



# **Palliative and End of Life Care Services**

## **A Summary of the Review**

**FINAL**

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The Aged Care and Disability Team would like to thank the members of the Palliative Care Reference Group for their guidance and contributions to the review of end-of-life services in C&C DHB.

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**Abbreviations:**

AT&R	Assessment, Treatment and Rehabilitation
C&C DHB	Capital and Coast District Health Board
CHF	Congestive Heart Failure
CVD	Cardiovascular Disease
CMI	Chronically Medically Ill, the funding stream for long term support services for people with personal health diagnoses under 65
COPD	Chronic Obstructive Pulmonary Disease
DSS	Disability Support Services
GP	General Practitioner
HHS	Hospital and Health Services
PHO	Primary Health Organisation

# 1 Executive Summary

Palliative care implies a holistic assessment and intervention in response to the physical, psychosocial and spiritual needs of a person approaching death. People living with a diagnosis of life limiting illness may have a wide range of health, social and palliative needs.

The population of people at the end of life is undergoing significant changes. People are dying older, their main caregivers are also older, and diseases causing death are now predominantly chronic illnesses of varying duration. Comorbidities are frequent within the population diagnosed with terminal illnesses.

Internationally palliative care is increasingly thought to be important and underutilised in addressing the increasing demands on health systems resulting from the changing disease profile and demographics of the population. Furthermore, traditional palliative care service models result in significant unmet need, particularly for people with diagnoses other than cancer.

Increasingly across the world health services are recognising the benefits of improving end of life care, and in particular, adopting a palliative approach to care for all people diagnosed with life limiting illness. Benefits include ensuring palliative needs of all people at the end of life and their families are met, enabling people to make informed and active decisions about how they want to live and die, and supporting people to die in the setting of their choice. For health systems, benefits include increased patient satisfaction and reduced unplanned hospital admissions.

The main service directions internationally include ensuring access to palliative services are based on need and not solely on diagnosis or prognosis; integrating the palliative approach earlier into the course of life limiting illness, and integrating care across all service settings.

In July 2004, C&C DHB commenced a review of palliative care services and services accessed by people diagnosed with life limiting illness. A reference group of key stakeholders helped to identify issues within the current environment and provided guidance to the recommendations for improving care at the end of life.

Three overarching goals to improve care for people with life limiting illness were established. These goals are:

1. Services enable people to die in the setting of their choice
2. People make active decisions about their care and treatment options at the end of life
3. People from all ethnicities have access to culturally competent services that enable them to live and die as they wish

The main areas where provision of timely, quality palliative care was identified as suboptimal in C&C DHB were:

- coordination of services
- care planning
- service gaps in the community
- early identification of palliative need
- timely referral to specialist palliative care services

The summary of the review concludes with recommendations for improving care for people diagnosed with life limiting illness in the district, including:

- 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

Improvements will be implemented by integrating palliative care services into the service model defined by the Home, Community, Primary and Specialist Programme, by developing community care packages to respond to the needs of people with life limiting illnesses, and by service development – particularly in aged residential care, workforce development and community education.

## 2 Introduction

Palliative care is a growing area of expertise and service development worldwide. Interest in palliative care has been driven by the changing patterns of diseases that cause death and changing population demographics, which combine to place increased pressure on existing service structures. Internationally it is recognised that current service models do not adequately meet the needs of people diagnosed with life limiting illnesses.

Terminal illnesses have changed from mainly acute illnesses with a short duration, to predominantly chronic illnesses, such as cancer and chronic heart and/or respiratory diseases. Although such diseases have varying patterns and courses, they tend to have a much longer duration than acute illnesses and can cause considerable disability in the months and years preceding death. The changing needs of people at the end of life are discussed in detail in the Palliative Care Literature Review (Appendix 1).

In 2004/2005 the Aged Care and Disability team commenced a review of community based care and support programmes and services for people in their last year of life. The review has encompassed the needs of all people, regardless of age or prognosis, diagnosed with a life limiting illness. The strategic directions outlined in the Palliative Care (2001), Health of Older People (2002), Primary Health Care (2001) and Cancer Control (2003) Strategies have been drawn upon in the course of the review, and international directions in care for people with life limiting illness have been reviewed.

This report outlines the benefits and goals of improving services for people diagnosed with life limiting illness in Capital and Coast District Health Board (C&C DHB). Services currently available, and linkages between services are identified. Particular issues that impact on palliative care identified within the current environment are presented. The report presents recommendations to the Board for improving services for people living with life limiting illnesses, and their families/whanau.

### **3 What are we looking at? Scope and Definitions**

#### **3.1 The C&C DHB review of services accessed by people with a diagnosis of life limiting illness**

The review of services for people with life limiting illness in C&C DHB began in July 2004.

The project initiation document outlined the services provided for people with life limiting illness to be included in the scope of this project:

CMI and DSS funded services, including home help, personal care, residential care and carer support.

Community Health Services

Mary Potter Hospice

Cancer Society

Child Health Services

PHOs

Hospital Palliative Care Service.

A reference group of key stakeholders met regularly to identify and discuss the issues for people diagnosed with life limiting illness, and for services working with people at this time.

Analysis was completed to identify the population with life limiting illness who access services at the end of their lives in C&C DHB (Appendix 2). Further analysis into the service utilisation patterns of this group of people is also presented.

International directions in palliative care have been drawn upon in the course of this review, and are presented in the Palliative Care Literature Review (Appendix 1).

The Steering Committee, Reference Group and Capital and Coast Board have considered the recommendations presented in this paper for improving care for people living with life limiting illness in C&C DHB.

### 3.2 Definitions:

Palliative care, as defined by the World Health Organisation, is:

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

*provides relief from pain and other distressing symptoms  
affirms life and regards dying as a normal process  
intends neither to hasten or 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 the illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications."*

*World Health Organisation, 2002.*

People diagnosed with life limiting illness have varying needs, and varying levels of need. People may access services from a wide range of health, palliative and support providers: from acute admissions to hospital to regular contact with their general practitioner; from specialist palliative intervention to assistance getting dressed in the mornings. Family and whanau also have wide ranging individual needs when supporting someone with life limiting illness: from grief support to respite from caring.

As a relatively new and growing area of expertise and development there are some differences in terminology and definition of palliative and end of life services. In this document:

*palliative care* - describes the holistic approach to assessment and intervention for people diagnosed with life limiting illness, and their family/whanau.

*specialist palliative care* – describes palliative care services provided by specialist palliative care providers.

*a palliative approach* - is an holistic approach to the care of people with terminal illness provided by non (palliative care) specialist providers and their family/whanau, for example General Practitioners, District Nurses and other medical or surgical specialists. This care may also be described as *generalist palliative care*.

*End of life care* – in international literature the term “end of life” care is sometimes used to define the total care (health, social and palliative) of an individual diagnosed with life limiting illness. It can, however, also mean the clinical care provided when someone is actively dying. To avoid confusion, the term end of life care is not used in the review documentation. These ideas are explored in more depth in the Palliative Care Literature review (appendix 1).

### **3.3 Relationship between definitions:**

The vision outlined in the New Zealand Palliative Care Strategy (2001) is that “*all people who are dying and their family/whanau 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*”.

People with life limiting illness live for variable, and often considerable, lengths of time. Chronic life limiting diagnoses include, but are not limited to, COPD, Cancer, CHF, Diabetes, Renal Failure, Dementia and/or Alzheimer's, Multiple Sclerosis, and Parkinsons Disease. An estimation of the number of people living with a chronic life limiting disease in C&C DHB is given in Appendix 2. People often concurrently have several diagnoses, or comorbidities. To varying degrees, such chronic illnesses result in a wide range of health, palliative and support needs.

Not all people with diagnoses of life limiting illness require intervention from specialist palliative care services. However, it is important that all people who work with individuals with living with life limiting illness have skills in identifying and responding to palliative need (i.e. employ a palliative approach to care), which at times will include referring to other appropriate services to address palliative needs where necessary.

## **4 Benefits from Improving Services for People living with Life Limiting Illness**

Improving services available to people living with life limiting illness has many potential benefits, for people with the illnesses and their families and for providers of services accessed by these people.

Improving access to services and integrating the palliative approach earlier in the course of the disease will enable people with chronic terminal illnesses to be presented with the full options available to them. Early identification of palliative need will enable people actively to make decisions about how they want to live the rest of their lives, including what courses of active treatment they wish to pursue. People will also be able to make decisions about the involvement and support of families, and make advance decisions about preparing emotionally, spiritually, physically and financially for dying. The holistic approach of palliative care has also been shown to have significant benefits for family and carers of dying people, including reduced morbidity and mortality.

In the two years preceding death, health and support service utilisation increases exponentially. Early identification of palliative needs and appropriate care planning will avoid many unnecessary Emergency Department presentations, hospital admissions and futile interventions towards the end of life.

Despite most people explicitly stating their wish to die at home, 29% of the population who die in C&C DHB die within a public hospital, and a considerable number die in aged residential care facilities. Improving services for people with life limiting illness will enable more people to die in the setting of their choice.

## **5 Improving Care for People with Life Limiting Illness in C&C DHB – The Goals**

The review highlighted three interlinking goals that C&C DHB can work towards in order to achieve the overarching goal of improving services for people diagnosed with life limiting illness in our district:

Services enable people to die in the setting of their choice.

People make active choices 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.

The necessary components for obtaining each of these goals are identified in the course of the review and discussed. Issues within the current system that prevent the achievement of these goals are highlighted.

### **5.1 Services enable people to die in the setting of their choice:**

Of all deaths that occur in C&C DHB each year, approximately 29% happen in a public hospital (over 400 per year), 11% in a hospice and the remaining 60% elsewhere in the community. A significant number of people die in aged care facilities, however the exact number is not known due to data collection issues. Approximately 5.7% of the population over 65 (or 1561 people) in C&C DHB live in an aged care facility at any given time, and almost all remain in a facility until they die.

The reference group highlighted several service and service model attributes that combine to enable people to die in the setting of their choice. These included:

security

good communication between services

timeliness of services involved

patient-centred care

assessment and recognition of caregivers' needs and skills

high level health and support packages supporting people in the community.

A number of problems within the current system were highlighted, which impact on the ability of people to fulfil their wish to die at home:

- poor coordination of services
- lack of care planning
- service gaps in the community.

These problems are discussed in detail below.

#### *5.1.1 Coordination of services:*

People living with life limiting illness may have health and support needs from many different services. Immediately preceding death people often have very high levels of health and support need. The review highlighted major problems within the current service configuration that impact significantly on people who receive services from providers of care.

No one service has a mandate for coordinating all care for an individual. It was clear that this causes significant problems for both individuals accessing services, and service providing care.

Both Capital Support and the Cancer Society are tasked specifically with coordinating some community providers. Most other services have developed coordination or key working roles in an attempt to address service interface issues.

Examples were given of coordination between services working well. However, these were the result of individual clinicians from different services developing good relationships and communicating well - in spite of the system in which they are operating. Numerous examples were presented of people not receiving necessary services, or experiencing delay, at times resulting in admission to hospital, hospice or aged care facility.

The issue is further compounded by the differing inclusion and exclusion criteria and screening processes of different services. The result in some cases is untimely and poorly coordinated services, and significant time spent by clinicians negotiating between services.

Successful coordination of all care supporting people in the community is essential to enable people to die at home.

### *5.1.2 Care planning*

People with a diagnosis of life limiting illness need a care plan which covers all of their health and support needs. At the moment, each service involved in the care of an individual patient assesses and completes a care plan around their intervention and referrals to other services. Individual patients and their caregivers therefore undergo many assessments covering similar information. Such multiple assessments can cause significant distress, especially when a person is very unwell and/or close to dying.

As no one assessment covers all aspects of an individual's care, some aspects of care are at times overlooked.

The importance of people and their families knowing who and where to turn to for advice in times of change or crisis was also highlighted. There is potential for comprehensive care planning to assist in preventing and managing crisis situations, greatly relieving stress for patients and their caregivers, and avoiding untimely and stressful presentation to after hours medical centres or the Emergency Department.

### *5.1.3 Service gaps in the community*

The review highlighted a number of specific service gaps in the community, which placed significant stress on families caring for people with life limiting illness at home. These gaps sometimes contribute to untimely admissions to acute services, or inappropriate long term placement in aged care facilities.

#### *Palliative care in aged residential care facilities*

People with recognised and high level palliative needs who are unable to cope at home may require care in a facility that is not a hospital or hospice. Aged care facilities usually provide services in these circumstances. This may be for an indefinite period until death, or for periods of respite in the period leading up to death.

Variability in the skills available and willingness of aged residential care providers to provide the level of care required for this group of patients exists, and key stakeholders have identified a need for a distinct type of care outside the currently contracted and provided aged care services. This need is in part due to the expertise involved in the care, and in part due to the extra costs of medication and equipment involved for people with high palliative needs. Whilst Mary Potter Hospice educates and supports staff in aged care facilities caring for people with high level palliative need in the district, the patients, and therefore

information and skills gained, are disseminated across staff in 37 facilities across the district.

Key stakeholders also voiced their concern that aged care facilities are not appropriate places for short or long term placement of younger people with high palliative need. It was identified that inappropriate or inadequate support in the community for younger people with high needs and their families often precipitates the need for inpatient care.

*Palliative care for children:*

Dying children often have very high levels of health need, and their families need considerable support to enable children to remain at home. The level of domiciliary nursing and caregiving expertise often needed in these situations is sometimes unavailable. Whilst dying children and their families endeavour to stay at home, the lack of appropriate places for overnight stays to allow families respite from caring was identified as a service gap.

The coordination of services into the home of dying children is difficult in the current system. The need for services is identified by the Child Health Service, who then refer to Capital Support for the coordination of support services. This system can be difficult to negotiate when needs are changing rapidly, or a crisis situation develops.

*Palliative care after hours:*

During the course of the review concerns were raised about after hours care of people with palliative needs living in the community.

Difficulties accessing GPs after hours, and the funding barriers to such services were highlighted as problems for people in the community. There were reports that some GPs make themselves available for home visits after hours when they are aware that someone is dying. It appears, however that this is uncommon, as this service is not specifically contracted for, and when available usually comes at considerable expense to the individual accessing care.

Community Health district nurses also provide an on call service over night. However, if medical intervention is required after hours then after hours medical services or the Emergency Departments are accessed.

Specialist palliative care nursing advice is provided by Mary Potter Hospice 24 hours a day, by phone. Difficulty accessing GPs after hours for support and assistance was highlighted as an issue by other providers working with people

with life limiting illness outside of normal working hours, such as district nurses and support workers.

Anecdotally, the skill level of generalist providers in after hours situations is sometimes inadequate to respond to the crises at hand. Non specialist palliative care skills are discussed in more detail below.

Communication of individual patient information between services was also identified as an issue in out of hours situations.

#### *Home nursing at the very end of life for people with diagnoses other than cancer:*

At the moment, home nursing is available to support people with cancer at home during the last 72 hours of their lives. A similar service does not exist for people with other diagnoses.

#### *Inpatient hospice beds*

The inpatient unit of Mary Potter Hospice is located in Newtown. The travel time and costs were identified as barriers to inpatient hospice care for people living in the C&C district outside Wellington.

It was suggested that a culturally appropriate environment, such as a converted house in Porirua, for dying people and their families would reduce the barriers to inpatient hospice care for the Maori and Pacific communities in Porirua.

## **5.2 People make active choices about their care and treatment options at the end of life**

Empowering people to make informed and active decisions about how they live and die with a terminal illness is important in a system providing care for people with life limiting illness. As discussed below, current organisational philosophies and service specifications combine with the current service configuration to limit the ability of individual patients to make active and informed decisions about their care and treatment.

Where people are presented with palliative options only at the very end of life, their ability to make informed choices is limited. These situations are often crisis points, and patients and families are still in the early phases of the grieving process, and are already trying to process large amounts of complex information.

There were several incidences reported of people undergoing extensive and futile treatments in the time preceding death, causing considerable distress for both individuals and their families.

The following improvements to end of life care would enable people to make informed and active decisions. Barriers to achieving such improvements within the current system are discussed.

### *5.2.1 Early Identification of palliative need*

The need for early identification and comprehensive assessment of palliative need was highlighted as an important factor enabling people with life limiting illness to make active choices about their care and treatment. There is a meritorious argument that all people with a diagnosis of life limiting illness should have palliative needs assessed at the time of diagnosis and regularly reviewed throughout the course of their disease.

It is essential that people have good information about their disease. Information about the options for treatment and their implications should also be explicit throughout the course of the disease.

People should also have good information about the range of services available to them, including both palliative and disease modifying interventions and support services. In part, this is limited in the current system as a result of the divide between palliative and traditionally active or disease modifying care, which is discussed in more detail below.

### *5.2.2 Timely referral to specialist palliative care services*

Timely referral to specialist palliative care services is an important component necessary to ensure that the holistic needs of people with life limiting illness are addressed. Benefits gained by referral to specialist palliative care services are limited by late referrals.

Anecdotally, referrals to specialist palliative care are made later than desirable in C&C DHB. The time from referral to Mary Potter to date of death is shown in Figure 1. 33% of people referred to the hospice died within four weeks of referral, and 61% of people referred died within three months. Clients with a length of stay of less than one week usually died prior to the referral being received by the Hospice.

Five percent of patients remain in the care of Mary Potter for longer than 12 months.

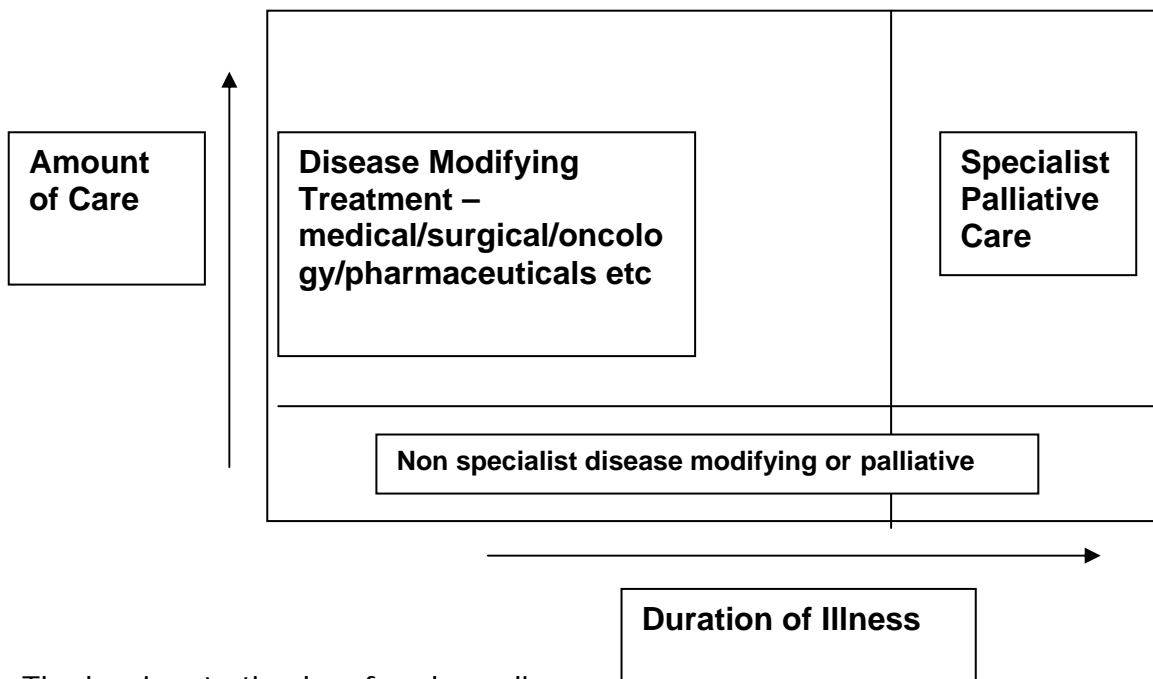
The reference group highlighted the value of community providers being able to refer directly and urgently to Mary Potter Hospice for assessment and advice.

**Figure 1: Time from Referral to Mary Potter Hospice to Date of Death**

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The interface between disease modifying and palliative services is blunt, as shown in Figure 2 below; people access either one or the other.

**Figure 2: Relationship Between Curative and Palliative Services**



The barriers to timely referral are discussed below.

*Organisational philosophy and structure*

In the current services, a person with chronic terminal illness is not considered to be eligible to access palliative services until a clinician has offered a firm prognosis of no longer than twelve months, and the person agrees to forfeit curative options for care.<sup>1</sup>

<sup>1</sup> The service specifications for specialist palliative care state that “A palliative care service provides the essential services for people who have been diagnosed with a terminal illness for which curative treatment is no longer an option. It is likely (but not always the case) that people utilising the palliative care service will die within twelve months of entry to the service”.

The service specifications reinforce the distinct separation between traditionally active or disease modifying care, and palliative care.

The distinct interface between active treatment and palliative care is further reinforced by longstanding organisational and medical practices (this is discussed in more detail in the Palliative Care Literature Review in appendix 1).

Making accurate prognosis about length of time until death is difficult under any circumstance. However it is particularly difficult for clinicians working with people with non cancer terminal illnesses, as the courses of these illnesses are difficult to predict. Clinicians are often reluctant to offer time limited prognoses until very late in the course of the disease.

Furthermore, in many instances the medical culture encourages all options for cure to be attempted. Clinicians and patients may be reluctant to accept that further intervention is futile. The result is delayed or late referrals to palliative care, and a greater likelihood of people undergoing extensive and futile treatment at the end of life.

#### *Public perception of palliative care*

In general in New Zealand, the term palliative care is synonymous with hospice care. The public perceives palliative care as being the very last option available to people, and the place where people go to die. The prevailing perception is that palliative services are only accessed once all options for cure have been exhausted.

#### *5.2.3 All people, regardless of diagnosis, have palliative needs recognised and addressed:*

The reference group identified groups of people less likely to have palliative needs assessed and met, in particular, people with diagnoses other than cancer.

The following issues may limit the recognition of palliative need in all individuals:

#### *The skills of generalist palliative providers in recognising palliative need*

The ability of all health and support providers in recognising and responding appropriately to palliative need (including referring to specialist services when appropriate) is varied. Some providers take a great interest in care of people

with life limiting illness; however in many instances skill levels and knowledge of the issues facing people with life limiting illness are limited.

A recent survey of GPs in the C&C DHB by Dr Helen Carter of Mary Potter Hospice highlighted the limited GP knowledge of palliative care issues and of services available for people with palliative need.

Mary Potter Hospice provides some education for generalist providers, in particular in supporting the care of individual patients. However the success of such knowledge dissemination is hampered by barriers including the varying level of interest and engagement of individual clinicians and services, turnover of staff, and financial barriers to releasing staff for training.

#### *The fluctuating needs of people with terminal disease other than cancer*

The different disease trajectories of people with life limiting illnesses are discussed in detail in the palliative care literature review. Palliative needs may fluctuate throughout the course of the disease.

In terms of specialist palliative care, 20% of people who access Mary Potter services have a diagnosis other than cancer. In many instances, ongoing specialist palliative care is not necessary or desirable; however palliative assessment and advice for both patients and their regular health and support workers should be available to be accessed from time to time as diseases relapse and remit.

### **5.3 People from all ethnicities should have access to culturally competent services that enable them to live and die as they wish**

The specific needs of all individuals should be recognised and met in culturally appropriate and respectful ways.

The holistic approach of palliative care is in many respects close to Whanau Ora and Whare Tapa Wha models of care. Palliative care by definition seeks to address physical, psychological and spiritual issues, with patient and family/whanau considered the unit of care.

Dying at home with whanau and family present is identified as very important for Maori and Pacific people. Service delivery at the end of life needs to have sufficient flexibility to enable this to occur, as discussed in more detail below. Quality and culturally appropriate community and domiciliary services that are

skilled in working with people with life limiting illness and providing high levels of care into the home are necessary.

## **6 Services Available Across C&C DHB for People with Life Limiting Diagnoses:**

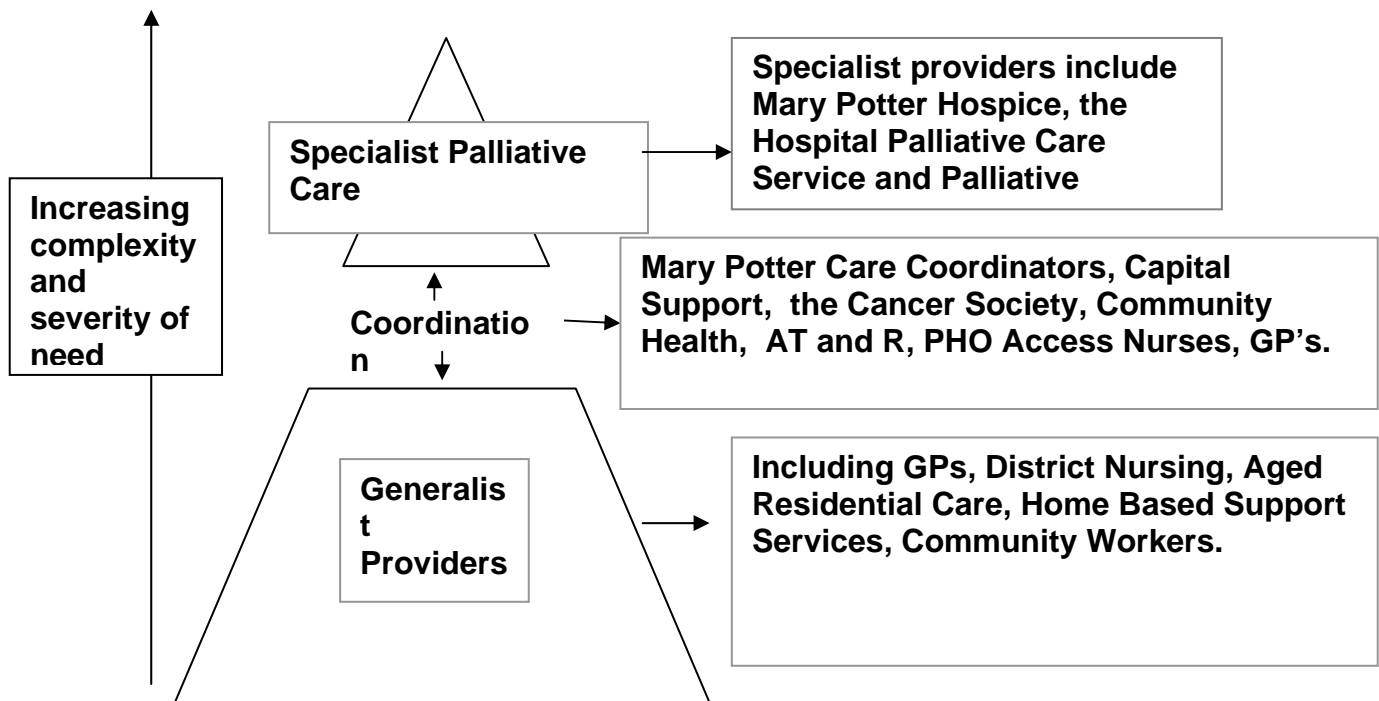
Both in New Zealand, and internationally, it is recognised that palliative care is provided by a wide range of clinicians in many different settings.

Specialist palliative care services should be available to people with high levels of palliative need, and to support other clinicians and services who are working with people with recognised palliative needs.

Other health and support services working with people with life limiting illness provide a variable level of generalised palliative care. In many instances, generalist providers will be able to recognise and meet the needs of people at the end of life. In some instances, however, specialist assessment and advice may be needed, or a patient may require referral to specialist services for intervention.

An overview of the relationship between services available to people in C&C DHB at the end of their lives is shown in Figure 3. The services are discussed in more detail in this section.

**Figure 3: Services accessed by people with life limiting illness in C&C DHB**



## 6.1 Specialist Palliative Care Services

The New Zealand Palliative Care Strategy outlines the essential palliative care services. These are:

assessment and care co-ordination

clinical care, which comprises:

- a. inpatient clinical and respite care
- b. domiciliary care aimed at managing the person's terminal illness at home
- c. bereavement counselling for family/whanau

Support Care, including home support and long term residential care for people who are unable to be cared for in their own home.

### 6.1.1 Hospice

The Mary Potter Hospice is a specialist palliative care provider in C&C DHB. Services include specialist medical and nursing care, physiotherapy, occupational

therapy, social work, spiritual care and counselling. Services are provided in an inpatient environment (the 18 bed hospice is located in Newtown) and in the community. The hospice also holds outpatient clinics and day programmes in Wellington and Kapiti.

The Hospice has designated care co-ordinators with a specialist palliative care nursing background, who provide assessment, monitoring, support and advisory service for people, their family/whanau and for other health professionals involved in a client's care.

The hospice receives approximately half of its total funding from C&C DHB, and half from fundraising. Funding of hospice services is being reviewed nationally.

Over the last five years, Mary Potter has accepted an average of 447 people per year into its services, with an average age of 69 years. 84% of people were 55 years or over. The numbers of Maori and Pacific people accessing Mary Potter Hospice were proportional to those dying in the population. Five percent of people enrolled at Mary Potter were of Maori ethnicity, four percent were of Pacific ethnicity, and ten percent of people had no ethnicity recorded. The remaining 81% were of "Other" ethnicities. The proportion of people accessing services from the Kapiti region is higher than their relative population proportion; however this is expected given the number of older people living in Kapiti.

**Figure 4: The Number of Admissions to Mary Potter Hospice by Domicile and Ethnicity:**

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82% of all patients who accessed Mary Potter services had a primary diagnosis of cancer, as shown in the graph below (figure 5). Patients with a diagnosis of cardiac, respiratory and renal disease consisted of two percent each of the total patients accessing services.

**Figure 5: Number of Mary Potter Clients by Disease Category, 1999-2004**

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### *6.1.2 Hospital Palliative Care Service*

The Palliative Care Strategy states that *“hospital palliative care teams are necessary to educate and advise all hospital services on the palliative care approach and the need to provide palliative care as an option for people who are dying”*.

Until recently, the Mary Potter Hospice provided the Hospital Palliative Care Service. However, the Hospice withdrew from this service in November 2004, stating difficulties providing the service in the hospital environment as an external provider. The service has been transferred to the District Health Board Hospital and Health Services (HHS), and currently consists of one consultant. A business case was submitted recently requesting additional team members, and outlining the potential health improvements and financial savings to be made by developing the team.

## **6.2 Hospital Services**

### *6.2.1 Inpatient, Outpatient and Community Services*

In their last year of life, whether identified as palliative or not, people may access a wide range of other HHS provided services. Services may be required in response to emergency situations, for example presentations to the Emergency Department and resulting admissions to medical and surgical wards, or routine admissions to the Cancer Centre for treatment. People with life limiting illness may also have contact with specialist medical and surgical services on an outpatient basis.

The HHS also provides community allied health services, through Community Health, Therapies and AT&R. For example, a physiotherapist may be required to assess a patient’s mobility and safety, or an occupational therapist to provide environmental supports. Referrals are received from across C&CDHB for these services.

Information about the utilisation of hospital services for a group of Capital and Coast residents with terminal illness at the end of their lives is presented in Appendix 3.

### *6.2.2 Community Health Services*

Clinical care by registered community nurses is provided by the HHS Community Health Service. This service is defined in the Palliative Care Community service specifications (the same service specifications that cover community services provided by the hospice). Community Health also provides short term home support for clients receiving palliative care under the supervision of district nurses.

Patients may be referred to Community Health for palliative district nursing and home support if they have a prognosis of 12 months or less to live. Many patients receiving care from Community Health are not classified as "palliative" but do have diagnoses of life limiting illnesses.

Over 40% of nurses at Community Health hold postgraduate qualifications in palliative care, including some with masters level qualifications. Palliative care is also a core competency for all district nurses. In a recent survey over 90% of District Nurses rated palliative care an important component of their daily practice (Carter, 2005).

The Community Health Service also includes specialist oncology nurses. Patients are transferred from oncology to palliative district nursing on a client by client basis, usually in consultation with the Cancer Centre and Mary Potter Hospice.

### *6.2.3 Capital Support*

Capital Support currently provides Needs Assessment/Service Coordination and budget management for support services, including Aged Residential Care and Home Support.

### *6.2.4 Child Health Services:*

The Child Health Service provides specialist medical and nursing care for children diagnosed with terminal illness. The Community Paediatric nursing team provides holistic assessment and care coordination for dying children and their families, as well as specialist nursing advice and intervention. The team also provides 24 hour on call services.

C&C DHB does not employ a specialist with expertise in palliative care for children. As with other specialties, the skill level and knowledge of clinicians in dealing with dying children varies. Specialist advice is available through Starship Hospital, although in some instances distance prevents or limits access to this service.

## **6.3 Community Services**

### *6.3.1 Primary Care*

GPs are often the main regular medical professionals involved in the care of people with life limiting illness.

As discussed previously, the skill and willingness of GPs in recognising and dealing with issues facing people with life limiting illness varies widely.

Financial barriers to accessing GPs regularly or out of hours were highlighted as an issue in maintaining consistency of primary care. Care Plus funding for PHO enrolled people with high health needs became available in 2004, providing some assistance in accessing care for people with chronic medical illnesses.

### *6.3.2 Community Support Providers – Aged Residential Care and Home Support*

There are 37 providers of Aged Residential Care in C&C DHB. Services are covered by a standard national Aged Residential Care contract. There are four distinct categories of care provided: Rest Home, Dementia, Continuing Care and Specialised Continuing Care (or “Psychogeriatric”). A needs assessment carried out by Capital Support determines need for and access to these services.

As discussed previously, most people admitted permanently to aged care facilities die there. The service specifications do not refer to assessing or meeting the palliative needs of residents, and providers’ ability in this area is mixed.

Respite (short stays in aged care facilities) and day programmes to enable carers to have a break, are also accessed through Capital Support following an assessment of need. People are allocated up to four weeks a year in an inpatient environment, although this is extended for individual need from time to time.

There are three externally contracted providers of home support services (household management and personal care) in C&C DHB.

### *6.3.3 Cancer Society Home Nursing Coordination*

The Cancer Society acts as a coordination service for home nursing services for people in the last 72 hours of their lives. Referrals are generally received from Community Health or Mary Potter Hospice, and services are provided by a variety of private, non DHB contracted community nursing services.

The service is provided across the Capital and Coast and Hutt Valley District Health Boards. An average of seven clients per month access the service, receiving an average of between 20 and 30 hours of nursing care and/or home support.

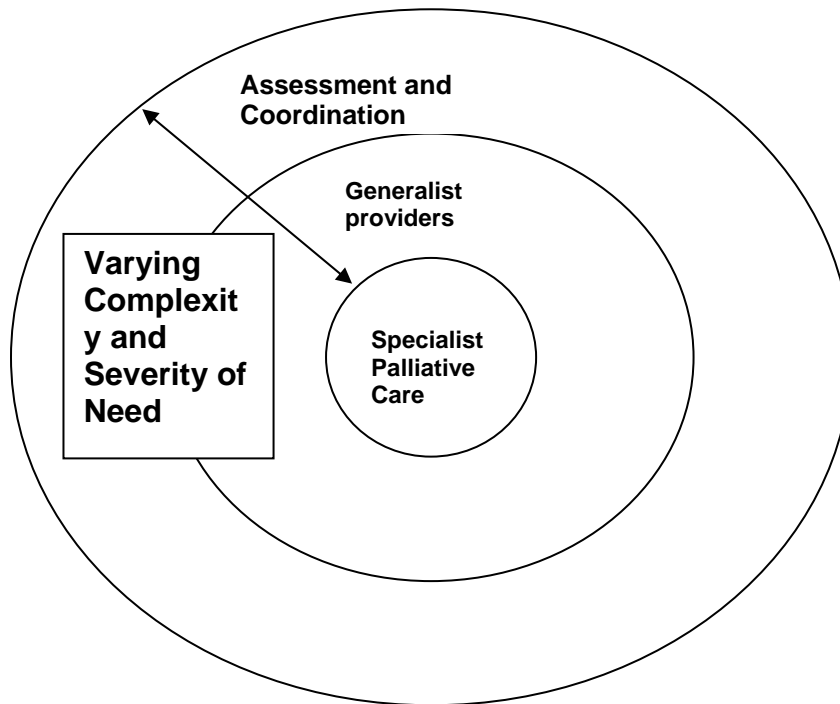
## 7 Recommendations for Improving Care for People with Life Limiting Illness in C&C DHB

This section contains recommendations for C&C DHB to improve care for people with life limiting illness in our district by meeting the objectives listed above.

**The holistic approach of both generalist and specialist palliative care, across a range of settings, should be available to people with any diagnosis of life limiting illness early in the disease process.**

The proposed relationship between services is represented by Figure 6 below.

**Figure 6: Proposed Relationship between Services for People with Life Limiting Illness:**



The goals of improving care for people with life limiting illness in C&C DHB as defined above are:

1. Services enable people to die in the setting of their choice
2. People make active choices about their care and treatment options at the end of life
3. People from all ethnicities have access to culturally competent services that enable them to live and die as they wish

These recommendations are made in the context of service reconfiguration currently underway through the Home, Community, Primary and Specialist services programme in C&C DHB.

## 7.1 Services Enable People to Die in the Setting of their Choice:

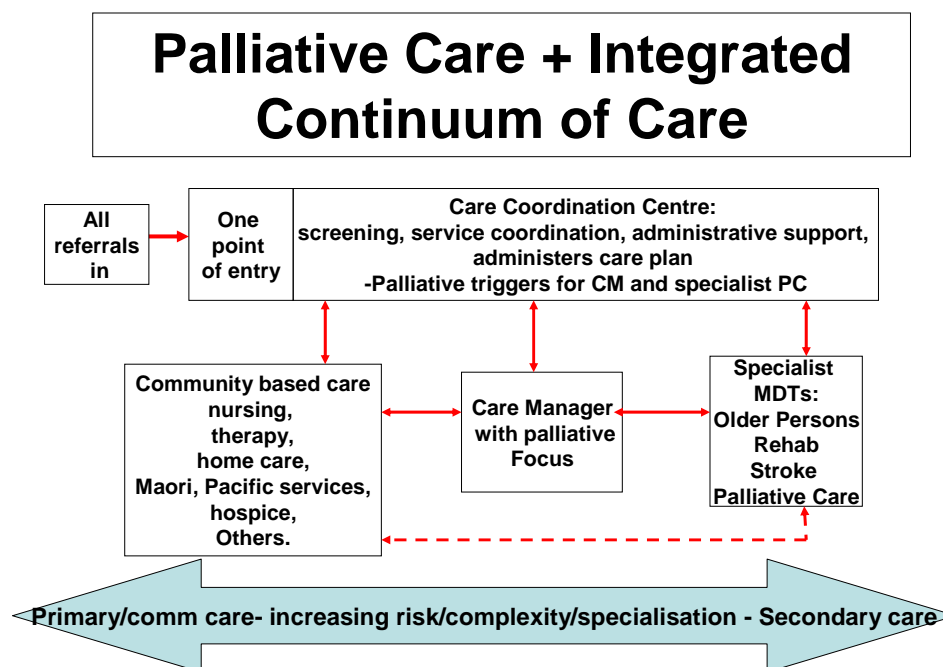
### 7.1.1 Coordination of Service:

The Home, Community, Primary and Specialist Services Programme is currently being implemented in C&C DHB. The new configuration of services provides many opportunities to improve care for people living with life limiting illness in Capital and Coast. Further information on the changes and service model can be found at [www.ccdhb.org.nz/primary.htm](http://www.ccdhb.org.nz/primary.htm).

It is important that palliative services are able to work optimally within the service configuration outlined in the Programme. In fact, the opportunity exists to integrate palliative care into this service configuration, improving coordination of services and early identification of palliative need. Access to and improved timeliness of referral to specialist services for all people with life limiting illnesses will also be enhanced.

The proposed model for integrating palliative care into the new service configuration is shown below in figure 7.

**Figure 7: Palliative Care in the Integrated Continuum of Care:**



Once established, the Care Coordination Centre will provide a one point of entry for all home, community and specialist services. This will reduce service duplication, and people falling into the gaps between services.

It is recommended that:

palliative care services are integrated into the home, community, primary and specialist service model, as shown in Figure 7

the population served by the service model will include all people receiving home and community services at the end of life

service specifications for the Care Coordination Centre ensure that urgent referrals for specialist palliative care services are processed without delay

Care Coordinators at Mary Potter Hospice are given the mandate to function as Care Managers as defined in the Home, Community, Primary and Specialist services model (see further discussion below).

The Cancer Society currently carries out the coordination role for home nursing services at the very end of life. This service includes home nursing and/or care up to 72 hours before death, but is available only to people with cancer. The Cancer Society has stated that they do not view this as core business.

It is recommended that:

that the Care Coordination Centre assume responsibility for coordinating home nursing services at the very end of life, a role currently carried out by the Cancer Society

home nursing services for people at the very end of life will be available to people with diagnoses other than cancer

all home nursing services providing care for people with life limiting illness are contracted appropriately through the DHB to ensure quality and accountability.

### *7.1.2 Care Planning*

Care Managers have recently begun working in C&C DHB. Care Managers are using the Inter-RAI Minimum Data Set assessment tool, and are generating care plans that cover both clinical and support needs of patients.

Care Managers, based in the community, are well placed to, at the same time, provide assessment of palliative need, and to initiate, liaise with, and/or refer to other health professionals involved in care to ensure that these needs are met.

It is recommended that:

all Care Managers receive training in recognising and meeting palliative need through assessment, care planning, liaison and referring to other services when necessary

some Care Managers are appointed who are experienced and trained specifically in palliative care.

### *7.1.3 Care in the Community*

People at the end of life with high levels of health, support and palliative needs require flexible packages of quality home nursing and support services to enable them to die at home, and to support their family and whanau at this time.

Within the Home, Community, Primary and Specialist Services Programme C&C DHB is working to define and purchase packages of care that integrate home nursing, support, allied health and other services into the home and community.

The course of the review highlighted the need for palliative education and support for generalist providers in the community. Formal and informal carers at home and in residential facilities, as well as other providers working in the community will benefit from palliative education and support.

It is recommended that:

flexible packages of quality care for people with diagnoses of terminal illness, and high levels of palliative, nursing and support needs are developed to enable people, including children, to live and die in the setting of their choice

C&C DHB fund a palliative liaison and education position to increase carer and community knowledge of palliative care.

#### *7.1.4 Palliative Care Nursing Services*

Mary Potter Hospice employs specialist palliative care nurses. In the community, the specialist nurses work as a consultant and advisory service for the district nurses, who are contracted to provide palliative nursing care.

The current service specifications of both Mary Potter Hospice and Community Health do not adequately describe the palliative care nursing that they currently provide or the roles and responsibilities of each service in delivering community nursing. Access criteria to both services need to be reviewed to reflect the need for specialist palliative care rather than proximity to death. Responsibilities and linkages with other services within the new service model should to be clearly identified.

It is recommended that:

a stock take of the specialist and non specialist palliative care services is undertaken, and service specifications for community palliative care nursing are reviewed to ensure that services and linkages are appropriately defined

the review of service specifications takes place in conjunction with development of packages of care for people in the community within the Home, Community, Primary and Specialist Programme

the stock take and service specification review consider the best configuration of specialist palliative care nursing in terms of workforce development and multidisciplinary linkages.

#### *7.1.5 Service Gaps:*

##### *Palliative Care in Aged Residential Care*

The review has highlighted the need for two specific service developments in the aged residential care sector.

Firstly, a small number of people have very high levels of palliative need, and require short term placement in aged residential care. The needs are often intensive, and require an increased level of skill than that defined in the national Aged Residential Care contract.

Secondly, all people residing in aged residential care would benefit from a less intensive, holistic palliative approach to their care.

It is recommended that:

the group of people requiring high level short term palliative care in aged care facilities are clearly identified and that service components be clearly specified, and that a contestable process will be run for the high level of palliative care in aged care facilities service

one facility in each territorial local authority is contracted to provide this service

key clinical nurse managers/leaders in some aged residential care facilities are supported to complete post graduate nursing qualifications in palliative care.

### *Palliative Care for Children*

Flexible packages of quality home nursing and support are required to enable dying children to remain at home with their families. At present there is no appropriate place for children to access short term respite in C&C DHB.

It is recommended that:

the Child Health Service continues to provide assessment and coordination for dying children in C&C DHB, in liaison directly with the Care Coordination Centre

the need for a facility to provide short term respite for children is reviewed once quality high level packages of home care are in place.

### *Palliative Care After Hours*

The difficulties accessing after hours medical and specialist palliative advice and intervention in C&C DHB were highlighted as a significant concern in the course of this review.

Comprehensive care planning will help people to plan for, and in many instances prevent crisis situations from occurring. At times, however, people will need to access medical and nursing advice or intervention after hours. After hours services are the subject of a separate review currently underway.

It is recommended that:

the goal for after hours care for people living with life limiting illness in C&C DHB is 24 hour, 7 day a week nursing and medical assessment, available in the home without barriers of cost or location

access to medical advice and intervention after hours for people with life limiting illness is included in the scope of the current review of after hours services in C&C DHB.

the specific issues relating to the provision of medical and nursing palliative care are addressed through the C&C DHB after hours review.

## **7.2 People make active choices about their care and treatment options at the end of life:**

### *7.2.1 Early Identification of Palliative Need*

Early identification of palliative need of all people with diagnoses of life limiting illness will greatly assist their ability to make active choices about their care and treatment options. Care Managers with training in recognising and responding to palliative need will be able to identify palliative issues earlier in the disease process. The Care Coordination Centre will need to identify people with life limiting illness and ensure Care Manager assessment takes place where appropriate.

It is recommended that:

the service specification for the Care Coordination Centre include the development and implementation of a screening tool to identify people with palliative needs early in the course of their disease and trigger Care Manager assessment where appropriate.

### *7.2.2 Timely referral to Specialist Palliative Care Services*

The review has highlighted the benefits to be gained from making palliative care available for people earlier in the course of life limiting illness. Specific identifiable barriers to the integration of palliative care with disease modifying treatments exist and can be addressed by the recommendations below. However, it is recognised that changes to clinical practice will develop slowly over time.

Access to timely specialist palliative care in the hospital is restricted at present as a result of the limited resourcing of the Hospital Palliative Care Service. It is important to note that increased and new demands will be placed on specialist palliative care as a result of early detection of palliative need, improved identification of palliative need of people with diagnoses other than cancer and improved timeliness of referral to specialist services.

Specialist palliative care services also play an important role in raising the profile and knowledge of palliative care within the hospital and other treatment settings. However, it is also important to ensure that generalist clinicians have skills in recognising and responding to palliative need. Clinical nurse managers and leaders trained in palliative care will assist in improving basic palliative care knowledge in aged care facilities. It may be beneficial to offer similar training to some primary care nurses based in PHOs.

It is recommended that:

the Hospital Palliative Care Service is expanded to include two palliative care specialist nurses and team secretarial support

specialist palliative care service specifications are reviewed to ensure that the consultation, liaison and advice role for patients and their health and support workers is clearly defined, and access to these services is based on need rather than proximity to death

the review of specialist palliative care service specifications is undertaken as part of the contract review process and considers resourcing issues, including those identified in the national review

support for postgraduate palliative nursing is available to those working in both aged care suitable applicants working in primary care

C&C DHB supports and encourages the integration of palliative care earlier into the disease process (and where necessary in conjunction with disease modifying treatment), for all people with life limiting illness.

### *Public Perceptions of Palliative Care*

As discussed previously, the prevailing perception of palliative care is that it is a last resort, and only appropriate when all options for active treatment have been exhausted. It is important that people realise the potential benefits of palliative care and are aware of the all services that are available to people living with life limiting illness.

It is recommended that:

C&C DHB funds a palliative liaison and education position to implement a district wide strategy of community education about palliative care.

### **7.3 People from all ethnicities have access to culturally competent services that enable them to live and die as they wish.**

Enabling Maori and Pacific people to die at home and supporting their whanau and family in the process are essential in meeting the needs of Maori and Pacific people living with life limiting illness.

The development of flexible, culturally appropriate home care services is essential to enable Maori and Pacific people to die at home. Having flexible and tailored services also improves the experience of care for people of all ethnicities. At the moment, the location of the hospice in South Wellington does place geographical barriers for people accessing inpatient hospice care.

It is recommended that:

the need for inpatient hospice beds for people actively dying in the Porirua region is reviewed once high level packages of home care are in place.

The Care Coordination Centre has access to flexible funding and direct payment options to support people of all ethnicities in home and community settings when mainstream services are unavailable or inappropriate.

## **8 Conclusion:**

The review has highlighted that there are many potential benefits in ensuring that a palliative approach is incorporated early in the disease process for people with any life limiting diagnosis.

Some specific barriers to care exist in the current service framework. The means to address these are recommended in this document. The resulting changes to the current service framework will result in improved care for people living with life limiting illness. The changes will also provide a framework to support the changing of attitudes and philosophies of clinicians, patients and the community over time.

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# Appendix 1 – Palliative Care Literature Review

## Executive Summary

Palliative care has received much attention internationally at both strategic policy and service provision levels in recent years. Governments and health and palliative care collaboratives in many countries, including New Zealand, have released policy documents proposing new models of care in response to the internationally recognised changing needs of people with terminal illness.

Changing needs at the end of life are predominantly the result of changes in the disease profile and demography of the population. Acute illnesses are no longer the main cause of death, instead chronic diseases with varying disease trajectories prevail. At the same time, the population is growing older and both people with terminal illness and their caregivers have increased prevalence of disability.

Traditional palliative care models have predominantly addressed the needs of people with a diagnosis of cancer. In part this is due to the fact that the disease course of cancer is relatively predicable and clinicians are more ready to make prognoses than for other chronic terminal illnesses. Referral to palliative services has traditionally been made when all options for curative treatment are exhausted. Current palliative care models predominantly describe specialist palliative care services at the very end of life.

Issues identified with current palliative care models include that:

- the patient group that currently access palliative care services is often referred late thereby reducing potential benefits
- large groups of people diagnosed with terminal illnesses do not access palliative services despite having significant capacity to benefit.

In New Zealand, the Ministry of Health released the Palliative Care Strategy in 2001. The strategy outlines a vision that *“all people who are dying and their family/whanau who could benefit from palliative care have timely access to quality palliative care services that are culturally appropriate and provided in a coordinated way”<sup>1</sup>*.

New models of care are proposed to address the changing needs of people with terminal illness and to respond to the strategic directives. In particular, new service models should seek to:

1. Ensure access to palliative care is based on individual need rather than diagnosis.
2. Integrate curative and palliative services for people with terminal illnesses.
3. Integrate general and specialist palliative services across all care settings.

Whilst there is limited empirical evidence to support new service models, research to date indicates that there is certainly potential for significant benefits for patients, and for providers and funders of services for people with chronic terminal illness.

## **Introduction and Background**

Capital and Coast District Health Board (C&C DHB) is currently undertaking a review of palliative care services across the district.<sup>2</sup> This literature review aims to assist in the planning of services in C&C DHB by examining directions and developments overseas since the release of the Palliative Care Strategy in 2001, and assessing their relevance to the New Zealand context.

The literature review will:

- present relevant definitions of palliative and end of life care
- outline issues and unmet needs identified internationally regarding the provision of care for people at the end of their lives
- present an overview of policy approaches recommended in New Zealand and internationally
- provide an overview of traditional palliative care service models
- examine examples of service models adopted overseas in response to these issues.

### Methodology

To date the empirical evidence related to palliative care systems and models of care is limited. To a large extent this literature review derives logical causality from reliable evidence built explicitly on expert opinion.

The review also includes summaries of policy and strategy documents in New Zealand and overseas, and of the limited research articles available at present describing palliative service models.

## Definitions of Palliative Care

The World Health Organisation defined palliative care in 2002 as:

*"...an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"* World Health Organisation, 2002<sup>3</sup>.

The term "end-of-life" care is also frequently used throughout the literature in discussion of the care of people who are dying. In some instances end-of-life care appears interchangeable with palliative care. In others, however, it describes all care for all people who are dying (not only those who have identified "problems associated with life-threatening illness"), and therefore encompasses and extends the World Health Organisation definition of palliative care.

The British Columbia Ministry of Health has defined end-of-life care as:

*... "the term used for the range of clinical and support services appropriated for dying patients and their families. It is the total care of people who are dying. It is active comfort care.*

*The goal of end-of-life care is the same regardless of the setting – to ensure the best possible quality of life for dying patients and their families".*<sup>4</sup>

The definition of palliative care in the New Zealand Palliative Care Strategy differs slightly again:

*" Palliative care is the care of people who are dying from active, progressive diseases or other conditions that are not responsive to curative treatment. Palliative care embraces the physical, social, emotional and spiritual elements of wellbeing – tinana, whanau, hinengaro and wairua – and enhances a person's quality of life while they are dying. Palliative care also supports the bereaved family/whanau."*<sup>1</sup>

## History of Palliative Care

Palliative care emerged as a distinct medical specialty in the 1960s, and to a great extent developed alongside the hospice movement.<sup>5</sup> 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 hospice to open in New Zealand, in 1979.<sup>6</sup>

## Changing Needs at the End of Life

### Changing Demographics and Disease Profile

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<sup>7-12</sup>.

Increasingly people also present with comorbidities 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.<sup>8</sup>

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.<sup>11,12</sup>

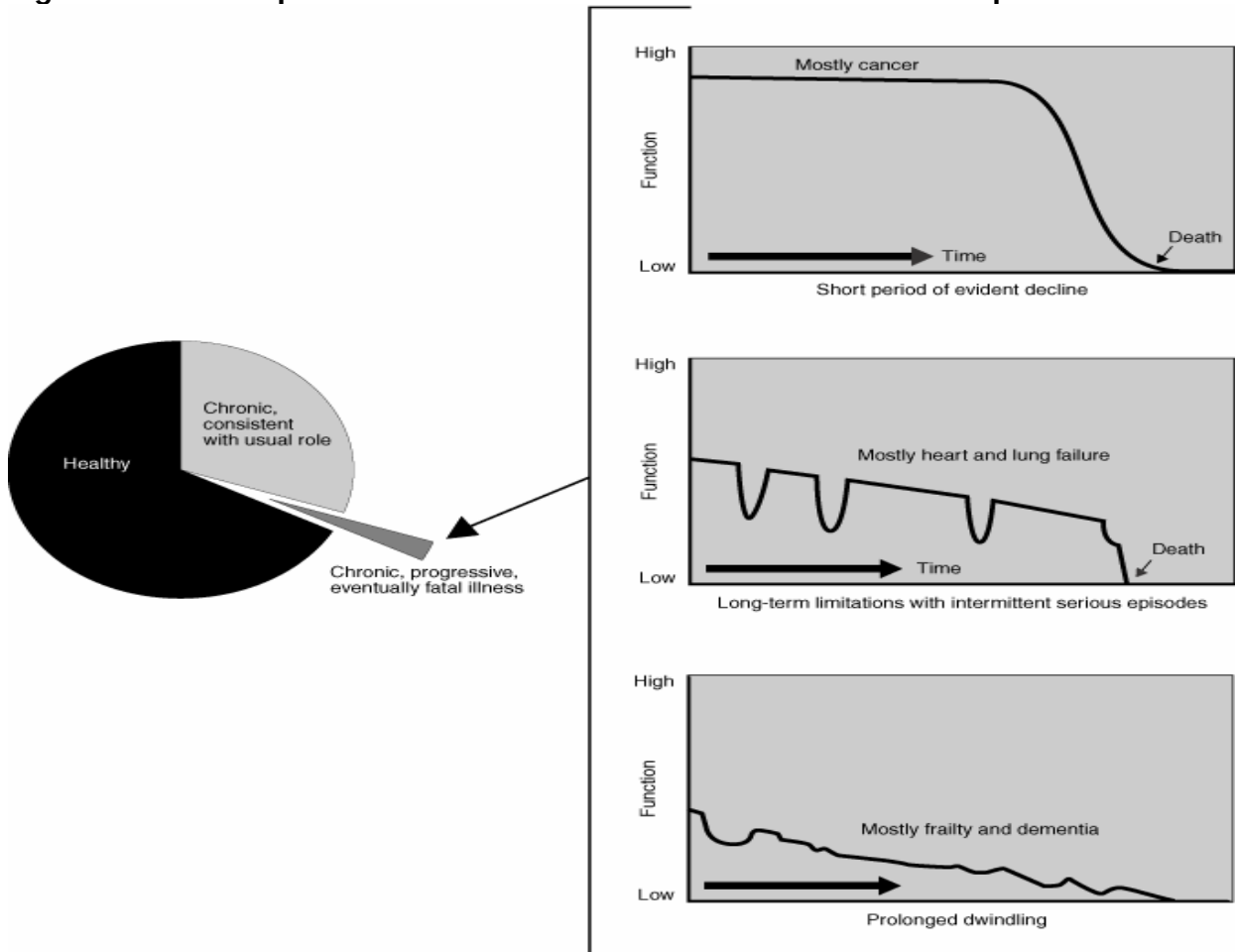
As a result of these disease profile and demographic changes, the needs of people at the end of life have also changed significantly over recent decades.

### The differing trajectories of terminal illnesses

Different diseases have different patterns and trajectories at the end of life (Figure 1). Chronic terminal illness, 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.<sup>13</sup> People with CHF or COPD may live for many years and often experience some level of disability in this time. The active dying phase for these diseases is difficult to predict and patients often die suddenly from exacerbations.<sup>8,14</sup>

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.<sup>14</sup> Figure 1 also shows the disease trajectory for people with increased frailty and dementia.

**Figure 1: Disease profile of Chronic Terminal Illnesses 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.<sup>8</sup>

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.<sup>11,12</sup>

### **Current Unmet Needs at the End of Life**

Traditional palliative care models have predominantly addressed the needs of people with a diagnosis of cancer. In New Zealand, 90% of hospice patients are diagnosed with cancer.<sup>1</sup> However, people with other chronic terminal illnesses also have capacity to benefit from the holistic approach adopted by palliative care. Often the palliative symptoms of people with chronic terminal illness are unrecognised and/or under treated. For example, there is evidence to show the recognition of pain for people with dementia is poor.<sup>9,15</sup>

Difficulty in making accurate prognoses of chronic terminal illnesses can result in inability and/or reluctance of clinicians to predict time frames associated with

disease progression. This can result in people not receiving the information about their disease necessary to make advance decisions about prioritising their resources, including time, psychological energy and financial resources.<sup>7</sup> Furthermore, people with chronic terminal illness may receive unnecessary, unsuccessful and costly life prolonging treatments.<sup>9</sup> Feinmann reports that up to 35% of patients die during intensive therapy.<sup>16</sup>

Referral to traditional palliative care services occurs when all options for active treatment have been exhausted.<sup>8-12</sup> Referrals to palliative care services are therefore often made late in the course of terminal illness, and often when patients are in the active phase of dying. In many instances the palliative needs of such patients are not being met, and late referrals may reduce the potential benefits to be gained from palliative intervention.<sup>7</sup>

Carers and families of people with chronic terminal illness also have capacity to benefit from timely access to palliative care. Studies show that caregivers often have impaired physical and psychological health. It has also been shown that family are more likely to experience an extended grief period when the person they care for has unresolved spiritual or psychological symptoms at the end of their lives.<sup>9</sup>

## **International Palliative Care Policy Directives:**

Whilst conclusive evidence for specific palliative models of care is lacking, the profile of palliative care has risen internationally in recent years at government, professional and service development levels as countries attempt to address the issues outlined above. The following discussion outlines the major international strategy directions in recent years, conducted by a variety of organisations, including Government and palliative/medical collaboratives.

### New Zealand

The Ministry of Health released the Palliative Care Strategy in 2001.<sup>1</sup> The strategy outlines a vision that “all people who are dying and their family/whanau who could benefit from palliative care have timely access to quality palliative care services that are culturally appropriate and provided in a coordinated way”.

The strategy outlines essential palliative services which include:

Assessment and care coordination

Clinical care, specifically:

- inpatient, clinical and respite care
- domiciliary care aimed at managing a person's terminal illness at home
- bereavement counselling for family/whanau.

Support care, including home support and long term residential care.

The Strategy seeks to clarify the role and type of palliative care service available for people with progressive disease, who are likely to die within 12 months. The strategy focuses predominantly on specialist palliative services and their integration and coordination with other services. The Palliative Care Strategy states explicitly that further work is required to address the needs of people with chronic and disabling disease/conditions.

The Palliative Care Strategy links with the Health of Older People<sup>17</sup> and Primary Health Care<sup>18</sup> Strategies in addressing the end of life needs of the population. The main focus of the Health of Older People's Strategy (2002) is integration and coordination of health and support services, and enabling older people to make well informed choices about living arrangements, health and support services. The Primary Health Care Strategy (2001) also identifies the coordination of care across service areas as a key direction, and outlines the responsibility of primary care in improving, maintaining and restoring health.

### Australia

A National Palliative Care Strategy was released in 2000 in Australia.<sup>19</sup> The Strategy proposes a definition of a palliative care patient group, and states that referral to specialist services should be based on the complexity and severity of individual need rather than diagnosis.

The strategy recognises that palliative care may be provided by a range of groups with various skill levels, including specialist and generalist providers, and support services across a wide range of settings, including home and community settings, inpatient palliative care beds and acute hospitals.

The strategy aims to increase awareness and understanding of the roll of palliative care by the community, support quality improvement of palliative care service delivery, and to promote partnerships and provide infrastructure to support people who are dying and their families.

Palliative Care Australia recently (2004) released a policy paper which proposes a population based service planning approach to meet the needs of people who are dying.<sup>20</sup> This is proposed as an alternative to specialist services development for the current palliative patient group. The population based model seeks to understand and plan for the needs of the population as a whole, and ensure services are accountable for providing quality care to patients currently accessing services, as well as those who are not.

The population based approach recognises that patients have unique and different levels of need, and correspondingly require different levels of service. The patients and services broadly fall into three main groups:

1. patients with complex needs requiring specialist care
2. patients who have occasional or sporadic exacerbations requiring specialist consultation
3. all other dying patients who do not require specialist care at all, and whose needs can be met by primary care providers.

Access to services is emphasised, and it is recommended that service models recognise individual need, respond to all levels of need, and ensure that there are clearly identifiable and effective pathways that allow patients to move between general and specialist care. Improved coordination of care and relationships between multiple providers and service levels are required to achieve this.

Palliative Care Australia also recommends a health promotion approach to community education around issues relating to death and dying. Such issues may include, for example, information about local palliative, bereavement and counselling services, positive grieving, positive ageing, and living a healthy lifestyle while living with a life threatening illness.

The role and importance of informal caregivers is highlighted in the population based service planning approach, which promotes support for patients and primary caregivers through education and encouragement, as well as through specialist consultation.

### Canada

The results of a large health policy research project commissioned by Health Canada, "Integration of End of Life Care" were published in March 2004.<sup>21</sup> The study aimed to identify best practice delivery models and approaches for integrated end of life care in Canada. Four key components to a best practice service delivery model or approach were identified:

#### *1. Universality*

A broad range of health care and social support services need to be available to all persons who are near the end of life, and their family and friends.

#### *2. A defined care coordinator*

All services for a person at the end of life need to be coordinated by an identified clinician with palliative knowledge, who can assess palliative need, coordinate appropriate services and monitor their impact. An identified coordinator should be accessible and available at all times.

#### *3. A broad range of end of life services*

Both basic and advanced health and social services need to be available and able to respond to individual patient needs.

Essential services include care coordination, home support and equipment, caregiver support, respite options, spiritual and psychological support, bereavement support, rapid assessment of palliative needs in all settings and on call specialist and end of life care information.

4. *An assurance of end of life services regardless of care setting*  
End of life care should be provided in all settings where a patient resides, whether temporary or permanent.

### United Kingdom

In March 2004 the National Institute of Clinical Excellence (NICE) released "Guidance on Cancer Services: Improving Supportive and Palliative Care for Adults with Cancer".<sup>22</sup> Whilst the document focuses specifically on addressing the needs of people with cancer, NICE states that it may inform service development for other groups of patients.

NICE states that Cancer Networks, responsible for implementing the Cancer Plan, also have a responsibility for the supportive and palliative care of patients with cancer.

The model highlights the importance of coordination of care. In particular, the physical, psychosocial, social, spiritual and financial needs should be assessed at key points in the course of a patient's disease. The key assessment points include diagnosis, at commencement, during, and at the end of treatment, at relapse, and when death is approaching.

The guidelines discuss the importance of communication between professionals and services. Sensitive communication and information dissemination to patients and their families, allowing them to make choices and plan ahead, is also highlighted.

The guidelines recognise that patients receive most professional support from professionals who are not palliative care specialists and recommends training and support for these clinicians. In particular, the model recommends implementing the Gold Standards Framework and Liverpool Care Pathways for the Dying Patient in primary care teams. The National Council for Hospice and Specialist Palliative Care Services also endorses the implementation of the Framework and Pathways in primary care.<sup>23</sup>

Access to and availability of specialist palliative care services across the UK are also highlighted.

## United States

The National Consensus Project for Palliative Care is a collaborative group of clinical and research palliative care and hospice organisations.<sup>10</sup> In May, 2004 the group released Clinical Practice Guidelines for Quality Palliative Care.

The Guidelines assert that palliative care enhances the traditional disease model of medical treatments, and therefore can be delivered either in conjunction with life-prolonging treatment, or as the main focus of care.

The definition of the patient population served by palliative care proposed by the guidelines is very broad, and includes all people living with life-threatening or debilitating illnesses. Continuity of care across care settings is recognised as important for this patient group, and coordination and communication are highlighted.

Models of service delivery proposed in the guidelines include:

- structures that enable palliative care provision from the time of diagnosis

- palliative care services integrated into specific care settings

- ensuring clinicians in primary treatment settings are trained in the fundamentals of palliative care

- established referral patterns and access to specialist palliative care services

- services tailored to local needs of patients, providers and care settings

- interdisciplinary teams providing family support, continuity of care, optimal use of institutional and community resources and collaboration between professionals involved in a patients' care.

Integrating palliative care into curative treatment for people with cancer from the time of diagnosis is also recommended by the Institute of Medicine (2001).<sup>24</sup>

In 2003 the Rand Institute released a White Paper examining the provision of healthcare for people with serious chronic illness in old age. The paper proposes that this patient group has both curative and palliative needs, with the balance between the two needs changing as the disease progresses. Disease modifying interventions may provide benefit for people until death, however in general palliative needs will progressively increase and curative needs will decrease as the disease progresses.<sup>8</sup>

## Europe

The World Health Organisation (WHO) Regional Office for Europe released in 2004 a policy document bringing palliative care to the attention of policy makers and outlining the need for a new approach to caring for the dying population.<sup>11</sup>

The same group also released in the same year a further policy document outlining palliative care for older people.<sup>12</sup>

The Office recommends that palliative care be needs based, and not based on diagnosis or prognosis. It also recommends that new concepts that allow palliative care to intervene alongside curative treatment be developed to address the needs of all people of all ages. *“Palliative care must not be something that only specialised teams, palliative care services or hospices offer when other treatment has been withdrawn. It should be an integral part of care and take place in any setting”*<sup>12</sup>

The Office also recommends early identification of palliative needs as these develop, and before they become unmanageable. The Office states that simple measures, including pain relief, sensitive communication and well coordinated care, are effective in relieving symptoms and suffering.

## **Current models of palliative care**

Traditional and current service models of palliative care predominantly describe the provision of specialist palliative care services. Both internationally and in New Zealand hospices are the main providers of specialist palliative care services. Hospices in New Zealand provide combinations of services which may include inpatient care, community care, day care, respite and bereavement care and counselling. Specialist palliative care services are also provided in some acute hospital settings.<sup>1</sup>

The role of health professionals who are not palliative care specialists, such as general practitioners, district nurses and aged residential care providers, is recognised to various extents in New Zealand and internationally. Current models of service provision generally do not encompass palliative services provided by non specialist services, except by way of referral to specialist services.

Initially, palliative care service models were distinct from other medical specialties by nature of their patient centred approach. Palliative Care Australia states that the palliative patient focussed model “allowed great flexibility in the structure and organisational relationships between different service elements, however provided little guidance as to ‘best practice’ approaches to service organisation, coordination or access.” As a consequence service planning has focussed on the development of specialist services to serve the needs of those patients currently accessing palliative services, most commonly those with cancer or complex medical needs.<sup>20</sup>

In traditional models of palliative care referral to palliative care services is made when all options for active treatment of the terminal disease have been explored and exhausted. The resulting gap between curative and palliative services is

exacerbated as patients and clinicians may be reluctant to accept or refer to palliative care, as this involves foregoing all curative treatment.<sup>10,25</sup>

Funding models also exacerbate the divide between curative and palliative services. This is especially evident in the United States, where eligibility for Medicaid/Medicare hospice benefits requires a confirmed prognosis of six months or less, and patients must agree to forego medical treatments focused on cure or prolongation of life.<sup>25</sup>

Traditionally, palliative care has predominantly been accessed by and offered to people with a diagnosis of cancer. Most palliative care services will accept referrals for people with other diagnoses, however people with diagnoses other than cancer access current palliative services at very low rates internationally.<sup>11,12</sup>

## **Proposed Service Models for End of Life Care**

In recent years services have begun to develop internationally in response both to the changing needs of people at the end of life and to the current unmet needs identified above. At this stage however the empirical evidence to support one model of care over another is limited.

An extensive literature review of international end-of-life care delivery models and approaches was conducted in Canada in late 2003.<sup>21</sup> 43 articles were included in the review. The authors concluded that evidence to support the efficacy of palliative service delivery models is deficient and that, at this stage, no model can be considered superior. The literature does indicate that special consideration to developing services for children, non cancer patients and people of different cultures should be given.

From the international policy and strategy documents outlined previously, three main directions are apparent and supported in the literature. The directions provide a basis for future models of palliative and/or end of life care service provision.

The main directions are:

1. Access to palliative care based on individual need rather than diagnosis.
2. Integration of curative and palliative services for people with terminal illnesses.
3. Integration of general and specialist palliative services across all care settings.

Literature supporting these directions is discussed in more detail below.

## Access to palliative care based on individual need rather than diagnosis

International interest in and re-evaluation of palliative care services has to a large extent been driven by changing population demographics and disease profiles. The literature consistently calls for identification of palliative need and increased access to palliative care for people with diagnoses other than cancer.

The CHOICES (Comprehensive Home-based Options for Informed Consent about End-stage Services) programme in San Francisco was established with the aim of increasing access to palliative care for people with chronic terminal illnesses.<sup>26</sup> The programme involves a team of clinicians working alongside individual patient's primary care physicians, and offers both disease modifying and palliative treatments for at risk people with high burden of disease. The team also provides focussed education for patients and carers, advanced planning and care giver support.

The programme was evaluated by case study over a three and a half year period. The study compared service utilisation between programme enrollees who died in hospital and those who died at home, and compared utilisation rates of programme enrollees to national and/or state averages.

Of the enrolled patients, 80% had a non cancer diagnosis (compared to less than 15% enrolled in hospice care nationally). The rate of people enrolled in the study who died at home was 59 percent, compared to a stage average of 26.9%.

The authors reported some significant difficulties with the model – in particular, the complexity of determining prognosis for people with chronic illness caused difficulties defining the client group. 44 percent died during the study, and 51% were discharged as their disease had stabilised. As a result, the service developed discharge criteria.

Overall the authors concluded that the service model was successful in increasing timely access to palliative care for all people with chronic terminal illness, and in particular those with non cancer diagnoses.

Other service models have developed specifically in response to the palliative needs of people with CHF and COPD in the States. The FOCUS programme in North Carolina is provided by a Hospice provider, and offers coordinated and comprehensive disease and symptom management alongside primary physician care, specifically for people with COPD and CHF.<sup>27</sup> The Improving Care at the End of Life programme in Washington provides care coordination and advanced planning in a primary care setting.<sup>28</sup> These services have not yet been evaluated in the literature, but staff report decreased hospitalisation rates for enrolled patients and good client satisfaction rates.

## Integration of palliative and curative services

Ensuring that palliative needs are identified and appropriate care is offered earlier in the disease process is recommended explicitly in the documents discussed from the UK, the United States and Europe.

The current, virtually universal model of palliative care is shown in the first diagram in Figure 2. The second diagram illustrates how an integrated curative and palliative approach would differ.

Figure 2: Traditional and Integrated Palliative Care Models



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.<sup>8</sup>

A number of authors have suggested that a combined approach is the most beneficial approach for people with chronic terminal illness, including cancer, as many patients may still receive benefits from life prolonging or disease modifying treatments while having their palliative care needs addressed simultaneously.<sup>7-12,25,29</sup>

The idea of providing curative and palliative treatment concurrently for people suffering from CHF is further explored by Pantilat et al. While there are now many effective therapies available for the treatment of CHF, patients often experience distressing symptoms, and by nature of the diagnosis have an increased likelihood of death. The authors argue that a combined approach of curative and palliative care is required and should be provided by clinicians.<sup>13</sup>

Palliative care services have developed in the United States in recent years to specifically span the divide between curative and hospice care. One such programme is the Tricentral Palliative Care Program developed by Kaiser Permanente, a Health Maintenance Organisation.<sup>25,30</sup>

The service consists of an interdisciplinary team providing community based care management and palliative care alongside curative care. Patients are not required to forgo curative treatment to join the services, although over time, as the disease progresses, the focus of treatment usually becomes increasingly palliative.

The primary intent of the service is to provide comfort and improve quality of life for enrolled patients. The core team consists of the patient and family, as well as a physician, a nurse and a social worker, all with expertise in symptom management and biopsychosocial interventions. The team takes responsibility for "coordinating and managing care across all settings, and provide assessment, planning, care, follow-up, monitoring, and continual reassessment of care". The team also fulfils an education and support role for patient and family, which includes self management and crisis intervention planning. Telephone consultation by a specialised nurse is also available 24 hours a day, seven day a week.

The service model was evaluated by comparing outcomes for people who had died over a two year period enrolled in the palliative programme to those enrolled in 'usual' home care services

The authors concluded that this service model, and in particular integrating palliative care into curative care earlier in the disease process, had many benefits. The statistically significant results included improved consumer satisfaction, decreased use of medical services (emergency visits, hospital days, nursing and physician visits), and an increased likelihood of dying at home. In total the authors estimated that overall treatment costs were reduced by 45 percent.

### Advanced Care Directives:

Advanced care directives are frequently discussed in palliative literature and are considered another important mechanism in incorporating a palliative approach into traditional curative medicine. Advanced care directives are defined as a patient's formal or informal instructions concerning expectations of care and choice of treatment options in response to potential illnesses or conditions.<sup>31</sup> They are therefore advocated by many as a means to allow people to make decisions about how they choose to live in the time preceding death, and how they choose to die.<sup>7-9</sup>

Some reports suggest that currently advanced directives are often not enforced until very close to death, if indeed at all.<sup>7</sup> Lack of forward planning for people may lead to inappropriate crisis admission in the last days despite patients and relatives expressing a wish to stay at home.<sup>32</sup>

Lynn recommends that advanced directives are routinely incorporated into the care of older people with cancer and chronic diseases.<sup>8</sup> Pantilat states that it is appropriate to discuss with people with CHF in advance the exacerbations that can result in sudden death and plans should be made in conjunction with the patient.<sup>13</sup>

### Integration of general and specialist palliative services across all care settings

Throughout the literature it is widely accepted that there are levels of palliative need, which require and respond to different levels of palliative care services. Furthermore, palliative care should be accessible and provided in all care settings. A common theme in the literature is that care should be integrated and coordinated across the different levels of palliative services.

Coordination of care across services and settings is highlighted as important in the care of older people with chronic disease. Coordinated care minimises medical, psychological and financial burdens for both patients and caregivers.<sup>9</sup>

Increasingly approaches such as case management, case coordination and key working are used for such patient groups. Whilst empirical evidence regarding these approaches is limited, the literature reflects their potential to improve the transfer of information across services for people with chronic terminal illness<sup>11,12</sup>.

A recent study described a service model in New York which incorporates palliative assessment with care management for people with chronic terminal illness.<sup>33</sup> The programme aims to introduce palliative care to a wider group of people at an earlier stage, within the context of an existing care management service.

Care management was provided by a private, for profit company, and the service was already in place for high risk patients with complex, often terminal, needs (25-30% of enrolled clients would die or be referred to hospice from the service). The care management service consisted of locally based nurse case managers, and a centrally located clinical nurse manager and physician. The service had already achieved high levels of patient and family satisfaction and been shown to reduce overall care costs (predominantly by reducing admissions).

In the palliative care programme, case managers were trained in palliative care assessment, identification and implementation of treatment interventions, and in giving feedback to local physicians about an individual patients' palliative needs.

Final analysis is yet to be published, however in an interim report the authors state that preliminary results indicate the combined approach of care management and palliative assessment is "a logical, feasible and effective strategy to improve the care of seriously ill patients living in the community"<sup>33</sup>. To this end the care management company has already incorporated the palliative approach in its other centres.

## **Conclusion:**

The needs of people diagnosed with terminal illnesses are changing over time, as a result of changing population disease profiles and demographics. These changes are placing increased pressure on current services and resources both internationally and in New Zealand. Current service models have gaps which need to be addressed, and new approaches to the provision of care for all people at the end of life need to be adopted.

Traditional models of palliative care focus on the provision of specialist services to people with terminal cancer. This review indicates that palliative service models have potential to improve end of life care needs of all people. A wider view, encompassing all aspects of end of life care including health, social and palliative needs, is appropriate. It is important that service models recognise different levels of need and the role of non specialist providers.

The literature indicates that significant benefits are likely with improved access to palliative care and new approaches to end of life care. Potential benefits include more choice for individuals with chronic terminal illnesses about how they choose to live and die and improved client and family satisfaction with care.

Early access to palliative care which is integrated with curative services is supported by expert opinion, international experience and some empirical evidence.

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## Appendix 2 – C&C DHB Supporting Analysis

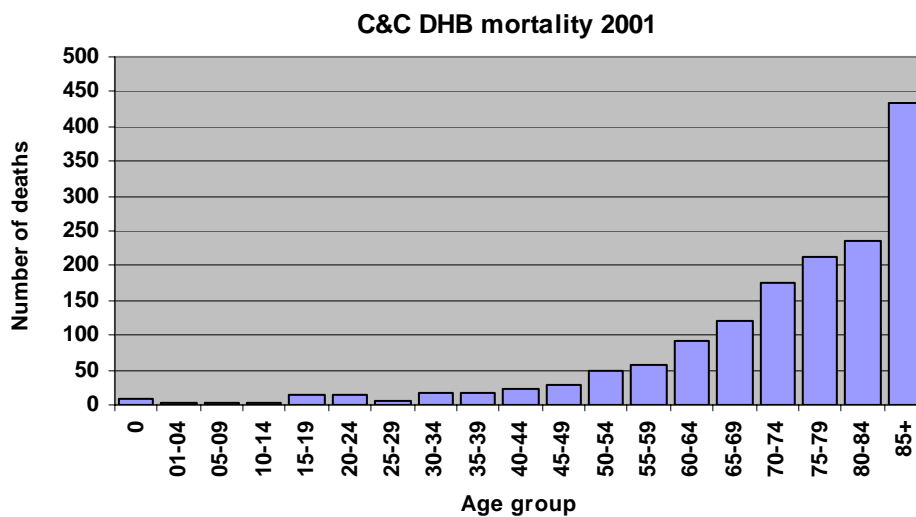
### End of Life Population in C&C DHB

To help us assess the needs of people in C&C DHB at the end of life, we undertook a review of all deaths in the Capital and Coast district in 2001 (this year was selected for data availability). In 2001, 1517 residents of the Capital & Coast district died (618 deaths per 100,000 population).

#### Demographics of the End of Life Population

The age distribution of the people who died in 2001 is shown in the graph below.

**Figure 1: Age distribution of people who died in C&C DHB in 2001**



Data source: National Mortality Collection

Mortality increases with age and the average age of death is 74. Seventy percent of all deaths are people aged 70 years and over.

Females have longer life expectancy than males, so at younger age groups there are more male deaths, and at older age groups (80+) there are more female deaths. Six percent of all deaths were Maori, five percent were Pacific and the remaining 89% were of other ethnicities.

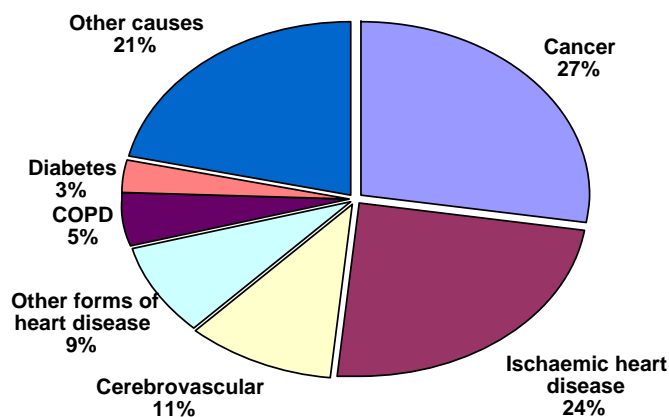
## Disease Profile of the End-of-Life Population

This section contains information about the disease profiles for the end of life population, with greater detail on the leading causes of death.

The data was obtained from the National Mortality Collection and significant issues around the coding of deaths exist, which are difficult to quantify. These problems arise because someone with a chronic terminal illness often has co-morbidities, and coding does not always capture the underlying cause of death.

A breakdown by cause for all deaths is shown in the chart below.

**Figure 2: Cause of Death in C&C DHB**



Data source: National Mortality Collection

The leading causes of death are heart disease<sup>2</sup> (33% of deaths), cancer (27% of deaths), cerebrovascular disease (11% of deaths) and COPD (5%).

The leading causes of and rates of death are shown in table 1.

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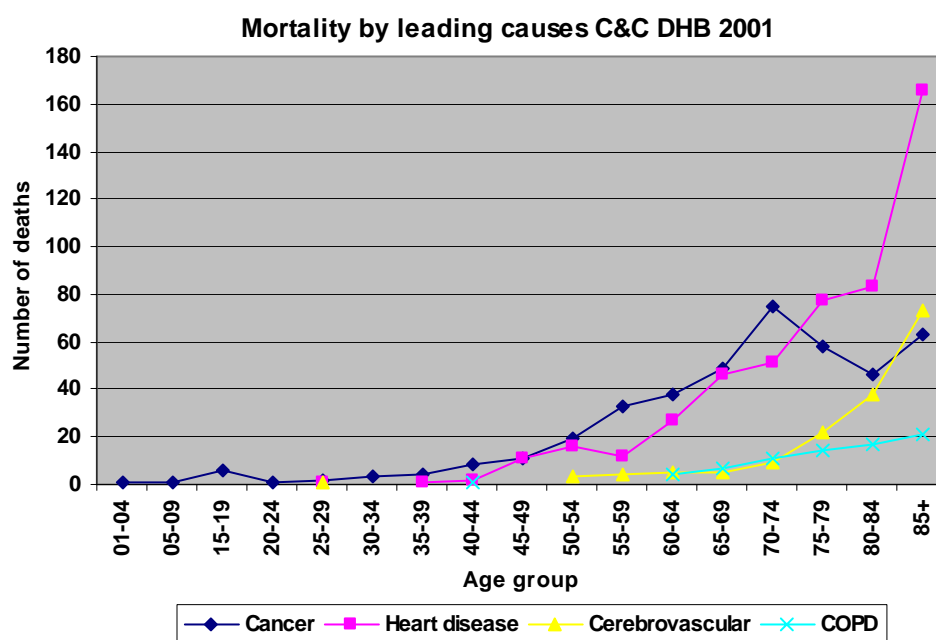
<sup>2</sup> "Heart disease" includes ischaemic heart disease and other forms of heart disease

**Table 1: Rates and Absolute Impact of Leading Causes of Death in C&C DHB in 2001.**

Disease	Rate per 100,000 people	Number of death in C&C DHB
heart disease	201	493
cancer	170	418
Cerebrovascular	65	160
COPD	31	75

The age distribution of people dying from these illnesses is described below.

**Figure 3: Age Distribution of Mortality by Leading Causes in C&C DHB in 2001**



Data source: National Mortality Collection

### *Cancer*

The cancer mortality rate is 170 deaths per 100,000 people. Although the age distribution is wide, the average age of death was 70 years. In 2001, 53% of deaths were females and 47% were males. Cancer accounts for 25% of all Maori deaths, 25% of all Pacific deaths and 28% of deaths people of other ethnicities.

### *Heart disease*

The mortality rate from heart disease is 201 deaths per 100,000 people. The average age of death was 78. 52% of deaths were male and 48% were female. Heart disease accounts for 27% of all Maori deaths, 35% of all Pacific deaths and 33% of deaths of people of other ethnicities.

### *Cerebrovascular Disease*

The cerebrovascular mortality rate is 65 deaths per 100,000. 83% of deaths were people aged over 75 and the average age of death was 83 years. Two thirds of deaths were female. (A high percentage of female deaths would be expected due to the higher proportion of females in the elderly population.)

### *Chronic Obstructive Pulmonary Disease*

The COPD mortality rate is 31 deaths per 100,000 people. The average age of death was 80 years. The age distribution shows gender differences, with males dying earlier than females. 51% of deaths from COPD are females and 49% are males.

### *Other Causes of Death*

It is important to note once more that the issues with coding of multiple diagnoses will reduce the perceived incidence of these causes of death.

The following table shows some other causes of death in C&C DHB in 2001:

**Table 2: Other Causes of Death in C&C DHB in 2001:**

Primary Diagnosis	Number of Deaths
Diabetes	45
Dementia	34
Alzheimers	19
Parkinsons	8
Chronic Renal Failure	7
Multiple Sclerosis	4
HIV	2
Huntingdon's Disease	0
Motor Neuron Disease	0

## Prevalence of Chronic Terminal Illness in the Community:

This section provides estimates of the numbers of people in C&C DHB living with a chronic terminal illness. These numbers are based on national prevalence rates applied to the Capital and Coast population, and it is important to note that actual disease rates in C&C DHB may be different from national rates.

**Table 3: Prevalence of Chronic Terminal Illness in the Community:**

Disease	Estimated Number of people affected in C&C	Estimated Prevalence
CVD	15,306	1 in 5 people over 45
COPD	10,933	1 in 7 people over 45
Diabetes	6,378	1 in 12 people over 45
Stroke	3,061	1 in 25 people over 45
Alzheimer's	2020	8% of people over 65
Parkinsons	491	1 in 500 people
Multiple Sclerosis	246	1 in 1,000
Renal Failure	13	-
Huntingdon's	16	-
Motor Neuron Disease	2-4 cases per year	-

## Place of death

Approximately 29% of deaths occurred in public hospitals (around 400 per year), 11% in a hospice and the remaining 60% elsewhere in the community. It is difficult to estimate the number of people dying in rest homes and private hospitals as these facilities are not required to submit data to the National Minimum Data Set<sup>3</sup>.

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**3. NMDS: The National Minimum Data Set is the standard collection of NZ public hospital inpatient events. All public hospitals are required to submit data to the NMDS, which is maintained by the New Zealand Health Information Service.**

## C&C DHB Age Range Population Projections:

Table 4 shows the projected population in age groups over 50 over the next 10 years.

**Table 4: Projected Population over 50 in C&C DHB in 2011 and 2016**

C&C DHB population projections<sup>4</sup>

Age group	2005	2011	Total increase	Average annual increase
50-64	41,110	47,760	16%	2.5%
65-74	14,890	17,530	18%	2.8%
75-84	9,750	10,070	3%	0.5%
85+	3,250	4,350	34%	5.0%
Age group	2011	2016	Total increase	Average annual increase
50-64	47,760	52,730	10%	2.0%
65-74	17,530	21,530	23%	4.2%
75-84	10,070	11,110	10%	2.0%
85+	4,350	5,180	19%	3.6%

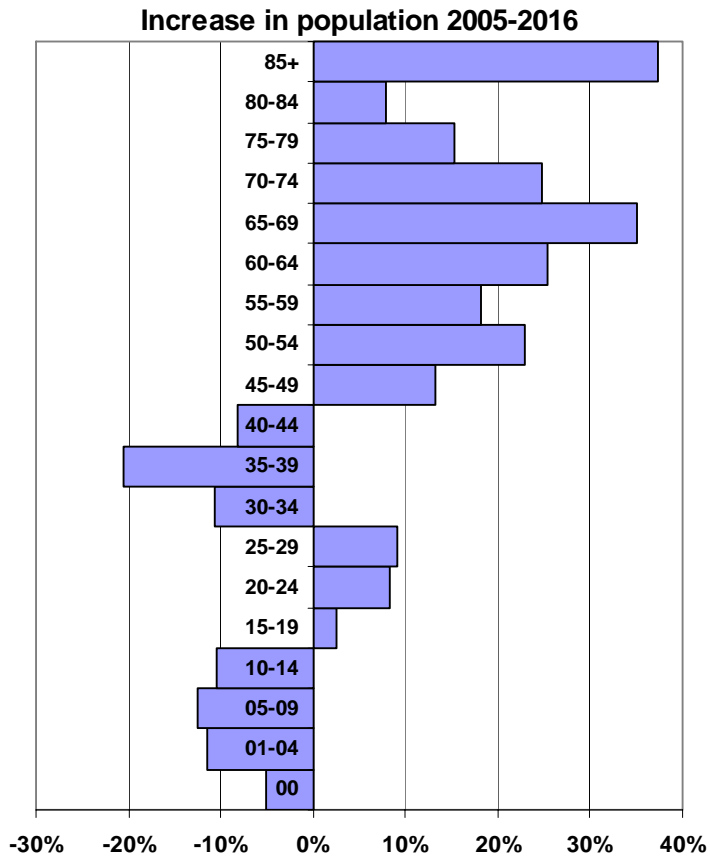
Source: Statistics New Zealand

Figure 4 below shows how the age structure of the population in C&C DHB will have changed by 2016. In particular, the percentage of the population aged between 30 and 45 will decrease, and the percentage over 45 will increase significantly.

The number of people over 85 is projected to increase by nearly 2000 people by 2016. This represents a 37% increase on the 2005 figure.

<sup>4</sup> Population projections are medium series projections based on the 2001 Census assuming medium levels of fertility, mortality and net migration.

**Figure 4: Percentage Increase in Population by 2016 by Age Group**



## **Appendix 3 : Hospital Services accessed by people in C&C at the End of Life**

The following section gives an indication of the types and volumes of services accessed by people with palliative conditions. It is not a complete picture of the utilisation of services by people with palliative conditions, as both a definitive list of those people and individualised utilisation information are not available at this time. Instead, it paints a picture of volume and patterns in service use by people at the end of life. In particular, the analysis below looks at the utilisation of services for two mutually exclusive groups of people. Note that the information is only for services where information was available by NHI<sup>5</sup> and hence does not include any utilisation of primary care services by this group.

The two groups are:

- Group 1: People who died of a chronic terminal illness in the 2002/03 financial year, whose death was notified to DHB.
- Group 2: People who accessed palliative services through DHB community services in the 2002/03 financial year, but for whom the DHB has no notification of death.

The final NHI list of 421 NHI for Group 1 was obtained by combining the following lists:

- The NHI for people who died in hospital of chronic terminal illnesses (based on diagnosis information) in the 2002/03 financial year (108 people).
- The NHI for people who received community services in the 2002/03 financial year through DHB community services where there was notification of their death of a chronic terminal illness (120 people).
- The NHI for people who died in the hospice or were discharged from the hospice to die at home during 2002/03 (193 people).

The NHI list for Group 2 was obtained from the DHB provider arm and consisted of community service/therapies clients who had had palliative care activity during the 2002/03 financial year (excluding any already included in Group 1).

### **Service utilisation for Group 1**

The utilisation of hospital services by the 421 people in the year preceding their death is summarised below.

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<sup>5</sup>NHI: National Health Index number used in health data to uniquely identify a patient.

### *Inpatient events*

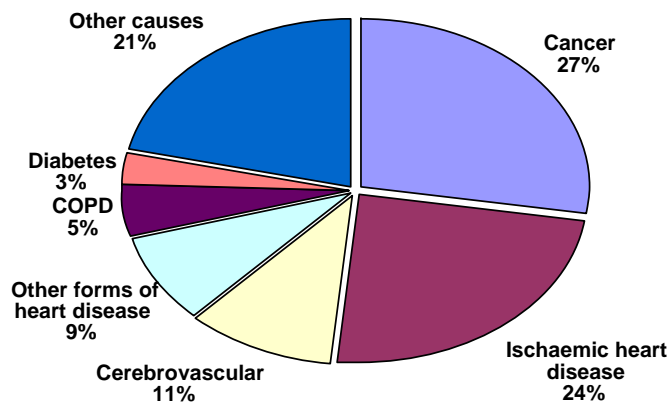
358 of the 421 had at least one in-patient event in year preceding death (and a maximum of 18 events). The average age of the people who had events was 68 years. They had a total of:

- 1300 events (an average of 3.1 in-patient events per person)
- 1935.71 caseweights<sup>6</sup> (an average of 4.6 caseweights per person)
- 964 mechanical ventilation hours
- 8089 days stay (an average of 19.2 days stay per person).

Males of other ethnicity had the highest number of events, and of those who had events they also had the highest average number of events per head (average of 4 events per head versus 3.2 for females of other ethnicity). No comment is made on the utilisation figures for other ethnicities as the number of events are too low to give reliable results.

The primary diagnoses at admission for Group 1 patients are shown in Figure 5:

**Figure 1: Primary Diagnosis for Group 1 Patients**



### *Outpatient events*

372 of the 421 people had at least one out-patient event in year preceding death (and a maximum of 321 events). On average they had 31 out-patient events in the year preceding death. Of people who had events, once again males of Other ethnicity had the highest number of events, and also the highest average

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<sup>6</sup>**Caseweight: Hospital events are assigned a 'caseweight' to reflect relative resource consumption. Caseweights may give an indication of complexity.**

number of events per head (average of 38.8 events per head versus 28.5 for females of other ethnicity).

### *Other Services*

279 of the 421 people generated 2685 allied health events through the therapies service (an average of 6.4 events per person).

AT&R services were accessed by 65 of the 421 people generating 936 events (an average of 2.2 events per person).

Community Health Services were accessed by 316 of the 421 people generating 15476 events (an average of 36.8 events per person).

**Table 1: Other Hospital Services Accessed by Group 1:**

Percentage of Group 1 accessing service	Service	Average number of events per person
75%	Community Health Services	36.8
66%	Therapies (allied health services)	6.4
15%	AT&R	2.2

### **Service utilisation for Group 2**

The following resource utilisations are for the 453 people identified as receiving palliative services during 2002/03, but for whom the DHB has no record of their death.

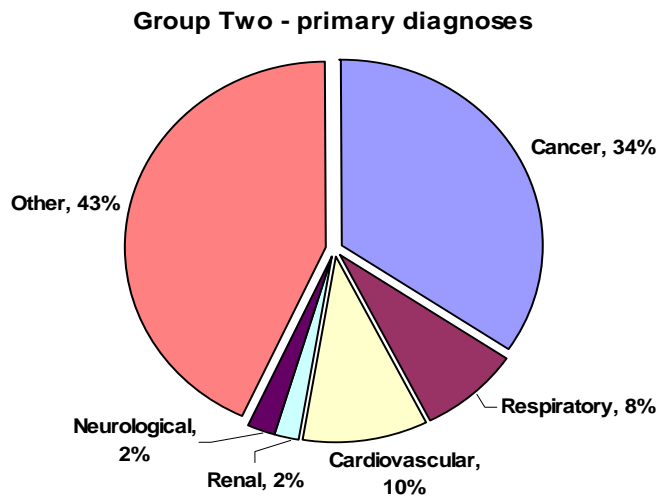
#### *In-patient events*

328 of the 453 people had at least one in-patient event in the 2002/03 year (and a maximum of 12 events). The average age of the people who generated the events was 67 years. They had a total of:

- 891 events (an average of 2 in-patient events per person)
- 1349.28 caseweights (an average of 3 caseweights per person)
- 399 mechanical ventilation hours
- 5151 days stay (an average of 11.4 days stay per person)

Females of other ethnicity had the highest number of events, and of people who had events they had a slightly higher average number of events per head (average of 2.8 events per head versus 2.6 for males of other ethnicity). No comment is made on the utilisation figures for other ethnicities as the number of events are too low to give reliable results.

**Figure 2: The Primary Diagnoses at Admission for Patients in Group 2**



*Out-patient events*

407 of the 453 people had at least one out-patient event in 2002/2003 (and a maximum of 233 events). On average they had 27.1 out-patient events in 2002/2003. Out of people who had events, females of other ethnicity had a slightly higher average number of events per head (31.1) than for males of other ethnicity (27.9).

*Other Services*

As this group of people was sourced from Community Health Services data, all 453 people accessed Community Health services, and generated 24,916 events (an average of 55 events per person).

Allied Health Services by the Therapies Services were accessed by 307 of the 453 people generating 3261 events (an average of 7.2 events per person).

AT&R services were accessed by 70 of the 453 people generating 966 events (an average of 2.1 events per person).

**Table 2: Other Hospital Services Accessed by Group 2:**

Service	Percentage of Group 2 accessing service	Average number of events per person
Community Health Services	100%	55
Therapies (allied health services)	68%	7.2
A, T and R	15%	2.1

### **Summary**

The patterns of service use in both Groups 1 and 2 show a high utilisation of all services when compared to the general population.

There are a number of differences between the two groups, notably:

Patients from Group 1 were more likely to be admitted to hospital, more often, for more complex conditions, and with greater lengths of stay in hospital.

Patients from Group 2 were more likely to have outpatient events, but if they did they had on average fewer events per head than patients from Group 1.

Males in Group 1 had relatively higher service utilisation.

Group 2 patients were more likely to have Therapies events and high utilisation of these services.

Females in Group 2 had relatively higher service utilisation.

Patients from Group 2 were much more likely to be accessing community services through the HHS and had a higher average number of events per person.

The differences between the two groups may be influenced by different disease profiles. All people in Group 1 died in 2002/2003. Group 2 were receiving palliative community services, but we are unable to comment on proximity to death. They may have died in the community in 2002/2003, in hospital after this time, or they may still be alive. It is likely that people in Group 1 were "closer to death" than those in group 2, which may explain the increased use of inpatient services.