

The New Zealand Palliative Care Strategy

Published in February 2001
by the Ministry of Health
PO Box 5013, Wellington, New Zealand
ISBN 0-478-24310-3 (Book)
ISBN 0-478-24311-1 (Internet)
HP 3418

This document is available on the Ministry of Health's Web site:
<http://www.moh.govt.nz>

Front Cover Sketch:
Tinakori St Sketch by Ian Donovan, patient of Te Omanga Hospice

Foreword

The New Zealand Palliative Care Strategy sets in place a systematic and informed approach to the future provision and funding of palliative care services. This Government is concerned to ensure that all people who are dying and their family / whānau have access to palliative care services, provided in a co-ordinated and culturally appropriate way. That is why this Government has committed additional funding to ensure that the strategy can begin to be implemented immediately.



The health and disability sector is currently being reconfigured to increase local decision-making and improve the responsiveness of health funders and providers to their communities. These changes also signal a need for communities, providers and funders to work together at a local level to ensure that services in their area make sense and are focused on the needs of the population. I would therefore like to encourage communities and all providers of palliative care to start working together to ensure the Palliative Care Strategy is implemented in the most optimal way, both in your local area and across the country.

Many people have assisted in the development of the strategy by providing feedback on the discussion document and, in particular, by serving on the sector advisory group. I would like to take the opportunity to thank all these people. I would also like to thank all those involved with the delivery of palliative care services, especially the many volunteers who give of their time to assist and be with people who are dying.

A significant amount of work needs to be undertaken in order to implement the New Zealand Palliative Care Strategy. I look forward to your continued involvement and enthusiasm in carrying forward the vision and strategies outlined in this document.

A handwritten signature in black ink that reads "Annette King". The signature is written in a cursive, flowing style.

Hon Annette King
Minister of Health

Contents

Foreword	iii
Executive Summary	vii
1 Introduction	1
Background	1
What is palliative care?	2
When should palliative care services commence?	2
Why a palliative care strategy?	3
The Palliative Care Strategy in context	4
Aim of the Palliative Care Strategy	6
2 A Vision for Palliative Care Services in New Zealand	7
Access to the essential palliative care services	7
Service configuration for palliative care services	9
Needs of specific population groups	12
Summary	14
3 Strategies to Implement the Vision	15
Strategy 1: Ensure access to essential palliative care services	15
Strategy 2: Each DHB to have at least one local palliative care service	16
Strategy 3: Develop specialist palliative care services	17
Strategy 4: Implement hospital palliative care teams	17
Strategy 5: Develop quality requirements for palliative care services	18
Strategy 6: Inform the public about palliative care services	19
Strategy 7: Develop the palliative care workforce and training	19
Strategy 8: Ensure that recommendations from the Paediatric Review are implemented	20
Strategy 9: Address issues of income support	20
Appendices	
Appendix 1: New Zealand Work on Palliative Care	21
Appendix 2: Advisory Group Members and Terms of Reference	24
Appendix 3: People/Organisations Who Made Submissions or Attended Public Meetings on the Discussion Document	25
Appendix 4: Overview of Palliative Care Services	31
Appendix 5: Issues Relating to Palliative Care Services in New Zealand	43
Appendix 6: Palliative Care in the United Kingdom, Australia and Canada	51
Appendix 7: Explanation of Key Terms	53
References	56

Executive Summary

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, whānau, hinengaro and wairua – and enhances a person’s quality of life while they are dying. Palliative care also supports the bereaved family/whānau.

This palliative care strategy has been developed because:

- evidence shows that palliative care is effective in improving the quality of life for people who are dying
- palliative care needs to be better understood and accepted by health professionals so that dying people have timely access to palliative care
- there is a demonstrable need for palliative care now and increasingly into the future
- palliative care provision is complex, and a range of issues need to be addressed.

The aim of the strategy is to set in place a systematic and informed approach to the provision and funding of palliative care services through the implementation of the following vision:

All people who are dying and their family/whānau who could benefit from palliative care have timely access to quality palliative care services that are culturally appropriate and are provided in a co-ordinated way.

In order to implement this vision there is a fundamental need to raise the profile of palliative care among communities and health and disability providers, to increase the awareness of palliative care services among communities, and to develop a ‘palliative care culture’. Underpinning this is the development of:

- *a set of essential services for dying people who could benefit from palliative care.* These services would include assessment (initial and ongoing), care co-ordination, clinical care and support care
- *a flexible service configuration* that builds on existing services, takes account of the future direction for primary care, and is co-ordinated to ensure that dying people have access to all essential services via two inter-linked levels of palliative care services that include:
 - local palliative care services provided from each District Health Board area, which provide access to the essential services for people who are dying
 - specialist palliative care services in each region, particularly in Auckland, Hamilton, Palmerston North, Wellington, Christchurch and Dunedin. These providers would have particular responsibility for providing the specialist palliative care advice for the region, maintaining linkages with the tertiary hospitals and undertaking regional and national quality improvement and educational activities.

Nine strategies have been developed which will be implemented over a 5–10-year period in order of priority. The first priorities will be to ensure that essential services are available for all dying people and that at least one local palliative care service is available in each District Health Board. Additional funding has enabled the implementation of these strategies to be started.

The other strategies will be implemented in line with other government priorities outlined in the New Zealand Health Strategy.

1 Introduction

Background

In September 1999 the Ministry of Health and Health Funding Authority (HFA) commenced work on a 5–10-year strategy for palliative care services. The need for a strategy was identified in response to an increasing number of problems and issues identified by providers (particularly hospices), Hospice New Zealand, previous reports and working parties. The strategy development was also an opportunity to conclude aspects of the Care of the Dying project that was undertaken by the National Health Committee from 1997 (see Appendix 1).

In developing the strategy document the project team undertook extensive consultation and analysis, which included literature searches, analysis of previous reports, needs analysis, the use of contract and questionnaire information on palliative care service provision (hospice and hospital), an informal telephone survey of Independent Practitioner Associations (IPAs), informal discussions with stakeholders (providers and interest groups), a Māori working party, and informal discussions with a range of providers and interest groups.

An eight-person expert advisory group was appointed to assist the project team (see Appendix 2). In addition, a reference group was established to complement the expertise of the advisory group, to ensure representative advice from all involved with palliative care.

In mid-July 2000 over 1900 Palliative Care Strategy discussion documents were mailed out to stakeholders and sector interest groups. In response 116 groups and individuals provided a written submission on the discussion document. There were also 12 public meetings and focus group meetings around New Zealand to gain direct feedback from the public, providers, carers and people receiving palliative care. An analysis of the submissions has been distributed to those who made written submissions.¹

This strategy has been developed with the assistance of the expert advisory group and using feedback from the written submissions and the meetings (see Appendix 3).

¹ Copies are available from the Ministry of Health, or can be found on the Ministry Web site: www.moh.govt.nz.

What is 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.

Principles of palliative care

There are five guiding principles that 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).

When should palliative care services commence?

It is not always easy to know when the provision of palliative care services should commence. Some people may live for many years with an illness or condition that is not curable and yet they may not be in the terminal phase of their illness.

The palliative approach assists health professionals to determine the stage in a person's illness or condition when palliative care services are needed. This is a holistic approach to care, informed by the knowledge and practice of palliative care principles, and which promotes a person's physical, psychological and social wellbeing (Doyle 1990; Llewellyn et al 1999). The palliative approach assists

a health professional recognise all the care needs of a person from the time of diagnosis, as well as informing the decision on when to commence discussing referral to palliative care services with a dying person and their family/whānau.

This strategy recommends that palliative care should generally be available to people whose death from progressive disease is likely within 12 months. The introduction of palliative care or referral of a person to palliative care services should be:

- guided by referral protocols
- supported by the advice of a health professional, and, most importantly
- based on the person's needs and choices.

Until people require palliative care it is important that they receive appropriate support care and clinical care to enable them to maintain their independence for as long as possible or desired. This strategy recognises that further work needs to be undertaken to address the needs of those with chronic and disabling diseases/conditions, particularly in relation to the type of services needed for those who do not yet require palliative care.

Why a palliative care strategy?

A palliative care strategy is necessary because of the following factors.

Palliative care is effective

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, and that it should be a central feature of all good clinical practice (WHO 1990; NCHSPCS 1994; Bruera et al 1999; Higginson et al 2000). In New Zealand, palliative care has not always been well understood or accepted by providers and incorporated into clinical practice. This is particularly so in some hospital services, primary care services, rest homes and private hospitals. 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). A strategy is therefore needed to raise awareness about the effectiveness of palliative care among health and disability professionals and providers and the general population.

Increasing need for palliative care services

At present approximately 90 percent 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 percent of cancer deaths). The proportion of the population aged 65 or over is projected to more than double (from 12 percent to 26 percent) over the next 50 years. It is also estimated that by 2011 the number of people with cancer will increase by 24 percent. There will thus need to be sufficient palliative care services to meet the needs of an increasing number of people with cancer.

In addition, there is an increasing awareness that people with non-malignant diseases can benefit from palliative care services. Currently only 10 percent of those people accessing hospice services have non-malignant diseases, but many more people with non-malignant diseases could benefit from them. It is estimated that if all the people with non-malignant diseases accessed hospice services, the numbers accessing the services would double. This could place a heavy burden on palliative care services if they are not resourced to manage this (see Appendix 4 for an overview of palliative care services).

Service issues need to be addressed

There are a number of factors preventing the delivery of good palliative care to people who are dying and their families/whānau, including:

- lack of a palliative care approach in some services
- variable access to palliative care services due to:
 - service gaps and national variation in different aspects of care
 - lack of recognition that people who are dying from conditions other than cancer can benefit from palliative care services
 - cultural barriers, in particular for Māori and Pacific peoples
 - lack of services in rural areas
 - lack of services designed for children and young people
 - interface, framework and funding boundaries between personal health and disability support services
- poor integration and lack of co-ordination of palliative care services, making for service variability
- lack of standard quality specifications or performance indicators/outcome measures, making benchmarking impossible
- lack of workforce planning for palliative care (there are not enough palliative care specialists in New Zealand and relatively few palliative care health professionals for Māori and Pacific peoples)
- variability in the funding of palliative care services, particularly for hospices that are not fully funded by government.

See Appendix 5 for more detail.

The Palliative Care Strategy in context

The health and disability sector has been reconfigured to increase local decision-making and improve the responsiveness of health funders and providers to their communities. The HFA and the Ministry of Health have been amalgamated, and funding is to be devolved to 21 District Health Boards (DHBs), which are currently being established. DHBs will be responsible for working within allocated resources to ensure that services reflect the needs of individuals and communities at a local level. Each DHB will enter a funding agreement with the Crown. This agreement will outline the Crown's expectations

of each DHB in relation to the services that should be funded and provided. The new sector is designed to take a more integrated and co-operative approach to health care.

The changes are being guided by the New Zealand Health Strategy (Minister of Health 2000), which provides an overarching framework for the health sector. This strategy outlines seven fundamental principles for the health sector as well as key goals and objectives.

The Government has identified 62 objectives for the health sector. Of these, 13 population health objectives have been highlighted for the Ministry of Health and DHBs to focus on for action in the short to medium term.

The New Zealand Health Strategy's priority population health objectives:

- to reduce smoking
- to improve nutrition
- to reduce obesity
- to increase the level of physical activity
- to reduce the rate of suicides and suicide attempts
- to minimise harm caused by alcohol, illicit and other drug use to both individuals and the community
- to reduce the incidence and impact of cancer
- to reduce the incidence and impact of cardiovascular disease
- to reduce the incidence and impact of diabetes
- to improve oral health
- to reduce violence in interpersonal relationships, families, schools and communities
- to improve the health status of people with severe mental illness
- to ensure access to appropriate child health care services, including well child and family health care, and immunisation.

The strategy also highlights three priority objectives to reduce disparities in health status. These are:

- to ensure accessible and appropriate services for people from lower socioeconomic groups
- to ensure accessible and appropriate services for Māori
- to ensure accessible and appropriate services for Pacific peoples.

In addition to the above priority objectives the New Zealand Health Strategy highlights five service delivery areas the Government wishes the health sector to concentrate on in the short to medium term:

- public health
- primary health care
- reducing waiting times for public hospital elective services

- improving the responsiveness of mental health services
- accessible and appropriate services for people living in rural areas.

One of the 62 objectives that the Government has highlighted is to ensure access to appropriate palliative care services. As palliative care is not one of the priority service or population areas, full implementation of this strategy will occur in the medium term rather than the short term. Priority will, however, be given to the most urgent issues facing palliative care; that is, filling service gaps and integration of services (see Strategies to Implement the Vision). Additional funding of \$7.5 million per annum has been provided for this purpose.

The New Zealand Disability Strategy will be implemented alongside the New Zealand Health Strategy once it has been developed. The Disability Strategy aims to help open the way into community life for people experiencing disability by removing the barriers to their participation.

Both the New Zealand Health Strategy and the New Zealand Disability Strategy acknowledge the special relationship between Māori and the Crown under the Treaty of Waitangi.

Central to the Treaty relationship and the implementation of Treaty principles is a common understanding that Māori and the Crown will have a shared role in implementing health strategies for Māori. The draft Māori Health Strategy outlines the three key principles for achieving Māori health gain: *partnership*, *participation* and *protection*.

The Government is also committed to developing a number of other strategies that will be implemented alongside the Palliative Care Strategy and under the umbrella of the New Zealand Health Strategy and the New Zealand Disability Strategy. These include the Pacific Health Strategy, the Primary Health Care Strategy and the Health of Older Person's Strategy.

Aim of the Palliative Care Strategy

The aim of the strategy is to set in place a systematic and informed approach to the provision and funding of palliative care services. In developing this strategy, key objectives are to:

- develop a practical strategy that builds on current service arrangements (including services provided by hospices, hospitals, GPs, district nurses, Māori health providers, home support, rest home, aged care hospital and charitable organisations such as the Cancer Society, Multiple Sclerosis Society and Motor-Neurone Disease Association)
- develop a more responsive system that can support a person's choice to die at home: research shows that 50 to 70 percent of people would prefer to have the choice of home care; at present, only 31 percent of people with cancer die at home (although for Māori and Pacific peoples the figure is 53 and 42 percent respectively)
- raise awareness of the importance of good palliative care
- incorporate work already done in relation to palliative care (Ministry of Health 1993, 1998; Robertshaw 1994; Penny 1997)
- learn from overseas directions in palliative care, which point to the need for more co-ordination and integration of services (NCHSPCS 1997; Palliative Care Australia 1998; Nichols 1998; Bruera 1999; Hospice NZ 1998) (see Appendix 6).

2 A Vision for Palliative Care Services in New Zealand

The vision for the provision of palliative care services in New Zealand is that:

All people who are dying and their family/whānau who could benefit from palliative care services have timely access to quality palliative care services that are culturally appropriate and are provided in a co-ordinated way.

Underpinning the vision is a community model of palliative care services. This means that palliative care services should be provided for most dying people and their families/whānau in their own home, where this is their wish. The vision also assumes that the family/whānau will be active in assisting with care where this is appropriate.

In order to implement the vision there is a fundamental need to develop an awareness and knowledge of palliative care among communities and providers of health and disability services. There is also a need to identify clearly:

- the essential and accessible palliative care services for people who are dying and their family/whānau
- the service configuration required to ensure access to co-ordinated quality palliative care services that are culturally appropriate.

Access to the essential palliative care services

A set of essential services that dying people and their families/whānau should have access to has been developed. This set of services is consistent with overseas practice and current thinking in New Zealand (NCHSPCS 1997; Palliative Care Australia 1998; Nichols 1998; Burera 1999; Hospice NZ 1998). It also recognises that for people to have the option of dying at home there must be access to a range of services provided in the community.

The Government is committed to funding essential palliative care services to ensure that services are available. It should be noted, however, that services provided to dying people by primary care providers who are not part of palliative care services will be addressed as part of the Primary Health Care Strategy, which will recommend that over time the Government will commit additional funding to primary care.

The essential palliative care services that dying people and their families/whānau should have access to are described below.

Assessment and care co-ordination

Assessment

Following confirmation that a person's illness or condition has reached its terminal stage, the dying person should have an initial multidisciplinary assessment to identify the person's and their family/whānau's physical, social, spiritual and emotional needs. Following this initial assessment, there should be ongoing assessment by team members directly involved in the person's care. A multidisciplinary assessment is important to ensure that all needs are identified early, and that an individualised care plan is established. It is important that the multidisciplinary team include the GP/practice nurse of the dying person to ensure continuity of care.

Care co-ordination

Each person who is dying should be allocated a care co-ordinator at, or following, the initial assessment. The care co-ordinator is responsible for ensuring that the dying person and their family/whānau are provided with information regarding palliative care options and services, and that the family/whānau are provided with the necessary information and skills to assist in caring for their dying family member.

The care co-ordinator also has responsibility for co-ordinating and ensuring access to the appropriate palliative care and other services, including:

- specialist palliative care
- primary care services
- hospital services
- Māori provider services
- residential care services
- home support
- services provided by social support agencies (for example, Work and Income New Zealand)
- voluntary services (for example, Cancer Society, MS Society and Motor-Neurone Society).

The care co-ordinator will ensure care is appropriate to the person's needs and culture. They will have responsibility for promulgating the palliative care approach and for liaising with and maintaining working relationships with all providers and volunteers.

Clinical care

Each person who is dying should have access to clinical care that includes:

- access to medical services (including primary care and specialist services), domiciliary nursing services, and equipment to provide symptom control, nursing and medical management 24 hours a day, seven days a week, in the community
- access to inpatient care for respite care and/or control of symptoms that cannot be adequately controlled in a community setting; inpatient care should also be provided if required or preferred
- bereavement counselling and spiritual care for the person, and for their family/whānau, before and after death to assist them to work through their bereavement.

Support care

People who are dying and their families/whānau should have access to support services based on need, including:

- support in the home (for example, picking children up from school, general household management)
- long-term residential care in an appropriate setting for people who are unable to be cared for in the home. Most older people accessing residential care with palliative care needs currently undergo income and asset testing, as do other older people accessing rest home care.

Service configuration for palliative care services

A service-based framework is required which ensures that dying people and their family/ whānau can access the essential palliative care services they require.

This framework needs to:

- build on the existing services and workforce
- integrate/co-ordinate services at a local, regional and national level to ensure continuity of care
- ensure that all palliative care services are culturally appropriate for all population groupings, including Māori and Pacific peoples
- ensure the quality of palliative care services
- provide the flexibility to meet people's needs, including for those who do not wish to die at home
- take account of the future direction for primary health care.

On this last point, the Primary Health Care Strategy outlines six key directions for the primary health sector. The local structures to achieve these directions will be Primary Health Organisations. People will be encouraged to join a Primary Health Organisation by enrolling with a provider of primary care services such as a general practice or local health clinic. The roles of Primary Health Organisations include improving and maintaining the health of their enrolled population, providing first-line services to people when they are unwell, providing continuity of care, working in a multidisciplinary team and responding to the needs to their populations.

Palliative care service networks

To ensure that dying people and their family/whānau have access to the essential palliative care services, a service framework with a network of two inter-linked levels of palliative care services is required:

- local palliative care services
- specialist palliative care services.

Local palliative care services

Each DHB area will be required to have at least one provider that provides palliative care services at a local level. These providers should be able to meet most of the palliative care needs of the community.

Providers of local palliative care services may be a hospice, a hospital community-based service and/or a primary health organisations. Each will be required to:

- provide access to the essential palliative care services in both community and institutional settings for their DHB area in line with the Funding Agreement between DHBs and the Minister of Health
- have a formal agreement with specialist palliative care services in line with specialised palliative care services outlined below
- have formal links with relevant service providers in the area, including hospital services, primary care services, Māori providers, Primary Health Organisations and disability support service providers
- develop a plan with local Māori to ensure there is appropriate access to the palliative care services that Māori need.

People requiring local palliative care services are likely to be either self referred or referred from a number of services, including primary care, Māori provider organisations, hospitals, rest homes, and community provider organisations. It is important that these providers understand and utilise the palliative care approach to ensure that a timely referral to palliative care services is made.

GPs and primary health care nurses are very important in providing continuity of care for the dying person and their family/whānau. Primary care providers should be part of the palliative care multidisciplinary team and local palliative care service. Community support providers should also be considered part of this team and service.

Providers who do not have respite or long-term care beds will need to have formal links with rest homes or private hospitals and should have the responsibility for ensuring the person receives quality palliative care services.

It is important that where there is more than one provider, services are well co-ordinated to ensure that the dying person and their family/whānau receive seamless care.

Specialist palliative care services

All DHBs should have access to specialist palliative care services, but it will not be possible for all DHBs to provide these services directly. To ensure an appropriate level of access there should be at least six specialist palliative care services based in Auckland, Hamilton, Palmerston North, Wellington, Christchurch and Dunedin, where:

- there can be close geographical proximity to tertiary hospital services
- there are existing hospices/hospital services in these regions that provide specialised palliative care.

Providers of specialist palliative care services are likely to be either a hospice, a hospital or both of these service providers working together. Specialist palliative care service providers will provide the essential services for their community and a full range of specialist palliative care services which include:

- providing evidenced-based specialist advice to local palliative care providers, on-site care and consultation where necessary
- establishing effective links with local palliative care providers in the region
- facilitating quality improvement in all local palliative care providers in the region
- ensuring that appropriate specialist education and training is available (this would include the provision of clinical placements for medical and nursing staff)
- establishing effective links with specialist palliative care services nationally and undertaking national work on quality improvement activities (for example, developing evidenced-based referral and best-practice guidelines, developing outcome/performance indicators and undertaking benchmarking activities)
- undertaking/participating in palliative care research activities.

Specialist palliative care services will employ health professionals with a broad range of palliative care competencies, including:

- two or more full-time equivalent doctors with a recognised palliative care specialist qualification
- a majority (over 60 percent) of their registered nursing staff with a recognised palliative care qualification and the rest working towards completed palliative care qualifications
- one or more trained bereavement counsellors with skills in palliative care
- access to trained occupational therapists, physiotherapists and pharmacists with palliative care expertise.

Specialist palliative care services will have to meet the Health and Disability Sector Standards before being eligible to be recognised as a specialist palliative care service. It is also likely that they would be either accredited or working towards accreditation using Quality Health's Palliative Care Standards.

Specialist palliative care services will also have formal links with hospital palliative care teams. These teams, while linked to specialist palliative care services, will work in the tertiary hospitals. 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. They will

also assist hospital providers in ensuring that people access the appropriate palliative care service in their communities.

While hospital palliative care teams will initially operate in the tertiary hospitals, it is expected that over time all hospitals will have the presence of health professionals with palliative care training/experience.

Role of the community

This strategy recognises that community organisations and volunteers play an important part in the delivery of palliative care services. It recognises the many hours that volunteers contribute in caring for those who are dying and strongly supports the continued role of volunteers. This strategy also recognises that volunteers play an important role in reflecting community values and ownership in health service provision. It is important, however, that where volunteers are assisting in palliative care services, appropriate induction and ongoing training is made available. Hospice New Zealand is currently undertaking national work on volunteer education.

Needs of specific population groups

While most of the people requiring palliative care are older and have varying needs, some other population groups have specific needs. The needs of Māori, Pacific peoples, people with disabilities and non-malignant disease, people under the age of 65, and children are outlined below. Other groups will also have specific needs, so it is important that palliative care services be flexible enough to ensure that all needs are met.

Māori

In order to address the needs of Māori, it is important that:

- palliative care services have policies in place that recognise the specific needs of Māori
- there are linkages between palliative care providers and Māori development organisations, and that a plan for services for local Māori is developed to assist in meeting the specific needs of Māori
- at a local level, where appropriate, each provider should employ one or more care co-ordinators who could meet the special needs of Māori, particularly in those areas with a high Māori population. The care co-ordinator would co-ordinate services and work with the whānau (who are often caring for the person) to ensure that the needs of the dying person are met in a culturally appropriate way. The care co-ordinator could be employed in conjunction with local Māori providers. It is important that the principles of cultural safety are recognised in the employment of Māori.

Pacific peoples

Palliative care services and other health services need to understand Pacific cultures in terms of care of the dying. It is also important that Pacific peoples have information about palliative care services. Where there is a high Pacific population it is important that palliative care services recruit Pacific health professionals and volunteers. It is recognised, however, that there are very few trained Pacific health professionals and there is a need for more to be trained.

People with disabilities and non-malignant disease

It is important that palliative care services recognise the palliative care needs of people with disabilities and those with non-malignant disease (for example, those with motor neurone disease, multiple sclerosis and chronic obstructive airways disease). These diseases are often longer in duration than diseases such as cancer and often require a higher level and complexity of support care. There is a need to consider the availability and suitability of support services and other services for these people following diagnosis of their condition and prior to their receiving palliative care services. There is also a need to ensure they have timely access to palliative care services when they require it.

People under the age of 65

Local palliative care services and community support services should generally be able to meet the palliative care needs for people under the age of 65.

A small proportion of these people cannot be cared for at home and require longer-term inpatient care. Residential care services, which mainly cater for older people, are not always suitable for this population group. When organising longer-term care for people under the age of 65 it is important that palliative care services consider the suitability of the available services.

Children

Children require different palliative care services. Children who are dying need the expertise of a paediatrician and paediatric nurse with palliative care experience.

The *Paediatric Review* identified a need for a children's care co-ordinator at the local level. The care co-ordinator needs to have experience in paediatrics and palliative care and to be part of a multidisciplinary team, which includes a paediatrician and paediatric nurses.

Given that only a very small number of children need to access palliative care compared to adults, and that their needs often require highly specialised services, this strategy supports the implementation of the recommendations from the *Paediatric Review*. These include:

- the development of a national network for those involved in paediatric palliative care and a working group of representatives, both to advise on the national standards of care required and to monitor these standards
- the development of a national palliative care team to provide expert advice to local teams (this has been in part implemented with the appointment of the child palliative care team at Starship Hospital, which has both a regional and national role)
- the employment of a co-ordinator of paediatric palliative care for each local specialist child health team and each paediatric oncology unit
- recognition that much of the care will be delivered by local specialist child primary health teams.

While this strategy is supportive of the national palliative care team and local teams (including co-ordinators) for children, it is important they have formal links with local and specialist providers of palliative care services for adults. This linkage should assist with sharing expertise and ensuring that children receive appropriate bereavement counselling if a parent dies.

Summary

The vision for palliative care is: ‘*all* people who are dying who could benefit from palliative care and their family/whānau should have timely access to quality palliative care services that are culturally appropriate and provided in a co-ordinated way’. This vision is underpinned by four key features:

- an awareness and knowledge of palliative care among communities and providers of health and disability services
- the provision of essential palliative care services for people who are dying and their family/whānau (these include care co-ordination to ensure that services are co-ordinated and appropriate for each individual)
- a framework that is based around a palliative care network comprising two inter-linked levels of care
- well co-ordinated and flexible service arrangements to ensure that the needs of all different population groupings can be met.

3 Strategies to Implement the Vision

The strategies below have been developed to ensure that quality palliative care services based on need are available for all New Zealanders. While additional funding for palliative care services may eventually come from savings made through fewer expensive interventions and fewer inappropriate acute admissions for people who are dying, in the shorter term it is recognised that additional funding is required to implement these strategies.

However, this is a 5–10-year vision, and most of the strategies outlined will require a significant amount of lead-time for implementation. As the Government has identified that the 13 priorities within the New Zealand Health Strategy will take priority in the short to medium term, it is important that the implementation of the New Zealand Palliative Care Strategy focuses first on the most urgent strategies.

In implementing the strategies an important aim is to build a ‘palliative care culture’ in which:

- all providers, where necessary, adopt a palliative care approach
- there are good linkages with and between palliative care service providers
- people are aware of the palliative care services that are available in their communities.

Strategy 1: Ensure access to essential palliative care services

This is the first priority for the implementation of the palliative care strategy. Essential services include assessment and care co-ordination, clinical care and support care.

Additional funding for palliative care services has enabled this strategy to be partly achieved already. Purchase units, a service specification and a pricing model for hospice palliative care services have been developed by the HFA and are currently being implemented in line with the New Zealand Palliative Care Strategy. As palliative care services vary in their provision of services, ongoing work on the pricing model will be undertaken by the Ministry of Health. Palliative care providers will be required to provide ongoing information for this purpose.

Additional work being undertaken by the Ministry of Health includes the identification of gaps in essential services (including rural areas) and the capacity in each area for providing essential services. Using the extra funding for palliative care services (\$7.5 million per annum), the extent to which service gaps can be filled in each DHB area is currently being determined. DHBs continue this work as a requirement of the Funding Agreement between the Minister of Health and each DHB.

Additional work needs to be done to ensure that dying people have access to the support services they need. This work includes a review of disability support services which analyses:

- the extent to which interface and boundary issues between personal health and disability support services influence access to support services
- how many people are currently accessing personal health and disability support services, and what gaps there are in community support services that will require additional funding
- the extent to which existing community support services are robust enough to provide ongoing support for people with a palliative care need
- the extent to which existing residential care services can be utilised to provide both short-term and long-term residential support for dying people; this needs to be done in relation to those people under and over 65
- the costs of providing support services.

This work needs to wait until high-level policy decisions have been made on whether funding for services for older people will move to Personal and Family Health, as this would change the funding boundaries and have an impact on the nature of the work to be undertaken.

Strategy 2: Each DHB to have at least one local palliative care service

This strategy needs to be implemented alongside Strategy 1.

In a number of places, providers – particularly hospices – already fulfil most of the requirements necessary to be a local palliative care service. In other places, particularly rural areas, providers may need to work together or co-ordinate with each other to provide the essential services. For example, primary care providers could link up with district nursing services.

Each DHB will need to develop a plan that identifies:

- local needs for palliative care
- local service providers (including Māori providers), service provision and capacity to provide all the essential services, including support services
- justification of the choice of providers for delivering local palliative care services.

DHBs will be able to build on the work already started by the HFA. In particular they will need to utilise the information on needs analysis and service provision collected by the Ministry of Health.

Strategy 3: Develop specialist palliative care services

This strategy is a medium-term priority in line with the New Zealand Health Strategy, and will be implemented after Strategies 1 and 2.

Each DHB should have access to a specialist palliative care service. It is recommended that there be at least one specialist palliative care service in Auckland, Waikato, Palmerston North, Wellington, Christchurch and Dunedin to ensure appropriate geographical access for communities.

Specialist palliative care services will provide local services for their community, but will also have additional responsibilities for providing evidenced-based specialist advice, facilitating quality improvement among local palliative care providers, and providing specialist education and training for medical and nursing staff. They also have responsibility for working with specialist palliative care services nationally on quality improvement activities.

Specialist palliative care services can be provided by a hospice or hospital, or a joint-arrangement between these organisations. The development of these services can be achieved through:

- the development of purchase units and service specifications for additional services offered by providers of specialist palliative care services. (The price and cost of services will need to be determined. This work will be done by the Ministry of Health in conjunction with DHBs and palliative care providers)
- DHBs working together to identify likely providers for the specialist palliative care service in the region in conjunction with palliative care providers
- the establishment of a timeframe and plan by DHBs for implementing the specialist palliative care service
- DHBs working with providers in the region to establish the specialist palliative care service and network.

Strategy 4: Implement hospital palliative care teams

This strategy should be developed alongside Strategy 3.

Hospital palliative care teams have a particularly important role in ensuring that the palliative care option is available for dying people, as well as in providing advice and assistance to staff in hospitals on the care of dying people. They also have an important role in co-ordinating services for the dying person and their family/whānau to ensure they receive services when they are discharged from hospital.

Hospital palliative care teams will have formal links with the specialist and local palliative care services but are likely to be employed by the hospital.

Currently there are four existing hospital palliative care teams based in Auckland, Waikato, Christchurch and Wellington. The implementation of hospital palliative care teams across the country can be achieved through the development of purchase units and service specifications for hospital palliative care teams, and calculation of the price and cost of the service. This work will be done by the Ministry of Health in conjunction with DHBs and will include:

- the identification of hospital services that currently utilise or will utilise hospital palliative care teams
- the identification of existing sources of hospital funding for hospital palliative care teams based on current contract lines and the calculation of any additional funding that may be necessary
- the implementation of hospital palliative care teams in those tertiary hospitals that do not currently have hospital palliative care teams.

Strategy 5: Develop quality requirements for palliative care services

This strategy will be implemented alongside Strategies 1 to 4.

In order to assure the quality of palliative care services, the following need to occur.

- DHBs will have to monitor palliative care providers to ensure that they meet the quality requirements as detailed in contracts.
- DHBs will have to ensure that palliative care providers are working towards meeting the Health and Disability Sector Standards. Once the legislation is in place, palliative care providers will be audited (by the appropriate service) to ensure that they meet the standards and legislative requirements.
- Specialist palliative care services (once fully implemented) will take responsibility for:
 - promoting an evidence-based approach to the provision of palliative care across all palliative care services in the region
 - developing referral and best-practice guidelines
 - developing outcome measures/performance indicators for palliative care services
 - undertaking national benchmarking activities across palliative care services, including audit.

The above activities will occur in conjunction with the professional colleges and national organisations, particularly Hospice New Zealand.

Strategy 6: Inform the public about palliative care services

This strategy will be implemented following Strategies 1 to 4 in consultation with relevant national organisations, including Hospice New Zealand and the Australia and New Zealand Society for Palliative Medicine (ANZSPM).

Public information specific to each DHB area is necessary to:

- outline the public's rights/entitlement to palliative care services
- describe the services offered by palliative care providers
- provide information on what the public should expect from a palliative care service.

Strategy 7: Develop the palliative care workforce and training

In order to develop the palliative care workforce and training requirements the following need to occur.

- Workforce and education requirements for specialist and local palliative care services need to be determined. This should include work to determine the numbers of Māori care co-ordinators and Māori palliative care health professionals that are required.
- The Medical and Nursing Council should be asked to:
 - provide guidelines to medical and nursing schools on the minimum content of palliative care training at the undergraduate level
 - take account of future nurse prescribing in postgraduate palliative care courses.
- Schools of Medicine should be requested to implement the Australasian medical undergraduate palliative care curriculum.
- The Clinical Training Agency should be requested to work in conjunction with educational bodies and professional organisations (for example, Hospice New Zealand) to determine the gaps in postgraduate palliative care training and identify what the clinical training needs are for palliative care and what can be provided through the Clinical Training Agency.
- Palliative care services should be asked to provide induction and ongoing training for volunteers. A national course has been developed by Hospice New Zealand.

Strategy 8: Ensure that recommendations from the Paediatric Review are implemented

This strategy supports the implementation of the *Paediatric Review* recommendations.

It is recommended that the Ministry of Health in conjunction with DHBs work with hospitals to:

- identify and implement the national children's palliative care team
- develop and implement the local paediatric palliative care co-ordination service.

DHBs will need to review existing hospital funding sources and implement the children's palliative care service in line with the available budget.

Strategy 9: Address issues of income support

A significant financial burden can be placed on people who are dying and on their families. It is important that criteria for accessing income support can take into consideration individual circumstances. In resolving issues relating to accessing income support it is recommended that a working party comprising the Ministry of Health, the Department of Work and Income and relevant providers be established.

To avoid duplication of work this working party should also address other income support issues that have arisen through other strategy work; for example, the national transport and accommodation policy and the Health of Older People Strategy.

Appendix 1:

New Zealand Work on Palliative Care

In recognition that limited central planning of palliative care services had been undertaken by the Government, the Core Health and Disability Support Services Committee undertook work in 1992 on palliative care service provision. The report recommended that hospice services be given priority by regional health authorities over the following two years.

As a result, a number of agencies in New Zealand undertook work in palliative care. This work focused on identifying the issues and problems in palliative care provision (Barnett and Smith 1992; Ministry of Health 1993, 1998; Robertshaw 1994; Penny 1997).

More recently, the National Health Committee and the HFA have undertaken significant work in the palliative care area.

The National Health Committee project: 'Care of the Dying'

This work was conducted over a two-year period beginning in January 1997. The aim was to 'provide clear specifications of services that should be available to people who are dying, settings in which it would be most appropriate for these to be provided and the service providers who would be available to provide them'.

The Committee was also charged with reviewing primary and secondary care involvement, workforce development needs, the impact of changing demographics, conditions appropriate for palliative care and changing expectations of access to services.

The project was overseen by an advisory group, and areas of particular interest were addressed by five working parties. These covered:

- service specifications
- best practice
- ethical/legal issues
- decision-making
- Māori issues.

The following recommendations were agreed as part of this work.

Recommendation 1

All people should have access to core health and support services appropriate to their needs.

Recommendation 2

Services for the care of people who are dying should be fully integrated into and recognised as an essential part of the wider sector of publicly funded health and disability services.

- The contribution of volunteers should be recognised and the cost of volunteer deployment included in funding provision.
- Pilots should be established to assess the effectiveness and practicability of integrated palliative care services.

Recommendation 3

Medical and other health professionals should inform patients and their family/whānau about palliative care and continuing support as an option for clinical management at the end of life.

- Health professionals, especially doctors and nurses, should be adequately trained in communicating with patients and their family about the goals of care. They should be able to offer advanced care planning, including palliative care, as an option to active treatment.
- Health professionals should be trained at an undergraduate level in the basic principles of palliative care and be able to make timely and appropriate referrals to palliative care services when this is clinically indicated and in line with patients' preferences.
- Clinical pathways and clinical guidelines on the management of specific conditions should include guidance on when treatment might be considered futile, and the palliative care option should be discussed with patients.
- Guidance should be available to clinicians dealing with cases in which rationing decisions result in the palliative care option being pursued.
- The professional colleges should encourage postgraduate training for doctors and nurses in managing patients at the end of life and counselling patients about the goals of treatment, the relative risks, benefits, etc.
- Health professionals should encourage patients to anticipate their health care needs and express their preferences for a time at some future date when they may no longer be mentally competent to do so.
- Treatment should reflect a shared understanding among health professionals of patient preferences for the goals of care.
- Acute palliative care intervention, consultation and referral for ongoing management should be available in all secondary care facilities.
- Enhanced communication between health professionals and their patients/families is preferable to increased use of advanced directives.

Recommendation 4

Education of health professionals and volunteers should promote attitudes and behaviours that respond to the needs of people who are dying and their family/whānau.

- The ANZSPM undergraduate medical palliative care curriculum should be adopted by the medical schools in New Zealand, and palliative care should be approached in a systematic way throughout the undergraduate years.
- Specialist palliative care providers should be actively involved in the planning and implementation of appropriate continuing medical education.
- Schools of nursing should access palliative care resources to facilitate student preparation for care of the dying.
- Funding should be available for postgraduate palliative care nursing education and continuation of the delivery of the Hospice New Zealand modules.
- The role of the volunteer should be recognised, with volunteer education included in service provision funding.
- The HFA/Ministry of Health should purchase a health promotion strategy, including information for people facing a life-threatening illness, health care providers, churches, marae and other voluntary helping agencies, and a media strategy aimed at increasing public awareness and understanding of issues related to palliative care.

Recommendation 5

Services need to address the specific needs of Māori.

Recommendation 6

Patients who are dying should receive adequate pain control. The law should be amended to enable people to appoint others to make a greater range of decisions on their behalf if they become incapable of making them for themselves.

Relevant work undertaken by the HFA

In 1998 the HFA, in conjunction with Hospice New Zealand, initiated the development of a national purchasing strategy for palliative care. This was halted in March 1999 to enable the HFA to undertake interim work that addressed the particular funding difficulties of some hospices.

This interim work produced information that was then provided to the HFA's localities for funding consideration in the 1999/2000 year. In many cases adjustments were made to the funding levels of hospices as an interim measure while the national work was being completed. The strategy was then resumed in conjunction with the Ministry of Health.

Appendix 2: Advisory Group Members and Terms of Reference

Terms of reference

1. Provide expert advice on the current provision of palliative care to the Ministry of Health, National Health Committee and HFA project team. This may include but is not limited to advice related to:
 - how the current provision of palliative care can be improved
 - improving integration of palliative care services
 - improving boundaries of palliative care services
 - removal of gaps in the provision of palliative care and improving access to palliative care services
 - improving quality/monitoring of palliative care services
 - workforce issues associated with palliative care
 - improving equity of funding of palliative care.
2. Review documents/information during the development of the national palliative care strategy and purchasing project.
3. Provide expert advice to the project team on strategy options for the provision and funding of palliative care in New Zealand prior to consultation.
4. Provide expert advice to the project team on the results of consultation on the national strategy and purchasing options for palliative care in New Zealand.

Membership of the Advisory Group

Dr Rod MacLeod	Director of Palliative Care, Mary Potter Hospice
Ms Jan Nichols	Manager, St Josephs Hospice
Ms Robin Stead	Manager, Health Waikato
Ms Janice Wenn	Manager, Whaiora Whanui, Masterton
Dr Mark Jeffery	Oncologist with Canterbury Health
Ms Maggie Barry	Consumer representative; former Chair of the National Health Committee palliative care project
Dr Brian King	GP, Wellington City, with an interest in AIDS/HIV; member of AMTAC; formerly at Mary Potter Hospice
Mr Mervyn Monk	President of Hospice New Zealand; Manager Arohanui Hospice

Appendix 3:

People/Organisations Who Made Submissions or Attended Public Meetings on the Discussion Document

This list includes those members of the reference group who made submissions.

Names of submitters

John Gibson, Executive Officer, Age Concern Wellington (Inc), Wellington
Beverley Revel, Manager, Hospice HomeCare, Henderson, Auckland
Suzanne Brocx, Hospice Co-ordinator/Nurse, Hospice Bay of Islands, Kerikeri
Kerrin Arcus, Wellington
Eastern Bays Hospice, Glendowie, Auckland
Peter Buckland, Chief Executive, North Shore Hospice Trust, Takapuna, Auckland
Elaine Chisnall, CPG Manager, Oncology and Haematology, Healthcare Otago, Dunedin
Kathryn Campbell, Palmerston North
John Carter, Clinical Leader, Wellington Cancer Centre, Capital Coast Health, Wellington
Rachel Brydon, Co-ordinator, Far North Palliative and Cancer Care, Kaitaita
Suzanne Russell, Hospice Manager, Southland Hospice, Invercargill
Fuafiva Fa'alau, Pacific Research Centre, Department of Māori and Pacific Health, School of Medicine, Auckland
Dr Blair McLaren, Physician/Oncologist and, Drs F Beswick and A Robert (Pain Clinic Specialists), and S Williams (Social Worker), Timaru Hospital, Timaru
Robin Williams, Manager, and Deborah Hughes, District Nurse, Community Health Services, Coast Health Care, Greymouth
Elizabeth Cochrane, c/- Amberley Medical Centre, Amberley, North Canterbury
D Crampton, Christchurch
Jane Hautain, Hospice Trust Board Member, Whakatane
Hazel Hill, Manager, Community Hospice Service, Whakatane
Elaine Dow, South Auckland Hospice, PO Box 560, Manuwera, Auckland
Joan Carter, Vauxhill, Dunedin
Mrs Pip Egerton, Paroa, Greymouth
Esme MacDonald, Community Team Leader; Jan McLean, Nursing Team Leader; Dr Garry Nixon, Medical Team Leader; Central Otago Health Services, Clyde, Central Otago
Kate McKenzie, Senior Social Worker, Palmerston North Hospital, Palmerston North
Jane Patterson, Manager Policy and Support, New Zealand Medical Association, Wellington
David Ryan, Chief Executive Officer, Otago Community Hospice, Dunedin
Pauline Thwaites, Dunedin
Leslie McCulloch, Associate Director of Nursing, Capital Coast Health Limited, Wellington
Ruth Vincent, National Information Manager; Linda Gray, Field Officer; Taranaki MS Society, Wellington
Patricia Watt, 'Bee Block', Dargaville

Dr Robert Cook, Dargaville Medical Centre, Dargaville
Debra Sedgwick, Health Services Manager, Wairarapa Health, Masterton
Annie Stroh, Client Service Manager, Quality Health New Zealand, Wellington
Yvonne Boyes, Oncology Resource, District Nurse, Whakatane Hospital, Whakatanae
Patrick F Fahy, Chief Executive, New Zealand Charter of Health Practitioners Inc, Northcote, Auckland
Mary Mathews, Wellington
Jim Thomson, Chief Executive and Registrar, Pharmaceutical Society of New Zealand, Wellington
Bridget O'Brien, c/- Home Health Care, Middlemore Hospital, Auckland
Colleen Ranford, Auckland
Eileen McKinlay, Wellington
Thames Community Cancer Support Group, Thames
Cathy Cooney, Service Director, Clinical Support, Lakeland Health, Rotorua
Associate Professor Margaret Horsburgh, Division of Nursing, Faculty of Medical and Health Sciences, University of Auckland, Auckland
TA Joll, Chief Executive Officer, Hospice Wanganui, Wanganui
Dr Tim Carey-Smith, for South Link Health Inc, Dunedin
Dr Kate Baddock, Warkworth Health and Medical Centre, Warkworth
Imelda King, c/- Age Concern North Shore, Takapuna, Auckland
Lynda Smith, Auckland Division, Cancer Society of New Zealand, Auckland
Margaret W Guthrie, Wellington
Cassandra Sternoway, Oncology/Haematology Social Worker, Dunedin Public Hospital, Healthcare Otago, Dunedin
RL Logan, Medical Director, Hutt Valley Health Limited, Lower Hutt
Anne MacLennan, Wellington
Kaipara Palliative Care, c/- Josie Scott, Dargaville Hospital, Dargaville
David Ryan, Chief Executive Officer, Otago Community Hospice, Dunedin
Karen Foster, Clinical Leader; Desma Dawber, Palliative Care District Nurse; District Nursing Services, Timaru Hospital, Timaru
Mary Schumacher, Chief Executive Officer, Mary Potter Hospice, Wellington South
John Doggett, Executive Officer, South Canterbury Hospice Inc, Timaru
Judy Macready, Contract Professional Hospice/Palliative, Care and Health Management, Algies Bay, Warkworth
Dr Bruce Foggo, Senior Medical Officer, St Joseph's Mercy Hospice, Newmarket, Auckland
Ann Moore, Cromwell
The Trustees and Staff, Te Omanga Hospice, Lower Hutt
Dr CJ Diggle, Royal New Zealand College of General Practitioners, Devonport, North Shore
Jane Eyres, Chairperson, Nurses for Children and Young People of Aotearoa, NZNO, Wellington
Dr Anne O'Callaghan, Palliative Care Team, Auckland
Ann Martin, Chief Executive Officer, Hospice New Zealand, Wellington
Sue Morris, Wairau Hospital, Nelson Marlborough Health Services, Blenheim
Allan Farnell, Medical Director, St Joseph's Mercy Hospice, Newmarket, Auckland
Stephanie Waterfield, Chief Executive Officer, Nurse Maude Association, Christchurch
Margaret Blake, General Manager, Waipuna Hospice, Tauranga
Bice Awan, Chief Executive, Skylight Trust, Wellington
Dr David Hamilton, Consultant Oncologist, Wellington Cancer Centre, Wellington Hospital, Wellington
Gaylene Kolodzinski, Palliative Care Nurse Specialist, Waitemata Health, Takapuna, Auckland
Dennis Paget, Wellington
Health Spokesperson, Grey Power Federation of New Zealand, Blenheim

Elaine McFelin, Trust Chairperson, The Care Central Trust, Dunedin

Dr Anna Holmes, Milton UFS Health Centre, Milton, Otago

Ron McInnes, Manager, Hibiscus Coast Hospice, Whangaparoa 1463

Te Omanga House, Masterton

Dr Simon Allen, Chairperson, New Zealand Branch of the Australia and New Zealand Society for Palliative Medicine, Palmerston North

Nelson Region Hospice Trust, Manuka Street, Nelson

Mervyn G Monk, Executive Director, Arohanui Hospice Service Trust, Palmerston North

Esther Sweet, c/- Te Omanga Hospice, Lower Hutt

Helen Sullivan, Co-ordinator for Support and Volunteer Services, Cancer Society of New Zealand, Wellington

Sue Marlow, Lower Hutt

Teresa Riordan, Auckland

Te Waka Hauora, Health Waikato Limited, Hamilton

Reverend Theo Carpenter, Health Committee, Kapiti Coast Grey Power Association Inc, Paraparaumu

Dr K Lum, Medical Director, and Mrs A Robinson, Principal Nurse, Cranford Hospice, Hastings

Elizabeth Kelly, Invercargill

Dr Tim Carey-Smith, for Otago Community Hospice, Dunedin

Mrs Colleen Moore, Vice-Chair North Otago Hospice Group, Oamaru Hospital, Oamaru

Louise Forsyth, Nurse Manager, Taranaki Hospice Foundation Inc, Westtown, New Plymouth

Mark Jeffrey, Oncologist, Canterbury Healthcare Ltd, Christchurch

Elizabeth Maria Hancy, Bay of Islands

Adrian Trenholme, Paediatrician, Middlemore Hospital, Auckland

Paula Shepherd, Ministry of Youth Affairs, PO Box 10 300, Wellington

Dr Lorraine Scragg, Total Health Whakatane, Whakatane 3080

Merrin Watts, Staff Nurse, Ward 25, Health Waikato Ltd, Hamilton

Harata Heni Baucke, President, Aotearoa New Zealand Association of Social Workers, Dinsdale, Hamilton

Jan Mackay, Policy Analyst, Age Concern New Zealand Inc, Wellington

R Thomas, Social Worker, Christchurch Hospital, Christchurch

Trish Clark, Rosalie Maaka, Dr Kate Bayslon, Oncology Unit, Southland Hospital, Invercargill

Jane Wilson, Service Leader Child Health, Child Health Service, Healthcare Otago, Dunedin

The New Zealand Home Health Association, Wellington

Richard Hursthouse, Clinical Advisor, Comprehensive Health, Primary Care Organisation, Auckland

Capital Coast Health Ltd, Wellington

Barbara Glenie, National President; Beryl Anderson, National Secretary; National Council of Women of New Zealand, Wellington

Felicity Sidford, Integration Co-ordinator, Pegasus Medical Group, Christchurch

Ann Crawford, Social Work Department, Christchurch Hospital, Canterbury Health, Christchurch

Lorraine Sutherland, Senior Social Work Practitioner, Oncology, Social Work Service, Christchurch Hospital, Christchurch

Megan Smith, Social Worker, Social Work Services, Christchurch Hospital, Christchurch

Kathy Lynch and Debbie Wise, St Joseph's Mercy Hospice, Newmarket, Auckland

Ann Morgan and Dr Kate Grundy, Christchurch Palliative Care Team, Christchurch Hospital, Christchurch

Janice Donaldson, Manager, Ngai Tahu Development Corp, Christchurch

Shona Lawson, Women's Health Action, Newmarket, Auckland

Age Concern, Wellington

Peter Woolford, General Practitioner, New Lynn Medical Centre, New Lynn, Auckland

Ministerial Advisory Council for Senior Citizens, Wellington.

Names of attendees at meetings

Northland

Heather Michaels (Careplus), Cindy Haika (Careplus), Leanne McLiver (Home Support), Tina Darkins (Northaven Hospice), Murray Lints, Jo Loney (Nurse), John Bonetti (Northaven Hospice), Gay Bonetti (RD5 Whareora), Margaret Curry (Cancer Society), Naias Nasaverr (Northaven Hospice), Susanne Brocx (Hospice Bay of Islands), Helen Brown (Home Health/District Nursing), Jill Henderson (Home Health Care), Josie Scott (Kaipara Palliative Care / Dargaville Hospital), Dave Bowden, Laura Lambie and Louisa Ryan (HFA).

Auckland

Dr A O'Callaghan (Auckland Healthcare), Sharon Knowles (Auckland Healthcare), Lorraine Goodlass (Auckland Healthcare), Jackie Robinson (Auckland Healthcare), Jill Rodgers (Hibiscus Coast Hospice), Ron McInnes (Hibiscus Coast Hospice), Graeme Smith (Nelson Region Hospice), Yvonne Bray (University of Auckland), Noelene Harris (Palliative Care Partnership), Joan Monkton (Eastern Bays Hospice), Mr Alan Earnell (St Joseph's Mercy Hospice), Elaine Dow (South Auckland Hospice), Peter Buckland (NorthShore Hospice), Mr K McIver (NZ Charter Health Inc), Jan Nichols, Laura Lambie (HFA), Wendy Cook (HFA), Tearoha Rahui (HFA).

Hamilton

Trish McHugh (Lakeland Health), Doreen O'Conner (District Nurse), Jan White (District Nurse), Steve Smith (Health Waikato), Ian Millward (Waikato Hospice), Graham Callis (Waikato Hospice), Allison Rowe (Waikato Hospice), Jane Hanson, Chris Page (Trevelyn Resthome), Valda Mehrtens (Trevelyn Resthome), Robyn Segedin (One Health Waikato), Des Swanelvelder (Health Waikato), Lyn Little (Health Waikato), Margaret Stevenson (Health Waikato), Ann Inglis (Te Aroha Community Hospital), Merrin Watts (Health Waikato), Dot Davies (Health Waikato), Judy Tunnicliffe (District Nurse), Julie Eiles (Community Liaison), Moira Grennell (Waikato Hospital), Rangi Komene (Health Waikato), Harata Baucke (Health Waikato), Julie Biengen (Health Waikato), Glennis Retemeyer (Raukawa Development Trust), Laura Lambie and Elizabeth Bang (HFA).

Wellington

Mary Schumacher (Mary Potter Hospice), Ann Martin (Hospice New Zealand), Mervyn Monk (Hospice New Zealand), Rayden Day (Cranford Hospice), Chris Murphy (Mary Potter Hospice), Rod McLeod (Mary Potter Hospice), Belinda Hodge (Mary Potter Hospice), Mary Bingham (Domiciliary Nurse), Jean Parr (Te Omanga Hospice), Beverley Chapel (Advisory Council for Senior Citizens), Biddy Harford (Te Omanga Hospice), Alan Brown (Te Omanga Hospice), Jean Parr (Te Omanga Hospice), Suzanne Hammond (Te Omanga Hospice), Kate Gellatly (Mary Potter Hospice), Pam Diamond (Mary Potter

Hospice), Daphne Geisler (Mary Potter Hospice), Kathryn Campbell, Thomas Morgan (Ancillary Service Provider), Deborah Woodley (Ministry of Health), Laura Lambie (Health Funding Authority), Sarah Zino (HFA), Sue McTavish (HFA).

Christchurch

Felicity Sidford (Pegasus Health), Jan Whyte (Pegasus Health), Ann Crawford (Christchurch Hospital), Kate Grundy (Christchurch Hospital), Anne Morgan (Christchurch Hospital), Margaret Hakey (Nurse Maude Association), Shona Lawson (Nurse Maude Association), Vicki Telford (Fairhaven Palliative Care Unit), Fran Pucilauslu (Wesley Care), Liz Cochrane (Amberley Medical Centre), Diana Gunn (Nurse Maude Hospice), Mardine Iggo (Nurse Maude Association), Julia Holyoake (Nurse Maude Association), Marie Glenys (Nurse Maude Association), Anna Hutt (Christchurch Hospital), Catherine Hughes (University of Canterbury), Kate Grundy (Christchurch Hospital), Colleen Walker (SC Hospice), John Doggett (SC Hospice), Liz Horn (Cancer Society), Neroli Iles (Nurse Maude Association), Caroline Gartwright (NZ Nurses Organisation) Susanne Trim, Kate Reid (Hospice Education Trust), Daphne Crampton, A Macleod (Nurse Maude Association) Deborah Woodley (Ministry of Health) Sarah Zino and Jill Nuthall (HFA).

Central Otago

Joanne Tuare (Central Otago Health Services), Ann Ibbotsen (Council of Social Services), Dian Craig (Otago Daily Times), Laura Lambie and Paul Martin (HFA).

Otago

Dave Ryan (Otago Community Hospice), Tim Carey-Smith (Otago Community Hospice), Elaine Chisnall (Health Care Otago), Elaine McFelin (Central Trust), Sharon Shaw (Cancer Society), Sue Johnston (Otago Community Hospice), Joan Carter (Health Care Otago), Sharon Dickel (Otago Hospital), Brenden Ray (Health Care Otago), Charlotte Paul (consumer), Mark Hettan (Otago Hospital), David Holdaway (Oamaru Rural Trust), Suzanne Russel (Southland Hospice) Merren McKay (Southland Hospice) Laura Lambie, Paul Martin and Elizabeth Beresford (HFA).

Māori Focus Group, Kerikeri

Margaret Hati, Elizabeth Hancy, Astor Toia Parkinson, May Hati, Suzanne Broacx (Hospice Bay of Islands), Laura Lambie and Louisa Ryan (HFA).

Māori Focus Group, Porirua

Coleen Wineers (Capital Coast Health), Renei Hill (Capital Coast Health), Charlene Williams (Te Runanga o Toa Rangitira – Ora Toa Health Unit), Laura Lambie and Sue McTavish (HFA).

Pacific People’s Focus Group, Auckland

Susana Hukui (consumer), Denise Kivell (Kidz First Home Care), Fuafiva Faalae (Researcher Pacific Health Research Centre), Meia Schmid-Uili (Paediatrician), Graeme Kidd (South Auckland Hospice), Alec Ekeroma (Pacific Medical Association), Metua Faasisila (Starship Hospital), Ben Taufua (South Auckland Health), Niusulu Charlton (Auckland Hospital), Linola Kowamatangi (Auckland Hospice), Karenina Siao Simeo (Auckland Hospital).

Carer Focus Group, Dunedin

Marion Sinclair, Jack South, Jo Scott, Colleen Ischia, Margaret Pirrett, Tom Winter, Bev Abernethy, Graeme Dunn, Susan Joka, Sue Johnstone, Eri Bennett.

General Practitioner Focus Group

Tim Carey-Smith (South Link Health), Graeme Kidd (South Auckland Hospice), Willie Landman (South Auckland Hospice), Phil Jacobs (Pegasus, teleconference), Laura Lambie (HFA), Deborah Woodley (Ministry of Health).

Appendix 4:

Overview of Palliative Care Services

This appendix provides demographic information and identifies the need for palliative care, describes palliative care services provided from 1998–99, and describes the workforce currently caring for people who are dying.

Demographic trends: identifying the need for palliative care services

Causes of death

Table A1 shows the age-standardised death rates for selected causes of death in 1996. The leading causes of death in 1996 were cancer and ischaemic heart disease. Cancer has been the leading cause of death since 1993, accounting for around 26 percent of all deaths per year.

Table A1: Causes of death, 1996

Cause of death	Rates per 100,000 population ¹
All causes of death	493.3
Total cancer	140.0
Ischaemic heart disease	106.1
Cerebrovascular disease	38.1
Hypertensive disease	4.4
Other forms of heart disease ²	19.5
CORD ³	19.5
Pneumonia and influenza	15.8
Diabetes mellitus	10.5
HIV	0.9

¹ Age-standardised to Segi's world population.

² Includes heart failure, cardiomyopathy, pericardial and endocardial diseases.

³ Chronic obstructive respiratory disease.

Determining the need for palliative care

The need for palliative care services can be estimated from cancer statistics and statistics of end-stage non-malignant disease (Higginson 1996).

Cancer

People who are dying of cancer often have physical, psychological and spiritual needs appropriate to palliative care. The greatest need for palliative care will be from people with cancer aged 60 and over. In 1996 there were 7461 deaths from cancer and 78.8 percent (5879) of these deaths were people aged 60 and over. Māori cancer deaths accounted for 8.6 percent of cancer deaths.

Between the periods 1997 to 2001 and 2007 to 2011 we can expect the number of people dying from cancer to increase by approximately 24 percent (Cox 1995); this is probably due mainly to the aging population.

Utilising overseas research (Higginson 1996) it can be estimated that around 84 percent of people dying of cancer will experience pain that may need palliation. Using the 1996 mortality data, this would work out to be 6267 people.

Data collected from hospices in 1998/99 indicate hospice providers cared for 4886 people who were dying; approximately 90 percent of these people died from cancer. Using the above estimate of those requiring palliative care services, this would suggest that approximately 1800 people who are dying from cancer are either not receiving palliative care or are receiving palliative care by other providers. These are likely to be hospital providers (see Table A2).

Non-malignant diseases

Overseas experience indicates that there is an increasing need for palliative care services for those with non-malignant diagnoses (Kite et al 1999; Higginson 1998). Estimates of the number of cancer deaths range from 20 to 100 percent (Higginson 1996; APMGBI 2000). Those needing palliative care may have diseases such as ischaemic heart disease (the second highest cause of death), or disabling diseases such as motor neurone disease and multiple sclerosis, which often require palliative care in the terminal phase. Currently approximately 10 percent (489) of people with non-malignant disease access hospice services (HFA 1999).

Children

Although cancer is a leading cause of deaths in New Zealand adults, in 1996 it was responsible for only 40 (18.3 percent) of the 635 deaths in children aged 0–14. The majority of children's deaths (417) are in the first year of life and are mainly from respiratory infections, sudden infant death syndrome, congenital abnormalities and accidents. The remaining group (178) can have a wide range of diseases which are often rare, some of which can have a long terminal phase and require palliative care that is developmentally appropriate.

In considering children’s palliative care needs it is important to note that children who are dying are mainly cared for at home. Some dying children may require hospital paediatric care and less than 1 percent of children who are dying are cared for in a hospice (HFA 1999). Their palliative care needs differ from adults’ needs.

Place of death

Table A2 shows the place of death for New Zealanders (hospices are included in the private hospital statistics along with institutions such as rest homes). The table shows that overall a higher proportion of people with cancer and non-cancer diseases died in hospital than died at home. Fifty-three percent (340) of Māori people with cancer die at home; this is higher than the proportion of non-Māori people. Pacific peoples have almost as high a proportion of home deaths as Māori.

Overseas research supports the view that people prefer to die at home. Research by Higginson (1998) shows that 50–70 percent of people would prefer to have the choice of home care.

It is important in the planning of New Zealand palliative care services to ensure that sufficient palliative care services and community support are available if this is what people want.

Table A2: Place of death, by ethnicity, 1996

Place of death	Cancer deaths 1996 (%)			Non-cancer deaths 1996 (%)		
	Māori (n = 639)	Other (n = 6651)	Pacific peoples (n = 171)	Māori (n = 1991)	Other (n = 18,362)	Pacific peoples (n = 565)
Public hospital	35.5	39.0	42.1	39.2	41.3	45.7
Private residence	53.2	30.8	41.5	41.0	23.8	38.6
Private hospital or other institution	8.5	29.4	16.4	5.6	29.4	7.9
Psychiatric hospital	0.0	0.1	0.0	0.1	0.3	0.0
Other	2.8	0.6	0.0	14.3	5.2	7.8
Total	100	100	100	100	100	100

Service provision

This section provides information on palliative care service provision from 1998 to 1999. Dying people can receive services from a wide range of providers, including hospices, hospitals, community health services, GPs, rest homes, private hospitals, home support agencies, individual carer support providers and volunteers, but access is dependent on the availability of services.

Hospices

Geographical distribution of hospices in New Zealand

Hospices are distributed across the North Island and down the East Coast of the South Island. There are no hospices on the West Coast of the South Island, nor in particular areas such as the East Coast of the North Island, Wairau and Queenstown. The services provided by hospices vary across the country: five are voluntary-based services and employ no clinical staff. Voluntary hospices are situated in Kaipara,² Auckland, Tokoroa, Taupo and Oamaru. Where there are no hospices, hospitals and/or primary care providers provide care for dying people. Clearly, not all New Zealanders have access to the 37 hospice palliative care services currently available.

Service provision in hospices

In 1998/99 hospices cared for 4886 people, 80 percent of whom were 60 years and over (HFA 1999). Hospices are mainly free-standing units that provide dedicated palliative care to dying people in line with the World Health Organization philosophy of palliative care (WHO 1990). Care is mainly delivered to people in their home.

Hospices may provide inpatient care, domiciliary (medical and nursing) care, day care, respite care and bereavement and counselling (Table A3). No hospice provides the full range of services (HFA 1999). Over half provide inpatient care, which is generally required for short admissions for symptom control and respite care, although some may use rest homes for respite care. Only a third of hospices provide night carer relief for patients,³ while a large proportion provide bereavement counselling.

² Kaipara now employs a full-time palliative care nurse co-ordinator.

³ The Cancer Society can provide night carer relief in certain areas but only for cancer patients. The provision of night carer relief is dependent upon each particular division.

Table A3: Hospice services in New Zealand, 1998–99

Type of service	Number of hospices providing this service	Percentage of hospices providing this service
Inpatient care	19	59
Night carer relief	11	34
Medical advisory service	15	47
Nursing advisory service	21	66
Domiciliary palliative care nursing	19	59
Bereavement counselling	27	84
Spiritual care	18	56
Social work service	9	28
Day-care programme	22	69

Note: n = 32.

Hospitals

Service provision in Hospital and Health Services (HHSs)

Hospital services are particularly important where there are no hospice services, such as on the West Coast and in Central Otago. Each hospital has a number of facilities that provide services in outlying areas; for example, community and sub-acute hospitals.

Hospitals mainly provide services to dying people as a component of other services (for example, acute care or general care). This is generally not tailored for dying people. Inpatient care is mainly provided through general medical/surgical, oncology and older people wards. Community nursing care is provided through district nursing services. Allied health professionals provide some other services, such as social work services.

Information gained from HHSs is summarised in Table A4 and indicates that:

- the bulk of hospital service delivery for people who are dying is by district nurses through community health services
- dedicated beds for dying patients are provided in only 27 percent of hospitals – availability of other beds is dependent on demand for beds in any particular hospital
- there are hospital palliative care teams in four hospitals – Auckland Hospital, Waikato Hospital, Wellington Hospital and Christchurch Hospital
- in addition to the three hospitals above, Starship Hospital provides a children’s palliative care service.

Table A4: Percentage of Hospital and Health Services and hospices providing palliative care type services as reported by providers, 1998–99

Type of service	Number HHSs providing this service	Percentage of HHSs providing this service
Inpatient care	6	27
Night carer relief	7	32
Specialist palliative care hospital teams	3	14
District nursing	20	91
Bereavement counselling	12	55
Spiritual care	18	82
Social work service	21	95
Day care programme	0	0

Note: n = 22.

Availability of beds in hospices and hospitals

Table A5 shows that the majority of dedicated palliative care beds (85 percent) are provided by hospices. The total availability of beds in each locality has been calculated to provide an indication of where dedicated beds for dying patients are lacking. The table shows that beds in each locality range between 0.64 per 100,000 (Waikato) and 7.73 per 100,000 in Wellington. Britain has an average of 5.1 palliative care beds per 100,000 (Eve et al 1997). If Britain is used as a comparison, Auckland, Waikato, Bay of Plenty and Nelson/Marlborough would appear under-resourced in terms of dedicated beds, although there may be (less appropriate) access to acute beds in general medical/surgical and oncology wards, or in assessment, treatment and rehabilitation units. In some areas (for example, Waikato where there are a low number of beds) hospices may use rest home beds for people who are dying.

Table A5: Palliative care beds, by type, locality and location, 1998–99

Locality	Dedicated beds in an acute hospital	Hospice beds	Total beds for region	Beds/100,000 populationin
Northland	1	5	6	4.38
Auckland	4	36 ¹	40	3.70
Waikato	2		2	0.64
Bay of Plenty	2		2	0.77
Taranaki		6 ²	6	5.62
Tarawhiti/Hawke's Bay	2	8 ³	10	5.28
Wanganui/Manawatu		13	13	5.96
Wellington		32	32	7.73
Nelson/Marlborough		0 ⁴	0	0.0
Canterbury/West Coast	5	16	21	4.21
Otago/Southland		14	14	4.93
Total	16	130	146	4.03

- 1 Excludes 3 rest home beds subcontracted to a rest home by West Auckland Hospice, but includes 6 beds at the Auckland City Mission that are for HIV/AIDS patients.
- 2 Six beds are sub-contracted to Taranaki Hospice by Taranaki Healthcare Ltd.
- 3 Including 2 beds at the Rollinson Unit (Napier Hospital).
- 4 During the data collection, Nelson hospice was a community-based service with no beds. It now has 4 beds, which gives Nelson/Marlborough 3.34 beds/100,000.

Primary care service provision

GPs and primary health care nurses generally provide care for dying people in the surgery or through home visits, in addition to care provided by a hospice or hospital if geographically accessible. GPs may also be employed by hospices to provide medical care.

While varying in scope between individual practitioners, primary care provision has an important role in ensuring continuity of care for dying people and in facilitating relevant access to hospital and hospice services.

Carer support and residential care

People who are dying and their families may access disability support service (DSS) managed carer services, provided either at home or in a provider setting, usually for 28 days. The person can choose

to use their carer support allocation for night carer relief. The criteria and methods for access to carer support vary between regions.

Dying people who cannot access community support or who require longer-term inpatient care than that provided by hospitals or hospices sometimes access residential care through DSS, most often through services for older people. Access to this service is also variable across the country. All people accessing DSS-funded residential care and who meet the Ministry definition of disability must go through a needs assessment/service co-ordination process (NASC). Outside of the DSS process dying people can either:

- access residential care via a NASC agency without going through a formal needs assessment process; or
- access care by referral from a hospital department or a GP.

Some people will already be in a residential setting and either develop a terminal illness or have their illness become terminal (for example, those who develop cancer or end-stage motor neurone disease). These people are likely to stay in the residential setting and will need to access palliative care services.

The quality of residential palliative care is dependent on staffing levels, numbers of registered personnel and the amount of palliative care experience within the institution. Some hospices have formal links with certain rest homes and provide education on palliative care.

Voluntary services

There are a number of voluntary organisations that provide care to dying people, such as the Cancer Society, which offers counselling, and some support services for people with cancer. In some areas in New Zealand they also fund night carer relief services. However, volunteers working for hospices, form the largest group of voluntary support. Table A6 shows that in 1998/99 volunteers gave 322,672 hours.

Palliative care service provision for children

Much work in identifying palliative care services available for children has already been completed by the *Paediatric Review* (Ministry of Health 1998). The review identified that palliative care services for children are delivered mainly by oncology units, local specialist child health teams and primary care providers in conjunction with DSS, voluntary agencies and other groups, including paediatric specialists.

In response to the review, a children's palliative care team has been introduced into Starship Hospital. The team has been active for over a year and includes a full-time palliative care nurse specialist, two part-time social workers and a child psychotherapist. It provides a regional service in the Auckland area and advice on palliative care nationally.

Funding of services

Hospices

Funding for hospices varies between regions. For example, hospices in the central region have in the past been funded on a per patient basis while hospices in the southern region were mainly funded on numbers of bed days. At the time of this research, hospices were partially funded by the Government to approximately 50 percent of their operating costs. This percentage is increasing. The balance is raised through fundraising and voluntary donations.

Hospitals

All hospital services are funded by the Government to provide free care. The cost of domiciliary services is funded by the volumes of community district nurse visits. The funding of inpatient palliative care is not explicit and is generally funded by case weights (case mix) through a number of contract lines, including general medical/surgical, oncology and older people.

Primary care services

The funding for palliative primary care services is similar to that for other primary care services. Depending on whether people have a Community Services or High User Health Card they pay either a full or part charge for the service provided.

Carer support and residential care

Funding of carer support and residential care is mainly through DSS. People receiving carer support services are not income and asset tested.

If a person with an age-related disability requires aged-care residential services they may be income and asset tested by the Department of Work and Income, in which case they may be required to contribute towards the cost of their care. Anecdotal evidence suggests that some people receiving residential care to meet their palliative care need may also be undergoing income and asset testing as if they had an age-related disability. In other situations, people needing palliative care may be bypassing the income and asset testing process altogether, with either themselves or their family funding their residential care. In regions where there is funding available for palliative residential care, this service is usually fully funded (for example, Wellington) for those people who meet the criteria, and the income and asset testing regime does not apply.

Palliative care workforce and training

Workforce and training issues are an integral part of planning for palliative care services and ensuring that quality palliative care services are available. Table A6 provides a summary of the palliative care workforce.

Table A6: Summary of hospice and hospital workforce, 1998–99 (FTE)

Workforce	Hospice	Hospital
Palliative care specialists	8.9	3.2
Other medical doctors	15.5 Mainly provided by GPs	Provided by oncologists, physicians, geriatricians
Hospital palliative care nurses*	–	5
Palliative care nurses	116.2	Provided by district nurses. Approximately 50 percent of district nursing services have one or more district nurses with palliative care training.
Registered and enrolled nurses	106.1	
Counsellors	14.1	As part of generalist services
Chaplains	3.8	As part of generalist services
Other allied health professionals**	9.4	As part of generalist services
Volunteers	322,672 hours	

Source of data: HFA 1999

*Acting in a nurse consultant role.

** Includes social workers (2.5 FTE), pharmacists (1.4 FTE), physiotherapists (1.1 FTE) and occupational therapists (4.4 FTE).

The key findings from the workforce data are as follows.

- 8.9 FTE palliative care medicine specialists were employed by hospices during 1998–99.⁴ A number of these specialists worked part-time and were situated in Auckland, Waikato, Taranaki, Wanganui/Manawatu, Wellington, Christchurch and Otago. The largest number were employed in Wellington (3.3 FTE). Where there is no palliative care medicine specialist available, a GP or other doctor (for example, an anaesthetist) provided medical care.
- 3.2 FTE palliative medicine specialists were employed in hospitals during 1998–99, yet approximately 40 percent of cancer and non-cancer deaths occur in hospital (see earlier). Inpatient medical care to dying patients in hospitals is mainly provided by oncologists, physicians and geriatricians.

⁴ Since this research approximately 12 additional doctors have completed the chapter of palliative care medicine (FACHPM). However, only a few of these doctors would currently be working in palliative care services. They are mainly working in general services.

- Just over half of the hospice nursing workforce have some training in palliative care. There is no clear definition of a specialist palliative care nurse. Few palliative care nurses have specialist qualifications beyond a graduate certificate level.
- Registered nurses in hospitals with palliative care training/experience are generally employed either in a hospital palliative care team or as a district nurse. Approximately half of the district nursing services had one or more district nurses who have completed some training in palliative care.
- Although allied health professionals are seen as part of the multidisciplinary team, there were very few working solely in palliative care. Few allied health professionals hold appropriate postgraduate palliative care qualifications.
- Volunteers make up a large part of the hospice workforce. Volunteers donated a total of 322,672 hours to the national hospice workforce during 1998–99: inpatient care 19 percent, administration 32 percent, community 12 percent, and fundraising 37 percent.

Training of the palliative care workforce

Both undergraduate and postgraduate education of the workforce is important in the provision of quality palliative care. Currently, undergraduate education provides only a limited amount of training in palliative care, and workforce data indicates there is a need for more at the postgraduate level.

Postgraduate courses available for health professionals who work in palliative care include:

- Royal College of Physicians' education for doctors becoming a palliative care medicine specialist
- Hospice New Zealand graduate certificate in palliative care for all health professionals
- some nursing master's programmes offer education in palliative care
- overseas programmes (for example, through Flinders University in Australia).

The Goodfellow Unit at Auckland University is currently proposing a six-month certificate and a one-year diploma in palliative care

Volunteers tend to undergo a variety of education programmes depending on the particular hospice. There is a need to determine the required level/standard training of health professionals and volunteers who are providing palliative care services in New Zealand. This would include determining the standards/training needs of Māori.

Future workforce and training requirements

It is difficult to estimate future workforce and training requirements in the context of an evolving palliative care service.

The Association for Palliative Medicine of Great Britain and Ireland has attempted to estimate the number of palliative care medicine specialists required for Britain. The methodology is based on numbers of cancer and non-cancer deaths, the proportion likely to use palliative care medicine

specialists, and numbers of new referrals seen by specialists. Using this methodology it can be estimated that 17.4 FTE palliative care medicine specialists would be required for the New Zealand setting – 8.5 FTE more than was available in 1998–99. With the chapter in palliative care medicine (FACHPM) available it is expected that by the year 2001 there will be approximately 25 doctors with qualifications in palliative care.

This information needs to be considered alongside other palliative care workforce needs, geographical factors and the future direction of palliative care services in New Zealand, while encompassing the changing workforce. When proposed legislation enables nurse prescribing for the child and family and older people, palliative care nurses will be offered an additional one-year training course (at master's level) in prescribing. The ability to prescribe to dying people would have implications for the future palliative care workforce and delivery of palliative care services, in rural areas for example.

Appendix 5:

Issues Relating to Palliative Care Services in New Zealand

A range of issues and areas of concern currently face palliative care service provision in New Zealand.⁵ These include:

1. a lack of a palliative care approach in some services
2. variable access to palliative care services
3. lack of integration and inflexibility of palliative care services
4. a lack of standard quality specifications or performance indicators/outcome measures
5. a lack of workforce planning for palliative care
6. variability in the funding of palliative care services.

Issue 1: Lack of a palliative care approach

Hospitals have a strong curative, intervention-focused culture, and with 39 percent of cancer deaths occurring in public hospitals it appears likely that the palliative approach may be lacking in the hospital environment. There also appears to be scanty provision of palliative care in institutional settings for the care of older people and those with degenerative conditions.

A recent 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. 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.

The National Health Committee noted that too frequently people continue to receive inappropriate levels of intervention when they would have been better served by a palliative approach. The normality of death as a process in life's cycle is in danger of becoming 'medicalised' (Smith 2000).

⁵ See also consultation analysis available on the Ministry of Health Web site.

Issue 2: Access to palliative care services

Service gaps and national variation in different aspects of care

A number of service gaps have been identified in New Zealand (HFA 1999). This is consistent with findings overseas (Doyle 1990; Hatcliffe and Smith 1997) and is to be expected given the recent ad hoc purchasing approaches and inconsistent development of palliative care services. Service gaps identified include the following.

Night carer relief

There is a lack of provision of appropriate night carer relief in all areas of New Zealand, sometimes resulting in hospital admission. Cancer Society financial assistance is not available nationally, nor for people with conditions other than cancer.

Community care to support people wishing to die at home

While some hospices, GPs and hospital nursing services provide some good community care services, nationally there is a lack of sufficient community care and social support to allow people to die at home. Further, while some people caring for a dying person can access the 28-day carer relief support through DSS, the amount of care provided can be dependent on a needs assessment. The current nature of a 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.

Patients who do not have sufficient support at home may have to be admitted to a hospital, hospice or rest home.

Inpatient care

There is a large variation in the availability of palliative care beds in hospitals and hospices (HFA 1999). Many providers have advised that there are insufficient beds for palliative care, respite care and medium- to long-term care, and sometimes a lack of 24-hour and specialist palliative care.

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 a rest home. This care may or may not be appropriate, depending on the rest home's staffing levels, expertise, and links with palliative care organisations. Rest homes may not be appropriate for younger people who require longer-term care. Additionally, there can often be a significant user charge involved in accessing rest home care. As in

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.

Palliative care in rural areas

While someone in a city area may have access to a wide range of quality services, people living in a rural area may have significantly reduced access. Providers have reported access problems in rural Northland, Waikato, Bay of Plenty, Taranaki, Nelson/ Marlborough, and the West Coast.⁶ People dying in rural areas are generally dependent on GP, primary health care nurse and district nursing services, which are often in short supply.

Spiritual care or bereavement support in both hospices and hospitals

There is a need for people being cared for by community-based services to have access to appropriate spiritual and bereavement counselling. Current access to these services is not universal.

Information to patients and their families

There is insufficient information provided to patients who are dying and their family/whānau about treatment and palliation options and the services and providers available to meet their choices.

Access to palliative care for people with non-malignant disease

People with end-stage non-malignant disease (for example, those with congestive heart failure, chronic obstructive respiratory disease, AIDS, motor neurone disease and multiple sclerosis) may not be viewed as having a 'terminal' illness in the same way as someone with cancer. These people do not always receive the same types or level of palliative care support (McIlpatrick and Curran 1999), either because it is not available or because the need for palliative care has not been identified as an option.

This is also true for children. The Ministry of Health publication *Children and Young People with Terminal Illness* (1994) reports that resources available to this medically fragile group compare poorly with those available to clients with cancer. This is largely due to the public sympathy towards children with cancer.

⁶ Health Funding Authority Database 2000.

Māori access to palliative care

The following issues affecting access to palliative care services for Māori have been identified.⁷

- There is a lack of awareness about palliative care services among Māori and the options that can exist when a life-shortening illness is diagnosed. There also needs to be more information provided to whānau at the time of diagnosis with regard to the prognosis and time to death.
- There are no Māori palliative care provider organisations. Currently this type of care comes from mainstream services or through Māori providers with no specific education in palliative care. Training in palliative care is needed for Māori providers.
- There should be better co-ordination of services, particularly between mainstream and Māori providers.
- Over half (340) the Māori people with cancer die at home. This aspect needs to be considered when planning palliative care services for Māori.
- There is a need to ensure that mainstream providers understand the whānau model of health and illness and provide care in a culturally appropriate way. 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.

Access to palliative care for children

The *Paediatric Review* found that while there was some provision of co-ordinated services (for example by oncology units), families may not be able to access the necessary palliative care services due to:

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

There is also a need for age-appropriate support for children whose parents are affected by terminal illness.

⁷ Issues identified by a Māori palliative care working party as part of this project and through work undertaken by the National Health Committee's work on Care of the Dying.

Access to palliative care for Pacific peoples

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 (Care of the Dying Project).

- There are well-established cultural protocols for dealing with people who are dying, dictated by spiritual beliefs, but these are not always applied.
- There is philosophical opposition to the NFR (not for resuscitation policies).
- Pacific peoples often have difficulties accessing information about palliative care services. More information needs to be disseminated to Pacific peoples on the palliative care services that are available.
- There are often communication/language difficulties. This can mean that the disease and treatment process are not always explained adequately to the wider family group to enable them to make informed decisions. People may not understand the condition of their dying relative and this can influence access to necessary care.
- It is preferable to have a Pacific health professional providing palliative care services, but they are difficult to recruit. There is a need for more training of Pacific health professionals in palliative care.
- There is a need to consider the specific needs of children within the context of the Pacific family.
- There is a need for palliative care services to understand Pacific cultures, especially in terms of the dying. In particular there is a need for hospitals to understand Pacific cultures better and when to introduce/refer people to palliative care services.
- Pacific peoples often prefer to manage on their own and may not ask for help.

Access to income support

There is an increased financial demand on families or the person who lives alone, either because they are no longer well enough to work or because they need to care for a partner or a child who is dying. For some it means there is no source of income while coping with the costs of caring for the one who is dying.

Rigidity in the rules that determine access to income support causes further financial stress. For example, there is generally a six-week to six-month stand-down period for people applying for the sickness, invalid or unemployment benefit. Social workers usually have to work with Department of Work and Income employees in manipulating rules to ensure that families have a source of income.

Failure to secure income can mean that the partner or parent cannot stop work to care for the dying adult or child who, perhaps denied the option of being cared for by family/whānau members, is admitted to hospital.

There is also a lack of support for families when institutional care is being provided. Home help is not available in this instance, although the spouse may be trying to balance children, work and visiting the patient.

Issue 3:

Lack of integration and inflexibility of services

While there are examples to the contrary, generally there appears to be little co-ordination or integration of services among providers (HFA 1999). There are also significant boundary issues impairing the delivery of seamless care (for example, in some places there are poor relationships between hospice staff and district and hospital nurses, and these are not helped by existing contracting mechanisms). Family members and people who are dying are reportedly having to navigate their own way through the different services, thus acting as the co-ordinators of their own care.

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
- discrepancies in the services that are funded (for example, the medicines that are available and the extent to which they are funded vary between hospital and hospice environments and the community setting)
- older people and people living alone having problems accessing services.

Issue 4:

Quality of services and monitoring issues

Hospices and hospitals will be expected to meet the New Zealand Health and Safety Standards by 2002 once the legislation is passed. Draft documents have been developed for cancer and palliative care nurses to enable them to standardise the care they provide (for example, the Hospice New Zealand Guidelines for Hospice/Palliative Care Nurses and the NZNO Cancer Nurses Section – Standards of Practice).

However, the quality of palliative care service provision and the requirements for quality delivery vary considerably throughout the country.

- Standard quality specifications for palliative care services are only now being included in hospice contracts.

- While requirements for quality in hospitals and Independent Practitioner Associations are included in HFA contracts, these are very general and are not specific to palliative care.
- There is no specific monitoring framework to ensure that palliative care is being provided appropriately.
- Little or no information is collected for the purposes of benchmarking against other service providers.
- There is a lack of outcome measurements/performance measurements for palliative care.
- There are no guidelines for referral and best practice.
- There is a need for more research or the application of overseas research in palliative care:
 - so that palliative care is regarded as a credible alternative to other forms of treatment
 - to develop an evidence base that can influence practice
 - to provide assurance to consumers that services are safe and valid.

Issue 5: Workforce and education

Issues relating to workforce and training also impact on the delivery and quality of palliative care services. These include:

- a need to develop national guidelines on palliative care workforce requirements to determine the appropriate number of staff that are required for palliative care services
- few palliative care medicine specialists working in palliative care services in New Zealand (8.9 in hospices and 3.2 in hospitals)
- few allied staff working solely in palliative care even though allied staff need to be part of a multidisciplinary team caring for the dying person
- anecdotal reports that volunteers are used inappropriately to deliver aspects of palliative care that should be undertaken by health professionals.
- lack of training in palliative care of allied workers (for example, home support workers and family members).

While there are a number of palliative care courses available in New Zealand, there is a need to:

- standardise education requirements for palliative care providers and the palliative care workforce in New Zealand (this includes training for volunteers)
- establish specific training in palliative care for undergraduate medical students: despite the approval by all the deans of the medical schools in Australia and New Zealand, the Australasian medical undergraduate palliative care curriculum has not been implemented
- develop undergraduate nursing education in palliative care further than the present minimal component.

Unless palliative care is given sufficient weight in the training of doctors and nurses it will be difficult to establish an enduring culture of palliative care or a palliative approach in the clinical setting.

Issue 6: Funding of palliative care

Different regions receive different levels of funding (HFA 1999), with insufficient public funding available to fill the service gaps identified earlier.

Hospices are only partially government-funded and rely on bequests, donations and fundraising activities. Because of charities competing for fundraising it is becoming increasingly difficult for hospices to secure additional funds for what they regard as the provision of core services. At the same time they are seeing an increasing number of referred patients from hospitals and other services. Some hospices have advised that if further public funding is not made available, they will need to limit the range of services they provide.

Hospitals, some of which provide services additional to their contracted function, also indicate that they are under-funded for providing palliative care (HFA 1999).

GPs do not receive funding for service calls to dying patients. Many do not feel able to ask for reimbursement when making house calls for the terminally ill. In some circumstances, GPs who cannot continue to make house calls may then refer patients to hospital. Home visits can be carried out for a fraction of the cost of keeping a patient in a hospital bed (Survey of IPAs, Ministry of Health 1999). In recognition of this, some Independent Practitioner Association (for example, Southlink Health) have a capped palliative care budget from which GPs can claim to cover some of the costs of seeing terminally ill patients.

Appendix 6: Palliative Care in the United Kingdom, Australia and Canada

United Kingdom (UK)

The first hospices were developed in the UK in the 1960s, largely through voluntary effort. Although hospices in Britain have gained some government funding, they are still only partially government-funded and, like New Zealand, rely on fundraising activities and voluntary work.

In 1995 the National Council for Hospice and Specialist Palliative Care Service developed a model for palliative care in the UK which utilises existing services rather than continuing the proliferation of small hospice/palliative care units (NCHSPCS 1997). The model suggests that three to four models of palliative care provision need to develop in Britain, including:

- *community-based care*, using beds and bases mainly in the voluntary sector: consultants and nurses would come from a broadly based training background very much as at present
- *oncology centre exclusively for cancer patients*: care would start at an early stage and the medical team would have extensive training in oncology
- *hospital palliative care teams*. Some may be provided from community bases in the National Health Service, voluntary sector or via a partnership between the two. Many will be associated with the specialist care services linked to oncology services. Others will be separate hospital services available for patients with active, progressive and far-advanced disease, with or without a few designated beds in any ward or department. There would be a continuing trend for the acute hospital to create joint appointments with local voluntary hospices and specialist care units and jointly developed specialist clinics (for example, for chronic pain, lymphodema or rehabilitation of people with chronic diseases)
- *care exclusively for AIDS/HIV patients*.

Australia

Like Britain, the development of a tailored approach to palliative care has its roots in the voluntary sector through the hospice movement. The hospice palliative care service, supported by charity and government subsidies, was established in 1982. In 1988 Commonwealth funding was provided to the states and territories for palliative care under a 'Medicare Incentives Package'. The aim of this package was to support people with terminal illnesses in their own home and minimise hospitalisation where possible (Commonwealth 1998).

The provision of palliative care is variable across Australia with similar issues and problems as in New Zealand (Commonwealth 1998). This led to the development of a five-year national Strategy for Palliative Care in 1998 to provide guidance to governments and other service providers to undertake activities that aim to improve the quality, range and coverage of palliative care services. The Australian strategy addresses four areas for policy development, integration, access and equity, quality improvement, evaluation and education and information. An annual report is to be provided to the Health Minister (Commonwealth 1998).

Canada

Canadian palliative care programmes were first developed in 1974/75 and have sought to be integrated into mainstream health care at both institutional and community levels.⁸ Palliative care is generally provided by an acute care inpatient unit that provides follow-up home care by nurses attached to the unit. A bereavement counselling service is also provided after death (Barnett and Smith 1992).

Various models of palliative care exist in Canada, including the Edmonton Regional Palliative Care Program, which provides an integrated programme of palliative care utilising hospice care, tertiary palliative care, and care by family physicians in the community (Bruera et al 1999). The Vancouver General Hospital Palliative Care Programme provides inpatient and community care, a consultancy service for other parts of the hospital and a bereavement follow-up programme (Tong 1993).

⁸ The Institute of Palliative Care, www.pallcare.org

Appendix 7: Explanation of Key Terms

Domiciliary or community palliative care nurses

These nurses provide care to people who are dying in the home or long-term residential facility. They generally work in a multidisciplinary team. The team may be attached to a general hospital with a cancer unit, inpatient hospice/palliative care unit or the community nursing service.

Hospice

The term hospice is used in two ways. It can refer to the philosophy and practice of hospice care, which is in effect the same as the philosophy and principles of palliative care in the definitions given in this document. It can also refer to a hospice unit. Usually this is a free-standing unit with inpatient facilities, where palliative care is practised, emphasising medical and psychosocial care. It usually has medical and nursing staff specially trained in palliative care and can offer day care, respite care and home support teams. Some hospices do not offer inpatient services.

Hospital palliative care teams

A hospital palliative care team provides palliative care within the acute hospital setting. The team has an advisory and education role and may provide direct care to patients and their families requiring a high level of palliative care skills. They also link people to services on discharge from hospital.

Inpatient care

The inpatient care given varies between service providers.

- Hospices provide inpatient care for the control of symptoms or for respite care. Some people may choose to die in a hospice. Inpatient care in hospices is generally for short stays of up to approximately 10 days.
- Hospitals provide inpatient care for acute care required by dying people. They can also provide care for symptom control and respite care, particularly where there are no hospices.
- Residential care mainly provides inpatient care for older people. However, dying people who can no longer stay at home but require care for a longer period than that provided by hospices or hospitals also access residential care.

Multidisciplinary team

This team would consist of a nurse, physician, social worker, physiotherapist, occupational therapist, pharmacist, bereavement counsellor, spiritual worker and dietician.

Night carer relief

Overnight nursing care for dying people to provide relief for families.

Palliative care services

A broad term that encompasses the provision of palliative care in both the home and inpatient setting by hospices, long-term residential care facilities and privately and publicly funded hospitals.

Palliative medicine

The study and management of people with advanced and progressive disease for whom the prognosis is limited and the focus of care is the quality of life. Palliative medicine includes consideration of the family's needs before and after the patient's death.

Quality of life

An individual's perception of their position in life in the context of the culture in which they live, and in relation to their goals, expectations and standards. The term incorporates concepts of physical and psychological wellbeing, levels of independence and autonomy, social relationships and support, and spirituality. Health-related quality of life emphasises the domains of physical and psychological wellbeing.

Rehabilitation

In the context of palliative care, rehabilitation refers to assisting dying people to achieve and maintain their maximum physical, emotional, spiritual, vocational and social potential in improving the quality of their remaining life.

Respite care

Respite care is essentially carer relief. In a model based on community care, respite care is fundamental for ensuring the family/carer is able to continue to care for the patient in the home. Respite care can take a number of forms and includes inpatient care provided by a hospice, hospital or rest home. Respite care can also include night carer relief, and other sitting-type services.

Specialist palliative care services

Palliative care services with palliative care as their core specialty. They require a high level of professional skills from trained staff. A significant minority of people whose deaths are anticipated need specialist palliative care services.

Terminal care

Usually refers to the management of patients during their last few days or weeks or even months of life from a point when it becomes clear that the patient is in a progressive state of decline.

Terminal illness

Active and progressive disease for which curative treatment is neither possible nor appropriate and from which death is certain. This varies from a few days to many months.

Terminal stage

Usually refers to a steady deterioration in the patient's condition, which indicates that death is close.

References

- Association for Palliative Medicine of Great Britain and Ireland (APMGBI). 2000. Annual General Meeting, March 2000, Warwick University, England.
- Barnett P, Smith K. 1992. *The Organisation and Funding of Hospices: An international and New Zealand view*. Wellington: Department of Health.
- Bruera E, Meumann C, Gagnon B, et al. 1999. Edmonton Regional Palliative Care Program: impact on patterns of terminal cancer care. *Canadian Medical Association Journal* 161: 290–3.
- Christakis NZ, Lamont EB. 2000. Extent and determinants of error in doctors' prognosis in terminally ill patients: prospective cohort study. *British Medical Journal* 320: 469–73.
- Commonwealth Department of Health and Aged Care. Background for a National Strategy for Palliative Care in Australia. 1998. Commonwealth Department of Health and Aged Care.
- Cox. 1995. *Projections of the Cancer Burden in New Zealand*. Wellington: Public Health Commission.
- Doyle D. 1990. Facing the 1990s: special issues. *Hospice Update* 2(1): 1–6.
- Eve A, Smith AM, Tebbit P. 1997. Hospice and palliative care in the UK 1994–95 including a summary of trends 1990–95. *Palliative Medicine* 11: 31–43.
- Hatcliffe S, Smith P. 1997. Open all hours. *Health Service Journal* 107: 40–41.
- Health Funding Authority (HFA). 1999. *Data from Hospice and Hospital Questionnaires*. Wellington: Health Funding Authority.
- Higginson I. Health care needs assessment: palliative and terminal care. In A Stephens and J Raftery (eds) *Health Care Needs Assessment*. Oxford and New York: The Wessex Institute, Radcliffe Medical Press.
- Higginson I. 1998. Who needs palliative care? *Journal of the Royal Society of Medicine* 91(11): 563–4.
- Higginson IJ, Finlay IG. 2000. *The Role of Palliative Care Teams: A systematic review of their effectiveness and cost-effectiveness. Executive summary*. Department of Palliative Care and Policy, King's College School of Medicine, London; and Velindre NHS Trust and Department of General Practice, UWCM, Wales.
- Hospice New Zealand. 1998. Paper to the Health Funding Authority.
- Kite S, Jones K, Tookman A. 1999. Specialist palliative care and patients with noncancer diagnosis: the experience of a service. *Palliative Medicine* 13: 477–84.
- Llewellyn I, Evans N, Walsh H. 1999. The role of the community hospital in the care of dying people. *International Journal of Palliative Nursing* 5: 247.
- Mcilpatrick S, Curran CI. 1999. District nurses' perceptions of palliative care services: Part 1. *International Journal of Palliative Nursing* 5: 215.
- Ministry of Health. 1993. *A Report of the Consensus Forum on Hospice/Palliative Care Services*. Wellington: Ministry of Health.
- Ministry of Health. 1994. *Children and Young People with Terminal Illness*. Wellington: Ministry of Health.
- Ministry of Health. 1998. *Through the Eyes of a Child: A national review of paediatric specialty services*. Wellington: Ministry of Health.
- Ministry of Health. 1999. *Survey of IPAs*. Wellington: Ministry of Health.
- Minister of Health. 2000. *The New Zealand Health Strategy*. Wellington: Ministry of Health.

- National Council for Hospice and Specialist Palliative Care Services (NCHSPCS). 1994. *Palliative Care: Needs, definitions, standards. A consultative document*. London: National Council for Hospice and Specialist Palliative Care Services.
- National Council for Hospice and Specialist Palliative Care Services (NCHPCS). 1997. *Dilemma and Directions: The future of specialist palliative care*. Occasional paper 11. London: National Council for Hospice and Specialist Palliative Care Services.
- Nichols J. 1998. Operating a community palliative care service. *New Ethics Journal* 1(5): 23–32.
- Palliative Care Australia. 1998. *State of the Nation Report of a National Census of Palliative Care Services*. Commonwealth Department of Health and Aged Care.
- Penny RH. 1997. *Review of Palliative Care Services within the North Health Region*. Auckland: North Health.
- Robertshaw J. 1994. *Children and Young People with Terminal Illness: Models of service delivery consumers prefer*. Auckland: North Health.
- Smith RA. 2000. A good death. *British Medical Journal* 320: 129–30.
- Tong K. 1993. Vancouver General Hospital Palliative Care Unit utilisation. *Journal of Palliative Care* 9: 32–6.
- WHO. 1990. *Cancer Pain Relief and Palliative Care*. Geneva: World Health Organisation.