

Palliative Care
Report of the Palliative Care
Expert Working Group to the
Cancer Control Steering Group

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Introduction

This document outlines the recommendations of the palliative care expert working group and provides supporting documentation for these.

Impact of cancer death in New Zealand

Death from cancer is still greatly feared in New Zealand society. For many, the word cancer conjures up images of intense physical and emotional suffering. However, over the past few decades much progress has been made in the management of pain and other symptoms. There has also been a greater acknowledgement that life-threatening illness and death has an impact that goes beyond the physical domain. Personal values, emotional wellbeing, spiritual beliefs, family structures and supports are brought to the fore and are often challenged. Therefore, care needs to focus on the whole person (holistic care) recognising spiritual, physical, emotional and family wellbeing.

It is also known that for Māori and Pacific peoples death is a sacred time during which integration of cultural values and customs is paramount. Cultural values influence attitudes, beliefs and practices throughout the treatment of sickness, the care of the dying and also the grieving process (Ngata 1987; MacLeod 2001).

Nearly 50% of people diagnosed with cancer in New Zealand die from that illness. Cancer is now the leading cause of death in New Zealand, accounting for 29% of deaths from all causes (NZHIS 2002). Total cancer deaths are projected to increase from 7447 deaths in 1997 to 8963 deaths in 2012, a 20% increase over a 15-year forecasting period (Public Health Intelligence 2002).

Development of hospices and palliative care

As a result of community and professional lobbying, modern hospices were first developed in New Zealand over 20 years ago. The impetus came from a need for improved pain and symptom control together with the acknowledgement that many people preferred to die in their own homes, cared for by their families. The philosophy of hospice care has since expanded into the practice of many professionals and institutions with the term 'palliative care' now being used to define care of the dying. In addition, there is now widespread recognition that the principles of palliative care should be applied as early as possible in the course of any chronic, ultimately fatal illness (WHO 2002).

Definition of palliative care

Palliative care is the total care of people who are dying from active, progressive diseases or other conditions when curative or disease-modifying treatment has come to an end. Palliative care services are generally provided by a multidisciplinary team that works with the person who is dying and their family/whānau. Palliative care:

- affirms life and regards dying as a normal process
- aims neither to hasten nor to postpone death
- aims to provide relief from distressing symptoms

- integrates physical (tinana), social (whānau), emotional (hinengaro) and spiritual (wairua) aspects of care to help the dying person and their family/whānau attain an acceptable quality of life
- offers help to the family/whānau/carers during the person's illness and their bereavement (Minister of Health 2001).

Principles of palliative care

The following five guiding principles underpin the above definition.

- The focus of palliative care is the person who is dying as well as their family/whānau.
- All dying people should be informed of their entitlement to palliative care and have access to quality health and support services appropriate to, and consistent with, their needs.
- Each person's uniqueness, culture and autonomy should be respected, with all care based on their expressed needs and wishes.
- Palliative care affirms and encourages the quality of life for each individual. While interventions (such as radiotherapy, chemotherapy and surgery) have a place in palliative care, the symptomatic benefit should outweigh any disadvantages of the procedure.
- The achievement of total care for the person requires both a multidisciplinary approach and continuity of care (before, during and after diagnosis of the terminal illness) (Minister of Health 2001).

Palliative care today

The World Health Organization (2002) holds that not only should palliative care be a central feature of all good clinical practice, but it should also be given priority status within public health and disease-control programmes. Palliative care is globally recognised as a legitimate component of health care. Evidence shows that palliative care is effective in improving the quality of life for people who are dying (NCHSPCS 1994; Bruera et al 1999; Higginson and Finlay 2000).

In New Zealand, palliative care has not always been well understood or accepted by health providers nor has it always been incorporated into clinical practice. This is particularly so in some hospital services, primary care services, rest homes and private hospitals. (Minister of Health 2001; Darkins 2002). Some dying people may therefore not be in a position to make an informed choice about their care (as required under the Code of Health and Disability Services Consumers' Rights). There is a need to make people and providers aware of the effectiveness of palliative care for dying people.

At present approximately 90% of people known to be accessing hospice palliative care services have cancer, and the large majority of these people are aged 60 years and over (this age group accounts for 78.8% of cancer deaths) (HFA 1999). The proportion of the population aged 65 or over is projected to more than double (from 12 to 26%) over the

next 50 years. It is also estimated that by 2012 there will be a 20% increase in cancer deaths (Public Health Intelligence 2002).

The needs of younger people (under 60) with cancer are often different and can be more complex. This group accounts for approximately 20% of people dying of cancer.

The New Zealand Palliative Care Strategy 2001

The New Zealand Palliative Care Strategy was launched in February 2001 by the Minister of Health to set in place a systematic and informed approach to the provision and funding of palliative care services. The strategy was developed following extensive consultation and a review of the evidence as well as hospital, hospice and primary care services.

The Strategy aimed to develop a set of essential services for dying people who could benefit from palliative care. Also, to develop local and specialist palliative care services that build on existing services. Nine strategies were developed in total to be implemented over a five to 10-year period. The first priorities were to ensure that essential palliative care services are available for all dying people and that at least one local palliative care service is available in each District Health Board (DHB).

The Strategy's progress to date

The Strategy has been in place for just over a year and the process of implementation has been started with an announcement by the Minister of Health in October 2000 of \$7.5 million additional funding for palliative care services. The following activities have occurred since the Strategy was launched.

- A service model has been developed for hospices (Ding et al 2000).
- A national service specification for hospital community services has been developed.
- Many DHBs are working towards developing local palliative care services and some have appointed palliative care providers within hospital services.
- The Clinical Training Agency (CTA) is funding a postgraduate certificate in palliative care nursing for 40 students which is available nationally.
- The Clinical Training Agency has also completed workforce planning for palliative care medicine specialists and is funding two training positions.
- Some primary care services (for example, in Auckland, Christchurch and Southland) have introduced palliative care programmes.

There is still some way to go in the development of palliative care services particularly in ensuring that palliative care is available for all people who are dying of cancer. This is particularly important for people in rural areas where there are still major gaps in service provision. There is also a lack of service co-ordination between primary care, cancer treatment and palliative care services. This means that some people who are dying of cancer do not access the full range of palliative care services. Some people receive care from multiple agencies while others access services too late to be of much benefit. It is therefore important that the cancer control strategy addresses these issues and builds on the work already begun by *The New Zealand Palliative Care Strategy (2001)*. This way all people with cancer who are unlikely to live should have access to the full range of palliative care services.

Candidate Priority Action One: To Continue to Improve Access to Essential Palliative Care Services which Provide Appropriate Symptom Relief and Emotional, Spiritual, Cultural and Social Support for the Person with Cancer and their Family and Whānau

(See *Towards a Cancer Control Strategy for New Zealand: A Discussion Document*, Goal 3, Objective 3, p 27.)

Background

The first stage of the implementation of *The New Zealand Palliative Care Strategy* (2001) has gone some way to increase access to palliative care services. However, there are still a number of factors preventing access to palliative care services for dying people with cancer and their families/whānau including:

- lack of a palliative care approach resulting in either no referral or late referrals to palliative care services
- variable access to palliative care services due to service gaps particularly in rural areas
- cultural barriers to access
- variable access to services designed for children and young people.

Lack of a palliative care approach

A palliative care approach is often lacking in the hospital environment as hospitals have a strong curative, intervention-focused culture. The National Health Committee (1999) noted that too frequently people continue to receive inappropriate levels of intervention when they could have been better served by a palliative approach. A study by Christakis and Lamont (2000) identified that doctors tended to overestimate a patient's survival by a factor of 5.3. This degree of overestimation may adversely affect the quality of life of patients as doctors continue to provide interventions when palliative care may be more appropriate. Patients may not, in fact, be given the option of palliative care and may not realise that services and palliative interventions are available.

There is also a perception by some health professionals that palliative care is only for those people who are 'imminently dying'; that is, within a matter of days or weeks, when in reality palliative care can be provided for up to 12 months before death. Palliative care should be 'recognised as an exercise in prevention – prevention of ultimate suffering through prioritising the diagnosis and skilful management of sources of distress, both in the form of physical symptoms and of psychosocial and spiritual concerns, at the earliest possible moment (MacDonald 1991 cited in WHO 2002).

Many people with cancer die in long-term care facilities (Minister of Health 2001). The quality of residential care is dependent on staffing levels, numbers of registered nurse personnel, level of and access to palliative care training, organisational attitudes and beliefs and the amount of palliative care experience within the institution (Clare and DeBellis 1997; Komaromy et al 2000; Maddocks et al 1999). Some New Zealand hospices have formal links with the sector and provide education programmes.

There are also barriers to access that arise from the general public's lack of understanding about the meaning of palliative care and the types of services and options available.

Variable access to palliative care

A review of hospice and hospital palliative care services identified a number of service gaps in New Zealand (HFA 1999). This finding is consistent with findings from overseas (Doyle 1990; Hatcliffe and Smith 1997). Although *The New Zealand Palliative Care Strategy* (2001) has made some progress in reducing service gaps, these still exist in some areas, particularly in rural New Zealand. These gaps include night-carer relief, community care, inpatient care, spiritual care and palliative care for children.

Community care

Overseas research supports the view that people prefer to die at home. Research by Higginson (1998) shows that 50–70% of people would prefer to have the choice of home care. In 1996, 53% of Māori, 41.5% of Pacific people and 31% of all other New Zealanders with cancer died at home (Minister of Health 2001). While some hospices, general practitioners (GPs) and DHB-based nursing services provide good community palliative care, nationally there is still a lack of sufficient community care and social support to allow people to die at home.

General practitioner involvement

General practitioners report that they do not receive adequate funding for visits to palliative care patients. 'Many say they cannot ethically ask the patient or family for reimbursement' (Darkins 2001). In some parts of New Zealand subsidised or free-to-patient GP visits are funded through the Independent Practitioners Association's surplus funds or bulk funds. Difficulties also arise when a patient does not have a designated GP or when a GP is unable to provide after-hours services. In some situations GPs need specialist advice and support with issues such as symptom control (Mitchell 2002).

Respite and support care

Successful community palliative care is frequently dependent on the availability of a family carer (McWhinney et al 1995). The ability to provide care long term may be enhanced by periods of respite during which an alternate caregiver helps out at home or the patient is admitted to a respite facility. While some people caring for a dying person can access the 28-day carer relief support through the Department of Social Services, the amount of care provided can be dependent on a needs assessment. The current nature of a Disability Support Services (DSS) needs assessment is often considered insufficient in determining the needs of people who are dying. Also, dying people requiring support care

may be prevented from access to support services because they do not fit the definition of disability and therefore are not eligible for services funded by DSS.

People who live alone are not entitled to the same range of services as those who have a resident family caregiver and may be disadvantaged. Patients who do not have sufficient support at home often have to be admitted to a hospital, hospice or rest home.

Night-carer relief

There is inconsistent provision of appropriate night-carer relief amongst services in New Zealand. This can sometimes result in hospital admission. The Cancer Society provides night-carer relief in some areas while elsewhere hospices or DHBs sometimes provide this service (Minister of Health 2001).

Inpatient care

A Health Funding Authority analysis found considerable variation in the availability of palliative care beds in hospitals and hospices (HFA 1999). This situation has been partially resolved with the first stage of implementation of *The New Zealand Palliative Care Strategy* (2001). However, there are still insufficient beds for palliative care, respite care and medium-to-long-term care, and sometimes a lack of 24-hour and specialist palliative care.

Although there are 37 hospices throughout New Zealand there are still areas which do not have designated hospice or palliative care beds. Arrangements are made, in some cases, with neighbouring hospices or local hospital services. This situation is both a rural and an urban issue.

The value of a palliative care specialist team presence within large public hospitals has been realised (Carter et al 2002; O'Callaghan et al 1999) in several areas since the publication of *The New Zealand Palliative Care Strategy* (2001). Specialist hospital palliative care teams have been, or are in the process of being, developed in several centres including Whangarei, Auckland, North Shore, South Auckland, Hamilton, Palmerston North, Wellington and Christchurch.

Accessing long-term care is a significant issue. Long-term care is generally not provided by hospices or hospitals. By default, patients often have to access care via rest homes and private medical hospitals (long-term care). This care may or may not be appropriate, depending on the long-term care facility's staffing levels, expertise, and links with palliative care organisations. Rest homes and private hospitals may not be appropriate for younger people who require longer-term care. Additionally, there can often be a significant user charge involved in accessing long-term care in some areas. As with support care, there is also an issue around people being denied access to these services because of interface and funding boundary issues between personal health services and DSS.

The issue of community support care and longer-term care for older people is partially being addressed through the *Health of Older People Strategy* (2002a). However the Cancer Control Strategy needs to address this issue for all people in all age groups with cancer.

Spiritual care or bereavement support

There is a need for people being cared for by community-based services to have access to appropriate spiritual and bereavement counselling. Currently access to these services is not universal even though it is a subset of one of the essential palliative care services.

Palliative care for children

Cancer accounts for 37% of childhood deaths in New Zealand (Jones et al 2002). The needs of children who are dying are unique and cannot be aligned with adults (Horsburgh 2002). Parents and/or family members in the home almost always care for terminally ill children and this places immense responsibility and often stress on families (Darbyshire et al 1997; Gold 1997). They need care themselves. Grief after the death of a child is described as 'the most painful and enduring' (Goldman 1998).

The Paediatric Review (1999) found a high degree of variability in accessing the paediatric community or outreach nurse and that families may not be able to access the necessary palliative care services due to lack of:

- a key co-ordinator and poor co-ordination of current services
- appropriate needs assessment for families
- suitable respite care
- dedicated family support
- co-ordinated grief and bereavement support and resources for this, mainly due to major deficiencies in the child mental health service
- resources and of a consistent network for provision of essential equipment and medication
- specific services for youth.

Many of these findings, particularly those relating to co-ordination, continuity, respite, psychological and emotional support are highlighted again in a recent New Zealand study (Horsburgh 2002).

Other issues that have been identified in this and other reports include:

- a lack of clarity about when paediatric palliative care should begin (Davies and Steel 1996)
- a need for clear information and support preferably from a key worker and a lead paediatrician

- problems associated with providing night-carer relief
- considerable financial burden on families
- the importance of acknowledging spiritual and cultural aspects of caring for a dying child (Horsburgh 2002)
- under-treatment of pain and other symptoms (Goldman 1998).

Since publication of *The New Zealand Palliative Care Strategy* (2001) the country's first paediatric palliative medicine specialist has been appointed at Starship Children's Hospital. He works within New Zealand's only dedicated multidisciplinary Paediatric Palliative Care Team. In other parts of the country paediatric palliative care is provided by a range of services including specialist paediatric teams, hospice and primary care services.

There is also a significant need for age-appropriate support for children whose parents, siblings, grandparents, other family/whānau members or peers are affected by terminal illness. Currently services, if they are provided, are accessed from a range of organisations including schools, hospitals or hospices and independent organisations such as Skylight.

Cultural barriers to access

There are also a number of cultural barriers to accessing palliative care services particularly for Māori and Pacific peoples.

Māori access to palliative care services

Many Māori people prefer to die at home nursed and cared for by their whānau. Māori view health as an interaction of factors. The whare tapa whā (four-sided house) model of health, for instance, acknowledges taha wairua (the spiritual elements), taha hinengaro (thoughts and feelings), taha tinana (the physical elements) and taha whānau (the family) (Durie 1994).

The following issues affecting access to palliative care services for Māori have been identified (Māori Palliative Care Strategy Working Party) and the National Health Committee (1999) (Minister of Health 2001; National Health Committee 1999).

- Māori may not access palliative care services because they lack an awareness of the existence of these services.
- There is a lack of Māori palliative care providers and a lack of palliative care education amongst current Māori providers.
- There is a lack of understanding by mainstream providers of the whānau model of health and illness. Clinicians in both hospices and hospitals do not always work with the wider whānau or Māori providers when co-ordinating care, yet the whānau is the main support for the Māori person who is dying.
- Some Māori choose to use traditional healing practices during the palliative phase of illness.
- Limited connections to whānau support or marae for some urban Māori (Pool 1991; Horsburgh 2002).

Pacific peoples access to palliative care

In general, Pacific peoples prefer to care for their dying family members at home. Pacific peoples have identified the following barriers to accessing palliative care (National Health Committee 1999).

- Providers lack knowledge of well-established cultural protocols for dealing with Pacific people who are dying. These protocols are often dictated by spiritual beliefs but are not always applied.
- Access to information about palliative care services is poor. Pacific peoples may experience language barriers (Horsburgh 2002) and are less likely to use mainstream sources of information such as written material.
- Communication/language barriers – the wider family group may not fully understand the disease and treatment process. This may inhibit access to appropriate palliative care for a dying relative.
- Lack of Pacific palliative care providers. Most Pacific peoples prefer to have a Pacific health professional providing their care.

Objective

To continue to improve access to a defined set of essential palliative care services for people dying of cancer in each DHB.

Actions

Each DHB will ensure that palliative care services:

- will build upon existing services including primary care
- are culturally appropriate, particularly for Māori and Pacific peoples
- information is available to the public.

Each DHB will provide at least one local palliative care service which includes access to the following services:

- assessment
- care co-ordination
- clinical care
- support care
- a hospital-based palliative care team
- access to a specialist palliative care service for patients dying of cancer with complications
- access to palliative care services for children.

Expected outcomes

- All DHBs will have a defined local palliative care service which is capable of meeting the physical, psychosocial, spiritual and cultural needs of their population.
- There will be evidence that referrers in community and hospital settings are referring patients to the local palliative care service.
- There will be evidence that referrals are responded to in a timely manner.
- All patients with cancer who are dying will have a defined care-co-ordinator.
- All DHBs will be monitoring and evaluating access to local palliative care services.
- The DHB population will state that they have knowledge about palliative care services.
- Users of palliative care services will express satisfaction with their care.

Candidate Priority Action Two: Co-ordination and Integration of Palliative Care Services

(See *Towards a Cancer Control Strategy for New Zealand: A Discussion Document*, Goal 5, Objective 2, p 35.)

A review by the HFA (1999) identified that there was very little co-ordination and integration of palliative care services. Since the introduction of *The New Zealand Palliative Care Strategy*, some DHBs have been working at improving integration and co-ordination of palliative care services. However, there is still a long way to go.

Lack of co-ordination and inflexibility of services can result in:

- people not being able to access the full range of palliative care services
- provision of inappropriate care (for example, hospital care when hospice or community care may be more appropriate and desirable)
- repeated acute admissions to hospital for some people in their last few months of life
- inefficient delivery of services (for example, some patients may be visited by more than four providers in a single day (HFA 1999))
- fragmentation and duplication of services
- an inability to provide flexible packages of care that are specific to an individual or their family's needs
- older people and people living alone having problems accessing services.

District Health Boards need to continue to work further on co-ordination and integration of the broad range of people and services involved in the care of a person with cancer. These services include primary care; hospital services such as oncology and surgical services; community-based services including district nursing, hospice services, Māori and Pacific peoples' services and groups; long-term support services; and voluntary agencies providing social support. The role of care-co-ordinator has been identified as having a key responsibility for ensuring appropriate access and co-ordination within and between services.

Objective

To ensure that a seamless service is provided for patients with cancer who require palliative care, no matter where they live.

Actions

Each DHB will ensure that:

- a palliative care referral, assessment and co-ordination system is in place
- a local palliative care network is established that focuses on service co-ordination.

Local palliative care services will form:

- local palliative care networks that will focus on service co-ordination
- regional palliative care networks to ensure the provision of specialist support. These networks will reflect the DHBs' populations.

Expected outcomes

- All DHBs should demonstrate effective linkages at the local and regional level in the provision of palliative care services.
- Users of palliative care services will indicate that they are satisfied with the continuity of care between different providers.

Candidate Priority Action Three: Palliative Care Workforce

(See *Towards a Cancer Control Strategy for New Zealand: A Discussion Document*, Goal 5: Objective 1, pp 34–35.)

Since *The New Zealand Palliative Care Strategy* was launched in 2001, some progress has been made towards the development of the palliative care workforce. In response to nursing workforce issues identified in the Strategy, the Ministry of Health (via the Clinical Training Agency) has implemented a fully-funded Post-graduate Certificate in Nursing (Palliative Care) in conjunction with Victoria University. In 2002, 40 nurses were undertaking this programme. Postgraduate palliative care programmes are also offered via Auckland and Otago Universities. The opportunity now exists for New Zealand registered nurses working at an advanced level of practice to apply for Nurse Practitioner status (Minister of Health 2002b). Palliative care has been identified by the Nursing Council as one of seven possible broad scopes of specialist practice for nurse practitioners (Nursing Council 2001b).

In response to a reported shortage of palliative medicine specialists in New Zealand, an analysis of the palliative medicine workforce was recently undertaken to establish current numbers of palliative medicine fellows and vocationally registered palliative medicine specialists (RACP and Ministry of Health 2002). Although there are two funded medical positions for training in palliative care there still needs to be further work to determine national palliative medicine requirements.

There are further issues to be resolved relating to the planning and development of the palliative care workforce. These issues include the cultural representativeness of the workforce and appropriate training for multidisciplinary team members including counsellors, chaplains, social workers, physiotherapists, occupational therapists, pharmacists, music and art therapists. Training and awareness raising of oncology, primary care and long-term care for health professionals involved in palliative care is another important issue.

Workforce planning

There is still a need to develop national guidelines on palliative care workforce requirements to determine the appropriate number of multidisciplinary staff required for palliative care services. This work needs to include workforce planning for Māori and Pacific palliative care providers, as there is a shortage generally of both these provider groups. Māori Health practitioners currently make up only 5% of the health workforce in New Zealand (HWAC 2001). There is also a serious lack of Pacific providers across all health occupations in New Zealand. Key issues for the development of a sustainable Pacific workforce are:

- staff recruitment
- staff retention
- upskilling
- promotion of a culture of learning.

Many Māori and Pacific doctors and allied professionals are unaware of the key roles they could play in palliative care (excluding informal support workers and alternative complementary health practitioners) (HWAC 2002).

There is also a need to consider the palliative care workforce in rural areas. One in four New Zealanders live in rural areas or small towns, and rural areas have a higher proportion of children and older people. Just on a third (32%) of Māori live in rural areas, compared with 23% of non-Māori. Of particular concern is the significantly poorer health status of rural Māori compared with rural non-Māori and urban non-Māori. If we are to reduce inequalities it is vital that enough palliative care practitioners are accessible to rural communities (HWAC 2001).

Palliative care training

There is a need to ensure that palliative care training is increased for undergraduate, graduate and postgraduate health professionals to make non-palliative care providers more aware of the palliative care approach and palliative care as an option for dying people with cancer. There is also a need to ensure that palliative care training is available for nurse aides/health-care assistants, volunteers and families who play a large role in the delivery of palliative care.

Objective

To ensure that the palliative care workforce continues to be developed so that it can meet the needs of current and future populations especially in relation to capacity and cultural diversity.

Actions

- Development of guidelines on workforce planning for palliative care.
- Further development of undergraduate, graduate and postgraduate health professional training in palliative care. This should take rural training into account.
- Vocational training positions in palliative medicine established nationally.
- Palliative care providers network to develop programmes which meet the needs of Māori, Pacific and other ethnic health professionals.
- Continuing education and professional development will be available for cancer and palliative care providers.
- Palliative care training will be available for nurse aides/health-care assistants, volunteers and family members.

Expected outcomes

- There will be modified attitudes, values and behaviours among emerging health professionals in relation to dying people and palliative care.

- There will be increased motivation, knowledge skill and participation amongst existing health professionals.
- The palliative care workforce will represent the need and diversity of the cancer population.

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