

Whole person approaches to maintain quality of life



**CAPITAL & COAST DISTRICT HEALTH BOARD
PALLIATIVE CARE PROGRAMME PLAN 2010-2015**

FORWARD

We are pleased to present this the first Capital & Coast District Health Board (C&C DHB) Palliative Care Programme Plan 2010-2015 to the people and communities of the district.

We would like to thank the members of the Palliative Care Forum and all stakeholders (both internal and external to C&C DHB who gave their time to share their stories, experiences, knowledge and expertise which has helped to define this Palliative Care Plan and inform the objectives and actions set forth to improve palliative care services in the district during the next five year.

We would like to make the following special acknowledgements and thanks:

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Lucy Gunn – RN – Work and Income
Julie Murphy – RN – Te Hopai Aged Residential Care
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Emma Hickson – District health nurse
Astuti Balram – Service Development- Long Term conditions
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1. INTRODUCTION

This document contains Capital & Coast District Health Board's five year plan to address service improvements and shortfalls in the delivery of palliative care services to people in the region who could benefit from those services. Meeting the challenges of changing disease and demographic profiles (see Strategic Context in appendix one), including the people living longer with long term and life limiting illnesses, coupled with limited health care resources requires that we step back and refocus on how we are providing palliative care services in the region.

The methodology used for the development of this plan involved:

- Carrying out a stocktake of current services (appendix two) delivered by Capital & Coast either directly or through purchases of services, to identify gaps and areas for incorporation into the plan;
- Face-to-face engagement with key internal and external stakeholders (appendix four) to identify the contribution and role of stakeholders in palliative care related services for preliminary consultation purposes.
- Focused group meetings with key internal and external stakeholder representatives to workshop the vision statement as well as the strategic objectives and strategies to be included in the Plan; and
- Review of statistical data and research material.

Key themes re fragmented service delivery and need for improved communication and collaboration between and among all service providers have resulted in the following person centred objectives:

- Need for accurate and timely age and circumstance appropriate information about all the help available to improve access to services by people known to be in need of the service and less likely to access formal palliative care services
- Need for comprehensive continuous and sustainable holistic care to clients
- Coordinated support closest to the person who needs the service

This plan should be read with consideration of the following two important and often misunderstood points.

1. *The provision of services is appropriate from the time of diagnosis and at anytime throughout a life limiting illness which might extend for several years.*

The World Health Organisation signaled a fundamental shift in focus recognizing that the provision of palliative care is applicable at any stage after diagnosis of a life limiting illness when it published the following definition:

“Palliative care is an approach that improves the quality of life of patients and their families facing life threatening illness, through the prevention and relief of suffering

by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (World Health Organization, 2002)¹

This definition informed the development of the New Zealand definition of palliative care noted in section four,

2. *The provision of palliative care services is not restricted to only persons with a diagnosis of cancer.*

Palliative care is broader than cancer alone and includes services, support and care for people of all ages who have a life limiting illness and whose needs change over time as the illness progresses. People with age-related functional changes or with chronic diseases such as diabetes, heart and respiratory disease, and motor neuron diseases may all benefit from palliative care services provided according to the individual’s specific needs.

It is further noted that this plan should be read in conjunction with the Cancer Control Strategy Plan – Goal number Four : *Improve the Quality of Life for those with Cancer, Their Families and Whānau through Support, Rehabilitation and Palliative Care.*

¹ World Health Organisation. WHO definition of palliative care. <http://www.who.int/cancer/palliative/definition/en/>. Accessed 16/09/09

2. EXECUTIVE SUMMARY- TO BE WRITTEN AFTER THE CONSULTATION

3. VISION AND MISSION

Vision

Whole person approaches to maintain quality of life

Mission

Capital and Coast District Health Board recognize the value of every person. We are guided by our commitment to quality palliative care services that respond to individual, family/whanau, and community needs. We demonstrate this by:

- Providing quality physical, emotional, spiritual and cultural care for individuals and their families/whanau
- Striving to meet our commitment to assuring equity of access and treatment for all, especially those most in need. This includes the provision of specialized services to a broader community
- Building a tradition which values and celebrates the dignity of the human person and of compassionate person centred caring.
- Advancing excellence in health services education
- Fostering a culture of discovery in all of our activities and supporting collaborative health sciences research
- Strengthening our relationship with our community, health service providers, other District Health Boards, cross sector agencies and tertiary education institutes
- Demonstrating social responsibility through the just use of our resources.
- Building partnerships with those we serve and with the community toward our mission permits us to maintain a quality of presence and tradition of caring in the provision of palliative care services in our region.

4. BACKGROUND

Over the last decade there has been significant work to improve care, services and the quality of life for people with life-limiting illnesses. The **Palliative Care Strategy (2001)**, **Cancer Control Strategy (2003)** and the **Cancer Control Action Plan (2003-2005)** are sentinel documents in providing direction for this work. (appendix three).

The **New Zealand Palliative Care: A working definition (2007)**, provides a clear contemporary outline:

Care for people of all ages with a life-limiting illness which aims to:

1. optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual and cultural needs.
2. support the individual's family, whanau, 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 Maori, children, and young people, immigrants, refugees, and those in isolated communities.

Consistent with the national strategies and responding to the findings of CCDHB service reviews, including the Palliative and End of Life Care Services Review (2005), a number of services improvements have been made in the District. These include (see appendix two for a more complete list)

- development of a care coordination centre to coordinate service delivery,
- development of packages of care
- implementation of a specialist palliative care service in the hospital,
- initiation of the implementation of specialist service specifications in the area end-of-life programme development
- involvement with the cancer and palliative care regional networks to improve collaboration and service coordination
- establishment of the C&C DHB Palliative Care Forum.

Going Forward

Through the process of engagement and stocktake of the services currently available, it has become apparent that while we have made progress, there are areas where we can do better.

A number of quotes from key stakeholders are included to illustrate the themes that have emerged from this engagement process. The following quote from a patient describes the essence of the work before us:

“I didn’t know it would be this hard to die,...no, not the dying...it’s all the people in and out...and I still don’t know who to call when I need help”

This quote illustrates that while we have made progress in building more services, focused on specialty services and have caring staff who know what they are doing there remains work to be done. While we have been busy developing services and systems to provide better care we have learned that we can do better in how we work together and how we work with people. Specifically, we can perform better by:

- attending to how we communicate with the people and each other,
- how we demonstrate respect for the dignity of people,
- honouring and respecting whānau,
- honouring and respecting relationships important to those we serve, and
- honouring traditional ways/cultural practices.

“We need to need to listen to patient/whānau/fanau, work to understand those we serve”

“I know I am getting good care when (the nurse/doctor/carer) pronounces my name properly.”

This forms our way forward with a renewed vision and direction which will concentrate on person-centred services and delivering services according to the needs of people with life-limiting illnesses. Key stakeholders have noted that when a person has a life-limiting illness many others are also affected; members of a person’s family/whānau, their friends, their employers or employees and colleagues. We also know that most people want to continue to be involved in managing their life and illness and benefit from having their loved ones present while they journey through the changes that their illness brings to their life. We recognize that the person and their significant others are key players in what and how palliative care services are provided because they:

- are present in the person’s day-to-day living and care arrangements;
- have detailed knowledge and history about the person’s health, social and spiritual preferences that contribute to sense of wellbeing; and
- are likely to be involved for the duration of the illness, be that hours, days, months, or years.

The graphic below is used to illustrate the intent of this plan: It is aligned with principles of the Treaty of Waitangi, He Korowai Oranga, and Te Plan II. Protecting the dignity of the whole person and assuring safe quality palliative care services, supporting and embracing the Participation of patient/whānau in staying in charge of their lives, and building linkages and Partnerships on a foundation of Primary and Community Health Care to assure the right supports are in place for individuals, whānau and communities as and when needed.



Assumptions

C&C DHB, makes the assumption that focusing on patient-centred objectives will serve the needs of the District population and in particular the needs of Maori and Pacific people. This is because the principle of responding to people who can benefit from palliative care services according to their individual or particular circumstances must incorporate cultural, spiritual and social aspects as well as physical and emotional matters.

We also make a presumption that all people want assurance that they will receive quality treatment and support and that the experience will maintain their mana and integrity, both as an individual and as member of family/whanau and their communities of interest.

We further recognise the place that health professionals and practitioners have in the lives of people who benefit from palliative care services. We recognise that the majority of palliative care services occur in the community, with the preferred site of care most often being one's home. We acknowledge that GPs and nurses tend to have much longer relationships with their patients, some working with a number of generations of family members, while specialist palliative care providers are more likely to have intermittent contact and/or develop a relationship with the person/whanau in the last stages of one's life. Comments such as "why can't I stay with my own (family) doctor"

support the importance of tending to how we work together to serve people who could benefit from palliative care services.

Stakeholders

C&C DHB has consulted a range of stakeholders who have an interest in palliative care services and have been involved in the development of this plan. A comprehensive list of contacts is recorded in appendix four.

Key Stakeholders:

- Planning and Funding
- Primary Care, Nursing and Community Integrated Services Teams (includes district nurses, ...)
- Primary Secondary Interface Committees
- Hospital Palliative Care Service
- Wellington Blood and Cancer Centre
- Persons who could benefit from palliative care services
- Primary Care practices
- Māori and Pacific Providers
- PHOs
- Aged Residential Care Facilities
- Work and Income``
- Service Providers –(such as in-home care providers)
- Specialist Palliative Care Providers

5. PROGRAMME APPROACH

- Person centred
- Family/whanau involvement
- Community based
- Ongoing stakeholder engagement (see attached list of stakeholders)
- Focus on redressing lack of access or fragmented services
- Formal consultation processes
- Building on current strengths, resources and systems

5.1 Governance and Key Linkages

C&C DHB Planning & Funding Directorate is responsible for developing and implementing an integrated and coordinated Palliative Care Programme (the Programme) of services. In 2005 the Palliative Care Forum (PC Forum) was established to provide advice and recommendations to the Planning & Funding Directorate.

The PC Forum is accountable and provides advice to C&CDHB through the Funding and Planning Directorate, Portfolio Manager Health of Older People and Palliative Care,

who in turn is accountable to the Director, Funding and Planning, the CEO, the Board and/or Advisory Committees of the Board.

It is essential that advice from the Forum is provided in parallel to key groups within C&CDHB responsible for planning and implementation of the programme. That is to say the Forum needs to maintain relationships and dialogue with the Cancer Advisory Group, Community Advisory groups and other groups as appropriate.

5.2 Constraints

- Funding mechanisms lack flexibility
- Limited resources
- Limited incentive for looking at collaborative creative ways of sharing resources
- Workforce and training
- Culture one of “value for money” need not be the opposite of person centred care. Lord Rutherford said that “when you run out of money you just have to think” - a great focus for the current times

5.3 Risks

- will use the CCDHB risk model as recommended by respondent
- workforce and supervision identified as high risk areas

6. THE PLAN

**“He aha te kai o te Rangatira?
He Korero He Korero He korero”**

“What is it that challenges the mind?
It is knowledge, It is options, It is choices”
(Broughton, 1999)

6.1 Strategic Goals:

- Availability to all of essential palliative care services for symptom relief and emotional, spiritual, cultural and social support.
- Fully integrated seamless palliative care services across the continuum of care and in their setting of choice.

6.2 Person Centred Objectives:

- Accurate, timely, understandable and circumstances- appropriate information about all the help available to improve access by populations known to be in need of health care and less likely to access formal palliative care services.
- Comprehensive and sustainable holistic care to clients
- Coordinated support closest to the person who needs the service

The first objective is focused on the development of client information resources that are available to both clients and service providers..

The last two are focused on service availability and service delivery.

6.3 Actions

"I didn't know it was possible for me to take of – at home. I don't know if we would have been able to manage, but maybe we could have."

"It is often just the little things that make the biggest difference like being able to continue to attend a favourite social event."

"I was so busy doing things for my patient I didn't really hear that what he really wanted was for me to just talk with him for a few minutes."

Strategies which cross all objectives include: workforce development, management and financial information systems development

Short Term (1 Year)	Medium Term (1 – 3 Years)	Long Term (3 – 5 Years)
Objective 1: Accurate and timely age and circumstances-appropriate information about all the help available to improve access by populations known to be in need of healthcare and less likely to access formal palliative care services.		
It is important for people who could benefit from palliative care services to know what kinds of services and supports they are available to them, depending on their circumstances. Because Palliative Care is a service that is designed to assist a person manage their illness and at the same time keep their lives going as normally as possible, the range of care and supports that are available are considerable. Being fully informed about what a person/whānau has available to them, is an important way of helping them stay in charge of their lives. <i>"All communications/information must be based on the 'just in time' principle"</i> culturally appropriate and in a language the person/ whānau can understand.		
Actions		
Survey patients to identify improvements in the process for applying/receiving entitlements	Develop information packages/resources to inform patients about services available, eligibility requirements and how to access local support. Development of information for different age Develop FAQ sheets about palliative care.	

Short Term (1 Year)	Medium Term (1 – 3 Years)	Long Term (3 – 5 Years)
	Development of resources to assist care providers in directing patients/whanau to help (ex referral to patient advocate; referral of patient who is a war veteran and who has a form of cancer or diabetes accepted as a service related war disability- to Veterans pensions and services)	
	Palliative information on C&C DHB website Links for Palliative Care information on NGO and selected websites. Links on local and central government websites.	Survey patients receiving palliative care services to assess relevance of current supports and identify gaps.
Investigate education models which have been demonstrated to be effective in “just in time” communications. <i>(ex Mason Durie model has been suggested)</i>		
Develop database/directory of care, support, rehabilitation and palliative care services for community wide distribution	Develop data and IT systems to capture service information	Evaluate the effectiveness of the data systems.
	Review of criteria for eligibility for care, support, rehabilitation and palliative care services	Expanded criteria for eligibility and access to care, support, rehabilitation and palliative care services
	Collaborative research projects and strong linkages with key agencies – such Starship -"The Voices of Whanau/Families and Health Professionals in Paediatric End-of-Life Care Planning." (In particular, this study is around communication and the language used when discussing what levels of care whanau want for children	

Short Term (1 Year)	Medium Term (1 – 3 Years)	Long Term (3 – 5 Years)
	who may die.)	
Comprehensive database/ directory of care, support, rehabilitation and palliative care services for wide distribution	Develop data and IT systems to capture service information	
Objective 2: Comprehensive and sustainable holistic care		
<p>Holistic care embraces all aspects of the cultural, physical, emotional, psychological, and spiritual needs of people with life limiting illnesses. The strategies below are centred on enabling people to be involved in planning their own care and support requirements. <i>“An essential point for me: Respect for the family/whanau’s ability to care or their want to take part in this process. We must never forget that not all families will want to take part – we have some amazingly able carers, some who need a little nudge to release skills they never knew they had and others who do not want any part in this process. All deserve respect for their stance.”</i></p> <p>The current funding models inhibit flexibility in delivering care across providers. We believe that exploring alternative funding models will allow better integration of services and ultimately benefit the patients and their family/ whānau.</p>		
Actions		
Investigate and initiate implementation of programmes which provide greater choice to persons in their place of care and death.	Interagency planning on development of systems to support a person to manage their illness and be involved in their own care and support requirements	Evaluate/audit patient/whanau satisfaction re service delivery, including their involvement in decision making and the support provided them
Establish multi-agency working group for developing Standards specifications for information requirements for referrals between health professionals and rehabilitation and palliative care services	Training for hospital and NGO palliative care services on the referral standards	
Expand involvement in national initiatives (such as the national palliative medicine training programme, the cancer and palliative care data group) and representation with other national and regional service groups	Support representation in a multi-agency working group to investigate the merits of CAMs for pain relief and symptom management for people affected by cancer	Inter-agency planning for care and support services to ensure coordination and complementary delivery
Investigate best practices in supporting and caring for family/ whānau caregivers.	Develop intersectoral linkages and systems to support family/ whānau caregivers Implement support systems for family/whānau caregivers, including	Evaluate the effectiveness of the support systems.

Short Term (1 Year)	Medium Term (1 – 3 Years)	Long Term (3 – 5 Years)
	education of care providers and employers.	
	Integrate consumer representative/advisory to all aspects of the palliative care programme to inform service and policy development	
Explore alternative funding models which will allow better integration of services and transition between services. (One area where this is extremely important though the numbers of patients are few is for any child who is physically an adult size and dependent for their cares (primarily but not limited to ages 16-early 20's) who need services provided by both paediatric and adults providers.	Investigate and develop system that enables people affected by to purchase rehabilitation and support from providers of choice	Training for hospital health professionals on system for planning and patient selection of support services
	Engage in collaborative research projects with key agencies, particularly in the area of palliative care services to Māori. (example of possible activities <ul style="list-style-type: none"> • Set up research forums on Māori and Pacific palliative care research – for staff development • An action research study on overcoming the barriers to doing Māori research, specifically in palliative care and oncology. • Focus turning research into action through more focused action research studies in palliative care. 	
Research and adopt best practice standards and guidelines available nationally.	Design and delivery of training on best practice standards and guidelines	Evaluate practice against standards and guideline
◊Review Multi-disciplinary Meetings for extending contributors to the treatment and care planning process to ensure rehabilitation	*Standardised framework for operating MDMs	†Recruitment of case coordinator skills to ensure all relevant information is provided/ available to MDMs

Short Term (1 Year)	Medium Term (1 – 3 Years)	Long Term (3 – 5 Years)
and palliative care arrangements are incorporated		
Advance the implementation of the specialist palliative care services specifications by initiating the implementation of the Liverpool Care Pathways in community and hospital	Advance the implementation of end of life programmes	Evaluate end of life programmes against standards and guidelines Evaluate the progress of specialist palliative care services implementation against national benchmarks.
Objective 3: Coordinated support closest to the person receiving the services		
A person with a life limiting illness having some control over what services and from whom is a continuing theme for this objective. Patient-centred approaches requires that all care, support, rehabilitation and palliative care factor in the preferences of people receiving services, ranging across from where they receive services, (including where they prefer to die), from whom they would prefer to receive primary care, their preferred primary health practitioner, from whom and what kind of counselling they receive, and the therapies they use. <i>“If we can occasionally be prepared to let go of our cherished beliefs about the rules and hierarchies of healthcare we may find there’s a better way of doing things. In our case, accepting patients as equal partners in designing services has opened up a repository of knowledge and experience that would not otherwise have been available to us”</i> John Pickels, Consultant Head&Neck Surgeon, Luton & Dunstable NHS Foundation Trust		
Actions		
Initiate development of a model of palliative care which recognises community as the primary setting for the provision of palliative care services.	Implement programmes (demonstration models) which support the provision of palliative care in primary care.	Evaluate the effectiveness and outcomes of community based models of care.
Initiate the implementation of an initial intersectoral project designed to help providers of care and services hear what is most important to the person and then support a person/whānau in managing their own care and support requirements.	Design workshops/seminars on holistic rehabilitation and palliative care planning	Deliver workshops/ seminars on holistic rehabilitation and palliative care planning
Initiate an intersectoral project to establish ongoing processes for providing palliative care services for children to assure ease of access to specialist support as and when	Implement agreed processes.	Evaluate the effectiveness of the paediatric palliative care service processes against agreed outcome measures.

Short Term (1 Year)	Medium Term (1 – 3 Years)	Long Term (3 – 5 Years)
needs change.		
Support the priority recommendations of the Maori needs assessment “Providing Palliative Care to Maori”		Evaluate the success of the service delivery advancements against agreed outcome measures.
Expand the development of advanced care planning in all settings	Evaluate the success of advances planning initiatives against standards, guidelines and expected outcomes.	
<p>Develop infrastructure for programmatic approach to CCDHB palliative care services such as the clinical networks model set forth in Clinical Networks: a Regional Blueprint, August 2009.</p> <p>Develop and implement a services improvement plan based on the strategic goals and objectives for person centred palliative care</p>	Evolve the development of a Hutt Wellington palliative care network	Evaluate programme improvements
Expand education opportunities in palliative care for carers, nurses and other care providers, with focus on increasing the numbers of Māori and Pacific nurses and care providers as well as nurses and carers in aged residential care.	Implement the nationally agreed palliative care nursing framework and competencies.	

APPENDIX ONE: STRATEGIC CONTEXT

Palliative care emerged as a distinct medical specialty in the 1960s, and to a great extent developed alongside the hospice movement.² The current hospice model of palliative care originated in the United Kingdom in the late 1960's, adopting a multidisciplinary approach to caring for the physical, spiritual, social and psychological needs of dying people and their families. Mary Potter Hospice in Wellington was one of the first hospices to open in New Zealand, in 1979.³

Over the last few decades the demographics, disease profile and needs of the dying population have changed, and continue to change significantly. Previously acute illnesses with short duration were the main cause of death. Recently however, chronic medical conditions including Congestive Heart Failure (CHF), Chronic Obstructive Pulmonary Disease (COPD), dementia and cancer are prevalent, and have increasingly become the predominant causes of death^{4,5,6,7,8,9}.

Increasingly people also present with co morbidities and/or increased frailty in the years preceding death, leading to increased disability. In the United States it has been estimated that people have on average two years disability in the years preceding death.⁵

At the same time populations are undergoing population ageing, and the social structure of the population is changing significantly. Informal caregivers of terminally ill patients are increasing in age, and up to three quarters suffer from chronic medical illness themselves. Families are smaller, more geographically dispersed, and have greater work commitments, which combine to limit their ability to provide care for people with terminal illness.^{8,9}

As a result of these disease profile and demographic changes, the needs of people at the end of life have also changed significantly over recent decades.

Different diseases have different patterns and trajectories at the end of life (Figure 1). Chronic terminal illnesses, such as CHF, COPD and dementia, have relatively unpredictable trajectories when compared to acute illnesses or many forms of cancer. This unpredictability results in difficulties in making accurate prognoses. Half of heart failure patients die within five years of diagnosis.¹⁰ People with CHF or COPD may live for many years and often experience some level of disability in this time. The active

² Hospice Education Institute. A Short History. <http://www.hospiceworld.org/history.htm> accessed 5/1/05

³ Mary Potter Hospice. <http://www.marypotter.org.nz/>. Accessed 5/01/05

⁴ Bern-Klug M. The Ambiguous Dying Syndrome. *Health and Social Work*, 2004. 29(1) pp55-65.

⁵ Lynn J., Adamson D.M. *White Paper: Living Well at the End of Life – Adapting Health Care to Serious Chronic Illness in Old Age*. Rand, 2003. <http://www.rand.org/publications/WP/WP137/WP137.pdf>. Accessed 19/11/04.

⁶ Morrison S., Meier, D. Palliative Care. *New England Journal of Medicine*. 2004. Vol 350. pp 2582-90.

⁷ National Consensus Project for Quality Palliative. *Clinical Practice Guidelines for Quality Palliative Care*. May, 2004.

⁸ World Health Organization Regional Council for Europe. *Better Palliative Care for Older People*. World Health Organization 2004.

⁹ World Health Organization Regional Council for Europe. *Palliative Care – the Solid Facts*. World Health Organization, 2004. <http://www.ilcusa.org/lib/pdf/facts.pdf>. Accessed 19/11/04.

¹⁰ Pantlat S.Z., Steimle, A.E. Palliative Care for Patients with Health Failure. *JAMA*, 2004. 291(20), pp 2476-82.

dying phase for these diseases is difficult to predict and patients often die suddenly from exacerbations.^{5, 11}

As illustrated in figure 1, the disease trajectory of COPD and CHF typically has repeated exacerbations and relapses, which often require acute admission. In Canada, authors state that during these admissions people do not receive any coordinated palliative or end of life care. There is also evidence that emergency life prolonging interventions occur more often in this group than for people with cancer.¹⁴ Figure 1 also shows the disease trajectory for people with increased frailty and dementia.

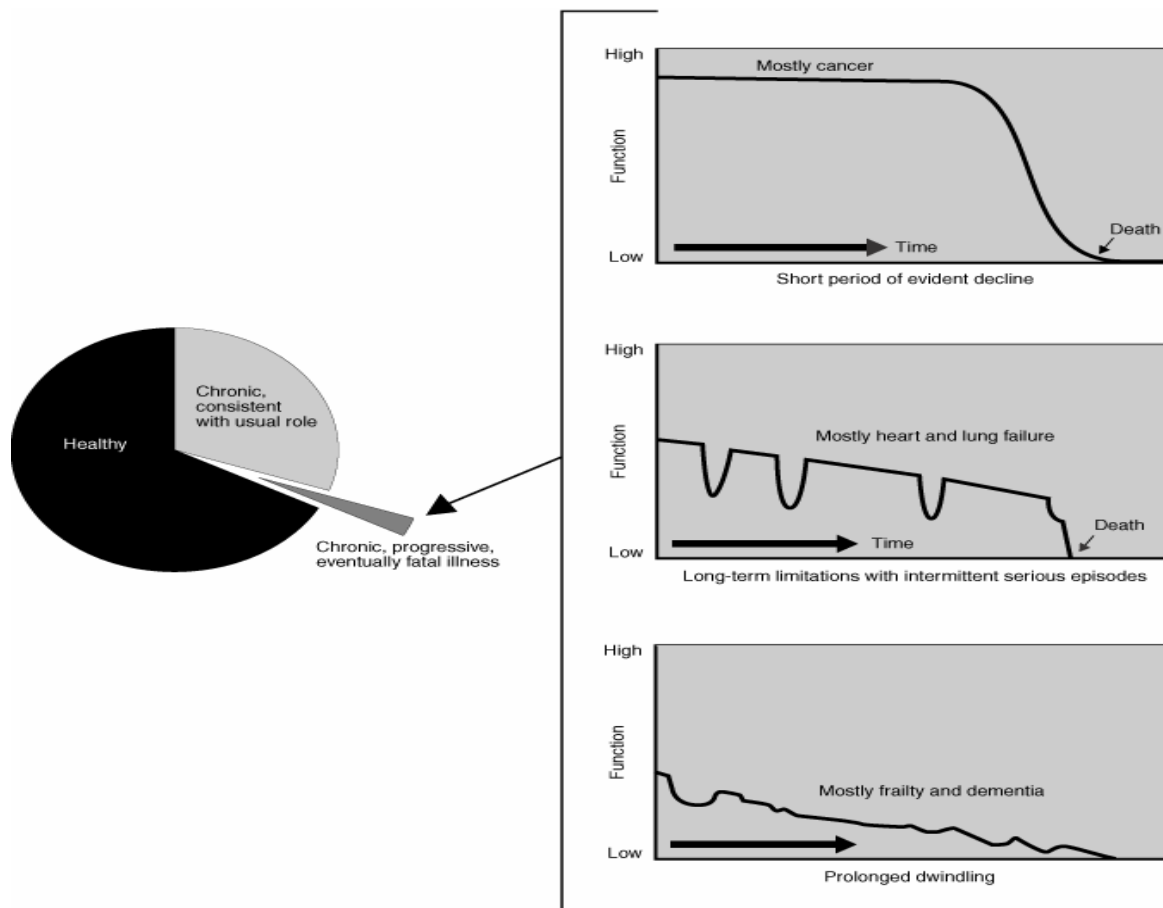


Figure 1: Disease Profile of Chronic Terminal Disease in Older People

From Lynn J., Adamson D.M., White Paper:
Living Well at the End of Life - Adapting Health Care to Serious Chronic Illness in Old Age. Rand, 2003.⁵

In comparison to COPD, CHF, dementia and frailty, clinicians are more ready and able to make a prognosis about the course of cancer. This in turn makes it relatively easier to recognise and plan for the needs of cancer patients and their families than those suffering from other chronic terminal illnesses.^{8, 9}

¹¹ Rocker G., Heyland, D. New Research Initiatives in Canada for End-Of-Life and Palliative Care. *JAMC*, 2003. 169 pp 300-1.

APPENDIX TWO: CURRENT PROGRAMMES AND SERVICES

Capital and Coast District Health Board

- C&C DHB generalist community palliative care services are provided by PHOs, GPs and District Nurses, as well as Residential Care Staff, home support and community care providers.
- Specialist community palliative care is provided by Mary Potter Hospice – and inpatient (in hospice) care when appropriate.
- The Specialist Hospital Palliative Care Consultation Service is available in Wellington Hospital to provide for the needs of patients and staff in Wellington and Kenepuru
- The Hospital Health Service (HHS) Child Health Services provides assessment, coordination and support for children who need palliative care, as well as to their families, within C&C DHB.
- Ambulatory services include chemotherapy, radiotherapy and blood transfusions for outpatients
- Community Oncology Nurses operate out of the Capital & Coast, Hutt Valley and Wairarapa District Health Boards. Their services are provided to people who have been diagnosed with and are receiving treatment for their cancers and who have been referred by a health professional – generally medical oncologists and radiotherapy specialists but occasionally GPs and surgeons. Community Oncology Nurses' services range from advice, support and monitoring patients undergoing cancer treatments, referral to other services, advocacy and education and information to patients and their families.
- The Wellington Blood and Cancer Centre (WBCC) provides inpatient and a limited outpatient specialist palliative and end-of-life care through the hospital specialist Palliative consultation service. The Centre aims to provide closer links with the local/regional hospices and primary care providers within the local catchment.
- Planning and Funding Director This Directorate is responsible for annual and strategic planning for Capital & Coast. Associated with that is securing all funding requirements for current and new health improvement initiatives and ensuring that investments of funds occurs on the basis of agreed priorities. It is in this Directorate that responsibility also rests for the development and management of contracts with service providers. There are a number of divisions within the Directorate, including:
 - Integrated Community Care (which includes Health of Older People and the Palliative Care Programme)
 - Integrated Nursing Care
 - Mental Health
 - Population Health, Intersectoral Strategy and Programmes
 - Pacific Health Directorate
 - Māori Health Development

Cancer Navigator Project -Kaiwhakatere

The Navigator Project was a separate but key contributor to the development of the Palliative Care Plan for Capital & Coast. The outcomes of the project, which involves mapping the journey of people who have been affected by cancer from diagnosis to treatment and survival stages, will inform best practice guidelines for future care, including palliative care services, diagnosis and treatment services.

Maori Health Development Group

The “Providing Palliative Care to Māori” project was a result of the previous health strategies for Māori which had identified the need to assess current service provision for Māori in palliative care and chronic disease in the district. Findings from the community engagement and recommendations from this project re access issues, gaps and barriers to service provision have informed the development of this Palliative Care Plan.

Health of Older People and Palliative Care Team

This team manages the planning and funding of home and community services for older people and people (aged 16 years+) with chronic illness in the Capital & Coast district. Home and community care services include:

- aged residential care;
- home support;
- palliative care;
- equipment;
- orthotics and prosthetics;
- information;
- home (district) nursing;
- community allied health and therapies;
- rehabilitation;
- mental health for older people; and
- assessment, coordination, care management and other services.

These services are provided to adult age groups (aged 16 and up) on both a short and long term basis. They are particularly important services for older people, people who have recently been discharged from hospital, and people who have chronic illness, especially those in their last year of life.

Other Advancements in Service

- The *Care Coordination Centre* is contracted to provide integration of community Palliative Care assessment and support services. This acts as the single point of

entry for all community Palliative Care referrals, including ongoing referral to specialist community Palliative Care services (Mary Potter Hospice). The Care Coordination Centre coordinates and arranges for home nursing services at the very end of life.

- The *Palliative Care Forum* has been established. The primary purpose of the Forum is to advise on district Palliative Care planning and funding priorities. The Forum aims to facilitate linkages and collaboration between primary and secondary care, to promote the ongoing planning and development of integrated and coordinated palliative care services within the region. Hutt Valley services are represented on at this forum through Te Omanga Hospice and the Palliative Care Programme Coordinator represents C&C DHB at the Hull Valley DHB Palliative Care Forum.
- C&C DHB funds a *Palliative Care liaison and education position* working out of Mary Potter Hospice to increase carer and community knowledge of Palliative Care. This position has been established to focus on provision of palliative care including when and how to access specialist palliative care services, with a primary focus on aged residential care and community care providers.
- C&C DHB has representatives on a number of national palliative care committees.
- C&C DHB through the Palliative Care Forum participates actively and has representatives on the following regional committees, The Central Cancer Network, the Central Region Palliative Care network, and the Hutt/Wellington Cancer Advisory Committee.
- C&C DHB is the lead DHB and employer of record for a *national palliative medicine trainee post*. This is a new programme resulting from a national palliative medicine workforce effort. The programme is a three year programme which includes rotations in Mary Potter Hospice, Te Omanga Hospice, Hospital Palliative Care Services, Community and Oncology. The first trainee has been selected and will be enrolled in the December 2009 run.
- C&C DHB funded Mary Potter to implement *PalCare Patient an electronic patient management system* that will enable not only Hospice staff but other health providers who are linked to be able to access up-to-date information on their patients who have been entered on the Mary Potter specialist service.
- The District Nurses, Community Services and Mary Potter Hospice collaborated to implement a shared care model to improve communication between providers of care.
- TeOmanga Hospice, Mary Potter Hospice, Wellington Hospital Palliative Care Team and Wellington Free Ambulance collaborated to develop protocols for assisting ambulance staff when responding to call outs to the home of a patient receiving specialist palliative care services.
- Wellington Hospital Palliative Care Team and Mary Potter Hospice are in the early stages of planning for the implementation of the Liverpool Care Pathway for the dying, an end of life programme which is being adopted throughout New Zealand.

APPENDIX THREE

Palliative Care Planning Over the Years – 2001 -2008: The mandates

Date	Document	Purpose	Strategies/Recommendations
2001	NZ Palliative Care Strategy	To set in place a systematic and informed approach to the provision and funding of palliative care services through the implementation of the following vision: “ All people who are dying and their family/whānau who could benefit from palliative care have timely access to quality palliative care services that are culturally appropriate and are provided in a co-ordinated way. ”	<ul style="list-style-type: none"> • Ensure access to essential palliative service • Each DHB to have a least one local palliative care service • Develop specialist palliative services • Implement hospital palliative care teams • Develop quality requirements for palliative care services • Inform the public about palliative care services • Develop the palliative care workforce and training • Ensure that recommendations from the Paediatric Review are implemented <p>Address issues of income support.</p>
2003 2005-2010	NZ Cancer Control Strategy NZ CCS Action Plan	To reduce the incidence and impact of cancer And reduce inequalities with respect to cancer.	<p>Goal 4: Improve the quality of life for those with cancer, their family and whānau through support, rehabilitation and palliative care.</p> <p>Objectives:</p> <ul style="list-style-type: none"> • Continue to improve access to essential palliative care services that provide appropriate symptom relief and emotional, spiritual, cultural and social support for those with cancer and their family and whānau. • Ensure an integrated and comprehensive service is provided to all those with cancer who require palliative care and their family and whānau.
2005	Palliative and End of Life Care Services: A Summary of the Review	A review by C&CDHB of palliative care services and services accessed by people diagnosed with life limiting illness.	<p>Three overarching goals were established. These goals are:</p> <ul style="list-style-type: none"> • Services enable people to die in the setting of their choice.

Date	Document	Purpose	Strategies/Recommendations
			<ul style="list-style-type: none"> • People make active decisions about their care and treatment options at the end of life. • People from all ethnicities have access to culturally competent services that enable them to live and die as they wish. <p>To improve care for people diagnosed with life limiting illness in the district:</p> <ul style="list-style-type: none"> • Improving coordination of services • Making comprehensive care planning available • Improving the quality and availability of home services • Addressing identified service gaps • Ensuring palliative care is available earlier in the disease process • Ensuring referral to specialist palliative care is based on individual need • Enhancing the palliative approach of non specialist providers • Building community awareness of palliative care and of all services available at the end of life.
2007	Integrated Home and Community Care	To advance the vision: <i>People and their carers/family/whānau receive coordinated and accessible home, community, primary and specialist care that proactively supports their ability to achieve their lifestyle goals.</i>	Development of a multi-service, multi-disciplinary model.
2007	Planning Day	<p>? To develop a shared understanding of the Strategic Context for PC</p> <p>To develop a common understanding of an integrated palliative care service model</p>	Information to inform the development of the PC Plan
2007	<i>C&CDHB PC Plan</i>	To provide a strategic direction for an integrated and coordinated C&CDHB palliative care.	The Vision: <i>All people with a life threatening illness and their family/whānau who could benefit from palliative care services have timely access to</i>

Date	Document	Purpose	Strategies/Recommendations
			<p><i>quality palliative care services that are culturally appropriate and are provided in a co-ordinated way. Underpinning this vision is a community-based model of palliative care services.</i></p> <p>Not a clear connection from the planning day to the plan.</p> <p>No stated goals or priorities;</p>
2008-2009	C&CDHB DAP	Finalise District 5 year Palliative Care Strategic Plan in collaboration with Palliative Care Forum.	

Note: It is recognised that other national documents must inform this work: such as He Korowai Oranga Māori Health Strategy, Primary Health Care Strategy and others.

APPENDIX FOUR

Stakeholder Engagement Summary

This table is intended to represent the scope of stakeholders contacted over from November 2008 through September 2009. In a number of instances there was more than one meeting or contact with an individual or organization.
Cancer Control Council Senior Analyst Palliative Care
Cancer Control Plan work session
Cancer Control Planner
Cancer Society (Wlgn)- management and educators
Capital PHO AGM
Capital PHO manager
Care Coordination Centre management representatives and staff meeting
CC Plan Workshop
CC pt navigator project manager
CCDHB Integrated Care Clinical Advisor
CCDHB Pacific Health Advisor
CCDHB Palliative Care Forum
CCDHB Child Health/Nursing Team
CCDHB Primary Care Nursing Director
CCDHB Primary Care Matrix Team
CCDHB Risk management Workshop
CCDHB/Hutt Cancer Advisory
CCDHB Primary and Integrated Care Nurse Leader
Central Region Palliative Care Network
Child Cancer Foundation counsellor
Clinical Leadership Sessions – Hutt – Leadership and multidisciplinary teams
Community Nursing and Community Health – operations and clinical leaders
Compass Clinical Quality Board
Compass Health Clinical Advisor
Compass Maori Hui
Fiji Community Health Forum
Guardian Funeral Home director
Health CareNZ - management
Health Indicators for Wlgn Reg Genuine Progress
Healthlink Health & Disability Forum
Healthlinks Public Forum
HospiceNZ CEO
Hospital Pacific Health Team
Hutt Valley DHB F&P team
Kapiti Community Forum
Kapiti Health Centre
Kapiti PHO manager
Kaupapa Maori Research Hui
Kemp Home & Hospital – management team
Local Palliative Care Nurses Forum

Member C&C DHB Board
Māori Health Development Group Director, Accountability Manager, Analyst
Māori Palliative Care Needs Assessment Project Manager
Māori Palliative Care nurse
Mary Potter Hospice AGM
Mary Potter Hospice – management and clinical teams
Ministry of Health - Renal services project manager
Ministry of Health Clinical Advisor Palliative Care
Ministry of Health National Manager Cancer Control
Ministry of Health Palliative Care Working Party Chairperson
Mary Potter Hospice Social Work Team
National LCP Office- Programme coordinator
Ora Toa- Clinical Group and managers
Pacific Health Services - Porirua
Pacific Services Advisory Group
PHOAG –(introduction only)
Primary Care Clinical Advisor- Hutt DHB
Primary Health Care Nurse reference group
<i>Radio Samoa</i>
Respiratory Medical Specialist
SECPHO Clinical Governance Group
Taeaomanino Pacific Provider
Te Roopuu Rangahau Hauora A Eru Poomare- Senior Research Fellow
TeOmanga Hospice- management and clinical Teams
Tūmai Community Caucas- Porirua
Tūmai Mō Te Iwi – manager
Vaka Tautau
Waitangarua Health Centre- Chronic Conditions nurse
Wellington Hospital PC Team – management and clinical
Wellington Blood & Cancer Nurses
Wellington Hospital Director Nursing and Midwifery
Wellington Hospital Social workers
Wellington Hospital Medical & Cancer Ops Manager
Wellington School of Medicine lecturer general practice
Whānau Care Services Team
Whanau Care-Kenepuru
Work and Income Nurse
Workshop with “coal face” representatives

GLOSSARY/ABBREVIATIONS

AGM	Annual General Meeting
CAMS	Complementary Alternative Medicines
CCN	Central Cancer Network
FAQ	Frequently asked questions
GP	General Practitioner
HHS	Hospital and health Services
LCP	Liverpool Care of the Dying Pathway
MDMs	Multi-disciplinary Meetings
NGOs	Non-governmental organisations
NZGG	New Zealand Guidelines Group
PHO	Primary health Organisation
WBCC	Wellington Blood and Cancer Centre

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