may initially participate in individualised palliative care planning conversations in primary care. Over time this support may reduce as primary care providers gain palliative care expertise, skills and confidence.

While approximately 43% of people suitable for a palliative approach die in aged residential care facilities, many facilities struggle with the provision of after hour's medical care for their residents, particularly for unexpected changes in conditions and prescribing needs. These services will be supported by the locality palliative care specialists.

### Clinical governance

Clinical governance is a framework through which organisations are accountable for continually improving the quality of their services and safeguarding high standards of care by creating an environment in which clinical excellence will flourish (Sally G, 1998). Clinical governance in conjunction with an agreed quality framework ensures the highest possible safety and quality of care (O'Rourke I, 2003). It provides a set of mechanisms to encourage people to work in teams to improve their workplace processes and performance. It represents an opportunity to emphasise systematically the importance of a range of ideas drawn from disciplines such as clinical practice improvement, organisational behaviour, management and quality and safety and use these in enhancing clinical and managerial processes (Sally G, 1998).

Effective system clinical wide governance will be required for the successful implementation of this plan. On-going service design and implementation will be led with effective clinical leadership and governance structure. A commitment to maintain the Lower North Island Managed Clinical Network for Palliative Care could be explored.

### Quality Framework

Services will be supported by a culture of continuous innovation, quality improvement and learning that is embedded in the service design. To support equitable access to quality care, we will implement a quality framework that spans across the range of services. A quality framework sets out reasonable expectations of quality care for people that would benefit from a palliative approach, and their whānau. The recent draft palliative care services review highlights the need for an agreed national set of core outcome, quality and activity data. It proposes the development of an agreed outcomes framework.

### Desired Outcomes

- A workforce with capability and capacity to deliver standardised high quality palliative care across the whole of the health and care system
- Palliative care education and resources that are available to all professionals, carers and community across the sub-region
- System wide clinical governance, quality framework and monitoring processes utilised in palliative care
- Sustainable and skilled workforce across the whole of health

## Actions

9. Complete a sub-regional workforce plan that considers the current gaps and future workforce requirements of specialists, nurses, and the allied health workforce. Such a Plan would identify ways in which the workforce across the sub region could best leverage off each other's skills and expertise, and work together to strengthen the workforce capacity and capability.
10. Develop and implement a sub-regional workforce training and professional development programme based upon evidence based practice and quality measures to include:
  - Clinical skills and prescribing management
  - Cultural perspectives for end of life
  - End of life recognition, planning and conversations for health professionals across the system
  - Specialist partnership staff working in primary care settings
  - Informal carers, volunteers and kaiawhina
11. Establish a system wide network/service level alliance in each district to oversee local implementation of the strategy
12. Implement the nationally agreed quality standards and increase the visibility of palliative care quality indicators in accountability arrangements, as proposed in the draft service review (Ministry of Health, June 2016). These would include:
  - A regional platform for the exchange, comparison and benchmarking of patient focussed best practice between providers and linked to clinical governance.
  - Linkages to education and research in palliative care.
13. Implement a patient/whānau satisfaction survey following initial referral/planning and the VOICES (Views of Informal carers – Evaluation of Services) survey to establish a baseline of consumer experience and measure improvement over time.

## Measuring success

- Curriculum and development programme for health professionals within primary and specialist palliative care providers across the palliative care system is in place and utilised
- Specialist services/primary provider partnership agreements in place and utilised
- Active palliative care clinical governance, quality framework and standards monitoring are in place
- Patients and whānau report a 'good death' in satisfaction surveys

## **Goal 5: Care in the last days of life is comprehensive, with good symptom control, is in the most appropriate setting in the company of family and friends (Last Days of Life)**

The identification and management of care needs in the last days of a patient's life requires particular attention. This phase can be identified by various signs and it is vital for the professionals involved with the patient to recognise and to communicate this to the patients and their whānau. It is also imperative that this recognition is then followed up by the making of any changes necessary in how care is provided. The care given to patients during their very last days of life is very much dependant upon health and social care professionals having previously taken steps to identify, discuss and assess palliative care needs and also planning and reviewing care.

Te Ara Whakapiri (MoH, 2015) provides a statement of guiding principles and components for the care of adults in their last days of life across all settings, including the home, residential care facilities, hospitals and hospices. It will be used as a foundation document to inform end of life care and education.

### Preparation for the dying phase

Early preparation is important to meet the support and care needs of patients that are nearing the end of their life as well as their whānau/carers. Care professionals that have built up a relationship with a patient over time are familiar with patients, and are able to observe signs of deterioration or other changes in physical and cognitive capacity. Being aware of significant changes in strength, appetite or cognitive function prompts care professionals to take the actions necessary to prepare for end of life care. For example, ARC facility staff will inform the GP and organise anticipatory medication to avoid inappropriate admissions to hospital at the end of life.

Once a patient has been identified as nearing the end of life, it is necessary to review the advance care plan continually to check that all the resources are in place to provide the preferred end of life care services. Information sharing and communication amongst various teams is critical at this stage, and the palliative care facilitator will need to be closely involved to ensure the right resources and services are available.

### Compassionate and person-centred care

A core aim of this strategy is that patients experience a 'good death'. To achieve this patients are treated as individuals with dignity and respect, without pain and other symptoms, in familiar surroundings (where possible), and in the company of close family and /or friends. Preparation underpinned by communication between various providers is key to compassionate and person centred care.

### Desired Outcomes

- Health professionals across the health systems recognise the transition of the patient towards the last days of life and are able to communicate this to the patient, whānau, carers and the wider health team occurs in a skilled manner
- Care provision is comprehensive and supportive for the end of life phase in the most appropriate and preferred place for the patient and their whanau
- Patients and their whānau are treated as individuals, with dignity and respect and given emotional support throughout the end of life phase
- Whanau and carers are well informed, have their needs supported, included in decisions and supported to provide physical care if they wish.

### Actions

14. Ensure a wide range of responsive and comprehensive service options exist, including 24 hours/ 7 days a week carer, specialist, nursing and medical support, and psycho-social support for those patients and their whanau in the last days of life.

### Measuring Success

- End of life transition moments are recognised, documented and well communicated.
- Health professionals feel well prepared and supported for patient's end of life care
- End of life care is resourced appropriately
- Support for a patient's whānau through the end of life phase is appropriate for them

## Goal 6: Whānau experience high quality care after death (After Death Support)

### Care of the person after death

It is clear that when a person dies, high quality end of life care also means providing due care and attention to the patient and their whānau after death, especially if there are any cultural or religious procedures that must be carried out after death. This would be outlined in the care plan of the deceased (as well as the wishes of the whānau). The whānau will also be supported with practical information that they may need such as obtaining a death certificate and registering the death. Efforts should be made to ensure a dignified and respectful farewell. Although this will vary across different settings, the common principle is showing respect for the individual who has died.

### Bereavement Support

The period after a person has died is obviously a sensitive time for any whānau as well as those involved in providing palliative care, including staff and volunteers. Currently support for bereavement care is limited, and for palliative care patients this is further limited and variable depending upon whether the patient is receiving services from a hospice or their GP. There is often comprehensive support for hospice patients but little for others. Having early discussions and enabling planning about what to do are crucial for all those involved. It is important to note that in reality, bereavement support begins earlier along the trajectory for both the palliative care patient themselves and their whānau in order to prepare and adjust to the impending loss.

Providing end of life care has tremendous emotional impact upon a whānau and anyone involved in a patients care needs to be sufficiently trained in communication skills and be able to signpost whānau to a source of support, such as carers group or bereavement support services.

The emotional impact of providing palliative care can also be felt by paid and unpaid staff working closely with someone who is dying. Recognising the emotions of staff is important to ensure that their motivation levels are sustained and that they have the emotional and physical capacity to continue to look after other patients.

### Desired Outcomes

- Due care and attention is provided to the patient and their whānau after death
- Bereaved whānau, formal and informal carers will have access to good quality information about the practical steps they need to consider and where to access emotional support if required.

### Actions

15. Implement culturally appropriate bereavement support services and enable equitable access for those in need of support after death

### Measuring Success

- Bereaved whānau have appropriate and accurate information about the post death requirements.
- Formal, and informal carers and whānau are aware of and able to access bereavement support.

## Section 3: Next Steps – Implementing the strategy

Achieving the future vision for palliative care across the sub-region will clearly involve a period of evolutionary change over the next five years. Despite the gaps and barriers of the current palliative care system there are some pockets of effective integration and partnership working in each district. The implementation plan will build on this and expand it across services to achieve further integration and enhance the coordination of palliative care services.

Implementation will be achieved through local, or sub-regional alliancing arrangements which will be responsible for driving agreed actions to improve the patient and whanau journey. These will ensure clinically-led service development and implementation is within a “best for patient, best for system” framework. The alliances are also expected to build on the work currently underway to implement the primary care component of the new initiatives funding for primary care announced in Budget 2015.

The alliancing arrangements will give consideration of the issues relevant to each district, i.e. the rural needs for some Wairarapa DHB patients, in order to:

- provide system-level advice, oversight, monitoring and evaluation of the implementation of the Strategy, ensuring connectedness and a whole of system approach to alliance activities;
- provide whole of system clinical governance with resourcing, which is in touch with region wide sector activities;
- support a distributed model of care (more emphasis on non-specialist /primary services);
- maximise opportunities to implement the 3DHB Palliative Care Strategy;
- create shared leadership for all palliative care initiatives across the region;
- agree the work, activity and services that need to be provided to meet the alliance objectives.

In order to ensure a stable and enduring transition to the future model, it will be important to protect the gains and relationships that have already been made in developing this strategy. The sector is motivated and committed to the coordinated change that is needed as we, locally, regionally and nationally, face the challenge of the increasing and changing nature of future demand.

# Appendices

## APPENDIX 1: Glossary of Definitions and Concepts (Ministry of Health, 2015)

**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.

**Individualised Palliative Care Planning:** Individualised palliative care planning is being introduced in primary care for patients that would benefit from a palliative approach. Patients and their whānau receive a free consultation(s) with their primary care team to consider all aspects of care over the next 12 months, including medical, nursing, physical, spiritual, psychosocial care. This is an opportunity to begin the early conversation for patients and their whānau, identify a lead palliative carer and will trigger the engagement of a palliative care facilitator. This information will also be used to inform the initial palliative care assessment.

**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 however they need to, 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:

- An explicit statement of the goals and key elements of care based on evidence, best practice, and patients' expectations and their characteristics;
- the facilitation of the communication among the team members and with patients and families;
- the coordination of the care process by coordinating the roles and sequencing the activities of the multidisciplinary care team, patients and their relatives;
- the documentation, monitoring, and evaluation of variances and outcomes; and
- 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 document 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.]

**Compassionate Communities:** A compassionate community is where a community provides support to someone who is dying has been introduced overseas. The community could be family, neighbours, local organisations, churches, local businesses or people living in a particular area. People in a compassionate community help care for a dying person through small acts of compassion, supporting the dying person and their family during their end of life, often enabling them to die well and, if possible, at home.

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

**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:** is that period of time prior to death but the duration can never be precisely defined in advance ((European Association for Palliative Care, 2016)).<sup>4</sup>

Recognising and identifying those people who are at risk of dying at some point in the year ahead enables the health and social systems to respond to the deteriorating person and their families/whānau/carers in a holistic and comprehensive way.

Although prognostication is inherently difficult, being better able to predict when people are reaching the end of life phase, whatever their diagnosis, makes it more likely that they receive well-coordinated, high quality care. This is more about the health care system meeting needs than giving defined timescales. The focus is on anticipating the needs of the person and families/whānau/carers so that the right care can be provided at the right time. This is more important than working out the exact time remaining and leads to better proactive care in alignment with preferences.

The end of life period is triggered by a transition in the place of care, levels of care and/or goals of care. The major transition to the end of life period is in changing the focus on the person from curative and restorative care, which aims to extend the quantity of life, to palliative care which aims to improve the quality of life.

**End of Life Care:** is the care guided by the person's needs and goals, and is the responsibility of all who work within the health sector.

Planning for coordinated end of life care across all levels of the health system is essential for District Health Boards. Tools such as the Gold Standards Framework, (National Gold Standards Framework Centre 2011) the Supportive and Palliative Care Indicators Tool (SPICT™) (Boyd and Murray 2014) or the interRAI Palliative Care assessment (interRAI 2014) can assist to identify those people who need a transition of care. This may include a transition in the place of care, levels of care and/or goals of care.

End of Life Care covers the full range of clinical services provided. It incorporates treatments, programmes, policies, initiatives, benefits and entitlements that are provided for the person and their family/whānau/carers from the point when a life-threatening condition or illness is diagnosed until after the death, to include the care of the deceased person's body and care of their family/whānau/carers.

**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 document 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.

**Integrated Care Team:** each patient will have one virtual integrated, inter-disciplinary care team who will ensure that the needs of the patient and their whānau are identified and met. The patient, whānau and any informal carers are crucial elements of this team. Each patient will have an individualised palliative care plan which will encompass all settings in which the patient receives care. This plan will clearly identify all the key members that are directly involved in caring for the patient, as well as a designated lead palliative carer (LPC) and a palliative care facilitator (PCF). The LPC is responsible for clinical/medical oversight and the PCF is responsible for coordinating services to meet need.

Additional membership of this team will vary depending on other services that might be required to identify and address the expectations and needs of the patient, whānau or informal carers. The team could typically include one or more doctors, nurses, social workers, spiritual advisers, pharmacists, and personal care workers with other disciplines becoming part of the team as resources permit (Ministry of Health, 2015). Team members may transition in and out of the caring team as they are needed i.e. locality palliative care specialists (see below) may be called upon to undertake assessment and/or provide episodic support/care during an acute phase.

**interRAI (Palliative Care) Assessment Tools (interRAI stands for International Resident Assessment Instrument)** provide a standardised, comprehensive clinical assessment of a palliative patient's medical and support needs and can provide information to help write tailor-made care plans. From July 2015 the interRAI became the mandatory clinical assessment tool for nurses to use in residential aged care facilities in NZ. A pilot project is currently underway to test the use of the interRAI Palliative Care assessment and care planning tools in three District Health Boards (Hawkes Bay, Mid Central and Canterbury) in the home based community setting. The findings will be used to inform requirements for a wider implementation of this tool across New Zealand.

**Lead Palliative Carer (LPC):** This is the lead carer in the community for palliative care patients and is the first point of contact for patients and their whānau. They will ensure, in partnership with the palliative care facilitator, that the individualised Palliative Care Plan details the arrangements for medical care and support 24 hours/ 7 days a week. This person takes the responsibility for the lead medical care for the patient and likely to be aGP, practice nurse or registered nurse (if the patient resides in an Aged Residential Care facility).

**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.]

**Locality Palliative Care Specialists:** Locality based palliative care specialists will support primary palliative care providers with expert consultation and advice. These specialists will work together to support a cluster of GP practices and ARC facilities, depending on the population within the locality. These virtual teams could include a gerontologist, a practice nurse with a special interest in palliative care, a gerontology nurse, allied health worker, clinical pharmacist, a palliative medicine specialist and nurse from the hospice community team. Their main role will be to make sure specialist knowledge is available for frontline workers. They will build and strengthen relationships and over time develop trust and confidence. This will improve the coordination between services and enhance the seamless experience of care for patients. These experts will indirectly, and at times directly, support primary providers in their locality with facilitating interdisciplinary review of palliative care patients, case reviews and educational support. Certain specialist's within this locality support team i.e. palliative medicine specialist will be contactable 24 hours/7 days a week.

**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. A palliative approach aims to improve the quality of life for individuals with a life-limiting illness and their families, by reducing their suffering through early identification, assessment and treatment of pain, physical, cultural, psychological, social, and spiritual needs.

Underlying the philosophy of a palliative approach is a positive and open attitude towards death and dying. The promotion of a more open approach to discussions of death and dying between health care professionals, patients and their whanau facilitates identification of their wishes regarding end-of-life care.

A palliative approach is not confined to the end stages of an illness. Instead, a palliative approach provides a focus on active comfort care and a positive approach to reducing an individual's symptoms and distress, which facilitates patients' and their families' understanding that they are being actively supported through this process.

**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,
- 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:

- Optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual and cultural needs.
- 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 Facilitator (PCF):** The palliative care facilitator refers to the clinician assigned the responsibility for facilitating and coordinating access to services. They will belong to the Palliative Care Facilitation Service and work in close partnership with the Lead Palliative Carer. They will fundamentally be the first point of call for the lead palliative carer seeking support for their palliative care patients and will maintain close linkages with locality specialists.

**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 specialist palliative care services (i.e hospice and hospital palliative care specialists) that comprises the palliative care system; it is the links that exist between them that tie together 'a system'.

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

**Informal Carer:** The informal carer (or carers) are generally from within the close kin network/family or whānau of the patient and usually self identified. They can be the patient's spouse, child, another relative, family member or friend. He/she may be supported by others, and will take a key role in the co-ordination and delivery of care and support to the patient. They provide for the practical needs of the patient and can take on additional tasks that may be of a technical nature, to provide ongoing care for the patient, e.g. the administration of medications.

**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 that 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.

**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. Complex 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'.

**Virtual Integrated inter-disciplinary teams:** A virtual team that enables shared care. Palliative care will be delivered by having a virtual integrated inter-disciplinary team (IDT) with each patient having a coordinated and continually updated palliative care plan. Each patient will always have a designated lead palliative carer (LPC) and a palliative care facilitator (PCF). These health practitioners will be responsible collectively for ensuring that the needs of the patient and their whānau are met.

**VOICES (Views of Informal Carers – Evaluation of Services) Survey:** collects bereaved peoples' views about the quality of care provided in the last three months of life. An adaptation of this survey is being piloted in New Zealand (South Island Alliance and Auckland DHB) at the time of developing this plan.

**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. This close kin network of the patient may encompass informal carer/ who provide for the practical needs of the patient and can take 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.

## APPENDIX 2: Engagement with Stakeholders

The following groups of stakeholders/partners have been consulted (either in meetings or by phone/email communications) and provided input to this Strategic plan:

### Consumer/Carer Group

A total of 29 groups of consumer/carers provided feedback from across the sub-region.

### Hospice staff

**Ria Earp** (CE, Mary Potter Hospice)

**Biddy Harford, Diane Greenwood-Havea, Eleanor Barrett and Mary Death** (Te Omanga Hospice)

**Suzie Adamson** (Hospice Wairarapa)

### Other DHB staff

**Adri Isbister** (CE, Wairarapa DHB)

**Anne Savage** (Palliative Care Nurse Educator, Wairarapa DHB)

**Lisa Burch Joanne Edwards, Ondine Claridge and Jan Marmont** (SIDU, Hutt, CCDHB and Wairarapa DHBs)

**Simon Allan** (Director of Palliative Care, Arohanui Hospice)

### PHOs

**Martin Hefford, Chris Kerr and Justine Thorpe** (Compass Health)

**Teiringa Davies** (Ora Toa PHO)

**Sharon Cavanagh** (Well health Trust PHO)

**Lyn Allen** (Cosine PHO)

**Dr Tony Becker** (Masterton Medical Centre)

**Bridget Allan and Paul Abernethy** (Te Awaikarangi Health Network)

**Dr Chris Masters** (Ropata Medical Centre)

### Hospital & Hospice Palliative Care specialists

**Dr Jonathan Adler** (CCDHB, Hospital Palliative Care Service)

**Dr Brian Ensore and Dr Annabel Dunn** (Mary Potter Hospice)

**Dr Thomas Middlemiss, Dr Salina Iupati and Dr Ian Gwynne-Robson** (Te Omanga Hospice)

### Community & Hospital Nursing

**Gabrielle Driscoll, Alison Rowe and Louise Forsyth** (CCDHB)

**Karen Blair** (HVDHB)

**Rosanne King** (Mary Potter Hospice)

**Mary Death, Jude Pickthorne and Sarah Shellard** (Te Omanga Hospice)

**Fred Wheeler and Carol Hinton** (Kahukura)

## NASC Organisations

**Lynn Jones** (Capital and Coast Care Coordination Centre)

**Michelle Main** (Life Unlimited)

**Myree Ahpene** (FOCUS Wairarapa)

**Susan Bowden** (Hutt Valley Service Care Coordination)

**Paul Moles** (Capital Support)

**Kym Park** (Mental Health Service Coordination Team)

**Helene Dore** (Wairarapa DHB and NASCA)

## Aged Residential Care and Rest Homes

### Capital and Coast/ Kenepuru

**Keren Lusty** (Retire Kapiti)

**Maria Ramsbottom** (Parkwood Lodge, Waikanae)

**Roxanne Rosquita** and **Ailene Ragotero** (Dementia Care NZ, Waikanae)

**Karen Gear** (Ultimate Care, Mt Vic, Wellington)

### Hutt

**Anneke Barkwith** (Woburn Home, Enliven)

**Eileen Thomson** (Riverleigh Residential Care, Lower Hutt)

### Wairarapa

**Irene Bull** (Wairarapa Masonic Village)

**Robyn Brady** (Arbor House)

**Adelita Ganotan** and **Christine Burton** (Lansdowne Court)

**Lynn Olds** (Wairarapa Metlife)

**Rebecca Waldron** (Glenwood Masonic Hospital)

**Mike Keyworth** (Kandahar)

**Jacqui Witbooi** (Ultimate Care, Greytown)

## Māori and Pacific Health

**Kuini Puketapu** (Māori Health HVDHB)

**Cheryl Goodyer** (Māori Health CCDHB)

**Taima Fagaloa** (Pacific Health, CCDHB)

**Tofa Suafole Gush** (Pacific Health, Wairarapa & Hutt Valley DHBs)

## Ambulance Services (Wellington Free Ambulance)

**Andrew Bos**, Executive Manager Service Delivery

**Paul Fake** Clinical Quality Improvement Manager, Clinical services

## APPENDIX 3: Summary of feedback

The following summarises what we heard from consumers/carers:

- Palliative care means different things to different people and it should be much more than just caring during the dying phase
- Hospice provide fantastic care and support
- We all want to die in our own beds, in our own homes
- We want to have early conversations
- We want information about what is available and what to expect
- We want to have access to medication when we need it
- We want to know who to call when we don't know what to do
- We want palliative care at an earlier stage for more of us
- We want to be involved in decision making
- We want to be supported to care and have easier access to respite

Feedback from other stakeholders included:

- Dying at home is the preferred option but is the exception rather than the norm
- Overall, patients experience good quality services from within each service
- There is a large discrepancy of care between those receiving hospice services and those receiving other services
- Transition between services/discharge processes need attention - systems to share information (i.e. assessments, plans, notes in a timely fashion) are not well connected "unfortunately no plan or notes were transferred...it was 24 hours before any pain relief or sedation could be provided"
- Bereavement support is only available for those under hospice care
- Peoples needs change so services need to be responsive, coordinated and flexible in meeting changing needs
- There are mixed views about a number of issues including duplicate/multiple assessments and the need for an inpatient unit in Wairarapa
- We are a death denying society where patients, families and some health professionals feel discomfort and denial about death and dying which can act as a barrier to accessing services to improved quality of life
- Generally ARC facilities deliver palliative care well, however both Hutt and Wellington ARCS want to do better in delivering end of life care
- Services are mostly available during normal working hours but patients needs are 24hours/7days a week.
- There is inequity of service dependent on patients choice of where to die/who the lead carer is "hospice took care of everything - we could focus on being with her rather than worrying about her care"
- There is variation in night support arrangements
- There is a need to strengthen partnerships with supports in the community
- A clear pathway for palliative care patients is needed (for W'ton & Hutt)

## APPENDIX 4: Population Information

### General overview

The sub-regional DHBs – Wairarapa, Hutt Valley, and Capital & Coast – represent three of the twenty DHBs in New Zealand in 2016. They are located in the lower North Island and comprise urban, rural and coastal settings. CCDHB is the largest DHB (by population) of the sub-region, followed by Hutt Valley and Wairarapa. The population of the sub-region was 463,194 at the last Census in 2013, which represented ten percent of New Zealand's total population of approximately 4.2 million.

The Wairarapa DHB includes three territorial authorities (council areas) – Masterton District, Carterton District and South Wairarapa District – and covers a total land area of 5,936 square kilometres. Like CCDHB and Hutt Valley, the area is served by the Greater Wellington Regional Council. The Wairarapa is a diverse rural area, separated from the rest of the Wellington region by the Rimutaka ranges. Masterton, Wairarapa's one large urban town, had a 2013 Census population of just over 23,000.

The land area of the Hutt Valley DHB is 916 square kilometres. The area is predominantly flat in the Hutt River valley, bordered by mountainous ranges in the east (Rimutakas) and north (Akatarawas and Tararuas) and a coastal southern edge. Lower Hutt City and Upper Hutt City are the Hutt Valley's two territorial authorities.

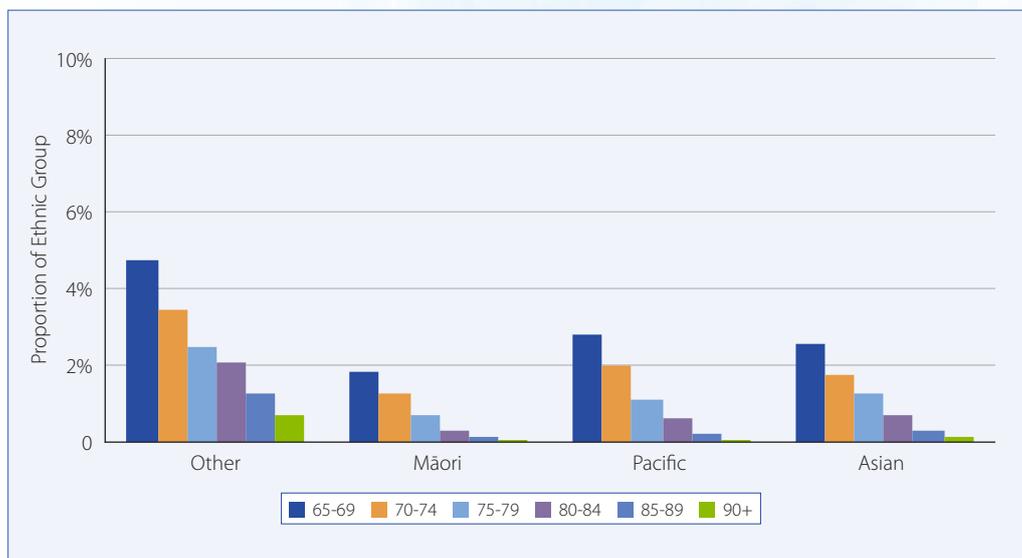
The Capital & Coast DHB has a land area of 739 square kilometres. It is made up of three Territorial Authorities: Wellington City, Porirua City and Kapiti Coast District. The Kapiti Coast District includes some territory which is part of the MidCentral DHB (Otaki and near surrounds). The CCDHB area has relatively high density residential living (by New Zealand standards), with on-going expansion of urban areas.

## Population and Projections

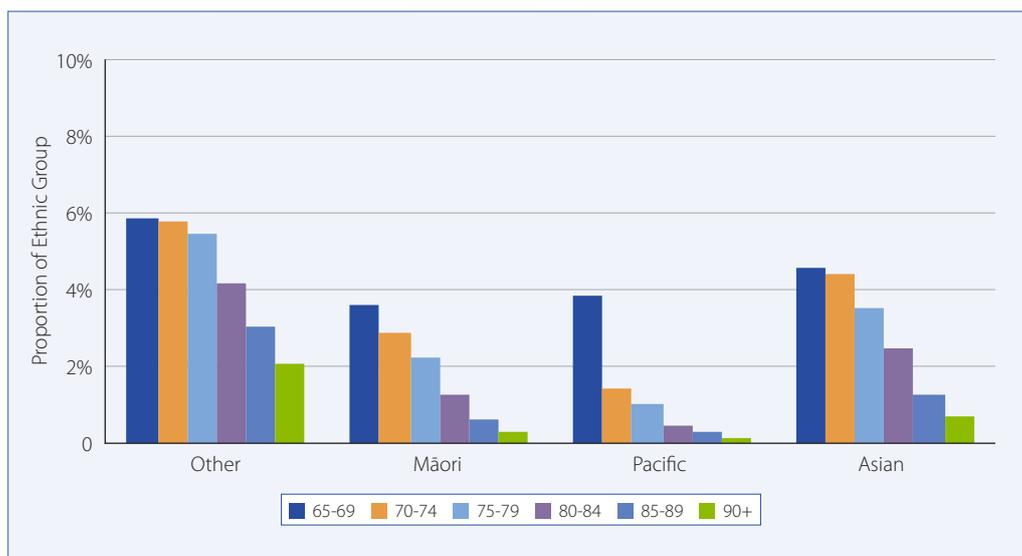
### Capital & Coast DHB - Population 65+ years in 2013 & Projected Population for 2038

The proportion of Capital & Coast DHB's population who are 65+ years is projected to increase from 12% in 2013 to 22% in 2038. The largest increases in people aged 65+ years are expected to be in the Other and Asian ethnic groups. The proportion of Other who are 65+ years in CCDHB is expected to increase by 12% from 15% in 2013 to 26% in 2038. The proportion of Asian residents who are 65+ years in CCDHB is expected to increase from 7% in 2013 to 17% in 2038. It is also projected that the proportion of Māori who are 65+ years will increase by 7% from 4% in 2013 to 11% in 2038. Between 2013 and 2038, there is projected to be no increase in the total proportion of Pacific people 65+ years of age as a proportion of their population.

Population 65+ years (2013), Capital & Coast DHB



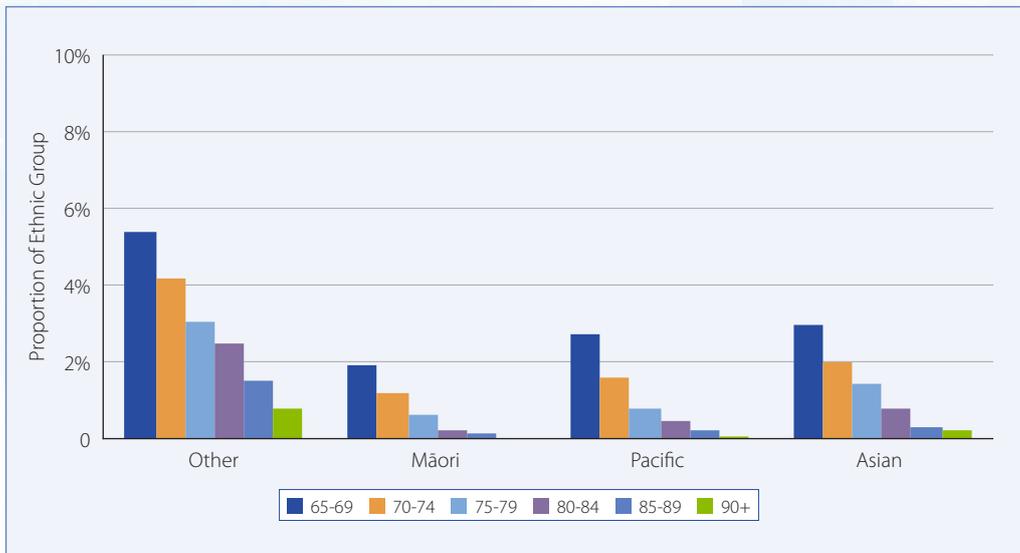
Projected population 65+ years (2038), Capital & Coast DHB



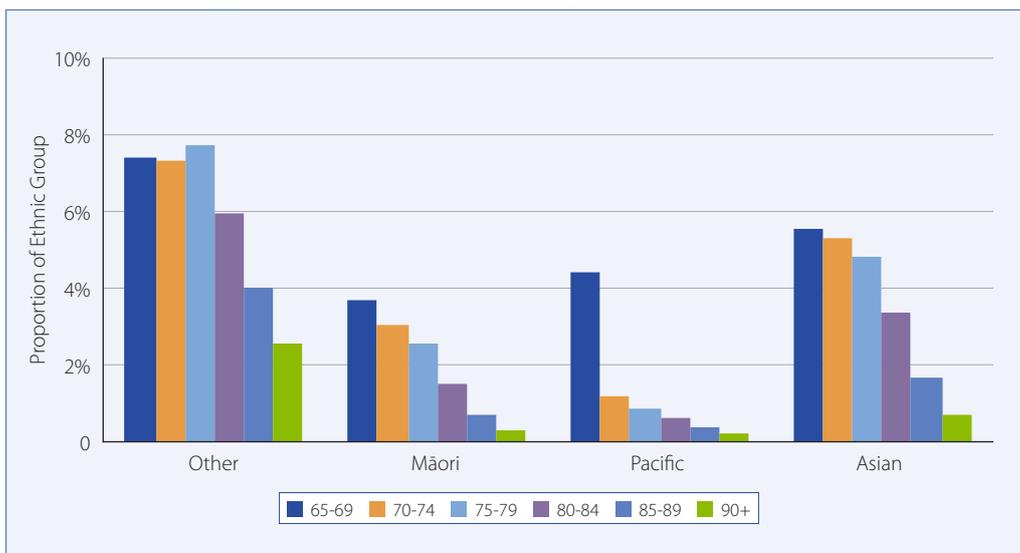
## Hutt Valley DHB - Population 65+ years in 2013 & Projected Population for 2038

The proportion of Hutt Valley DHB's population who are 65+ years is projected to increase from 13% in 2013 to 25% in 2038. The largest increases in people aged 65+ years are expected to be in the Other and Asian ethnic groups. The proportion of Other who are 65+ years in HVDHB is expected to increase by 18% from 17% in 2013 to 35% in 2038. The proportion of Asian residents who are 65+ years in HVDHB is expected to increase by 14% from 8% in 2013 to 21% in 2038. It is also projected that the proportion of Māori who are 65+ years will increase by 8% from 4% in 2013 to 12% in 2038. Between 2013 and 2038, the proportion of Pacific people aged 65+ years in HVDHB as a proportion of their population is projected to increase by 2% from 6% to 8%.

Population 65+ years (2013), Hutt Valley DHB



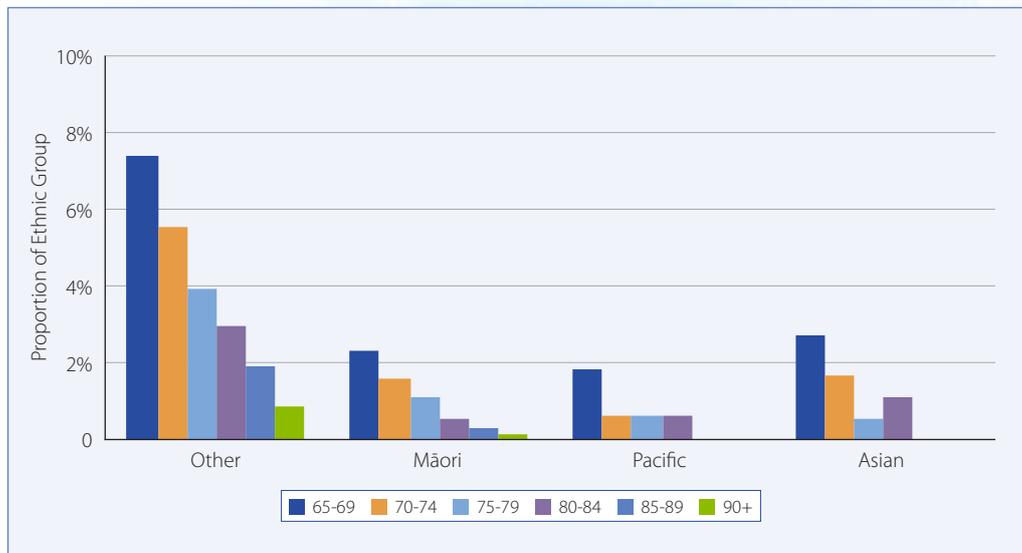
Projected population 65+ years (2038), Hutt Valley DHB



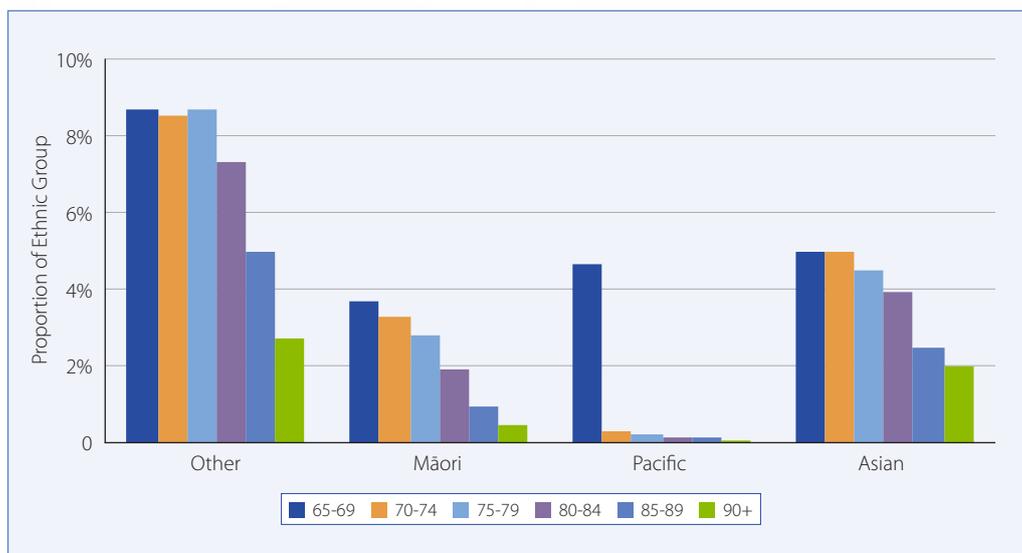
## Wairarapa DHB – Population 65+ years in 2013 & Projected Population for 2038

The proportion of Wairarapa DHB’s population who are 65+ years is projected to increase from 19% in 2013 to 32% in 2038. The largest increases in people aged 65+ years are expected to be in the Asian and Other ethnic groups. The proportion of Other who are 65+ years in WRDHB is expected to increase by 18% from 23% in 2013 to 41% in 2038. The proportion of Asian residents who are 65+ years in WRDHB is expected to increase by 17% from 6% in 2013 to 23% in 2038. It is also projected that the proportion of Māori who are 65+ years will increase by 7% from 6% in 2013 to 13% in 2038. Between 2013 and 2038, there is projected to be a 2% increase from 4% in the total proportion of Pacific people 65+ years of age as a proportion of their population.

Population 65+ years (2013), Wairarapa DHB



Projected population 65+ years (2038), Wairarapa DHB

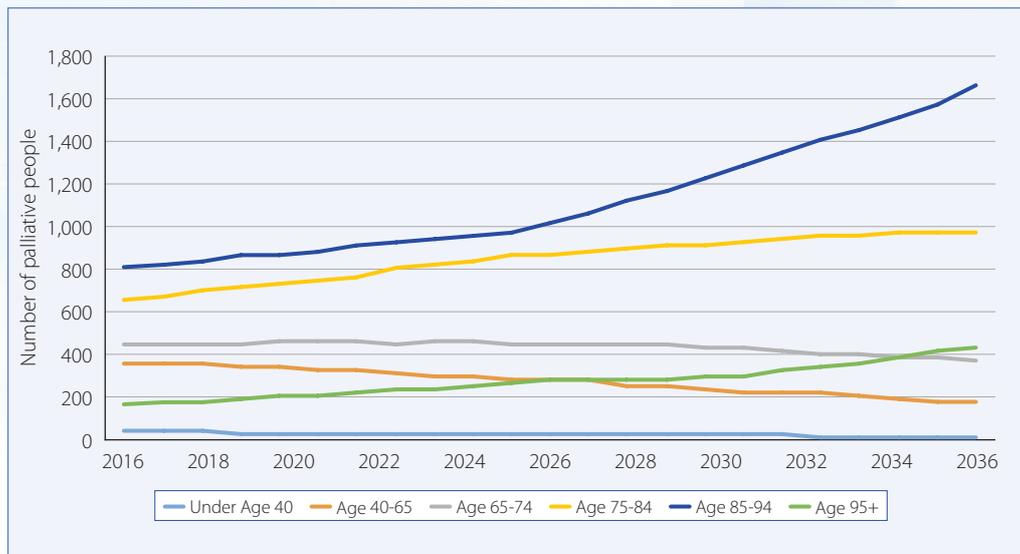


## Deaths in the sub-region

Across the sub-region, the top causes of death were disorders of the circulatory system (36% of all deaths between 2006 and 2010, inclusive), cancer (29%), disorders of the respiratory system (9%), and external causes (6%).

In the sub-region, it is projected that the number of older people 75+ needing palliative care will almost double by 2038 – from an estimated 1,630 in 2016 to 3,065 in 2038. The number of people under 74 needing palliative care is expected to decrease by a third, from an estimated 745 in 2016 to 560 in 2038.

*Projected number of people in the 3 DHB region who will need a palliative approach by age group*



Of these people needing palliative care in 2016, it is estimated that 43% (1,068 people) will die in residential care, 28% (680 people) will die in a public hospital, 12% (288) will die in a hospice inpatient unit, and the remaining 18% (435 people) will die in the community in 2016. Projections show the place of death is likely to be similar in 2038.

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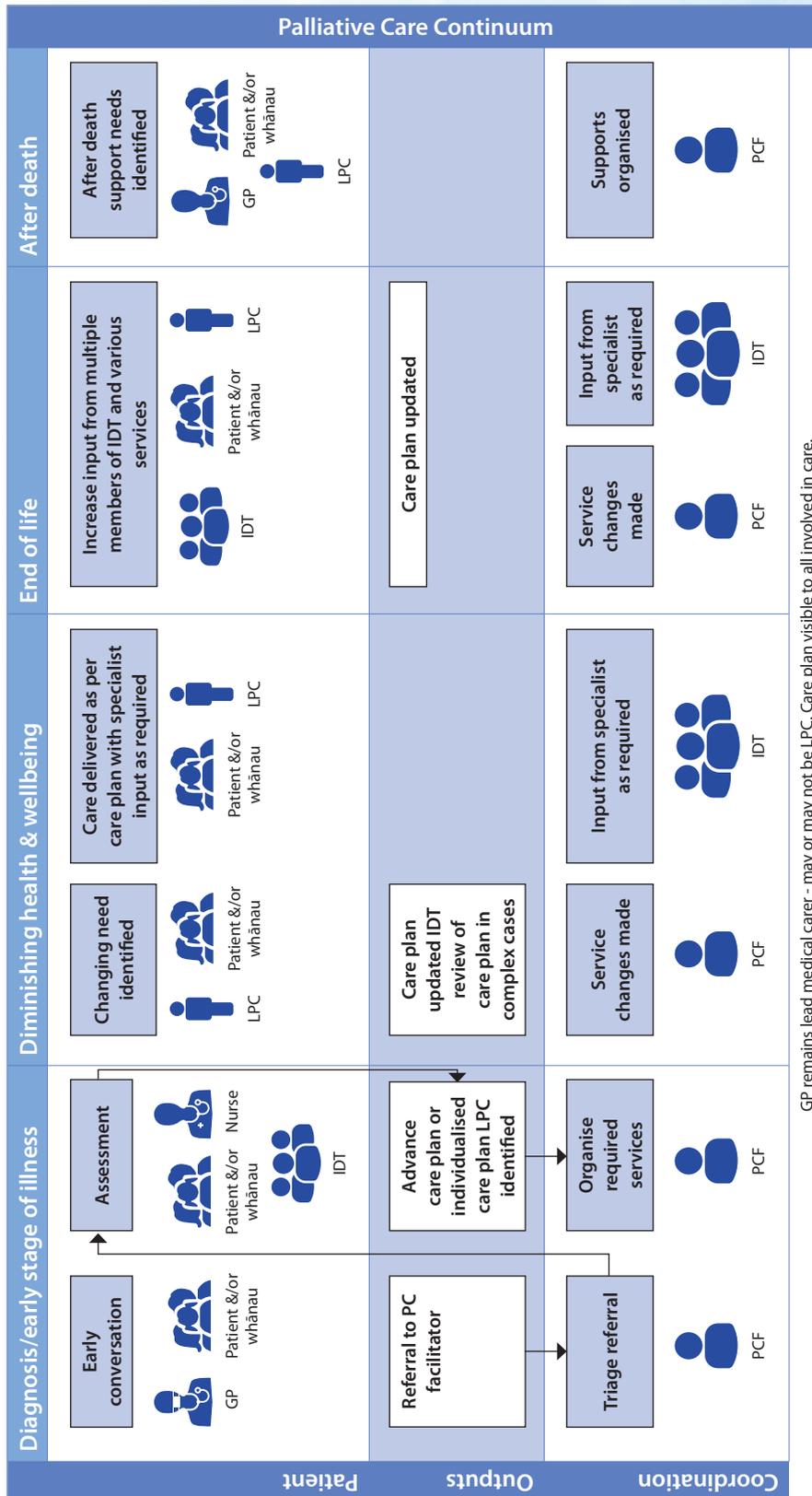
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## APPENDIX 6: Example of patient experience in future palliative care system

An example of the patient experience along the future palliative care continuum is outlined below.



## APPENDIX 7: Role functions and definitions

An example of the patient experience along the future palliative care continuum is outlined below.

Identification and Early Planning	Service Coordination and delivery 24/7	After death support
<p>Once a palliative patient has been identified then there is consultation with patient and/or family/whanau to begin an individualised Palliative Care Plan (PCP)</p> <p>This early assessment and planning could be facilitated by GP team or ARC nurse (depending upon where patient resides)</p>	<p>Referral to Palliative Care Facilitation Service</p> <p>This service will assign a locality Palliative Care Facilitator (PCF) within the service</p>	<p>Bereavement support</p>
<p>This individualised Palliative Care Plan (can be part of Advanced Care Plan) will outline:</p> <ul style="list-style-type: none"> <li>▪ Patient’s goals, basic symptom management and psychosocial needs are...</li> <li>▪ What is required to meet these needs...</li> <li>▪ Who will help meet these needs...</li> <li>▪ Lead Palliative Carer is...</li> <li>▪ After Hours support is...</li> <li>▪ Permission to share manage my health clinical record</li> </ul>	<p>The PCF will facilitate an assessment, when necessary, to build upon and expand the individualised Palliative Care Plan in order to access the services that the patient will require to meet increasing need. This might mean adding components of the InterRAI to the assessment and subsequent planning.</p> <p>Thus creating and binding together one virtual integrated inter-disciplinary team (IDT) that follows the patients individualised Palliative Care Plan</p>	<p>Lead palliative Carer and Palliative Care Facilitator will ensure that following death, an assessment of additional support following bereavement is undertaken and put in place.</p>

Functions	Roles – Who?	Notes	Output
Identification & referral	Primary care team Secondary care Community nursing Self or carer referral	People who will benefit from a palliative care approach  Referral sent to single point of service coordination (ideally electronic)	
Early planning	Primary care team	Free consults with GP and primary care team:  Early conversation  Identification of needs  Development of early plan including advance care plan and determining goal of care, curative to palliative with treatment as needed	Individualised palliative care plan
Preliminary triage	Single point of service facilitation (Palliative Care Facilitation Service)  Palliative care coordinator/facilitator (PCF)	Facilitator does preliminary triage and will coordinate access to services and equipment when needed, depending on where patient is along their palliative care journey.  Point of contact for lead palliative carer and makes things happen behind the scene. They will facilitate specialist assessment if needed, but endeavour to build upon information and not undertake duplicate/multiple assessment	
Specialist Assessment & Planning	Specialist palliative care nurse (based either in spec PC or NASC)	Interdisciplinary approach/ virtual assessment coordinated by the PC nurse if needed  Identify and assign lead palliative carer (LPC) if not already identified	Care plan for 24/7 care  Afterhours contacts both medical and nursing must be specified, noting that in most instances the lead palliative carer/ initial point of contact for patients /whanau, and nursing in the later stages of the PC journey. In rare cases, ambulance may be the most appropriate first point of contact.
Clinical management	Lead palliative carer (LPC)	Responsible for clinical management, arrangements for after hours medical contact and first point of contact for patients and whanau. LPC can change throughout journey as needs change (initial part of journey is likely to be GP, but as need increases may change to community nurse or spec pc nurse (in ARC likely to nurse / nurse manager of facility). GP will still remain involved to provide medical oversight.	

Functions	Roles – Who?	Notes	Output
Service & resource coordination	Palliative care facilitator (PCF)	After the LPC identifies need for service /resources, they contact PCF who will organise appropriate services as needed	
Planned service delivery	Palliative care facilitator (PCF) Primary, hospital, spec PC Community nursing and other community services Whānau, volunteers	Range of roles as specified in care plan	
Support in the home	Whānau HCSS Volunteers/NGOs	Depends on need identified by LPC	
Nursing	Practice nurse Community nursing ARC nurse Specialist pc nurse	Majority of nursing care is provided by practice and community nurses. When a patient moves into an ARC facility, nursing care is provided by facility nurses. Specialist nursing support is available to these nurses as and when required. As the final days of life approach, increasing support from specialist PC nurses may be appropriate.	
Medical	GP, Specialist doctors including palliative care, GPSIs and other medical specialities such as cardio	The GP remains the patient's primary /main medical carer. Specialist support is sought from PC and other specialities as and when required. Spec services available for consult liaison to support the GP to be the lead palliative (medical) carer.	
After hours	Lead palliative carer	Initial point of contact for patients	
Allied health	Social worker; Occ therapist, Counsellor Physio, Dietician	Support provided as outlined in care plan to address identified needs	
Other supports	Cultural support including Māori and Pacific liaison, chaplain services churches, community groups	Support provided as outlined in care plan to address identified needs	

## APPENDIX 8: Data sources

Statistical information about the need for palliative care in this document is based on the work by Heather McLeod completed in June 2016 - **National Model of Need for Palliative Care**.

The excerpts below are from "The Need for Palliative Care in New Zealand Technical Report – June 2016"

"The first estimate of the need for palliative care in New Zealand was produced by the Palliative Care Council in 2011. Three estimates were produced, a minimal estimate based on a list of conditions recorded on the death certificate, a mid-range estimate that included hospital admission data, and a maximal estimate based on a longer list of conditions. The report established, for the first time, the number of people who might benefit from palliative care in New Zealand. Overall, combining adults and children, the mid-range estimate in 2006 was that 56.3% of all deaths were amenable to palliative care."

"The historic patterns of deaths in New Zealand were examined using data from the Ministry of Health Mortality Collection (MORT). The data for this analysis was extracted in December 2015 and covers all deaths registered in the calendar years 2000 to 2013."

"The need for palliative care is an estimate of need at a population level for the whole palliative care system. Conceptually, the aim is to include all deaths that typically benefit from a palliative care approach."









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