The New Zealand Palliative Care Strategy

Discussion Document
Foreword

This discussion document sets in place a systematic and informed approach to the future provision and funding of palliative care services. The strategy seeks to ensure that people who are dying and their family/whānau have access to all the essential services, and that they are provided in a co-ordinated and culturally appropriate way. The strategy also seeks to build on current service arrangements.

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. In order to guide this reconfiguration, two strategies are under development: the New Zealand Health Strategy, and the New Zealand Disability Strategy. The Palliative Care Strategy will be implemented within the broader framework of these two strategies.

I would like to take the opportunity to thank all those involved with the delivery of palliative care services. There is a significant amount of work that needs to be undertaken in order to implement the vision and strategies outlined in this document. I look forward to your continued involvement and enthusiasm in carrying forward the vision outlined here.

This document is for discussion with the palliative care reference group, the health and disability sector and the wider public; a final document will then be published. I encourage you to respond. Section 4 shows how you may do this.

Hon Annette King
Minister of Health
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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 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 there are a range of issues that 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 should have timely access to quality palliative care services that are culturally appropriate and provided in a co-ordinated way.

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

1. A set of essential services for dying people who could benefit from palliative care. These publicly funded services would include assessment by a multidisciplinary team (initial and ongoing), care co-ordination, advisory and education services, clinical care and support care.

2. A flexible service configuration that builds on existing services and is co-ordinated to ensure that dying people have access to all essential services provided in a culturally appropriate way via three inter-linked levels of palliative care provided within six regional networks:
   - regional palliative care services delivered from Auckland, Hamilton, Palmerston North, Wellington, Christchurch and Dunedin. These providers would have particular responsibility for providing the specialist palliative care advice for the region and maintaining linkages with the six regional oncology units and all providers of palliative care in the region
   - local palliative care services provided from each District Health Board area encompassing all the essential services for people who are dying
   - care by all providers that encompasses a palliative care approach.
3. A pathway that ensures co-ordinated access to essential services via the critical role of a care co-ordinator and the establishment of effective multidisciplinary teams.

Nine strategies have been developed which will be implemented over a 5–10 year period in order of priority. While some development can start before the establishment of District Health Boards, the strategies have been developed with the future health sector structure in mind.
1: Introduction

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 (NHC) from 1997 (see Appendix 1).

In developing the strategy 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 those involved with palliative care (see Appendix 3).

What is palliative care?

Health and disability services and the approach to mainstream care have generally been centred around preventing or curing diseases. But people who are dying require an holistic approach to care which enhances the quality of their remaining life and which provides support for the family/whānau before and after bereavement. From the time of diagnosis of a serious life-shortening disease, a palliative approach should influence care. Once it is known a person is likely to die, palliative care should be made available as an option.

The palliative approach

The palliative approach to care aims to promote physical, psychological and social wellbeing regardless of whether a person has reached the terminal stage of their illness or condition. The palliative approach is informed by the knowledge and practice of palliative care principles and should be part of the care offered from the time of diagnosis of a chronic illness. Summary, palliative care aims to:

- respect patient autonomy and choice (for example, over treatment options)
- provide care that includes support for those people close to the person who is dying
- use a holistic approach that integrates the physical with social, psychological and spiritual aspects of care
- promote open and sensitive communication between health care professionals and the person who is dying and their family/whānau
• provide care that is culturally appropriate
• provide care that is people centred.

**Palliative care defined**

Palliative care operates from the time it is acknowledged that the aim of treatment is no longer curative and that a person’s death is very likely. It is the active total care of people by a multidisciplinary team when a person’s disease is not responsive to curative treatment, and:
• affirms life and regards dying as a normal process
• aims to neither hasten nor postpone death
• aims to provide relief from distressing symptoms
• integrates physical (tinana), social (whānau), emotional (hinengaro) and spiritual (wairua) aspects of care
• offers help to the family/whānau/carers during the person’s illness and their bereavement.

This definition of palliative care has been developed for the New Zealand setting but has been drawn from definitions developed by WHO, as well as the Australian, United Kingdom and New Zealand Hospice Associations. (A glossary is given in Appendix 7.)

**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 have access to quality health and support services appropriate to their needs. Their rights to appropriate and accessible care are the same as for people who require care for non-terminal conditions.
• 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 a multidisciplinary approach yet this care needs to be provided seamlessly.

**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 palliative care is effective for people who are dying, and that it should be a central feature of all good clinical practice. 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 the awareness about palliative care amongst 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. It is estimated that by 2011, the number of people with cancer will increase by 24 percent, largely due to New Zealand’s ageing population. In addition, there is an increasing awareness that people with non-malignant diseases can benefit from palliative care services. Currently only 10 percent of people with non-malignant disease access hospice services, yet it is estimated that the need could be as high as the number of people with cancer accessing hospice services. This could place a heavy burden on palliative care services if services are not resourced to manage this need. (See Appendix 4 for an overview of palliative care services.)

Issues to be addressed

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

- 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
- 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 few 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 which are only partially funded by government.

See Appendix 5 for more detail.
Palliative care strategy in context

The health and disability sector is being reconfigured to increase local decision-making and improve the responsiveness of health funders and providers to their communities. Overarching strategies are currently being developed to provide frameworks for the sector. The New Zealand Health Strategy provides an overarching strategy for the health sector. It sits alongside the New Zealand Disability Strategy, currently in development, which addresses disability issues.

The New Zealand Health Strategy and the New Zealand Disability Strategy also acknowledge the special relationship between tangata whenua 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, including Crown entities such as District Health Boards (DHBs), will have a shared role in implementing health strategies for Māori, based on these key principles:

• partnership in service delivery: a relationship between Māori and the Crown of good faith, mutual respect and understanding, and shared decision-making

• participation at all levels: the Crown and Māori will work together to ensure Māori (including whānau, hapū, iwi, and communities) participate at all levels of the health and disability sector

• culturally appropriate practices: the Crown actively contributes to improving the health status of Māori, while respecting cultural security, ensuring equal access to health services, and the development of Māori provider and kaupapa health services

The Government has given priority to reducing the disparities in social and economic outcomes for Māori and Pacific peoples. The work programme put in place to reduce these disparities has been called Closing the Gaps. The Ministry and DHBs will be working with communities to implement this work programme which includes:

• identifying ways to respond to communities’ needs and interests. For example, there are well-established cultural traditional protocols around death and dying among Pacific peoples which should be incorporated into the implementation of palliative care strategies

The New Zealand Health Strategy

This strategy identifies seven fundamental principles which are to be reflected in the sector:

• very good health and wellbeing for all New Zealanders throughout their lives

• an improvement in health status of those currently disadvantaged which include Māori and Pacific peoples

• collaborative health promotion and disease and injury prevention by all sectors

• timely and equitable access for all to a comprehensive range of health and disability services, regardless of ability to pay

• acknowledgement of the special relationship between tangata whenua and the Crown under the Treaty of Waitangi

• a high performing system in which people have confidence

• active involvement of consumers and communities at all levels.
• helping communities to access the optimum mix of resources to achieve their own goals
• adapting policies, programmes and funding to support successful community initiatives
• focusing on results.

This palliative care strategy will sit under the New Zealand Health Strategy and New Zealand Disability Strategy umbrella and acknowledges the special relationship between Māori and the Crown under the Treaty of Waitangi. It will also be linked to the Pacific Health Strategy, about to be developed, which will include components such as public health programmes, primary care programmes, improved specialist services based in the community, Pacific health workforce support and training, research, the collection of quality Pacific health information and more culturally competent services delivered by mainstream providers.

The aim of this 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 were to:
• raise awareness of the importance of good palliative care
• incorporate work already done in relation to palliative care
• develop a practical strategy that builds on current service arrangements (including services provided by hospices, hospitals, general practitioners (GPs), district nurses, Māori health providers and charitable organisations such as the Cancer Society)
• learn from overseas directions in palliative care that point to the need for more co-ordination and integration of services (see Appendix 6)
• develop a more responsive system that can support people’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 people the figure is 53 and 42 percent respectively).

This strategy does not address such issues as euthanasia.
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 should have timely access to quality palliative care services that are culturally appropriate and provided in a co-ordinated way. |

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

- the essential and accessible publicly funded quality palliative care services for people who are dying and their family/whānau
- the service configuration required to ensure access to quality palliative care and the provision of culturally appropriate services
- ways of ensuring that services are co-ordinated for dying people so they have timely access to the palliative care services they require.

Access to palliative care services

A set of essential services which 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. 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 essential palliative care services that dying people and their families/whānau should have access to are as follows.

Assessment

Following confirmation that a person’s illness or condition has reached its terminal stage, each person who is dying should have an initial multidisciplinary assessment to identify the person and their family/whānau’s physical, social, cultural, 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.
Case management/care co-ordination

Care co-ordination is important in palliative care to avoid fragmentation and duplication of service provision, given that most people need to have access to a range of services both within and outside the health and disability sector. Each person who is dying should be allocated a care co-ordinator following the initial assessment. The care co-ordinator is responsible for ensuring access to the appropriate services, including specialist advice, and for co-ordinating services for the person and their family/whānau.

Advisory and information services

Each dying person and their family/whānau should have access to information and advice regarding palliative care options and services. The care co-ordinator and/or members of the multidisciplinary team need to ensure that appropriate information is provided at the initial assessment and thereafter.

Clinical care

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

- access to medical services (including GP and specialist services) and domiciliary nursing services (including night nursing) to provide symptom control, nursing and medical management 24 hours, seven days per week, in the community
- access to inpatient care for respite care and/or control of symptoms which cannot be adequately controlled in a community setting – inpatient care should also be provided in the terminal phase 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
- equipment to enable the dying person to stay at home.

Support care

Support care is care provided to a person and/or their family/whānau to support people to die at home or if not appropriate, in an alternative setting. People who are dying and their families/whānau should have access to support services that include:

- support in the home (eg, 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
- reasonable transport assistance for people who need to travel for care.
Service configuration for palliative care services

The following discussion focuses on developing a service-based framework for the provision of palliative care services.

This framework needs to:

• build on existing services and workforce
• integrate/co-ordinate services in order to ensure that people have access to essential palliative care services
• ensure that all population groupings, including Māori and Pacific peoples, have access to palliative care services and that services are provided in a culturally appropriate way
• ensure the quality of palliative care services
• provide the flexibility to meet peoples’ needs, including those of people who want to die at home.

Regional and local networks of palliative care

Not all the proposed 21 District Health Board (DHB) areas have the population base, the throughput or the ability to provide palliative care services to a specialised level. It is therefore proposed that the services framework be based upon the development of regional networks of palliative care providers that have within them three linked levels of care:

• regional palliative care services
• local palliative care services
• care from all other providers.

It is proposed that there be six regional networks and that the nuclei of these networks be in Auckland, Hamilton, Palmerston North, Wellington, Christchurch and Dunedin. These sites are proposed because:

• there can be co-location with the six regional oncology and cancer services, who are the main users of palliative care services
• they are geographically dispersed
• there are existing hospices/hospital services in these regions that provide specialised palliative care.

Each network will encompass all providers within a geographic region (Figure 1).
The following discussion outlines expectations for each of the three levels of care and how they will relate to each other.

**Regional palliative care services**

Regional palliative care services could be provided by a hospice, a hospital or both of these service providers working together. Providers of regional palliative care services would provide a full range of specialist palliative care services and would have responsibility for:

- providing all the essential palliative care services in both community and institutional settings for their DHB area in accordance with the Funding Agreements between DHBs and the Minister of Health
- providing specialist palliative care to all people in the region either through advice to other providers in the region or through direct care
- establishing formal links with all palliative care providers in the region and developing a plan for the regional network to ensure that duplication of services does not occur
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• undertaking an evidenced-based approach to care and facilitating quality improvement in all palliative care providers in the region
• ensuring appropriate education and training for the palliative care workforce in the region.

It is also proposed that a hospital palliative care team be attached to each of the regional providers of palliative care. The role of the team would be 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. This is important, at least as an interim measure, in facilitating timely access to palliative care when dying people need it. Hospital palliative care teams would also assist hospital providers in ensuring that people access the appropriate palliative care service in their communities.

Local palliative care services

Each DHB area will be required to have at least one provider that provides palliative care at a local level. This care could be provided by a hospice, hospital community-based services and/or primary care organisations. As at a regional level, different providers would be required to integrate/co-ordinate palliative care services in order to provide a local palliative care service.

Providers of local palliative care services will be required to:
• provide all 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 formal links with the provider of regional palliative care services and the other providers in the area including Māori and Pacific providers
• develop a plan with local Māori to ensure there is appropriate access to the palliative care services that Māori need.
• in strategic locations, develop a palliative care strategy with Pacific providers.

Those providers who do not have respite or long-term care beds will need to have formal links with appropriate rest homes or private hospitals and would have the responsibility for ensuring the quality of care. Providers of local palliative care will also have responsibility for ensuring the provision of palliative care to people in other institutional settings.

Care from other providers

This level of care encompasses any other health and disability service that people who are dying come in contact with, and could include hospital services, a rest home, primary care provider, Māori and Pacific health providers or other community provider organisation.

All these providers will need to understand and utilise the palliative care approach, to ensure that people who have been diagnosed with a condition that may necessitate the provision of palliative care, are informed of palliative care as an option and the appropriate referral made. Explicit links also need to be made with providers of regional and local palliative care services.
Ensuring co-ordinated access to essential services

Figure 2 illustrates how the delivery of palliative care services could occur. The model is designed to ensure that the person receives the appropriate palliative care services in a co-ordinated and timely way. It demonstrates that following referral to a palliative care provider, a person and their family/whānau undergo a multidisciplinary assessment that identifies their physical, social, spiritual and emotional needs. A care co-ordinator is appointed to co-ordinate the care of the person and their family until the person dies and, for the family/whānau, beyond death.

The care co-ordinator will be a trained palliative care nurse and has a very important role in:

- providing information to the dying person and their family
- ensuring that the family/whānau have access to the services they require including hospital services
- facilitating admission to in-patient palliative care when required
- ensuring care is appropriate to the person’s needs and is culturally appropriate
- facilitating access to bereavement/spiritual counselling for the family/whānau following death
- facilitating access to income and other social support if needed
- promulgating the palliative approach and maintaining working relationships with the family GP, practice nurse and other community providers (including volunteers), hospital providers and palliative care specialists.

Another important aspect of the model is the utilisation of a multidisciplinary team for the provision of care, as no one person or organisation is likely to be able to meet all the needs of a person or their family/whānau. However, for care to work effectively, it will be essential that the multidisciplinary team works closely with the care co-ordinator.
Needs of specific population groups

Some people have specific needs that require an adaptation to the model outlined. The needs of Māori, Pacific peoples and children are outlined below; however, other groups will also have specific needs, so it is important the model is flexible enough to ensure all needs are met.
Māori

In order to address the needs of Māori, the following needs to be in place:

• quality specifications for essential services that include requirements for mainstream services to meet the particular needs of Māori

• linkages between palliative care providers and Māori development organisations in order to develop a plan for services for local Māori and to assist in meeting the specific needs of Māori

• at a local level, where appropriate, each provider would employ a care co-ordinator(s) who could meet the special needs of Māori. 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.

Pacific peoples

In order to address the needs of Pacific peoples, the following needs to be in place.

• The development of a suitable palliative care approach for Pacific peoples and quality specifications for essential services.

• In strategic locations, consideration of the employment of suitable care co-ordinator(s) to work with Pacific peoples and providers to provide culturally appropriate care.

Children

Children’s needs are not the same as adults’ needs, and they require different services. Children who are dying require 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. However, 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 to both 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 the regional and local providers of palliative care services for adults. This linkage would assist with sharing expertise and in ensuring that the children receive appropriate bereavement counselling if a parent dies.

Summary

The vision, ‘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’, is underpinned by four key features:

- an awareness and knowledge of palliative care amongst communities and providers of health and disability services
- the provision of five publicly funded essential palliative care services for people who are dying and their family/whānau
- a framework that is based around six regional networks comprising three inter-linked levels of care
- a pathway focused on the crucial role of the care co-ordinator whose role is to ensure that services are co-ordinated and appropriate for each individual.
3: Strategies to Implement the Vision

The strategies below have been developed to ensure that quality palliative care services based upon need are available for all New Zealanders. While in the longer term additional funding for palliative care services may come from savings made (due to fewer expensive interventions and fewer inappropriate acute admissions for people who are dying), in the shorter term there will need to be additional funding to implement these strategies.

However, this is a 5–10 year vision, and many of the strategies outlined will require a significant amount of lead time for implementation. It will be important to prioritise or stagger development to ensure realistic focus for implementation. While some development can commence prior to the establishment of DHBs, the following strategies have been developed with the future health sector structure in mind.

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 publicly funded palliative care services

This strategy will be achieved through:

• the development of purchase units and service specifications for essential services that can be provided by existing palliative care service providers. These services include assessment, care coordination, information and advice, and clinical care. The price and total cost of these palliative care services will need to be determined.

• identifying the capacity in each area for providing these services and fill service gaps in each locality/DHB. The extent to which service gaps can be filled will be dependent upon the available budget

• a review of support services (which are provided by DSS) to include:
  – analysis of the extent to which existing community support services are robust enough to provide ongoing support for people with a palliative care need
  – analysis of how many people are currently accessing disability support services and what gaps there are in community support services that will require additional funding
  – analysis of the extent to which existing residential care services can be utilised to provide long-term residential support for dying people
- analysis and identification of the costs of providing support services
- requiring palliative care providers to ensure that dying people have access to essential support services.

**Strategy 2 -
Ensure that local palliative care services are co-ordinated**

In some places the development of local palliative care services will be straightforward, as organisations such as hospices will be able to offer most of the essential services apart from support care. In other places, particularly rural areas, providers may need to combine to provide the full range of essential services. For example, primary care providers could link up with district nursing services.

Each locality/DHB will need to develop a plan to work with local providers to ensure that co-ordinated palliative care services are available for people in their communities. Where there is more than one provider, it is expected that one provider will take the responsibility for co-ordinating and delivering the essential services to dying people and their families/whānau.

The plan will utilise information on needs analysis and service provision from the HFA/Ministry and identify:

- 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.

**Strategy 3 -
Develop regional palliative care in Auckland, Waikato, Palmerston North, Wellington, Christchurch and Dunedin**

The provider of regional palliative care services will provide the local palliative care service for their community but will also have additional regional responsibilities for providing specialist advice, overseeing quality improvement and ensuring the appropriate education of local palliative care providers. The provider can be a hospice or hospital or a joint arrangement between these organisations and would have formal links with the regional oncology units. The development of regional palliative care services can be achieved through:

- the development of purchase units and service specifications for additional services offered by providers of regional palliative care services. The price and cost of services will need to be determined
- identifying likely providers for the regional palliative care service
- the establishment of a timeframe and plan for implementation of the regional palliative care service
- working with providers in the region to establish the regional palliative care service and network.
Strategy 4 - Implement hospital palliative care teams

Hospital palliative care teams have a particularly important role in ensuring the palliative care option is available for dying people, as well as in providing advice and assistance on the care of dying people to staff in hospitals. 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 would be attached to the regional palliative care service and regional oncology units. There are three existing hospital palliative care teams in Auckland, Waikato and Christchurch. In implementing hospital palliative care teams across the six regions the following steps need to be taken.

- Develop purchase units and service specifications for hospital palliative care teams and calculate the price and cost of the service.
- Identify services which currently or will utilise hospital palliative care teams.
- Identify existing sources of funding for hospital palliative care teams based on current contract lines and calculate any additional funding which may be necessary.
- Implement hospital palliative care teams in the six hospitals.

Strategy 5 - Develop quality requirements for palliative care services

In order to assure the quality of care provided the following needs to occur.

- Develop standard quality specifications for essential palliative care services. This would mean a quality plan that includes requirements to ensure that services meet Māori needs. Quality specifications would be adjusted once all regional and local palliative care services have been developed.
- Implement the Health and Disability Sector Standards by 2002. Palliative care providers would be audited against the sector standards and requirements for improving quality would be incorporated into quality specifications.
- Develop an evidenced-based approach to the provision of palliative care.
- Develop referral and best practice guidelines for regional and local palliative care services.
- Develop ‘cultural competence’ specifications for providing palliative care services for Pacific peoples.
- Develop a monitoring framework for palliative care services. This would include outcome measures/performance indicators for palliative care.
Strategy 6 -
Inform the public about palliative care services

Public information specific to each DHB area is necessary, for example, a website or a pamphlet that:

- outlines the public’s rights/entitlement to palliative care services
- describes the services offered by palliative care providers
- provides information on what the public should expect from a palliative care service.

Strategy 7 -
Palliative care workforce and training plan

To ensure that there is an appropriately sized and trained palliative care workforce the following is required.

- Undertake work to determine workforce requirements for regional and local palliative care services. This would include work to determine the numbers of Māori care co-ordinators and Māori palliative care health professionals that are required. The Ministry’s workforce committee could be asked to undertake this work.
- Undertake work to determine the staff training required in order to meet the needs of Māori, Pacific peoples and people from other cultures.
- Request professional groups to update current training to include training for the role of the care co-ordinator.
- Request professional groups to work with undergraduate and educational providers to agree on the minimum content of palliative care training at the undergraduate and postgraduate level.
- Request professional groups to develop standards and agree on the level of postgraduate palliative care education required for registered nurses, allied health professionals, volunteers, palliative care medicine specialists, GPs and other doctors.
- Request schools of medicine implement the Australasian medical undergraduate palliative care curriculum.
- Update the postgraduate training of some nurses to take account of future nurse prescribing.
**Strategy 8 -**  
**Ensure that recommendations from the *Paediatric Review* are implemented**

This strategy supports the implementation of *Paediatric Review* recommendations; the following work should be done.

- Develop purchase units and a service specification for the national palliative care team.
- Identify the number of local paediatric palliative care co-ordinators required in New Zealand and develop a service specification for the service.
- Implement the above services in accordance with available budget.

**Strategy 9 -**  
**Address issues of income support**

A significant financial burden can be placed on people who are dying and 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, comprised of HFA/Ministry, Department of Work and Income and relevant providers, be established.
4: The Way Forward

Further development and work is required to implement both the vision and strategies and to place palliative care in a more prominent and appropriate role within the health and disability sector. This work will be carried out over 5–10 years. The strategies outlined in the previous section will be prioritised and implemented in a staggered fashion but within the overall vision for the future provision and purchasing of palliative care services.

Finalise the strategy discussion document

The following timetable is proposed:

<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>14 July 2000</td>
<td>Discussion document released and consultation commences</td>
</tr>
<tr>
<td>First three weeks in August</td>
<td>Limited number of public meetings and focus groups</td>
</tr>
<tr>
<td>25 August 2000</td>
<td>Closing date for written submissions</td>
</tr>
<tr>
<td>September 2000</td>
<td>Final strategy document published</td>
</tr>
<tr>
<td>October 2000</td>
<td>Implementation of the first year of the strategy</td>
</tr>
</tbody>
</table>

Have your say

This discussion document is being widely distributed among health services providers, consumer groups, community organisations, non-governmental organisations, government agencies, and other organisations and individuals interested in health issues.

You can provide comments in a number of ways:

- Attend one of these public meetings:
  - Tuesday, 8 August 2000, 2–4 pm
    Ngaio Community Hall
    WELLINGTON
  - Wednesday, 9 August 2000, 2.30–4.30 pm
    Fickling Convention Centre
    546 Mt Albert Road
    Mt Roskill
    AUCKLAND
- Thursday, 10 August 2000, time to be confirmed  
  North Haven Hospice  
  Tikipunga  
  WHANGAREI

- Thursday, 10 August 2000, 2–4 pm  
  Knox Centre Lounge  
  28 Bealey Avenue (near corner of Victoria Street)  
  CHRISTCHURCH

- Tuesday, 15 August 2000, 7–9.30 pm  
  Denningham Suite, 4th Floor,  
  Dunedin Public Library  
  DUNEDIN

- Wednesday, 16 August 2000, 1–3.30 pm  
  Centennial Court Motor Inn  
  Conference Centre  
  96 Centennial Avenue  
  ALEXANDRA

Fono to be advised

- Make a written submission on your own behalf or as a member of an organisation. A series of questions that you may want to use to guide your response is given. You may want to copy and complete the question guide on the following pages.

Submissions should be sent to: Palliative Care Strategy Consultation  
  Ministry of Health  
  PO Box 5013  
  WELLINGTON  
  Fax: (04) 496 2342  
  E-mail: PalliativeCareStrategy@moh.govt.nz

The closing date for receipt of submissions is 25 August 2000
Submission guide

Please copy and complete this guide and the questions that follow. Please feel free to make any additional comments or use a different format if you want.

Name/s and contact details

Are you happy for your name to appear in the list of submissions in the final document?

Yes  No

How many people have been involved in preparing this submission?

Please circle the term of what best describes you.

- service provider
- health professional
- concerned member of the public
- other (please specify).

Thank you for taking the time to make your submission.
Questions for consultation

Question 1

This document identifies a number of issues related to the current provision of palliative care services.

Do you think there are there any further issues?  
Yes  No

Please comment:

Question 2

This document provides a definition and principles of palliative care.

Do you agree with the definition and principles of palliative care?  
Yes  No

Please comment:

Question 3

This document provides a vision for palliative care services.

Do you agree with the vision?  
Yes  No

Please comment:
Question 4

This document proposes that dying people have access to five essential publicly funded palliative care services, including:

- assessment
- care co-ordination
- advisory and education services
- clinical care
- support care

Do you think that these are the right essential services for people who require palliative care?    

[ ] Yes  [ ] No

Are there any other services you would consider essential?

Any other comments?

Question 5

The document proposes that local palliative care services are co-ordinated by one local palliative care provider.

Do you think that one provider having the responsibility for co-ordinating and ensuring the provision of the essential palliative care services would work?    

[ ] Yes  [ ] No

If not, what other ways could palliative care services become better co-ordinated to provide the full range of services for dying people and their family/whānau and ensure access?

Any other comments?
Question 6

This document proposes that a regional palliative care service is developed in Auckland, Waikato, Palmerston North, Wellington, Christchurch and Dunedin. This service is to provide specialist palliative care advice, oversee the quality of palliative care services and education of providers.

Do you think that having a regional palliative care service to provide the above services for the region would work? Yes No

Given the low number of palliative care specialists, what other ways could:

- specialist advice be provided?

- quality of palliative care services and education of providers in the region be managed?

Any other comments?

Question 7

This document proposes that hospital palliative care teams are implemented in the tertiary hospitals. They would be attached to Regional Oncology Units and linked to the regional palliative care service. Hospital palliative care teams would provide palliative care advice to hospital providers, assist people in hospital who have palliative care needs, and would link people to palliative care services when they are discharged from hospital.

Do you think that having hospital palliative care teams linked to the Regional Oncology Units would ensure that all hospital providers would have access to specialist palliative care advice? Yes No

What other ways could having hospital palliative care teams in tertiary hospitals facilitate access to palliative care services in the community?

Any other comments?

If you have any further comments please continue on a separate page.
5: Endnotes

1 Doyle D. 1990. Facing the 1990s: Special Issue Hospice Update 2:1 1–6.
Llewellyn I, Evans N and Walsh H. The role of the community hospital in the care of dying people.

• National Council for Hospice and Specialist Palliative Care ServicesPalliative Care: Needs,
Definitions, Standards. A consultative document
• Background for a National Strategy for Palliative Care in Australia.
• Bruera E, Numann C et al. 1999. Edmonton Region’s Palliative Care Program: impact on patterns
• Higginson IJ, Finlay IG. 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; Velindre NHS Trust and Department of General Practice,
UWCM, Wales.

3 • Ministry of Health1993 A Report of the Consensus Forum on Hospice/Palliative Care Services.
Wellington: Ministry of Health.
• Children and Young People with Terminal Illness. Models of Service Delivery Consumers
• Review of Palliative Care Services within the North Health Region, November 1997. Prepared
by RH Penny Ltd for North Health.

4 • Regional Palliative Care Program. 1998. Edmonton: Grey Nuns Community Health Centre.
• National Council for Hospice and Specialist Palliative Care Services. Drama and
• Palliative Care Australia. 1998State of the Nation Report of a National Census of Palliative Care Services.
• Hospice New Zealand. 1998. Paper to the Health Funding Authority.
A full bibliography is available on www.moh.govt.nz or from the Ministry of Health, PO Box 5013,
Wellington. See also references in appendices.
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 next two years.

Following this, 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 and included:


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 of the work 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:**

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

**Recommendation 2:**

That 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/whänau of choice of 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 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:**

That education of health professionals and volunteers promotes attitudes and behaviours that respond to the needs of people who are dying and their family/whänau

- The ANZSPM undergraduate medical palliative care curriculum should be adopted by the medical schools in New Zealand and palliative care approached in a systematic way throughout the undergraduate years.
- Specialist palliative care providers are 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:**

That services 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 Health Funding Authority 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 McLeod  Medical Director, 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 Jefferies  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 -
Reference Group Members and Terms of Reference

Terms of reference

1. Provide first-level consultation on the draft national strategy for palliative care.
2. Provide specific organisations’ feedback on the national strategy for the purchase and provision of palliative care.
3. Be available to the combined Ministry of Health, National Health Committee and Health Funding Project Team for additional expert/specialist advice.

It was not expected that this group would meet formally as a reference group.

Membership of the reference group

Age Concern Wellington
Aids Foundation
Auckland Healthcare
Australia and New Zealand Society for Palliative Medicine
Cancer Society
Cancer Society (Blenheim)
Cancer Society Care Giver Support Group
Canterbury Health
Capital Coast Health
Child Cancer Foundation
College of Nurses
Community Palliative Care Nurse Specialist
Eastern Bays Hospice Trust
Goodfellow Unit
Health Waikato
Healthcare Otago
Hospice Education Trust of Canterbury
Hospice New Zealand
Hutt Valley Health
Individual members
Liz Noule
Lorraine Goodlass
Dr Simon Allan
Jo Bransgrove
Nancy Sherwood
Koa Congdon
Ann Crawford
Trish McFadden, Chris Andrews
Kay Morris
Jenny Carryer
Martine Iggo
Richard Harris-Daw
Professor Ross McCormick
Margaret Stevenson, Dr Glenys Round
Elaine Chisnall
Kate Reid
Ann Martin
Jill Lane
Dr Ian Scott
Adrian Trenholme
Judy Macready
Appendix 4 -
Overview of Palliative Care Services

This appendix provides an overview of palliative care in New Zealand at the present time as well as expected future trends, and:

- provides demographic information and identifies the need for palliative care
- describes current palliative care services
- describes the workforce currently caring for people who are dying.

Demographic trends: identifying the need for palliative care services

Causes of death

Table 1 shows the age-standardised death rates for selected causes of death in 1996. As shown, 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 4.1: Causes of Death, 1996

<table>
<thead>
<tr>
<th>Cause of death</th>
<th>Rates per 100,000 population¹</th>
</tr>
</thead>
<tbody>
<tr>
<td>All causes of death</td>
<td>493.3</td>
</tr>
<tr>
<td>Total cancer</td>
<td>140.0</td>
</tr>
<tr>
<td>Ischaemic heart disease</td>
<td>106.1</td>
</tr>
<tr>
<td>Cerebrovascular disease</td>
<td>38.1</td>
</tr>
<tr>
<td>Hypertensive disease</td>
<td>4.4</td>
</tr>
<tr>
<td>Other forms of heart disease²</td>
<td>19.5</td>
</tr>
<tr>
<td>CORD³</td>
<td>19.5</td>
</tr>
<tr>
<td>Pneumonia and influenza</td>
<td>15.8</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>10.5</td>
</tr>
<tr>
<td>HIV</td>
<td>0.9</td>
</tr>
</tbody>
</table>

Notes: ¹Age standardised to Segi’s world population.

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

³Chronic 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 (Higgison 1996).

Cancer

People who are dying of cancer – the leading cause of death in New Zealand – often have physical, psychological and spiritual needs appropriate to palliative care.

Most need for palliative care will be from people with cancer aged 60 and over. In 1996 there were 7,461 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 and 2001, and 2007 and 2011, we can expect the number of people dying from cancer to increase by approximately 24 percent (Cox 1995); this is probably due, in the main, to the ageing population.

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

Data collected from hospices in 1998/1999 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 2).

Non-malignant diseases

Overseas experience indicates that there is an increasing need for palliative care services for those with non-malignant diagnoses. Estimates range between 20–100 percent of the number of cancer deaths.

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.

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5 Data from Hospice and Hospital Questionnaires. 1999. Health Funding Authority.
Children

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; their palliative care needs differ from adults’ needs.

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 which is developmentally appropriate.

Place of death

Table 4.2 shows the place of death for New Zealanders (hospices are included in the private hospital statistics along with institutions such as rest homes). Hospice care of a proportion of the people dying at home fits with the trend towards community-based care.

The table shows that overall a higher proportion of people with cancer and non-cancer diseases died in hospital than died at home. Over half (340) of Māori people with cancer die at home; this is higher than the proportion of non-Māori people dying at home. Pacific peoples have almost as high a proportion of home deaths as Māori have.

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 is available if this is what people want.

---

6 Data from Hospice and Hospital Questionnaires. 1999. Health Funding Authority.
Table 4.2: Place of Death, by Ethnicity 1996

<table>
<thead>
<tr>
<th>Place of death</th>
<th>Cancer deaths 1996</th>
<th>Non cancer deaths 1996</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Māori (n = 639)</td>
<td>Other (n = 6651)</td>
</tr>
<tr>
<td>Public hospital</td>
<td>35.5</td>
<td>39.0</td>
</tr>
<tr>
<td>Private residence</td>
<td>53.2</td>
<td>30.8</td>
</tr>
<tr>
<td>Private hospital or other institution</td>
<td>8.5</td>
<td>29.4</td>
</tr>
<tr>
<td>Psychiatric hospital</td>
<td>0.0</td>
<td>0.1</td>
</tr>
<tr>
<td>Other</td>
<td>2.8</td>
<td>0.6</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Pacific People (n = 171)</th>
<th>Māori (n = 1991)</th>
<th>Other (n = 18362)</th>
<th>Pacific People (n = 565)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public hospital</td>
<td>42.1</td>
<td>39.2</td>
<td>41.3</td>
<td>45.7</td>
</tr>
<tr>
<td>Private residence</td>
<td>41.5</td>
<td>41.0</td>
<td>23.8</td>
<td>38.6</td>
</tr>
<tr>
<td>Private hospital or other institution</td>
<td>16.4</td>
<td>5.6</td>
<td>29.4</td>
<td>7.9</td>
</tr>
<tr>
<td>Psychiatric hospital</td>
<td>0.0</td>
<td>0.1</td>
<td>0.3</td>
<td>0.0</td>
</tr>
<tr>
<td>Other</td>
<td>0.0</td>
<td>14.3</td>
<td>5.2</td>
<td>7.8</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

**Current service provision**

Dying people can currently receive services from a wide range of providers including hospices, hospitals, community health services, general practitioners, rest homes, private hospitals and individual carer support providers, but access is dependent upon 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 hospices are voluntary-based services and employ no clinical staff. Voluntary hospices are situated in Kaipara, 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 1997/1998 hospices cared for 4886 people, 80 percent of whom were 60 years and over. Hospices are mainly free-standing units that provide dedicated palliative care to dying people in line with the World Health Organization (WHO) philosophy of palliative care. Care is mainly delivered to people in their home.

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* Data from Hospice and Hospital Questionnaires. 1999. Health Funding Authority.
Hospices may provide inpatient care, domiciliary (medical and nursing) care, day care, respite care and bereavement and counselling (table 3), with no hospice providing the full range of services. 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, while a large proportion provide bereavement counselling.

### Table 4.3: Hospice Services in New Zealand (n = 32)

<table>
<thead>
<tr>
<th>Type of Service</th>
<th>Number of hospices providing this service</th>
<th>Percentage of hospices providing this service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient care</td>
<td>19</td>
<td>59%</td>
</tr>
<tr>
<td>Night carer relief</td>
<td>11</td>
<td>34%</td>
</tr>
<tr>
<td>Medical advisory service</td>
<td>15</td>
<td>47%</td>
</tr>
<tr>
<td>Nursing advisory service</td>
<td>21</td>
<td>66%</td>
</tr>
<tr>
<td>Domiciliary palliative care nursing</td>
<td>19</td>
<td>59%</td>
</tr>
<tr>
<td>Bereavement counselling</td>
<td>27</td>
<td>84%</td>
</tr>
<tr>
<td>Spiritual care</td>
<td>18</td>
<td>56%</td>
</tr>
<tr>
<td>Social work service</td>
<td>9</td>
<td>28%</td>
</tr>
<tr>
<td>Daycare programme</td>
<td>22</td>
<td>69%</td>
</tr>
</tbody>
</table>

### Hospitals

#### Service provision in Hospital and Health Services (HHSs)

Hospital services are particularly important where there are no hospice services, for example, on the West Coast, and Central Otago. Each hospital has a number of facilities that provide services in outlying areas, for example, community and 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 health-of-the-elderly wards. Community nursing care is provided through district nursing services. Some other services, such as social work services, are provided by allied health professionals.

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10 Data from Hospice and Hospital Questionnaires. 1999. Health Funding Authority.

11 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.
Information gained from HHSs is summarised in table 4.4 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 only three hospitals – Auckland Hospital, Waikato Hospital, and Christchurch Hospital
- in addition to the three hospitals above, Starship Hospital provides a children’s palliative care service.

Table 4.4: Percentage of Hospital and Health Services and Hospices Providing Palliative Care Type Services as Reported by Providers (n = 22)

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

Availability of beds in hospices and hospitals

Table 4.5 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. If we used Britain 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.

12 Middlemore Hospital employs one palliative care nurse specialist. This provider is not considered to have a Hospital Palliative Care Team.

13 Eve, A Smith, AM. And Tebbitt, P. 1997 Hospice and Palliative Care in the UK 1994-95 including a summary of trends 1990-5 Palliative Medicine 11:31-43
Table 4.5: Palliative Care Beds by Type, Locality and Location

<table>
<thead>
<tr>
<th>Locality</th>
<th>Dedicated beds in an acute hospital</th>
<th>Hospice beds</th>
<th>Total beds for region</th>
<th>Beds/100,000 population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northland</td>
<td>1</td>
<td>7</td>
<td>8</td>
<td>5.84</td>
</tr>
<tr>
<td>Auckland</td>
<td></td>
<td>36¹</td>
<td>36</td>
<td>3.33</td>
</tr>
<tr>
<td>Waikato</td>
<td>2</td>
<td></td>
<td>2</td>
<td>0.64</td>
</tr>
<tr>
<td>Bay of Plenty</td>
<td>2</td>
<td></td>
<td>2</td>
<td>0.77</td>
</tr>
<tr>
<td>Taranaki</td>
<td></td>
<td>6²</td>
<td>6</td>
<td>5.62</td>
</tr>
<tr>
<td>Tarawhiti/Hawkes Bay</td>
<td>2</td>
<td>8³</td>
<td>10</td>
<td>5.28</td>
</tr>
<tr>
<td>Wanganui/Manawatu</td>
<td></td>
<td>13</td>
<td>13</td>
<td>5.96</td>
</tr>
<tr>
<td>Wellington</td>
<td></td>
<td>32</td>
<td>32</td>
<td>7.73</td>
</tr>
<tr>
<td>Nelson/Marlborough</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>3.43</td>
</tr>
<tr>
<td>Canterbury/West Coast</td>
<td>4</td>
<td>16</td>
<td>20</td>
<td>4.01</td>
</tr>
<tr>
<td>Otago/Southland</td>
<td>14</td>
<td>14</td>
<td>14</td>
<td>4.93</td>
</tr>
<tr>
<td>Total</td>
<td>11</td>
<td>136</td>
<td>147</td>
<td>4.06</td>
</tr>
</tbody>
</table>

Notes:  
1. Excludes three rest home beds subcontracted to a rest home by West Auckland Hospice but includes six 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 two beds at the Rollinson Unit (Napier Hospital).

Primary care service provision

GPs and practice 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 DSS-managed carer support services, provided either at home or in a provider setting, usually for 28 days (this varies in different regions). The person can choose to use their carer support allocation for night carer relief, with the criteria and methods for access to carer support also varying 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, too, is 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
- access care by referral from a hospital department or a general practitioner.

There is a group of people who will already be in a residential setting who either develop a terminal illness or whose illness becomes terminal, for example, those who develop cancer or end-stage Motor Neurone Disease. These people are likely to stay in the residential setting and are likely to require 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 which provide care to dying people. The main organisation is 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.

**Palliative care service provision for children**

Much work in identifying palliative care services available for children has already been completed by the *Paediatric Review*. 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 disability support services, 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 just under 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.

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Funding of services

Hospices

Funding for hospices varies between the different regions. For example, hospices in the central region are funded on a per patient basis while hospices in the southern region are mainly funded on numbers of bed days. At present, hospices are partially funded by the Government to approximately 50 percent of their operating costs. The balance is raised through fundraising and voluntary donations.

Hospitals

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

Primary care services

The funding for palliative primary care services is similar to 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 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 (eg, 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 4.6 provides a summary of the palliative care workforce.
Table 4.6: Summary of Hospice and Hospital workforce (FTE and hours)\textsuperscript{15}

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

* 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)

Key findings from the workforce data

The key findings from the workforce data are:

- There are only 8.9 FTE palliative care medicine specialists employed by hospices yet there are 37 hospices in New Zealand. A number of these specialists work part-time and are situated in Auckland, Waikato, Taranaki, Wanganui/Manawatu, Wellington, Christchurch and Otago. The largest number is employed in Wellington (3.3 FTE). Where there is no palliative care medicine specialist available, a GP or other doctor (for example, an anaesthetist) provide medical care.

- There are only 3.2 FTE palliative medicine specialists employed in hospitals 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.

\textsuperscript{15} Data from Hospice and Hospital Questionnaires, 1999. Health Funding Authority.
• Just over half of the hospice nursing workforce has 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 have 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 are 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: 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 – that is, 8.5 FTE more than New Zealand has at present.

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. If proposed legislation does enable nurse prescribing for the child and family and older people, palliative care nurses will be offered an additional one-year training course (at masters level) in prescribing. The ability to prescribe to dying people would have implications for the future delivery of palliative care services, for example, in rural areas.
Appendix 5 -

Issues Relating to Palliative Care Services in
New Zealand

As a consequence of significant analysis undertaken specifically for the purposes of developing this
strategy, areas of concern with current palliative care service provision in New Zealand have been
identified. These are:

1. lack of a palliative care approach in some services
2. lack of access to palliative care services
3. integration/co-ordination of palliative care service
4. quality of services and monitoring
5. workforce and education
6. funding.

Issue 1 - Lack of a palliative care approach

With 39 percent of cancer deaths occurring in public hospitals, the palliative approach perhaps
appropriate to the dying person’s care may be lacking in the hospital environment. Clinical hospitals
have a strong curative, intervention-focused culture; institutional settings for the care of older people
and those with degenerative conditions offer scanty provision of palliative care.

A recent study by Christakis and colleagues (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 patient§:

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’.

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16 Christakis NZ, Lamont EB. Extent and Determinants of error in doctors’ prognosis in terminally ill patients: prospective
cohort study, BMJ 320: 469–473.

Issue 2 - Access to palliative care services

Service gaps

A number of service gaps have been identified in New Zealand18 and is consistent with findings overseas19, 20 and is to be expected given the recent ad hoc purchasing approaches and inconsistent development of palliative care services. Service gaps identified include:

1. 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, or for people with conditions other than cancer.

2. Community care to support people wishing to die at home

While some hospices, general practitioners 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 Disability and Support Services, the amount of care provided can be dependent on a needs assessment. The undefined nature of a needs assessment is often considered insufficient in determining the needs of people who are dying. Patients who do not have sufficient support at home may have to be admitted to a hospital, hospice or rest home.

3. Inpatient care

There is a large variation in the availability of palliative care beds in hospitals and hospices.21 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.

Patients accessing long-term care have difficulties when this is provided through disability services by default through the lack of long-term care in hospitals and hospices. People often have to access rest home care when they require longer-term care; this care may or may not be appropriate, depending on the rest home’s staffing levels, expertise, and links with palliative care organisations. Also, rest homes may not be appropriate for younger people who require longer-term care.

4. 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. People dying in rural areas are generally dependent on GP, practice nurse and district nursing services which are often in short supply.

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18 Data from Hospice and Hospital Questionnaires. 1999. Health Funding Authority.
21 Data from Hospice and Hospital Questionnaires. 1999. Health Funding Authority.
22 Health Funding Authority Database 2000.
5. 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.

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 (CORD), 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 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 the medically fragile group compare poorly with those available to clients with cancer. This is largely due to the public sympathy towards children with cancer.

Māori access to palliative care

The following issues that affect access to palliative care services for Māori have been identified:

- 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 are currently 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
- over half (340) of Māori people with cancer die at home (see table 2). There is a need to consider this aspect when planning for Māori needs for palliative care services
- 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

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24 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’.
• a lack of suitable respite care
• a lack of dedicated family support
• a total lack of co-ordinated grief and bereavement support and resource for this, mainly due to major deficiencies in the child mental health service
• a lack of resource and a lack of 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.

Access to palliative care for Pacific peoples

The following barriers to access have been identified by Pacific peoples.
• There are well-established cultural protocols for dealing with people who are dying dictated by spiritual beliefs but these are not always applied.
• Philosophical opposition to the NFR (not for resuscitation) policies.
• Pacific peoples often have difficulties in accessing information about palliative care services.
• There are often communication/language difficulties with people not understanding the condition of their dying relative and this can influence access to necessary care.
• The disease and treatment process is not always explained adequately to the wider family group to enable them to make informed decisions.
• 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 there are 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.

25 Sourced from an informal survey of some Pacific providers and the report, Children and Young People with Terminal Illness (September 1994).
Issue 3 - Lack of integration/co-ordination of services

While there are examples of good co-operation between providers of palliative care services, generally there appears to be little co-ordination or integration of services among providers. 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 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
- fragmentation and duplication of services
- an inability to provide flexible packages of care that are specific to an individual or their family’s needs.

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

- currently there are no standard quality specifications for palliative care services in hospice contracts
- while requirements for quality in hospitals and IPAs are included in HFA contracts these are very general and are not specific to palliative care
- 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 is a lack of 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.

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26 Data from Hospice and Hospital Questionnaires. 1999. Health Funding Authority.
27 Data from Hospice and Hospital Questionnaires. 1999. Health Funding Authority.
Issue 5 - Workforce and education

Identified issues relating to workforce and training also impact upon the delivery and quality of palliative care services. Workforce issues 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
- a shortage of palliative care medicine specialists 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.

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 workforce (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 throughout the country receive different levels of funding, with insufficient public funding available to fill the service gaps identified earlier.

Hospices are only partially government-funded and rely on bequests, donations and fund-raising activities to run their hospice. 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. Yet 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.

GPs, too, have indicated that they have funding issues in providing palliative care. They do not always 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.

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28 Data from Hospice and Hospital Questionnaires. 1999. Health Funding Authority.
29 Data from Hospice and Hospital Questionnaires. 1999. Health Funding Authority.
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, they 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.

The model suggests that three to four models of palliative care provision need to develop in Britain which includes:

1. 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.

2. Oncology centre exclusively for cancer patients. Care would start at an early stage and the medical team would have extensive training in oncology.

3. 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 (eg, for chronic pain, lymphodema or rehabilitation of people with chronic diseases).

4. 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.32

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32 Background for a National Strategy for Palliative Care in Australia, 1998.
The provision of palliative care is variable across Australia with similar issues and problems as in New Zealand. 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.

**Canada**

Canadian palliative care programmes first developed in 1974/1975 and have sought to be integrated into mainstream health care at both institutional and community levels. 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.

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. 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.

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33 Background for a National Strategy for Palliative Care in Australia, 1998.
34 Background for a National Strategy for Palliative Care in Australia.
35 The Institute of Palliative Care, www.pallcare.org
Appendix 7 -
Glossary

Domiciliary or community palliative care nurses
These nurses provide care to people who are dying in the home or long-term residential facility. These nurses 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:
1. 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.
2. It can refer to a hospice unit. Usually this is a free-standing unit with inpatient facilities, where palliative care is practiced, 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
A health care facility established under New Zealand Government legislation as a hospital or a free-standing day procedure unit and authorised to provide treatment and/or care to patients.

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
• 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; however 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 which is provided by hospices or hospitals also access residential care.

Multidisciplinary team
This team would consist of 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
This is 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
Palliative medicine is 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 her position in life in the context of the culture in which she lives, and in relation to her 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
Specialist palliative care services are those 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
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
Terminal illness refers to 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
The terminal stage usually refers to a steady deterioration in the patient’s condition, which indicates that death is close.