Positioning Palliative Care in New Zealand:

A review of Government Health Policy in relation to the provision of Palliative Care Services in New Zealand

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The Palliative Care Council of New Zealand

The Palliative Care Council (PCC) was established in 2008 by Cancer Control New Zealand (formerly the Cancer Control Council of New Zealand) to provide independent and expert advice to the Minister of Health, and to report on New Zealand’s performance in providing palliative and end of life care.

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## Contents

Executive Summary ........................................................................................................4
Introduction......................................................................................................................4
Palliative Care in New Zealand .......................................................................................4
Selected International Review .......................................................................................4
Recommendations ............................................................................................................5
Introduction......................................................................................................................7
Palliative Care in New Zealand Government Health Policy .........................................8
Palliative Care and Cancer Control ..............................................................................8
Other Health Related Strategies .....................................................................................10
Workforce.......................................................................................................................12
Selected International Review .......................................................................................13
Australia .........................................................................................................................13
United Kingdom ............................................................................................................13
Canada ...........................................................................................................................14
Conclusion ......................................................................................................................16
Recommendations .........................................................................................................18
References ......................................................................................................................20
Appendices .....................................................................................................................24
   Appendix 1: Links between Palliative Care and Cancer Control Strategies ............24
   Appendix 2: Comparison of priority areas for international palliative/end of life care strategies .................................25
Executive Summary

Introduction

1. Palliative care is a holistic approach to the care of people dying from progressive, incurable disease, which aims to prevent and relieve suffering. All people in New Zealand with a life-limiting illness, and their family/whanau, must have access to high quality palliative care, regardless of ethnicity, age, geographic location or diagnosis. It should be regarded as a basic human right for dying people to be treated respectfully and with expertise – the aim being freedom from pain and other symptoms if at all possible. This is best achieved through palliative care delivered in an appropriate, timely and co-ordinated way.

Palliative Care in New Zealand

2. Older people with cancer currently make up the vast majority of those who use palliative care services. However, this group is not representative of all those who could benefit from palliative care. It has been acknowledged internationally that this situation must be addressed by incorporating palliative care into the treatment of all people with non-cancer diagnoses. It is also likely that a number of other groups are not accessing palliative care services as often or as easily as they should be able to. This includes Māori and Pacific peoples and other minority ethnic groups, people in rural areas, children and adolescents, and the elderly in residential care. The availability of reliable data on palliative care services is poor, and as such firm conclusions cannot be drawn on the level and breadth of access to palliative care services in New Zealand.

3. A national Palliative Care Strategy has been in place since 2001. It focuses predominantly on establishing palliative care services. The Strategy has nine key strategic goals designed to create “a systematic and informed approach to the provision and funding of palliative care services” for all people dying from an incurable, progressive disease. Alongside this document, the New Zealand Cancer Control Strategy identifies specific outcomes for the provision of palliative care to people with cancer.

4. A review of strategic health documents across the health system reveals some support for palliative care as part of the patient journey in a number of other chronic diseases and patient groups. However, the role of palliative care is often not explicit within these documents. There is very little guidance on how the palliative care needs of these groups should be met. Particular issues that contribute to this situation are the lack of information on palliative care; specifically, population need, current services available and service utilisation, and a general lack of understanding and awareness of palliative care.

Selected International Review

5. A review of government health policy from the United Kingdom, Australia and Canada demonstrates that New Zealand is falling behind in the integration of palliative care into government health strategy. In some cases integration of palliative care into non-malignant disease strategies has occurred; however this is still not adequate nor explicit enough to ensure palliative care is fully integrated into chronic disease management outside of cancer. New Zealand has similar strategic goals for palliative care as these countries, with the exception of two important components. These components are 1. influencing policy and strategic
development and 2. research. The current Palliative Care Strategy is reaching the end of its original timeframe (2010) and work is needed now on future guidance on palliative care service development. The three countries mentioned above have already launched, or are currently developing, more contemporary national palliative care/end of life care strategies.

6. Since the launch of the Palliative Care Strategy in 2001, considerable work has gone into establishing service providers. But the general lack of information, as noted in points two and four, makes it difficult to assess whether the Strategy, and associated government investment, have had any impact on service provision or patient outcomes. No monitoring and evaluation of the Palliative Care Strategy has been undertaken, and there has been no national stocktake of service provision. While some progress has been made in relation to workforce and the development of quality requirements, the following challenges remain:

- Inequality of access; particularly based on diagnosis, but also in relation to ethnicity, age and geographic location.
- Lack/absence of data on population need, service provision and service utilisation.
- Lack of awareness/utilisation of palliative care services among the general public and health care professionals.
- Lack of inclusion in national health policy and strategic planning.
- Lack of a national strategic approach to research in palliative care.

**Recommendations**

It is apparent that there is a relatively poor understanding of the need for palliative care and a lack of information on services currently being provided and how they are being accessed by people with life-limiting illnesses. To shift palliative care to a stronger footing and start to address the challenges identified above, it is recommended that:

a) An outcomes focused monitoring and evaluation framework be developed, based on the Palliative Care Strategy and relevant outcomes of the Cancer Control Strategy Action Plan (2005 - 2010). This will allow for monitoring and evaluation at a strategic level.

b) An evaluation of palliative care service provision is undertaken using the above framework, to establish the current state of service provision and accurately identify achievements, gaps and opportunities for improvement.

c) A project is undertaken to determine, for the first time, the need for palliative care on a population basis for all people who would benefit from palliative care. This project will follow an established methodology to ensure meaningful results and allow comparison with other countries.

Based on the recommendations a, b and c, the following actions are needed:

d) Urgently address service gaps, especially for groups currently underserved by palliative care, and who would benefit greatly from improved access.

e) Review the New Zealand Palliative Care Strategy to ensure it addresses the contemporary issues facing palliative care.
f) Raise public, professional and government awareness of palliative care and the services available, especially in non-cancer disease groups.

g) Ensure palliative care is fully incorporated into overarching health policy and chronic disease strategies.
Introduction

Palliative care is a holistic approach to the care of people dying from progressive, incurable disease, which aims to prevent and relieve suffering through “early identification and impeccable assessment and treatment of pain and other symptoms” (World Health Organisation 2002, p. 84). It embraces all spheres of health including physical, psychosocial, spiritual and cultural aspects of wellbeing, and is centred upon achieving the best possible quality of life for the individual (Palliative Care Subcommittee 2007). Palliative care is an integral component of the health care continuum and may be provided when curative or disease modifying treatment has come to an end, or while treatment directed at the disease is still being given. Palliative care also encompasses the family/whanau and carer(s) of the dying person, and may continue to support these people after the person’s death.

All people diagnosed with a life-limiting illness must be able to make an informed choice about their treatment, and this should include the option of palliative care. At present in New Zealand the majority of people who access palliative care services have a cancer diagnosis and are over the age of 60 (Ministry of Health (MoH) 2001b). However, this group is not representative of all those who would benefit from palliative care, as it excludes people with other life-limiting illnesses, such as end stage HIV/AIDS, cardiac, respiratory, renal and liver disease, dementia, and neurodegenerative disorders, as well as other age groups, in particular children and adolescents. For this reason it is essential that any person with a life-limiting illness must have access to high quality palliative care, regardless of ethnicity, age, geographic location or diagnosis. It should be regarded as a basic human right for dying people to be treated respectfully and with expertise – the aim being freedom from pain and other symptoms if at all possible. This is best achieved through palliative care delivered in an appropriate, timely and co-ordinated way.

The purpose of this report is to establish the position of palliative care within New Zealand government health policy, and compare this to an international picture taken from three selected countries.


Palliative Care in New Zealand Government Health Policy

The New Zealand Health Strategy requires “access to appropriate palliative care services” (p.12) as part of its call for accessible and appropriate health care services (MoH 2000). It also identifies the need to reduce the impact of chronic diseases, which may be achieved through good palliative care, and address inequalities in health. In contrast, the Primary Health Care Strategy (MoH 2001c) does not specifically address palliative care, hospice or end of life care requirements, even though the World Health Organisation (WHO) describes primary health care as being the most important setting for palliative care (WHO 2007). Nevertheless, palliative care does fit within several of the key directions of this strategy. In particular these include: addressing health inequalities, ensuring access to comprehensive health services, co-ordinating care across service areas and developing the primary health care workforce.

Palliative Care and Cancer Control

In February 2001 The New Zealand Palliative Care Strategy was launched with the aim of setting in place “a systematic and informed approach to the provision and funding of palliative care services” for all people in New Zealand who are dying from an incurable, progressive disease (MoH 2001b). To achieve this, the Palliative Care Strategy outlines nine key strategies for achieving its vision:

1. Ensure access to essential palliative care services.
2. Each District Health Board (DHB) to have at least one local palliative care service.
3. Develop specialist palliative care services.
4. Implement hospital palliative care teams.
5. Develop quality requirements for palliative services.
6. Inform the public about palliative care services.
7. Develop the palliative care workforce and training.
8. Ensure that recommendations from the Paediatric Review1 are implemented.
9. Address issues of income support.

Following on from this work, an expert working group on palliative care provided a report in 2003 to inform the development of a national cancer control strategy. The report identified a number of barriers that were still preventing people with cancer receiving appropriate care two years after the launch of the Palliative Care Strategy. These barriers were:

- The lack of a palliative care approach by some cancer service providers, leading either to no referral or late referral to palliative care services.
- Uneven distribution of palliative care services throughout the country, resulting in service gaps, particularly in rural areas.
- Barriers to access, especially for Māori and Pacific peoples.
- A lack of services specifically designed for children and adolescents.
- Lack of co-ordination and inflexibility of services.
- Workforce planning and development (MoH 2003b).

In response to this report, The New Zealand Cancer Control Strategy (MoH 2003c) emphasises the need for palliative care as an integral part of the cancer control continuum. In particular, Goal four, Objectives six and seven of the Strategy relate

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1 Health Funding Agency and the Paediatric Society of New Zealand. 1998. Through the eyes of a child: a national review of paediatric specialty services. Wellington: Health Funding Agency.
specifically to the provision of palliative care for people with cancer and their family/whanau.

Objective 6: Continue to improve access to essential palliative care services that provide appropriate symptom relief and emotional, spiritual, cultural and social support for those with cancer and their family and whanau.

Objective 7: Ensure an integrated and comprehensive service is provided to all those with cancer who require palliative care and their family and whanau.

The New Zealand Cancer Control Strategy: Action Plan 2005 – 2010 (Cancer Control Taskforce 2005) provides more detail on how the objectives of the Strategy will be achieved. Implementing the Palliative Care Strategy is a phase one outcome of the Action Plan, which requires DHBs to develop and implement palliative care service plans as part of their annual plans. Objectives six and seven of Goal four require action to address issues of access, especially for groups currently underserved by palliative care services, improve availability of data on palliative care for monitoring purposes, and the formation of a national palliative care leadership body. Action is also required to develop national standards for palliative care service provision, review and address issues of resourcing and service delivery, including the development of service specifications, and institute local and regional palliative care networks to improve integration and coordination of services.

Goal 5 deals with workforce issues and Outcome 93 is aimed at addressing the current shortfalls in palliative care workforce numbers, ethnic imbalance in the workforce and meeting future workforce requirements.

Goal 5, Objective 1: Develop a co-ordinated national cancer workforce strategy.

Outcome/results 93. Increased recruitment and retention of palliative care workers to provide an integrated and comprehensive service throughout New Zealand.

Several other goals and objectives are also relevant to palliative care service development. These objectives are more broadly focused, but have an impact on palliative care service provision in relation to supportive care, such as psychosocial care and financial support, and including services appropriate to the needs of children and adolescents. These include:

Goal 3, Objective 4: Improve the quality of care delivered to adolescents with cancer and their family and whanau.

Goal 4, Objective 1: Establish integrated programmes of supportive care and rehabilitation with defined leadership.

Another objective of Goal 4 focuses on appropriate resourcing of supportive care services, in particular for those who currently have difficulty accessing services, e.g. Māori and Pacific peoples, and other ethnic and low socioeconomic groups.

Goal 4, Objective 2: Ensure people with cancer and their families and whanau are able to access the appropriate resources for support and rehabilitation that they need.
The Palliative Care Strategy and Cancer Control Strategy are the most comprehensive documents addressing palliative care in New Zealand and share a number of common themes. These include improving access to services, setting and monitoring quality standards and workforce development. The most important difference is in the focus of the Strategies. The Cancer Control Strategy focusing solely on people with cancer, while the Palliative Care Strategy has a focus on all people who are dying from active progressive disease. See diagram in Appendix 1, which illustrates some direct links between these two strategy documents. Note that Outcome 79 of the Action Plan: ‘A system and structure for national leadership in palliative care will be developed for the Cancer Control Strategy’, does not appear to have been addressed in the Palliative Care Strategy.

In *Mapping Progress II*, the Cancer Control Council notes that considerable work is in progress towards achieving the above objectives of the Action Plan, however there has been some delay in fully implementing the Palliative Care Strategy due to the lack of national leadership (Cancer Control Council of New Zealand 2008a). The Council has identified implementing the Palliative Care Strategy, through a palliative care working group, as a priority initiative to be achieved by the end of phase 2 (2010) of the Cancer Control Strategy Action Plan (Control Council of New Zealand 2008b). On a more encouraging note, from a cancer control perspective, the recently released *Clinical Practice Guidelines in Australia and New Zealand for the Management of Melanoma* (Australian Cancer Network Melanoma Guidelines Revision Working Party 2008) does include palliative care as a vital component of melanoma management, especially for those diagnosed with metastatic melanoma.

**Other Health Related Strategies**

There are a number of other health related government strategic documents and reports that also include some discussion and/or recommendations on palliative care. These are reviewed here in relation to potential inequalities in access to palliative care service, in particular age, ethnicity, geographic location and diagnosis.

**Age** can be a significant barrier to accessing appropriate palliative care, especially for children, adolescents and the elderly (in particular those in residential care). A 1998 report on paediatric specialty services in New Zealand (Health Funding Agency and the Paediatric Society of New Zealand 1998) recommended a national service model for children’s palliative care be developed. This would include a national paediatric palliative care team that would work alongside local co-ordinators and paediatric child health teams. The report also recommended developing a national network that would be responsible for developing and monitoring nationwide standards of care. Following on from this report, both *The Provision of Children’s Cancer Services in New Zealand* (MoH 1999) and *Youth Health: A Guide to Action* (MoH 2002) call for the needs of children and adolescents to be addressed as part of palliative care service development. Specific actions include:

*The Provision of Children’s Cancer Services in New Zealand* (MoH 1999, p.35)
- Policies and provision for paediatric palliative care (both in hospital and at home) should be defined and arrangements available for the offer of bereavement support and counselling.
Youth Health: A Guide to Action (MoH 2002f).
- Ensure the needs of young people (aged 12 to 24 years inclusive) are included in implementing the recommendations of the Palliative Care Strategy regarding children and young people.

Goal Nine
A measurable improvement in the health of disabled young people and young people with chronic illness.
- Health services that are more responsive to the needs of disabled youth, young people with chronic illness, and young people in palliative care (MoH 2002f, p.45).

Unfortunately, the establishment of palliative care services for children still does not appear to have been fully achieved, as documented in a submission from the Paediatric Society of New Zealand to the Palliative Care Working Group (Drake 2007). This submission notes that while a specialist paediatric team has been set up, it only services the Auckland region, and that most DHBs have not set up local paediatric palliative care co-ordinators and see palliative care as being necessary only for children with malignant conditions.

The Health of Older People Strategy: Health Sector Action to 2010 to Support Positive Ageing (MoH 2001a) suggests developing care pathways or guidelines to assist decision making for older people needing palliative care, and also requests appropriate palliative care for older people in long-term care. In addition, the report Dementia in New Zealand: Improving Quality in Residential Care (MoH 2002b) identifies palliative care as an essential service for older people with advanced (Stage 5) dementia.

Issues of access based on ethnicity are still cause for concern in New Zealand, most notably for Māori and Pacific peoples, but also for many other minority ethnic groups. There is limited recognition of this problem in both He Korowai Oranga: Māori Health Strategy (MoH 2002d) and The Pacific Health and Disability Action Plan (MoH 2002e). While both strategies mention palliative care as a need, it is given very little attention. The report Access to Cancer Services for Maori (MoH 2002a) notes access to palliative care services for Māori as being an issue, although actual usage is difficult to determine using currently available data. The report found that Māori are often referred very late and so do not get the full benefit of palliative care services. It also suggests that ‘place of death’ data may be incorrectly suggesting that Māori prefer to die at home, whereas it may actually reflect the fact that they are unable to access palliative care services. Cultural competency and mix of the palliative care workforce may also be an issue, along with a lack of understanding and awareness of palliative care services by health care providers and communities. There is very little recognition of end of life needs for other ethnic groups in New Zealand, apart from generic statements in both the New Zealand Health Strategy and Primary Health Care Strategy, which require equitable access to health services regardless of ethnicity.

The issue of accessing palliative care, particularly specialist services, can be influenced by the geographical location of the patient. In New Zealand there are significant issues for those in rural areas that may be served by small district hospitals and a small number of General Practitioners (GP). Several strategies of the Palliative Care Strategy address issues of inequalities of access, availability of local palliative care teams and access to specialist palliative care services. In addition, access is also addressed in the Cancer
Control Strategy. Outside of these two documents, access issues related to location are dealt with from a generic aspect in *The New Zealand Health Strategy* and *The Primary Health Care Strategy*.

The palliative care needs of people with a non-cancer diagnosis are addressed in a number of government documents, most notably *Meeting the Needs of People with Chronic Conditions* (National Advisory Committee on Health and Disability 2007). This report identifies the need for appropriate and timely referrals to palliative care services, improved assessment and management of pain, and effective delivery of palliative care by primary healthcare organisations. These opinions are echoed in *Doing Better for New Zealanders: Better health, Better participation, Reduced Inequalities* (MoH 2002c), which includes the requirement for “ongoing support for people with chronic conditions such as diabetes, or people who require palliative care or other in-home support” (p. 32). In addition, the *HIV/AIDS Action Plan: Sexual and Reproductive Health Strategy* (MoH 2003a) asked for a review of palliative care services to ensure they meet the needs of people with HIV/AIDS into the future. As noted earlier the needs of older people with dementia have also been reported (MoH 2002b). On a less positive note, the *Diabetes and Cardiovascular Disease Quality Improvement Plan* (MoH 2007b) does not discuss the requirements for palliative care or end of life needs of people with diabetes or cardiovascular disease. In addition, no specific strategies could be located that discusses palliative care for people with end stage respiratory, renal, liver or neurodegenerative diseases.

**Workforce**

Demand for health services in the future, including palliative care, will increase due to the increasing size and age of the population, as well as medical advances increasing survivorship in people with chronic conditions (Medical Training Board 2008). The need for health and disability services is highest near the end of life (mostly in the last year if life), in particular for those over age 70, who suffer from “increasing and accelerating health problems and disability levels” (Cornwall & Davey 2004, p. 1). Therefore, planning for future palliative care workforce requirements is crucial to meet the needs of New Zealand’s changing population demographics. The *Cancer Control Workforce Stocktake and Needs Assessment* published in 2007 (MoH 2007a) identified a significant lack of palliative medicine specialists and a poorly defined palliative care nursing workforce. The report recommended that work be undertaken to formally establish the required workforce capacity and capability for New Zealand, and establishing national frameworks for palliative medicine and nursing to support training and development. To begin to meet this need, the Clinical Training Agency (CTA) has made a commitment to physician training in palliative medicine in their purchase intentions for 2008/2009 (7.0 FTE training posts) (Clinical Training Agency 2008). The recently completed *Report on Palliative Care and Cancer Nurses’ Educational Needs* (Kent et al. 2008) found a significant increase in the number of nurses working in palliative care from 2004 to 2007, and recommended a need for ongoing education and development for this group. This has led to the development of *A National Professional Development Framework for Palliative Care Nursing in Aotearoa New Zealand* (MoH 2008), which provides a pathway for nurses to develop expertise in palliative care. Funding for postgraduate nursing education is no longer specified for palliative care, this is now included within CTA funding for all postgraduate nursing education, and provided direct to DHBs. At present, there does not appear to be any strategic approach to palliative care education for allied health professionals.
Selected International Review

In preparing this review three countries were chosen that have similar health care systems to New Zealand: Australia, the United Kingdom and Canada. The public access health related websites of these countries governments were accessed and relevant documents retrieved and reviewed for information on palliative care services. Aside from specific palliative/end of life care and cancer control documents, this also included, where available, overarching national health strategy documents and chronic disease management.

Australia

The National Palliative Care Strategy: A National Framework for Palliative Care Service Development was launched in 2000 to ensure consistent delivery of quality and accessible palliative care across Australia (Commonwealth Department of Health and Aged Care 2000). This strategy has 13 objectives across three main goals: raising awareness and understanding of palliative care, improving quality and effectiveness of services, and enhancing partnerships in care (see Appendix 2 for details of objectives). This strategy is currently undergoing review and updating to meet future palliative care needs within Australia. In addition to embedding palliative care within its National Service Improvement Framework for Cancer (National Health Priority Action Council 2006b); the Australian Government has also made a commitment to enhancing palliative care services in other groups. In both the National Chronic Disease Strategy (National Health Priority Action Council 2006a) and National Service Improvement Framework for Heart, Stroke and Vascular Disease (National Health Priority Action Council 2006c), there is substantial recognition of the role palliative care plays for those people with non-cancer diagnoses. Strategies on other chronic diseases were unable to be located. In December 2008, the National Health and Hospitals Reform Commission released its interim report which details proposals for the “long-term reform for the Australian health care system” (National Health and Hospitals Reform Commission 2008). This report devotes an entire chapter to the care of people at the end of life, and specifies five key reform directions to improve the care dying people receive. These include enhancing primary health services ability to care for dying people, strengthening access to specialist palliative care services – aiming to increase palliative care delivered in the community and aged residential care facilities, investing in advance care planning programmes and raising awareness of patient choice, including the right to decline treatment. Between 2003 and 2011, the Australian Government has pledged $284.8 million to the National Palliative Care Program. This funding will cover community palliative care, health care agreements across the states and local palliative care grants for health-related services (Australian Government Department of Health and Ageing 2008).

United Kingdom

In recognition of the broader requirements for palliative care services, the United Kingdom (UK) Department of Health (DH) has released a new national strategy for palliative and end of life care; End of Life Care Strategy: Promoting High Quality Care for all Adults at the End of Life (DH 2008b). The strategy focuses on 12 key areas (see Appendix 2), many of which relate to improving quality of, and access to care. Other areas include raising the profile of end of life care, education and training for health professionals, monitoring and research. The DH has also provided guidance for the National Health Service (NHS) on palliative care services for children and young people
in Commissioning Children’s and Young People’s Palliative Care Services: A Practical Guide for the NHS Commissioners (DH 2005a). However, a 2007 independent review of palliative care services for children and young people in England found a number of gaps, and recommended improving choice, access and continuity of care (Craft & Killen 2007). In response to this report, the DH published a new national strategy for children’s palliative care in 2008. Better Care, Better Lives has the vision that “every child and young person with a life-limiting or life-threatening condition will have equitable access to high quality, family centred, sustainable care and support, with services provided in a setting of choice according to the child and family’s wishes” (DH 2008a, p. 11).

Alongside The NHS Cancer Plan: A Plan for Investment, a Plan for Reform (DH 2000), in which palliative care is an integral component, the National Institute for Health and Clinical Excellence (NICE) has provided guidance for cancer palliative care in Improving Supportive and Palliative Care for Adults with Cancer (National Institute for Health and Clinical Excellence 2004). This guidance aims to ensure that supportive and palliative care services are developed that meet the needs of patients with cancer and their families. The DH has also recognised the importance of palliative care in guidance for non-cancer patient groups, including chronic kidney disease (DH 2005b) and neurological disorders (dementia and Parkinson’s disease in particular) (National Institute for Health and Clinical Excellence 2006a, 2006b). There is also substantial discussion and recommendations related to palliative and end of life care for people with HIV/AIDS in the Recommended Standards for NHS HIV Services (Medical Foundation for AIDS & Sexual Health 2003). Other examples of strategic work on palliative care include the NHS Quality Improvement Scotland work on clinical standards for specialist palliative care (Clinical Standards Board for Scotland, 2002), and a new project on national standards for chronic obstructive airways disease, which has end of life/palliative care as one of seven key areas (NHS Quality Improvement Scotland, 2009). In Ireland, the Health Service Executive and The Irish Hospice Foundation have collaborated on the report Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks (Health Service Executive and The Irish Hospice Foundation, 2008), which aims to ensure that palliative care is “available as a component part of chronic disease management frameworks and that all specialist palliative care services accept referrals based on needs rather than diagnosis”.

The UK Government has committed £286 million (over 2009 – 2011) to support the implementation of the End of Life Care strategy. In addition, improving the quality and experience of palliative care services has been included as a priority in the NHS Operating Framework 2007/08 and 2008/09. The current emphasis of the Framework is on “improving access to high quality, coordinated services close to home” (DH 2008, p. 35).

**Canada**

Health Canada convened a national action planning workshop on end of life care in 2002 with the aim of developing and launching a national strategy for end of life care. The workshop participants agreed on seven key areas for a Canadian palliative care strategy (see Appendix 2) covering access, professional education, public awareness, monitoring and research (Health Canada 2002). In 2007 the Coordinating Committee for the Strategy presented a final report on progress noting considerable achievements in enhancing the quality and accessibility of palliative and end of life care in Canada (Health Canada 2007). It also notes however, that work needs to continue to meet
remaining challenges and to meet the growing demand for health services as population demographics change. In recognition of the increasing need for palliative care by other patient groups, several other Canadian health strategies include it as a requirement of the patient care journey. This includes *Leading Together: Canada Takes Action on HIV/AIDS*, which has palliative care as an integral component (Canadian Public Health Association 2005). Palliative care requirements are also discussed in *The Growing Burden of Heart Disease and Stroke in Canada* and *Life and Breath: Respiratory Disease in Canada* (Heart and Stroke Foundation of Canada 2003, Public Health Agency of Canada 2007), although there is less emphasis in these documents. Again, strategies for other chronic diseases were unable to be located.
Conclusion

Internationally, palliative care is increasingly being recognised as an integral part of the health care continuum, especially in light of the increasing size and age of the population and the resultant increase in the number of people developing cancer and other chronic life-limiting conditions. The importance of incorporating palliative care into the management of people with non-cancer diagnoses has also been acknowledged internationally. The World Health Organisation (WHO) believes that palliative care should be given priority status within public health and disease-control programmes (WHO 2002). This position appears to be gaining some ground in New Zealand, with recent strategic health documents broadly supporting palliative care as part of the patient journey in a number of disease areas. However, the role of palliative care is often not explicit enough given its potential benefits for patients and their families/whanau, especially for those with non-cancer life-limiting conditions and those groups currently underserved by palliative care.

There are still significant gaps in palliative care services for children and adolescents in New Zealand; this is more so for those with non-cancer diagnoses. A viable national service model was recommended in 1998, but this has still not been fully implemented. It is also likely that a number of other groups are not accessing palliative care services as often or as easily as they should be able to, although this is hard to validate due to a lack of data on palliative care services in New Zealand. This includes Māori and Pacific peoples, and other minority ethnic groups, people in rural areas and elderly in residential care.

The current Palliative Care Strategy is focused on the initial setting up of services in New Zealand to ensure appropriate palliative care provision. However, given the development of services across the country since the launch of the strategy in 2001, this may no longer be the most important issue. This gives rise to an important issue in that it is in fact very difficult to assess whether progress made in palliative care over the past eight years has had any impact on service provision or indeed achieved the vision of the Strategy. No monitoring and evaluation of the strategy implementation has been undertaken, and there has been no national stocktake of service provision. What can be said is that progress has been made with regard to workforce development, through stocktaking, funding allocation and training programme development, although the need for continuing work to meet future needs has been acknowledged. Development has also occurred in the area of quality requirements for palliative care services with the development of draft specialist service specifications. What still remain as challenges are:

- Inequality of access; particularly based on diagnosis, but also in relation to ethnicity, age and geographic location.
- Lack/absence of data on population need, service provision and service utilisation.
- Lack of awareness/utilisation of palliative care services among the general public and health care professionals.
- Lack of inclusion in national health policy and strategic planning.
- Lack of a national strategic approach to research in palliative care.

A review of government health policy from the United Kingdom, Australia and Canada demonstrates that New Zealand is falling behind in the integration of palliative care into government health strategy. In some cases integration of palliative care into non-
malignant disease strategies has occurred; however this is still not adequate nor explicit enough to ensure palliative care is fully integrated into chronic disease management outside of cancer. New Zealand has similar strategic goals for palliative care as these countries, with the exception of two important components. These components are 1. *influencing policy and strategic development* and 2. *research*. The current Palliative Care Strategy is reaching the end of its original timeframe (2010) and work is needed now on future guidance on palliative care service development. The United Kingdom has just released new end of life care strategies for adults and children, while Australia and Canada are in the process of re-setting their national strategic goals for palliative care in light of progress made in the past five to ten years. Both the UK and Australian governments have announced significant funding for palliative care services indicating their commitment to improve patient care in this area.

It would appear that the way forward in New Zealand is for there firstly be a national stocktake of palliative care to establish the current state of service provision and accurately identify achievements, gaps and opportunities for change and improvement. This information would inform the future planning and development of palliative care at both policy and operational levels. To achieve such a stocktake there needs to be a monitoring and evaluation framework developed, based on the Palliative Care Strategy and relevant outcomes of the Cancer Control Strategy Action Plan. As a consequence of this work it is likely that the current Palliative Care Strategy will need to be reviewed and either updated or replaced by a new strategy that address the contemporary issues facing palliative care in New Zealand.

It would be extremely useful to have information on the current need for palliative care on a national and regional level. A national palliative care needs assessment should be undertaken to determine, for the first time, the need for palliative care in New Zealand on a population basis for all people who would benefit from palliative care. A project such as this could help identify the need for specialist and generalist palliative care provision, as well as regional requirements.

Current service gaps must be addressed urgently, especially for groups currently underserved by palliative care, but who would benefit greatly from improved access. This needs to include a concerted effort to raise provider and community awareness of palliative care and the services available to them. Undertaking a survey of public/provider perception of palliative care may be a useful starting point to establish beliefs and misconceptions around palliative care in New Zealand.

There is no doubt that palliative care providers in New Zealand are making a difference to the lives of many people dying from progressive, incurable disease. In many areas of care New Zealand services are achieving on a par with other countries. However, there still appear to be a number of gaps in service provision, although quantifying these is difficult due to a lack of available information. With a structured and collaborative strategic approach that addresses contemporary palliative care needs from government, health care providers and community perspectives, New Zealand can achieve comprehensive and responsive palliative care service provision.
**Recommendations**

It is apparent that there is a relatively *poor understanding of the need* for palliative care and a *lack of information* on services currently being provided and how they are being accessed by people with life-limiting illnesses. The following recommendations are made in response to the challenges identified in this report, and provide a positive way forward for palliative care in New Zealand.

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Rationale</th>
</tr>
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<tbody>
<tr>
<td><strong>1.</strong> Develop an outcomes focused monitoring and evaluation framework, based on the Palliative Care Strategy and relevant outcomes of the Cancer Control Strategy Action Plan (2005 - 2010).</td>
<td>To allow for monitoring and evaluation at a strategic level. To identify areas of achievement in progress towards achieving the Palliative Care Strategy vision, as well as opportunities for improvement. To inform decision making at policy level, as well as operational levels.</td>
</tr>
<tr>
<td><strong>2.</strong> Undertake a national evaluation of palliative care, using the above framework, to establish the current state of service provision and accurately identify achievements, gaps and opportunities for improvement.</td>
<td>To describe current situation in New Zealand and benchmark for future planning, evaluation and monitoring. To include both specialist and generalist providers.</td>
</tr>
<tr>
<td><strong>3.</strong> Undertake a national needs assessment using an epidemiological approach.</td>
<td>To determine, for the first time, the need for palliative care in New Zealand on a population basis for all people who would benefit from palliative care.</td>
</tr>
<tr>
<td><strong>4.</strong> Urgently address service gaps identified by the monitoring and evaluation project and needs assessment.</td>
<td>To raise awareness of, and address, access issues for groups currently underserved by palliative care, but who would benefit greatly from improved access.</td>
</tr>
<tr>
<td><strong>5.</strong> Review the Palliative Care Strategy to ensure it addresses the contemporary issues facing palliative care in New Zealand. The strategy needs to include a plan for investment in palliative care to ensure funding is provided to the areas most in need.</td>
<td>Palliative Care Strategy must meet needs of contemporary health care in New Zealand, with recognition of palliative care service developments since 2001, the CCS and Action Plan, and other chronic disease strategies. More explicit inclusion of non-cancer patient groups and those groups with particular needs/access issues (Mori and Pacific peoples and other cultural groups, aged care, children and young people, people with disabilities, etc).</td>
</tr>
<tr>
<td><strong>6.</strong> Raise public, professional and government awareness of palliative care and the services available, especially in non-cancer disease</td>
<td>To ensure that palliative care is integrated into the care of all people who would benefit from palliative care, through increasing awareness and understanding among communities, the</td>
</tr>
</tbody>
</table>
groups.

7. Ensure palliative care is fully incorporated into overarching New Zealand health policy and chronic disease strategies.

Palliative care needs to be incorporated into all health related government documents where the patient group would benefit from palliative care.

Palliative care should be a basic component of all chronic disease management strategies/programmes (policy and professional awareness).
References


Health Service Executive & The Irish Hospice Foundation (2008). Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks. Dublin; Health Service Executive and The Irish Hospice Foundation.


## Appendices

### Appendix 1: Links between Palliative Care and Cancer Control Strategies

<table>
<thead>
<tr>
<th>The New Zealand Palliative Care Strategy</th>
<th>NZ Cancer Control Strategy: Action Plan 2005 - 2010 - Palliative Care Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Ensure access to essential palliative care services.</td>
<td>76. The New Zealand Palliative Care Strategy will be implemented.</td>
</tr>
<tr>
<td>2. Each DHB to have at least one local palliative care service.</td>
<td>77. Access to palliative care for people with cancer from specific underserved populations will increase and will be delivered in an appropriate manner.</td>
</tr>
<tr>
<td>3. Develop specialist palliative care services.</td>
<td>78. Access to and need for palliative care services will be appropriately monitored.</td>
</tr>
<tr>
<td>4. Implement hospital palliative care teams.</td>
<td>79. A system and structure for national leadership in palliative care will be developed for the Cancer Control Strategy.</td>
</tr>
<tr>
<td>5. Develop quality requirements for palliative services.</td>
<td>80. National standards for service provision will be developed and implemented at local and network levels.</td>
</tr>
<tr>
<td>6. Inform the public about palliative care services.</td>
<td>81. Palliative care services will be appropriately resourced and delivered.</td>
</tr>
<tr>
<td>7. Develop the palliative care workforce and training.</td>
<td>82. Improved communication, integration and co-ordination of cancer services between patient's family/whanau and services.</td>
</tr>
<tr>
<td>8. Ensure that recommendations from the Paediatric Review are implemented.</td>
<td>83. Support care will be easily accessed, no matter where a person lives, or their age.</td>
</tr>
<tr>
<td>9. Address issues of income support.</td>
<td>93. Increased recruitment and retention of palliative care workers to provide an integrated and comprehensive service throughout New Zealand.</td>
</tr>
</tbody>
</table>
### Appendix 2: Comparison of priority areas for international palliative/end of life care strategies

|-------------|-------------------------|-------------------------|--------------------------|------------------|
| **Access**  | • Ensure access to essential palliative care services  
• Each DHB to have at least one local palliative care service  
• Develop specialist palliative care services  
• Implement hospital palliative care teams  
• Ensure that recommendations from the Paediatric Review are implemented.  
• Address issues of income support  
• Develop quality requirements for palliative services | • Partnerships in care  
  o Partnerships in care coordination  
  o Partnerships in service planning and delivery | • Identifying people approaching the end of life  
• Care planning  
• Coordination of care  
• Rapid access to care  
• Delivery of high quality services in all locations  
• Last days of life and care after death  
• Involving and supporting carers  
• Funding | • Availability and Access to Services  
• Ethical, Cultural and Spiritual Considerations  
• Support: Family, Caregiver and Significant Others |
| **Quality/monitoring** | • • | • Quality and effectiveness  
  o Standards  
  o Resource allocation and administrative support  
  o Accountability and reporting | • Measurement and research | • Surveillance |
| **Awareness (public/professional)** | • Inform the public about palliative care services | • Awareness and understanding  
  o Community awareness and capacity  
  o Families and communities of care  
  o Professional awareness  
  o Professional education  
  o Awareness at policy level  
  o Partnerships in policy development  
  o Service development  
  o Research and evaluation | • Raising the profile | • Public Education and Awareness |
| **Workforce development** | • Develop the palliative care workforce and training | | • Education and training and continuing professional development  
• Strategic commissioning | • Education for Health Care Providers |
| **Policy/strategic** | | | • Measurement and research | |
| **Research** | | | • Research | |