

**GUIDANCE FOR INTEGRATED
PAEDIATRIC PALLIATIVE CARE
SERVICES IN NEW ZEALAND**

September 2012

Report to the Ministry of Health

ACKNOWLEDGEMENTS

This project had a short time frame. The willingness of paediatric and palliative care service providers, who generously gave their time and shared their insights, experiences and opinions, made it possible. Thanks go to each of them.

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EXECUTIVE SUMMARY

In New Zealand the palliative care needs of children and young people and their families/whānau have been recognised since 1998. However, a corresponding development of services to meet these needs has not occurred.

There is only one specialist paediatric palliative care service, which is based at Starship Children's Health in Auckland. The service is not recognised or funded as a national resource, and access to specialist palliative care is inequitable. At the local level, the delivery of paediatric palliative care services is highly variable. Teams of public health service providers are sometimes supported by hospice services, and primary care providers are rarely involved in a systematic way.

This project was commissioned by the Ministry of Health to provide implementation-focused guidance to improve the integration of palliative care service delivery to children and young people in New Zealand. It examines paediatric palliative care services, both in New Zealand and internationally, and uses the results as the basis for a proposed framework for developing a coherent, integrated and co-ordinated system of paediatric palliative care service delivery.

Paediatric palliative care is a relatively new sub-specialty. In the absence of a robust evidence base, the key attributes of high-quality care and the systems features to support it are based on international opinion. The generally agreed attributes of high-quality care in this area are:

- adherence to the World Health Organization definition of paediatric palliative care
- philosophies of child- and family-centred care
- care that is provided in a preferred setting
- care that is based on need and implemented throughout the illness course, from the point of diagnosis to bereavement
- collaborative decision-making between the child, family and providers
- service delivery by providers with paediatric training and experience
- multidisciplinary teams
- integrated provider networks
- key workers
- respite care
- 24-hour support, 365 days a year.

In the proposed framework, the Starship Paediatric Palliative Care Team would be situated as the national specialist service, with national consultative and service development responsibilities. In each DHB or region nurse co-ordinators and lead paediatricians would lead service development and link local providers with the national specialist service. The framework would

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facilitate the local development of co-ordinated, responsive and locally appropriate services.

The responsibilities of the Ministry of Health, District Health Boards and service provider groups are identified, and a phased implementation process is outlined. It is recommended that, before it is implemented, the guidance be subjected to a project implementation evaluation, which would help to identify specific components, risks and costs.

PART A: INTRODUCTION

1 THE GUIDANCE PROJECT

1.1 Project overview

This project was commissioned by the Ministry of Health to provide implementation-focused guidance to improve the integration of palliative care service delivery to children and young people in New Zealand.

The project is a response to the national review of paediatric sub-specialty programmes (Ministry of Health 2010), which found that paediatric palliative care services in New Zealand, other than in Auckland, are not fully co-ordinated or sufficiently specialised, and generally provide no access to specialist care. The report pointed out that many families of children with palliative care needs rely on local primary health care, community services and non-government organisations (NGOs) for the provision of palliative care.

The goal of the project was to develop guidance that:

- is evidence-based, where possible
- provides analyses of current service delivery
- reflects stakeholder involvement
- proposes models of service delivery, with a focus on implementation
- can be implemented at no extra cost to the health sector.

1.2 Methodology

The project was conducted by an independent contractor, Elizabeth Bennett, over a four-month period. Regular contact between the contractor and key members of the Starship Paediatric Palliative Care Team throughout the project enabled the discussion of emerging ideas and confirmation of the direction of the project.

A project implementation group met twice during the life of the project. The members of the group are identified in Appendix 1. The first meeting agreed the direction of the project, and the second reviewed the draft guidance.

Literature review

The review utilised both peer-reviewed academic literature and 'grey' policy documents. Databases, which included Web of Science, ProQuest and PsychLit, were searched. This material was supplemented by policy literature drawn from a Google search by country and key word, along with material held by the Starship Paediatric Palliative Care Team. The search focused on

policy development, service implementation components and approaches, and assessment and critique.

Consultation

Consultation for the project was conducted with 93 paediatric providers and palliative care service providers in eight District Health Boards (DHBs) over a six-week period. DHBs were selected on the basis of their population, geographic or service delivery characteristics. An invitation, cascaded through the Palliative Care Special Interest Group of the Paediatric Society of New Zealand, yielded a mix of providers in each DHB. Māori participants were recruited via the networks of the Māori representatives on the project implementation group. The list of people consulted for the project is attached as Appendix 2.

A mix of qualitative individual and group interviews was used. The interviewer was the project contractor. A qualitative question guideline, which focused on service structures, linkages, gaps and enablers, framed the interviews. Responses were recorded, and a modified Grounded Theory data analysis method was used to thematically code the raw data, then to deconstruct and reconstruct the data as theoretical models.

The project consultation did not include families and was not representative of all providers. However, it did provide insight into local service delivery models, and revealed a consistency of opinion regarding service gaps, along with views about the future direction of paediatric palliative care.

Development of the guidance

Following data analysis, three clear options for national service development emerged. These were discussed with the Starship Paediatric Palliative Care Team and the Ministry of Health. Before final submission, the draft guidance document was submitted to the Ministry of Health and the project implementation group for comment.

1.3 Document structure

The aim in producing this guidance document is to provide a starting point for the development of paediatric palliative care services, and to act as a resource. It is presented in three parts.

- Part A introduces current concepts, principles and service delivery elements in paediatric palliative care, captures key policy in selected countries, and discusses quality initiatives and the development of standards.
- Part B looks at the New Zealand context. It describes the development of paediatric palliative care and the wider policy environment,

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- discusses assessment of need, and describes current service delivery models, enablers and gaps.
- Part C provides guidance for the development of paediatric palliative care services in New Zealand, including a suggested implementation timeframe.

2 PAEDIATRIC PALLIATIVE CARE

2.1 Overview

Paediatric palliative care is a new and developing medical sub-specialty. In the last 20 years it has evolved from the discipline of paediatrics rather than palliative care. Medical and technological advances have reduced infant and child mortality rates, but they have also improved survival rates for children with severe and long-standing conditions, who need complex palliative care (Himelstein et al 2004; EAPC 2009).

Paediatric palliative care has not kept pace with adult palliative care. Goldman et al (2006) suggest that the lack of attention to the issue of children with life-limiting illnesses and their families may be due to the fact that dying represents technological and medical failure for this group. They also point out that many health providers have a 'partial or distorted' understanding of the scope and approaches of paediatric palliative care. In particular, they suggest that clinicians may not appreciate the flexible nature of a service that can be delivered concurrently with curative therapies, or that all children with life-limiting illnesses – not just those with cancer – can benefit from palliative care interventions that promote quality of life.

The evidence base for paediatric palliative care service policies, service development and minimum standards is not well developed. The development of clinical guidelines is a very new approach, and, in the absence of evidence, is based on expert opinion and consensus (Stratman et al 2008). Although needs assessments underpin policy development in the UK, Ireland and Australia, these are usually based on mortality data and broad population projections rather than prevalence rates and precise service provision data. In the UK, appropriate codes from the International Classification of Diseases are currently being developed, which will more specifically determine disease prevalence and population need.

Despite the poor evidence base, there is a common approach in Europe, North America and Australia in terms of philosophy and service components. These include:

- adherence to the World Health Organization (WHO) definition of paediatric palliative care
- philosophies of child- and family-centred care
- care that is provided in a preferred setting
- care that is based on need and implemented throughout the illness course, from the point of diagnosis to bereavement
- collaborative decision-making between the child, family and providers
- service delivery by providers with paediatric training and experience
- multidisciplinary teams

- integrated provider networks
- key workers
- respite care
- 24-hour support, 365 days a year.

Much policy has emerged in the English-speaking countries in the last decade, but there is a lack of published assessment and critique related to the systematic development, implementation and provision of paediatric palliative care (Knapp 2010). Liben et al (2008) suggest that the development of paediatric palliative care services is dependent on:

- a clear definition of the population served
- improved understanding of the needs of children with life-threatening diseases and their families
- the development of an approach that is appropriate across different communities
- care that responds adequately to suffering
- strategies that support care givers and health care providers
- education programmes that promote change.

2.2 Defining paediatric palliative care

The WHO definitions of adult and paediatric palliative care have influenced the New Zealand definition. These are given below.

WHO definition for adults

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

- *provides relief from pain and other distressing symptoms*
- *affirms life and regards death as a normal process*
- *intends neither to hasten nor postpone death*
- *integrates the psychological and spiritual aspects of patients' care*
- *offers a support system to help patients live as actively as possible until death*
- *offers a support system to help the family cope during the patient's illness and in their own bereavement*
- *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated*
- *will enhance quality of life, and may positively influence the course of illness*
- *is applicable early in the course of the illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those*

investigations needed to better understand and manage distressing clinical complications. (WHO 2002)

WHO definition for children

Palliative care for children represents a special, albeit closely related, field to adult palliative care as follows (the principles also apply to other paediatric chronic conditions).

- *Palliative care for children is the total active care of the child's body, mind and spirit, and also involves giving support to the family.*
- *It begins when the illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease.*
- *Health providers must evaluate and alleviate a child's physical, psychological and social distress.*
- *Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.*
- *It can be provided in tertiary care facilities, in community health centres and even in children's homes. (WHO 2002)*

New Zealand definitions

New Zealand has further developed these definitions to take into account:

- the Treaty of Waitangi and Māori models of health
- the evolution and development of palliative care in New Zealand
- integrated service delivery by generalist and specialist providers
- acknowledgment of the diverse cultural beliefs and practices in new Zealand
- continuity of care by generalist providers.

The New Zealand working definition of palliative care, developed by the New Zealand Cancer Treatment Working Party (2007), is as follows.

- *Care for people of all ages with a life-limiting illness, which aims to:*
 - *optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual and cultural needs*
 - *support the individual's family, whānau, and other caregivers where needed, through the illness and after death.*
- *Palliative care should be provided according to an individual's need, and may be suitable whether death is days, weeks, or, occasionally, even years away. It may be suitable sometimes when treatments are being given aimed at improving quality of life.*
- *It should be available wherever the person may be.*
- *It should be provided by all health care professionals, supported, where necessary, by specialist palliative care services.*

- *Palliative care should be provided in such a way as to meet the unique needs of individuals from particular communities or groups. These include Māori, children and young people, immigrants, refugees, and those in isolated communities.*

This definition acknowledges the fact that palliative care for children and young people should be available on the basis of assessed need. Specialist paediatric palliative care should be provided in collaboration with other community and hospital paediatric providers. Home is recognised as the usual and preferred location of care for children and young people, despite the fact that, for some, long periods of hospital care may be required (New Zealand Cancer Treatment Working Party 2007).

When establishing a definition, it needs to be recognised that palliative care for children presents particular features.

- A small number of children die compared with the number of adults.
- Life-limiting conditions are diverse, and often rare and unpredictable.
- The child may survive into early adulthood.
- Many conditions are long term, extending over months and years, and require decision-making at different points of the disease trajectory.
- Some illnesses are familial and affect more than one child in a family.
- Care must include siblings and parents, who carry the burden of care.
- Consideration must be given to the developmental nature of childhood, and should address the impact of physical, emotional and cognitive development on the child's understanding of illness and death.
- Educational needs require complex multidisciplinary interactions (ACT and RCPCH 1997; Himelstein et al 2004; McConnell et al 2004).

2.3 Life-limiting illness typology

There is a widely acknowledged typology of life-limiting diseases which influences the development of services for children. The typology comprises four groups, each of which presents a different illness trajectory. These are described in Table 1.

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Table 1: Life-limiting disease groups and trajectories

Disease group	Examples	Illness trajectory
1. Diseases for which curative treatment may be feasible but may fail	Cancer; irreversible organ failure of heart, liver, kidney	Temporary deterioration following treatment, with subsequent recovery/remission and relapse. Partially successful further treatment, followed by deterioration and death.
2. Diseases for which premature death is anticipated, but intensive treatment may prolong good-quality life and participation in normal childhood activities	Cystic fibrosis; muscular dystrophy; HIV/AIDS	Condition is maintained with treatment over some years. Severe exacerbations characterise deterioration.
3. Progressive diseases without treatment options, for which treatment is exclusively palliative and may extend over many years	Batten's disease; mucopolysaccharidoses	Some improvement following initial treatment, followed by steady deterioration.
4. Diseases with severe neurological disability, which may cause weakness and susceptibility to complications. While not progressive, these diseases lead to vulnerability and complications likely to cause premature death.	Disabilities that follow brain or spinal cord injuries, such as severe cerebral palsy	Step-wise deterioration, with plateaux.

Sources: ACT and RCPCH 2007; Goldman 1998:49; Field and Behrman 2003; Hynson 2006

3 SERVICE AND SYSTEM REQUIREMENTS

3.1 Service elements

A seminal document published in 1997 by a joint working party of the Association for Children with Life Threatening or Terminal Conditions and their Families¹ (ACT) and the Royal College of Paediatrics and Child Health (RCPCH) has influenced global paediatric palliative care policy development. The document suggests that a palliative care system that meets the complex and changing palliative care needs of children and young people requires an intersectoral planning approach, flexibility and choice for families, child- and family-centred care, continuity of care, appropriately trained staff, and transition to adult services.

Specific elements of such a service are:

- mechanisms that enable co-ordination of services
- local services that are led by a paediatric professional, comprise a multidisciplinary network of providers, and are provided by core staff with paediatric qualifications and allied health providers
- training, information and support for generalist and specialist providers
- specialist hospital services
- secondary hospital services
- respite care, which may be provided in or out of the home, including emergency respite
- medication, medical supplies and equipment
- provision of aids and adaptation, with costs shared between the health and social sectors
- parent-held child health records
- a named key-worker system
- at the terminal stage, 24-hour nursing in the home, hospice or hospital, depending on wishes
- bereavement support
- monitoring that ensures continuity of care between the hospital and community sectors, and the timely provision of equipment and aids (ACT and RCPCH 1997).

Goldman et al (2006) identify, from a wide review of the literature, similar key components of any effective system. These are:

- multi-agency teams that are able to deliver care in a variety of settings, but predominantly at home

¹ The Association for Children with Life Threatening or Terminal Conditions and their Families subsequently changed its name to ACT (The Association for Children's Palliative Care) and since 2008 has been known simply as ACT.

- specialist palliative care teams, which support primary and secondary care teams delivering palliative care
- comprehensive assessment of needs for both the child and family members
- practical and explicit care planning
- planning ahead for expected complications and crises
- a key worker to act as a co-ordinator and advocate on behalf of families
- 24-hour access to a service, delivered in a setting that is desired and/or appropriate to needs
- good co-ordination of care, at any moment in time
- facilities for respite care
- continuity of care over the lifetime of the child, including transitions and into the bereavement period
- easy access to hospital
- clear standards and quality assurance of services (Goldman et al 2006:566).

3.2 System elements

The ACT and RCPCH (1997) identify four basic requirements for a functioning paediatric palliative care system.

1. A system to identify and keep track of children

The system should link primary, secondary and tertiary levels of care. Case co-ordination should be provided at the local level by a paediatrician who works in both hospital and community, and a community children's nurse. A good knowledge of the wider health and social service provision context is required. The paediatrician and nurse should liaise with general practitioners (GPs), providing them with advice and support, and should combine with them to provide shared care in the terminal phase.

Every child should receive medical care from a consultant with expertise in their condition. The consultant may be a tertiary specialist or a local paediatrician. There must also be a mechanism for regular assessment and continuity of care. Reviews should be conducted as the child's condition changes and as his or her development or social circumstances change.

2. Identification and recognition of a provider team/network, which comprises both the multidisciplinary network and the core provider group

The *multidisciplinary network* comprises:

- medical providers such as paediatricians, GPs, tertiary specialist paediatricians, hospice doctors and palliative care physicians

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- nurses from hospital, hospices, non-government organisations (NGOs), and community and primary care teams, who may work in hospitals, the community or in schools
- allied health providers, including mental health providers (such as child psychotherapists and child psychiatrists), therapists (such as occupational, speech and language, and play therapists, physiotherapists, play and music therapists, and complementary therapists)
- hospital and community pharmacists
- social workers and family support workers from the hospital, community and NGO sectors
- respite care workers
- teachers and other education sector providers
- counsellors, clergy and spiritual leaders
- staff from the NGO sector.

The *core provider group* is a smaller group of professionals who are closely concerned with paediatric palliative care, drawn from the above network. The group acts as a permanent resource. The core group meets regularly to discuss care and referral issues, monitor the choice and function of key workers and liaise with other providers. This group may or may not be the local service provider team for individual families.

3. Overall service co-ordination

An essential component of any palliative care system is a co-ordinator. This person should be a health care professional with experience in paediatric palliative care, who is respected and visible, and who has access to other providers and to funders of health and social services. The co-ordinator has a mandate to develop a service overview and to conduct service planning that enables access to a full range of services.

The team and network described above represent a variety of agencies and organisations. In order to enable relationships and agreements, the team needs good communication skills, complex management arrangements and a sound administration base.

An oncology model can be extended to children with non-malignant conditions for whom treatment may be provided and may fail, and for whom the period between the cessation of curative treatment and death is short. This model is usually community-based, with home care undertaken by nurses. A locally based model is more appropriate for disease groups 2, 3 and 4 (see Table 1). Children in these groups need palliative care services that are locally based and managed, are flexible and have strong links with social services. Local specialist nursing staff should be integrated with community children nursing teams wherever possible.

Integration of unlinked services is essential. An information resource should be established in each district. This should hold information on health and

social support providers, sources of financial help and equipment supply, local community and religious groups, funeral directors, cemeteries and crematoria. The information resource should also provide advice about accessing information about life-limiting conditions and other health information.

All staff engaged in children's palliative care should be part of a staff psychological support programme.

4. Service co-ordination for families

Named key workers provide a channel for discussion and information for families. They enable ongoing relationships and attachment by families, and so it is important for them to be acceptable to families. Key workers provide some aspect of care as well as access to other resources, enable links to other parts of the network, and ensure that a care plan is appropriate and is followed. The key worker may be a nurse or a social worker, and is usually part of a local network. Key workers should be linked with a team and must be supported through death and bereavement.

In summary, good communication is essential for good co-ordination of care. Good communication is facilitated by:

- parent-held child health records
- named key workers
- improved communication between secondary and primary level providers
- consolidated links between hospital and community, and between levels of care, including face-to-face contact between providers
- the sending and receiving of timely information (ACT and RCPCH 1997).

Goldman et al (2006) suggest that local circumstances should drive planning and service development. These include local epidemiology, resources and health care systems.

4 CARE PROVISION

4.1 The care pathway

Policy development in the UK has driven the development of services elsewhere in the world. This section looks at the key elements of service models developed in the last 10 years in England, Scotland, Wales and Northern Ireland. The *ACT Care Pathway* (ACT and Children’s Hospices UK 2009) identifies the roles of specialist, core and universal services in the three stages of the care pathway, as described in Table 2.

Table 2: The ACT Care Pathway

Stage	Specialist services	Core services	Universal services
Diagnosis/recognition	<p>Include: secondary and tertiary providers and the NGO sector (disease-specific groups, hospices, etc)</p> <p>Provide: accurate diagnosis; recognition of inappropriateness of active treatment and referral to palliative care services; support of complex needs</p>	<p>Include: providers with some palliative care training and experience (such as GPs and nurses with special interest); respite care services; hospital and community paediatric services; public health nurses; education and housing sectors; bereavement support</p> <p>Provide: accurate diagnosis and referral to specialist services if required; emotional support to families; discharge planning and support</p>	<p>Include: primary health care services (including GPs, practice nurses); school and child health nurses; allied health (including pharmacy, audiology); housing and education sectors</p> <p>Provide: recognition and referral process to required services; should be able to provide a palliative approach to care without referral to specialist palliative care services, and to deal with grief issues</p>
Living with the condition	<p>Include: disease-specific specialists; specialist community nursing services; disability services; specialist symptom management and psychosocial support teams</p> <p>Provide: information to multi-agency assessments and reviews; may provide a key worker</p>	<p>Include: paediatrics; psychological support; pathology; specialist education; 24-hour advice; community children’s nursing services; specialist outreach (such as oncology); mental health services; housing, social care and hospice services</p> <p>Provide: contribution to multi-agency assessments and reviews; ongoing emotional support to</p>	<p>Include: primary health care services (including GPs, practice nurses); school and child health nurses; allied health (including pharmacy, audiology); housing and education sectors</p> <p>Provide: contribution to multi-agency assessments and reviews; ongoing emotional support</p>

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		the child and family; may provide a key worker	
End-of-life care	<p>Include: specialist palliative care teams/providers; disease-specific specialist in palliative care to enable effective support and management of severe symptoms; specialist community nursing services; bereavement services</p> <p>Provide: 24-hour access to specialist care and advice, as required, by children and families, or other providers; services should be able to deal with complex grief and loss issues</p>	<p>Include: paediatric services; psychological support; interpreters; allied health support; children's community nursing services; education, housing and social care sectors; NGOs; foster care; bereavement services</p> <p>Provide: day-to-day care of the child and family, with access to 24-hour specialist advice through effective clinical networks</p>	<p>Include: primary health care services (including GPs, practice nurses); school and child health nurses; allied health (including pharmacy, audiology); housing and education sectors</p> <p>Provide: emotional and practical support to the whole family, and especially sibling support</p>

Source: ACT and Children's Hospices UK 2009

4.2 General principles

There is wide international agreement that children, young people and their families with palliative care needs require services that provide:

- access to competent care
- continuity of care that links local and specialist services and intersectoral services
- care delivered over long illness courses and that addresses transitions of illness
- respite care and caregiver support
- care at the time of death
- bereavement care
- relief from pain and other distressing symptoms
- care that meets developmental needs
- emotional and spiritual support
- help to live as normal a life as possible
- help with decision-making
- timely and truthful information
- family support that respects family choices, values and cultural traditions, and that considers family structure and support, location and access to health services

- help with financial and practical concerns
- transition for adolescents to adult services
- care that meets the needs of ethnic minority communities
- continued research and education (ACT and RCPCH 1997; American Academy of Pediatrics 2000; Field and Behrman 2003; Hynson 2006).

The goals of care for children and their families have been identified by Goldman et al (2006). These authors note that, in the absence of randomised controlled trials of palliative care interventions for children, these goals are based on a number of descriptive studies.

Child

The goals of care for the child are to:

- maintain independence
- provide good symptom control
- recognise the changing needs of children as they grow and develop
- improve quality of life
- involve children in decision-making.

Family

The goals of care for the family are to:

- promote family participation in defining priorities for care
- provide accessible information about the condition, prognosis and available options
- support choice over the venue of death, according to family wishes
- promote caring and connectedness with health care professionals
- enable parents to retain responsibility for their dying child
- reduce the psychosocial impact on parents, siblings and others
- provide support for practical problems related to daily living
- provide respite care
- recognise the child as special, while retaining as much normality in the family as possible (Goldman et al 2006).

4.3 Place of care

Hospital

In the US and UK, child deaths in hospital are less frequent than deaths at home or in hospices. However, Brook et al (2006) point out that long-term and complex illness requires hospital palliative care that is responsive and flexible, with attention given to the need to involve children and families in decision-making. Paediatric units often provide the only respite option for children.

Respite units linked to paediatric units have been established in the UK (ACT and RCPCH 2003).

Families are likely to choose hospitals as a place of care if they are anxious about symptom control or their ability to provide care at home, but palliative care in hospitals compromises privacy and the ability to accommodate the family (Royal Children's Hospital 2010).

Hospice

The first dedicated children's hospice was established in England in 1982. Children's hospices are now a feature of care in the UK, and 42 children's hospice services form a central component of service delivery systems. A smaller number of hospices provide care in Canada, the US and Australia (Friedrichsdorf et al 2007; Widger et al 2007; Royal Children's Hospital 2010). In the US the term 'hospice' is used to describe all palliative care, while elsewhere the term refers to specialist inpatient facilities and treatments (Brook et al 2006).

In the UK and Australia children's hospice services are NGOs that provide specialist palliative care to children and their families. The services include:

- planned and emergency respite care, which may be provided in a hospice facility or in the home, enabling children to have a break from parents and for parents to have a break from care
- hospice end-of-life care
- symptom management
- psychosocial support
- bereavement support.

Hospices often provide 24-hour support for families and other providers. Children's hospices adhere to the principles of holistic, family-based care, delivered in collaboration with other providers by interdisciplinary teams (Brook et al 2006; Children's Hospices UK; Royal Children's Hospital 2010). In Australia, geography and a dispersed population present problems for service delivery, and co-operation with adult services is one way of addressing these issues (Goldman et al 2006).

Home

Home is the preferred place of care for most children (Higginson and Thompson 2003). Care at home minimises disruption to the child's and family's usual activities and promotes a sense of being in control. Social networks and interpersonal relationships are more likely to be maintained in the home setting: care at home promotes family cohesion and enables families to adapt and cope (While et al 1996; Brook et al 2006).

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However, providing care at home does put enormous stress on families. There may be anxiety about providing appropriate and adequate symptom control and about the death occurring at home. Parents may also experience difficulty reconciling their parenting and care giving roles (Brooke et al 2006; Royal Children's Hospital 2010).

In summary, given the requirement for paediatric palliative care services to be flexible, co-ordinated and multidisciplinary, primary and community services form a critical component of service delivery systems (WHO 2002). Current service delivery emphasises the need for care along a continuum. However, the configuration of services depends on the care setting, the needs of the child and family, and the characteristics of the wider health care setting (Brooke et al 2006).

5 SERVICE DELIVERY IN SELECTED COUNTRIES

Paediatric palliative care is delivered in widely varied ways, both between and within countries. There are few published descriptions of national delivery systems or local provision, and analyses of palliative care delivery are lacking (Siden 2006). Goldman et al (2006) point out that services are still immature and unequal, and that there is considerable scope for development.

This section identifies, in selected countries, key policy statements and approaches. These develop the principles and approaches described above and provide points of reference for service development in New Zealand.

5.1 United Kingdom

The development of paediatric palliative care in the UK has influenced international service development. In the 1980s the first children's hospice, Helen House in Oxford, was established and the first specialist paediatric palliative care physician was appointed. ACT was established in the early 1990s and has provided influential guidance for comprehensive palliative care planning and delivery.

In 2004 the UK Government published *Every Child Matters: Change for children*, which was a framework for local change programmes to enable them to build services around the needs of children and their families. The framework was underpinned by the Children's Act 2004 and promotes outcome-focused change that is built on:

- integrated strategies, processes and service delivery
- services that are reconfigured around the needs of children and families, and that are delivered 'in place'
- specialist help for prevention and early intervention
- dedicated and enterprising leadership at all levels of the system
- shared responsibility across agencies
- consumer engagement in planning, service delivery and assessment (HM Government 2004).

This framework has guided subsequent UK policy.

5.2 England

The English national service framework draws on the *Every Child Matters* framework and the *ACT Care Pathway*. The English model emphasises the need for palliative care at the point of diagnosis of a life-threatening or life-limiting illness. Palliative care approaches support children and families to live as normal lives as possible by providing individualised palliative care services,

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which may be community-led, disease-specific or specialist-led (Department of Health 2005). Key features of the model are identified below.

The model recognises that a child or young person may enter a phase of palliative care as either a step change from the curative phase of a disease (such as malignancy), or as part of a continuum of previous supportive care (such as Batten's Disease). Following a single multidisciplinary assessment, the multi-professional team identifies a lead professional, a key worker and support workers. Most care is provided by community-led palliative care teams. These utilise multidisciplinary, culturally sensitive, tailored packages, which include:

- a written care plan
- children and parents supported to make informed choices regarding care decisions
- the option to be at home as much as possible
- discussion about end-of-life decisions
- care delivered by children's nursing teams, with support from appropriate medical input.

Primary care providers are central to the model. These include:

- GPs who are informed about and involved in treatment decisions, and other primary care providers, including school nurses (supported by 24-hour support), ambulance services, out-of-hospital services and walk-in centres
- community paediatric services
- other agencies, such as local social services, education agencies and NGOs (which provide equipment and aids, school liaison, benefits, support services, bereavement care and faith support).

Specialist teams, such as cystic fibrosis, cardiac and oncology services, remain involved at the end stages of the life of the child or young person. Specialist palliative care services are also provided, and include complex pain management, mental health support, nutrition services and tissue viability services.

Residential and outreach hospice services in England are a recognised part of the continuum of care, and work in partnership with specialist services. They provide involvement in elective planning, access to emergency beds, choice of site and service, respite breaks, and end-of-life and bereavement care (Department of Health 2005).

The national direction for service and system delivery in England was set out by the Department of Health (2008). This document builds on a review by Craft and Killen (2007) and identifies eight strategic goals:

- improved data
- equality of access to universal services

- responsible and accountable leadership
- choice of a preferred place of care and expansion of community services
- better end-of-life care
- stronger commissioning and value for money
- successful transition between children's and adult services
- planning and developing an effective and responsive workforce (Department of Health 2008).

Further policy has been developed concerning workforce development of specialist palliative care providers, non-specialist providers working in a palliative setting (such as allied health professionals), and non-palliative care providers who may or may not be specialists in their own field but who deliver palliative care within their own scope of practice (such as GPs, paediatric nurses, teachers or social workers) (ACT and Children's Hospices UK 2009).

5.3 Scotland

The aim of Scotland's palliative care plan, *Living and Dying Well* (Scottish Government 2008) is to integrate adults' and children's palliative care delivery. The plan emphasises flexible service provision by multi-agency, multidisciplinary teams and intersectoral co-ordination. It integrates with other Scottish health policies and programmes, and views palliative and end-of-life care as a component of health care and the patient experience (Scottish Government 2008). Despite the intent to include paediatric palliative care, the *Living and Dying Well* strategy is focused on adult palliative care definitions indicators and services (RCPCH Scotland 2010).

The formal framework for palliative care in Scotland will be the Palliative Care (Scotland) Bill 2010. The bill supports the implementation of the *Living and Dying Well* strategy.

The Scottish *Paediatric Palliative Care Guidelines* conform to the ACT definition, which identifies palliative care for children and young people as an active and total approach to care, embracing physical, emotional, social and spiritual elements and focusing on the enhancement of quality of life throughout the course of life-limiting illnesses, through death and bereavement. The aims of paediatric palliative care in Scotland are to:

- provide family-centred care in community and hospital settings for children with life-limiting/life-threatening illness
- offer support and advice for the child, family and staff
- provide education for the child, parents/carers, family, schools and professionals in the community, hospital and voluntary sectors
- co-ordinate care between home, clinic, hospital and respite/residential services, liaising with fellow professionals as appropriate
- provide specific advice on and treatment of pain and symptoms

- assist with the care of the child at home or in hospital during the terminal stages of their illness, in collaboration with the family, the multidisciplinary team and primary care
- provide bereavement support for family members and fellow professionals
- provide an evidence-based resource centre for paediatric palliative care.

5.4 Wales

The strategic direction for palliative care in Wales was established in 2003 (Welsh Assembly Government 2003) in order to address issues relating to varied and ad hoc service delivery for adults and children. The document noted the need for a separate needs assessment and strategy for children's palliative care that accommodates the overlaps between paediatrics and palliative care.

Subsequently, the Welsh Assembly Government (2008) has developed specialised paediatric palliative care standards, which are used in conjunction with a national service delivery framework (Welsh Assembly Government 2005). Its definition of paediatric palliative care aligns with other UK definitions, but it emphasises that all professionals working in the field should have an understanding of the field and their role within it, along with the ability to demonstrate expertise.

The standards utilise managed clinical networks, which ensure that varied local patterns of care adhere to agreed standards. A managed clinical network is a multidisciplinary group that works together in a non-hierarchical, collaborative way to develop protocols and care pathways (Welsh Assembly Government 2008). A proposed Welsh model envisages care being provided to the child and family by community paediatric nurses, district nurses, hospice staff and special school staff, with support from clinical nurse specialists, GPs and community paediatricians, who are in turn supported by paediatricians with an interest in palliative care and a paediatric palliative care consultant.

Six standards have been identified, related to access, staffing, facilities (including equipment), care of the child and family, communication, and education and training. Each is clearly justified, and a set of key actions is identified (Welsh Assembly Government 2008). No evaluation is available.

5.5 Republic of Ireland

Ireland has recently launched its national policy for paediatric palliative care (Department of Health and Children 2009), which is of particular interest given Ireland's comparable size. Like the UK, Ireland draws on the WHO definition and principles and needs identified by the ACT. Its policy is based on a

needs assessment published in 2005, which estimated the number of children living with life-limiting conditions.

Ireland's policy recognises the need to embed a care pathway in levels of care. Care is delivered by a consultant paediatrician, who has clinical, research and education, and service development responsibilities. The hospital multidisciplinary team comprises a children's palliative care team, children's outreach nurses (who co-ordinate services and support the collection of data), a 'hospice-at-home service' (which is predominantly a nursing service) and allied health therapists.

The objective is to provide most palliative care in the home. This is facilitated by primary care and local provider networks. Support is provided by specialist services and hospice-based respite care. Bereavement care begins at the point of diagnosis and continues after death.

The policy identifies the development of education and training for all health professionals, which includes e-learning and clinical practice training. It recommends that education be incorporated in wider paediatric education.

Standardised and nationally agreed patient assessments are recommended, which should be developed within paediatrics. A national database is also recommended, to be developed by a working group concerned with utilising ICD codes and developing data extraction processes and protocols (Department of Health and Children 2009).

5.6 Europe

Comprehensive palliative care services for children are not part of national health plans in most European countries, and services are generally inadequate and unevenly spread (Goldman et al 2006). The European Association for Palliative Care (EAPC) has examined paediatric palliative care in Europe and found recognition and diffusion of services to be inconsistent, and gaps and barriers that are organisational, cultural and economic. Paediatric palliative care that is an integral part of health care systems is advocated (EAPC 2009).

The EAPC proposes integrated networks of interdisciplinary services that respond to the child's and family's needs. It considers that integrated networks will:

- facilitate the efficient use of resources and reduce demand on acute hospitals
- create specific paediatric palliative care services
- guarantee appropriate management in a preferred location (EAPC 2009).

Comprehensive standards have been developed by the EAPC, which are described in section 6.2.

5.7 Canada

Palliative care services have a high public profile in Canada, despite the fact that these services are unevenly spread. Hospital-based consultation teams form the core of the Canadian delivery system, supporting community services (Goldman et al 2006; Widger et al 2007).

As in the UK, paediatric palliative care in Canada utilises a child- and family-centred model, which is planned and delivered collaboratively by interdisciplinary teams based on shared decision-making and sensitivity to family values and practices (Canadian Hospice Palliative Care Association and Canadian Network of Palliative Care for Children 2006). However, palliative care for children appears to have gaps and barriers that are similar to those in other English-speaking countries. A review of services found that, in 2002, an estimated 5–12 percent of children eligible for palliative care services actually received such services (Widger et al 2007). Of the eight dedicated paediatric palliative care services in Canada, seven are hospital-based and one is hospice-based. Widger et al point out that there are no data on barriers such as geographic isolation and no information about quality of care. They suggest that although Canadians wish to die at home, hospitals present a default option when home support services are insufficient.

Comprehensive principles and norms of practice have been developed by the Canadian Hospice Palliative Care Association and the Canadian Network of Palliative Care for Children (2006) with the aim of promoting a consistent approach across Canada. However, the approach does not insist on uniformity; rather, principles and norms are identified, and are intended to guide the local development of minimum standards. Principles and norms have been developed for child and family care, the process of providing care, programme support functions and resources.

An example of this approach is spiritual care, which is considered to be a component of child and family care. The principles of spiritual care are as follows.

1. *Spiritual care supports the child's and family's sense of hope and self-worth, meaning and purpose, interconnectedness with others, and connection to powers larger than themselves.*
2. *Individual family members may differ in their adherence to religious or spiritual practices.*

These principles underpin the following norms of practice.

1. *Formal caregivers ask about the child's and family's beliefs and values, and determine what distinguishes spiritual from religious practice for*

the child and family, and share this information with the rest of the team.

2. *Formal caregivers acknowledge and respect the things that are valuable and meaningful to the child and family.*
3. *The plan of care addresses the child's and family's spiritual expectations and needs, including any potential for conflict.*
4. *Formal caregivers address the child's and family's existential questions and spiritual issues (eg, the child dying before the parent), if able, or make referrals to spiritual counsellors.*
5. *Formal caregivers help the child and family access appropriate spiritual and/or religious resources, preferably those already known to the family. Where possible, personal spiritual advisors become part of the child's care team. (Canadian Hospice Palliative Care Association and Canadian Network of Palliative Care for Children 2006:23)*

5.8 United States

In the US the term 'hospice' is used for palliative care services. There are some 450 palliative care services in the US. However, services are varied and unequal in terms of access, admission criteria and service configuration (Goldman et al 2006).

The American Academy of Pediatrics supports an integrated model of care, which includes the following components.

- Palliative care is offered concurrently with curative care.
- Partnerships, which comprise the child, family and intersectoral teams of professionals, participate in creating care plans. These plans change as the disease progresses. Information is provided to the child in developmentally appropriate ways.
- Providers support parental adaptation and grief.
- The child is assisted to communicate his or her wishes and is encouraged to talk about emotions.
- The goal of palliative care is to enhance quality of life rather than to hasten death.
- Major barriers include: provider unfamiliarity or discomfort with providing palliative care; a Medicare funding model, which funds care for six months of life instead of addressing the long-term needs of palliative care for children; and hospice providers who lack expertise in dealing with children.

The American Academy of Pediatrics (2000) proposes minimum standards that involve mechanisms to ensure a seamless transition between providers, 24-hour availability of expert palliative care assistance, and an interdisciplinary team that is able to address the physical, psychosocial and spiritual needs of the child and family. The Academy suggests that, as a minimum, this team should include a physician, nurse, social worker, spiritual advisor and child therapist.

The following recommendations are made by the Academy.

- Palliative care and respite programmes need to be developed.
- An integrated model of palliative care should be offered on diagnosis of a life-threatening or life-limiting condition and continued throughout the course of illness, regardless of outcome.
- Medicare regulation and reimbursement of palliative care should be modified to address broader eligibility, concurrent treatment and palliative care, and provision of respite and other therapies.
- All paediatric providers need to become familiar with the provision of palliative care to children via education programmes.
- Support is required for research into effective programming, regulation and reimbursement, pain and symptom management, and grief and bereavement counselling.
- Physician-assisted suicide or euthanasia for children is not supported (American Academy of Pediatrics 2000).

The US not-for-profit organisation Children's Hospice International advocates for children with life-threatening illnesses and their families and promotes hospice care. It also promotes a model of integrated and comprehensive care that is delivered along a continuum, in a setting of choice, with respite and case management as central features (Children's Hospice International 2010).

5.9 Australia

Australia has well-developed paediatric palliative care services. These are informed by the *National Palliative Care Strategy* (Commonwealth Department of Health and Aged Care 2000b) and the *National Palliative Care Program* (Commonwealth Department of Health and Aged care 2000a), supported by 13 standards for palliative care provision to all Australians, including children (Palliative Care Australia 2005). The standards reflect principles of responsive, co-ordinated care delivered regardless of diagnosis, age, cultural background or geography. The standards and their development are described in section 6.2.

Australian paediatric palliative care is delivered across a continuum. Services comprise hospital-based teams, specialist paediatric palliative care physicians, co-operation with adult palliative care and community services, and two children's hospices (Bear Cottage in Sydney and Very Special Kids in Melbourne). Education programmes have been developed, including a nurse training programme and a physician training fellowship (Goldman et al 2006).

The Victorian Paediatric Palliative Care Program provides an example of integrated service delivery. The Program comprises the Royal Children's Hospital palliative care team of one paediatrician and one liaison nurse, the Monash Medical Centre and Very Special Kids. An advisory committee oversees the work of the Program. The hospital team does not provide direct

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patient care. Instead, it advises other providers and facilitates communication and transition between hospital and community providers (Royal Children's Hospital 2010).

Very Special Kids is part of the Victorian Paediatric Palliative Care Program and provides flexible services that are appropriate to children. These include counselling and emotional support, and sibling care at Very Special Kids House. The aim of the hospice is to provide a welcoming and friendly environment. As well as eight rooms, which are set up for children with complex needs, Very Special Kids House has activity areas that include a lounge and music room, and a playground. Care is provided by medical and nursing staff, carers, a music therapist, and trained family support volunteers (Very Special Kids 2010).

Despite the development of Australian services, there remains a need for more comprehensive home-based services, equity of access regardless of geography, and improved facilities and expertise (Goldman et al 2006).

6 ENSURING QUALITY

6.1 Evidence and the development of the quality improvement agenda

The assessment of quality and quality improvement is new in palliative care, with very limited evaluation of palliative care usage and effectiveness (Franks et al 2000; Higginson et al 2003; Ingleton et al 2003). As a result, there is a clear need for palliative care service delivery research that tests models of collaborative working, after-hours care, care in different hospital settings and care for people with non-malignant diseases (National Institute of Health Research 2007).

Significant challenges beset the development of a palliative care quality assessment agenda. Conceptualisation and measurement of quality of life in palliative care, and quality of death, are problematic (Higginson 1999; Higginson et al 2003), and palliative care research is confronted by methodological and ethical issues that preclude the development of large-scale randomised controlled trials (Grande and Todd 2000).

Paediatric palliative care research and the development of quality improvement encounter similar problems to those faced in adult palliative care. However, there is a lack of evidence for systems, processes and outcomes in paediatric palliative care, and no reports of large-scale quality improvement initiatives (Siden 2006). Siden suggests that a model of quality for paediatric palliative care needs to be based on standards (discussed below) or new guidelines, but should include:

- *systems*: a multidisciplinary provider team, respite facilities, and appropriate governance and administration
- *processes*: an intake mechanism and outcomes assessment of child and family needs, care to address those needs, and family-provider communication processes
- *outcomes*: multidimensional assessment based on a mission statement and external guidelines, which take into account client and provider perspectives at multiple points in time (including post-death) and utilise qualitative and quantitative methods

6.2 Standards

Standards for paediatric palliative care have been developed in several countries. Although they have not been directly tested, these standards are based on best available evidence and expert opinion, and have the potential to provide a basis for quality improvement programmes. They provide a starting point for the development of quality improvement programme

dimensions and targets, and frameworks for evidence-based research and evaluation.

This section describes three examples of sets of standards, each of which has relevance to the New Zealand context: quality markers developed by ACT in the UK, standards developed by the European Association for Palliative Care, and Australian standards developed by Palliative Care Australia. Despite local variation, each adheres broadly to the principles and approaches described earlier in this report.

ACT quality markers

In the UK, ACT has developed a simple set of 'quality markers', which can be used by service providers to develop and review services, and by commissioners to provide an expectation of improvement in the service commissioning process. The quality markers are described below.

Children's and young people's palliative care services will:

- have an action plan for the delivery of high-quality palliative care, which is reviewed for impact and progress and should encompass children and young people (including those in transition to adult services) and their families
- implement effective mechanisms to identify children and young people with life-limiting or life-threatening conditions, at any point from the time of diagnosis or recognition right through to the approach of their end-of-life phase
- ensure that the child's or young person's and their family's preferences and choices are documented and communicated to appropriate professionals, and that the needs of family members, including siblings, are appropriately assessed and recorded through a carer's assessment
- have mechanisms in place to ensure that care for children and young people is co-ordinated across organisational boundaries 24/7
- ensure that all children and young people who are approaching their end of life are offered a care plan
- have sustainable essential services available 24/7 to all children and young people who are approaching end of life – these services should be capable of offering home-based care at end of life if this is what the family chooses
- be aware of children's palliative care and end-of-life care training opportunities and enable relevant workers to access or attend programmes appropriate to their needs
- adopt a standardised approach (eg, the *ACT Care Pathway*) to care for life-limited children and young people throughout their whole care journey
- ensure mechanisms are in place to provide effective feedback and meaningful evaluation from parents and carers

- monitor the quality and outputs of children's palliative care, including end-of-life, and submit relevant information for local and national audits (ACT. 2009).

European standards

A paediatric palliative care task force of the EAPC has compared service delivery in several countries and has developed a comprehensive set of standards. More specific than the ACT quality markers, these are based on the WHO definition of paediatric palliative care and conform to the four groups proposed by the ACT and RCPCH (1997). Implementation of these standards requires an approach that is comprehensive and integrative, and implemented by a skilled, multidisciplinary team (EAPC Task Force 2007).

Unlike the UK jurisdictions, the EAPC employs the levels of care philosophy, which frames contemporary adult palliative care philosophy and practice. The three levels of paediatric specialisation described by the EAPC are as follows.

- *Level 1: palliative care approach* – palliative care principles are appropriately applied by all providers.
- *Level 2: general palliative care* – palliative care is provided by professionals who, although not wholly engaged in palliative care, have some additional training and expertise. This is an intermediate level.
- *Level 3: specialist palliative care* – services are provided by providers whose core activity is provision of palliative care services (EAPC Task Force 2007).

The standards recommended by the EAPC relate to core standards, pain and symptom management standards and ethics, and the legal rights of children receiving palliative care. These are listed below.

Core standards

Provision of care

- The aim is to enhance life.
- Families should be able to self-refer.
- Palliative care should begin at the point of diagnosis of a life-limiting illness.
- The components should be provided at diagnosis and continued throughout the illness.
- Palliative care should be given alongside treatments aimed at cure or prolonging life.
- Care should be provided at a site the child and family choose.
- Families should be allowed flexibility to move between sites of care without compromising care.

Unit of care

- The unit of care is the child and family, which is defined as those who provide care, regardless of genetic relationship.

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- A full range of appropriate clinical and educational resources must be available for the child and family.
- The child and family must be included in identifying the needs and priorities for care, once they have been given information as desired about disease and treatment options.

Core team

- The core team will recognise the individuality of each child and family and will uphold their values, wishes and beliefs, unless this exposes them to unnecessary harm.
- The palliative care team will have sufficient expertise to recognise the needs of the child and family.
- Minimum skills and services should include a physician, nurse, social worker, child therapist or psychologist and spiritual advisor.
- Professional resources from the child's own community should be utilised, if appropriate.
- Expert paediatric palliative care support and advice should be available to the child and family 24 hours a day, 365 days a year.
- Continuity of care should be ensured by planning.
- Direct caregivers should be provided with psychosocial support and supervision.

Care co-ordination / key worker

- One professional from the team must be identified as the family's co-ordinator or key worker.
- The care co-ordinator will help the family to build and maintain an appropriate support system of professions so that access to social services, practical support, spiritual and respite services are ensured.
- The care co-ordinator will be the main link, providing continuity and ensuring that care provided is consistent with the needs of the child and family.

Symptom management

- Every child should have access to professional pharmacological, psychological and physical management of pain and other symptoms, 24 hours a day, 365 days a year.
- Each child must have symptoms assessed to enable appropriate treatment that facilitates acceptable comfort.
- As well as physical symptoms, psychological, social and spiritual symptoms must be addressed.
- Symptom management must be accomplished by teams acceptable to the child and family.

Respite care

- Respite for the child and family carers is essential, whether for a few hours or a few days at a time.
- Respite should be possible in the home or away from the home.

Bereavement

- Bereavement support must start at diagnosis and continue throughout the illness, through death and beyond, for as long as it is needed.
- It must be available for the family, carers and others who are affected by the child's disease and death.
- Sibling support is an integral part of paediatric palliative care

Age-appropriate care

- Parents should be involved in all aspects of care, guided by the age and wishes of the child.
- The team and the care environment must meet the needs of different ages, developmental stages and different communication and cognitive abilities.
- Children and young adults should have access to appropriate recreational facilities.

Education and training

- All professional and volunteer palliative care providers should receive comprehensive training and support.
- Palliative care training must be a core curriculum component for all paediatric and related sub-specialty providers.
- Designated centres of excellence should provide formal teaching and postgraduate training in all aspects of care.

Funding for palliative care services

- Services should be available to all who need them, regardless of financial or insurance circumstances.
- Governments need to commit to sustained, adequate funding to provide holistic, multidisciplinary care in a variety of settings.
- There should be sufficient funding for the training of providers.

Euthanasia

- Physician-assisted suicide is not supported.

Pain and symptom management standards

Symptom recognition and assessment

- Every child should have their psychological, spiritual, social and physical symptoms assessed on a regular basis.
- The use of a multidisciplinary team in assessment is paramount.
- Information on symptoms must be elicited from all available sources, including the child, family and providers.
- Communicating with non-verbal or cognitively impaired children requires specific planning and co-ordination.
- Cultural expressions of suffering must be respected.

Core principles of symptom management

- Treating the underlying cause may be as appropriate as providing symptom control.
- Practical, cognitive, behavioural, physical and supportive therapies should be combined with appropriate drug treatment.
- Persistent symptoms should be treated with regular medication.
- Severe and uncontrolled symptoms should be treated as a medical emergency, with active intervention.
- Inappropriate and painful routes of drug administration should be avoided where possible.
- Medication side-effects must be anticipated and actively treated.

Core principles of pain management

- Unnecessary painful procedures should be avoided. Procedural pain prevention should be anticipated and actively treated.
- The WHO analgesic ladder should be used.
- Adequate doses of analgesics should be regularly administered.
- Sufficient doses of appropriate formulations should enable a night's sleep without waking in pain.
- The appropriate opioid dose is the one that relieves pain.
- Where opioid dose reduction is appropriate, withdrawal should be slow to avoid physical symptoms of withdrawal.
- Non-pharmacological therapies are a component of pain management.

Ethics and the legal rights standards

Equality

- Every child shall have access to palliative care, regardless of family financial capability.

Best interests of the child

- The best interests of the child shall be the primary consideration in decision-making.
- Treatments that impose burden without benefit will not be used.
- Every child has the right to adequate pain relief and symptom management, 24 hours a day, for every day needed.
- Every child shall be treated with dignity and respect and shall be afforded privacy, whatever the child's physical or intellectual ability.
- The needs of adolescents shall be addressed and planned for well in advance.

Communication and decision-making

- An honest and open approach shall be the basis of all communication.
- Parents shall be acknowledged as primary carers.
- Information for the child and family shall be provided according to age and understanding.
- Every child shall be given the opportunity to participate in decision-making.

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- Situations with the potential for conflict should be anticipated and procedures for early communication, therapeutic intervention or ethics consultation should be established.
- Every family should be given the opportunity of consultation with a paediatric specialist with particular knowledge of the child's condition.

Care management

- The family home shall be the centre of caring, wherever possible.
- In a hospital or inpatient hospice, children shall be cared for by paediatric trained staff in a child-centred environment, together with children with developmental needs. Children will not be admitted to adult hospitals or adult hospices.
- Children shall be cared for by paediatric providers whose training and skills enable them to respond to the child's physical, emotional and developmental needs.
- Every child shall have access to a multidisciplinary, holistic paediatric palliative care team, which includes a nurse, paediatrician, social worker, psychologist and spiritual/religious worker.
- Every family shall be entitled to a named key worker, who will enable the family to build and maintain a support system.

Respite care

- Every family shall have access to flexible respite care in their home and in a home-from-home setting, with appropriate paediatric multidisciplinary care.

Family support

- Sibling care, beginning at diagnosis, must be an integral part of care.
- Bereavement support shall be available to the whole family for as long as it is required.
- Every family shall have access to expert advice in procuring practical aids and financial support, and access to domestic help at times of stress.

Education

- Every child shall have access to education and be supported to attend their own school.
- Every child shall have the opportunity to engage in play and usual childhood activities (EAPC Task Force Steering Committee on Palliative Care for Children and Adolescents 2007).

Australian standards

Palliative Care Australia has developed 13 standards for palliative care provision to all Australians, including children (Palliative Care Australia 2005). The aim of the standards is to support the *National Palliative Care Strategy* (Department of Health and Ageing 2000b) and the *National Palliative Care Program* (Department of Health and Ageing 2000a). The standards are

implementation-focused and were developed after wide consultation with the end-of-life care and palliative care sectors. Each standard is informed by criteria for individual levels of care.

Standards for Providing Quality Palliative Care for all Australians

- 1. Care, decision-making and care planning are each based on respect for the uniqueness of the patient, their caregivers and family, whose wishes are acknowledged and guide decision-making and care planning.*
- 2. The holistic needs of the patient, their caregivers and family are acknowledged in assessment and care planning processes, and strategies are developed to address those needs, in line with their wishes.*
- 3. Ongoing and comprehensive assessment and care planning are undertaken to meet the needs and wishes of the patient, their caregivers and family.*
- 4. Care is co-ordinated to minimise the burden on the patient, their caregivers and family.*
- 5. The primary caregiver is provided with information, support and guidance about their role according to their needs and wishes.*
- 6. The unique needs of dying patients are considered, their comfort is maximised and their dignity is preserved.*
- 7. The service has an appropriate philosophy, values, culture, structure and environment for the provision of competent and compassionate palliative care.*
- 8. Formal mechanisms are in place to ensure that the patient, their caregivers and family have access to bereavement care, information and support services.*
- 9. Community capacity to respond to the needs of people who have a life-limiting illness, their caregivers and family is built through effective collaboration and partnership.*
- 10. Access to palliative care is available for all people based on clinical need and is independent of diagnosis, age, cultural background or geography.*
- 11. The service is committed to quality improvement and research in clinical and management practices.*
- 12. Staff and volunteers are appropriately qualified for the level of service offered and demonstrate ongoing participation in continuing professional development.*
- 13. Staff and volunteers reflect on practice and initiate and maintain effective self-care strategies (Palliative Care Australia 2005).*

Palliative Care Australia has developed a standardised assessment programme which builds on the standards described above. The programme's development was informed by clinical opinion. The National Standards Assessment Program provides a framework for continuous quality improvement in *specialist* palliative care services, which is based on self and peer assessment. Specialist palliative care services that register for the

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programme formally assess themselves against the standards every two years. Services are required to:

- establish multidisciplinary teams
- identify and collate evidence and data
- undertake a structured process of review
- develop an action plan for identified high-priority areas for quality improvement
- submit a report of the outcomes of assessment and an action plan to the National Standards Assessment Program project team
- undertake a peer review process (optional).

Palliative Care Australia has produced documents to guide the assessment process. Phase one of the project is now nearing completion at 36 national sites (Palliative Care Australia 2009a; Hanson 2009). No evaluation is available.

A paediatric version of the multidisciplinary self-assessment workbook has been developed (Palliative Care Australia 2009b). Each standard frames an explanation of the intent, and provides evidence sources, paediatric palliative care indicators, elements to guide team discussion and a tool to record the discussion and assessment. The tool is currently being used by the Starship Paediatric Palliative Care Team.

PART B: THE NEW ZEALAND CONTEXT

7 POLICY DEVELOPMENT

7.1 Introduction

Several key documents frame the development of paediatric palliative care in New Zealand. This section analyses nine of these, produced between 1998 and 2010, and summarises the policy directives that inform service development. The early documents (Ministry of Health 1998a, 1998b) identify a need for services that are needs-based, evidence-based, co-ordinated, integrated and fiscally responsible. These principles embed the development of paediatric palliative care as a new sub-specialty.

7.2 Strategy development

Child Health Strategy (Ministry of Health 1998a)

The *Child Health Strategy* provided a policy framework for the development of paediatric services in New Zealand. Developed by the Child Advisory Committee and based on extensive provider consultation, the Strategy proposed services based on the needs of children and their families that are delivered as close to home as possible by co-ordinated and equitable services in a culturally safe way. The restrictions on available resources were identified.

The Strategy proposed the following future directions for child health in New Zealand:

- a focus on health promotion, prevention and early intervention
- better co-ordination
- better information and research
- workforce development
- leadership in child health.

The Strategy identified the special needs of Māori and Pacific populations and the extra support required for children with disabilities and long-term conditions. It estimated that approximately 11 percent of children aged 0–14 years fitted this category.

Through the Eyes of a Child: A national review of paediatric specialty services (Ministry of Health 1998b)

This seminal document, a review of paediatric specialty services conducted by the Health Funding Authority and the Paediatric Society of New Zealand, with Ministry of Health participation, was an integral part of the *Child Health Strategy*. Like the Strategy, this report recommended a needs-based approach based on services that are:

- child and family focused
- as close to home as possible, within the bounds of quality and safety
- provided to achieve equity of outcome
- based on international best practice, research and education
- monitored and evaluated regularly
- integrated with other health services
- culturally safe
- fiscally responsible.

The review concluded that a national network of services with a child and adolescent focus was required. A series of recommendations focused on the establishment of a national network of paediatric services that would be appropriately managed and developed, with inputs from funders, providers and parents. The purpose of the proposed network was to develop standards of care and referral guidelines, and to ensure that peripheral clinics were provided with support and education. This would be underpinned by a common information system and information networks to develop key disease indicators and outcomes. Education and training was a key feature of the proposed network.

A set of recommendations regarding family support included preservation of choice, a national travel and accommodation policy, a review of respite and family support needs, telemedicine development, and the development of a national emergency transport system.

Paediatric palliative care was included in the review of specialist services. The review noted that palliative care was provided by a number of specialist services, including oncology, neurology, renal, respiratory and local child health teams, and it identified poorly co-ordinated services, which resulted in difficulties and confusion for families. In particular, there was a lack of:

- expertise in paediatric palliative care
- co-ordination
- respite care
- targeted resources
- key workers
- equipment
- youth-specific services
- community paediatric nursing

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- standards of care and service delivery
- community child mental health services.

The report recommended the establishment of a core 'terminal care team'. This team should include a paediatric palliative care specialist and be based at the specialist's site of employment. It was envisaged that the team would act as a national expertise resource for the terminal care of children and would include members from other centres. The team would provide expert advice on individual case management and the development of services.

Service delivery by local primary and specialist teams was recognised. However, the report recommended that each local team include a local palliative care co-ordinator, paediatric nursing and child mental health services, and services for Māori and other cultural groups.

A national paediatric palliative care network was recommended. This would be developed in collaboration with other specialties and would address national service requirements, standards, delivery, and education and training, and would advise the Ministry of Health. The report identified the following priority areas:

- appointment of one full-time equivalent paediatric palliative care specialist, and necessary support
- development of a national palliative care network, in association with other population-based specialties, to address all national issues in palliative care
- development of a core terminal care team as part of the national palliative care network
- development of local palliative care co-ordinators with necessary support
- development of a national programme of grief and bereavement support, with appropriate funding (Ministry of Health 1998b:47).

The New Zealand Palliative Care Strategy (Ministry of Health 2001)

The *New Zealand Palliative Care Strategy*, which frames the development of palliative care services in New Zealand, proposes the following vision for palliative care services:

All people who are dying and their family/whānau who could benefit from palliative care services have timely access to quality palliative care services that are culturally appropriate and are provided in a co-ordinated way. (Ministry of Health 2001:7)

Although children are broadly included in this vision, the Strategy makes explicit the fact that children require different palliative care services and that children who are dying require care from paediatricians and paediatric nurses who have palliative care experience. The Strategy utilises the

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recommendations of *Through the Eyes of a Child* (Ministry of Health 1998b) regarding:

- the development of a national network to develop and monitor national standards of care
- the development of a national palliative care team to provide support to local providers
- the appointment of a palliative care co-ordinator for each local team
- recognition that much care will be provided by local provider teams.

Four key features underpin the vision of the Strategy, each of which is appropriate to adult and child palliative care:

- awareness and knowledge of palliative care among communities and providers of health and disability services
- provision of essential palliative care services for people who are dying and their family/whānau (these include care co-ordination to ensure that services are co-ordinated and appropriate for each individual)
- a framework that is based on a palliative care network comprising two interlinked (specialist and generalist) levels of care
- well co-ordinated and flexible service arrangements to ensure that the needs of different population groupings can be met (Ministry of Health 2001:14).

Although the recommended nine implementation strategies focus on adult palliative care, Strategy 8 recommends that the recommendations of *Through the Eyes of a Child* be implemented. Specifically, Strategy 8 recommends that the Ministry of Health, in conjunction with DHBs, works with hospitals to:

- identify and implement the national children's palliative care team
- develop and implement the local paediatric co-ordination service (Ministry of Health 2001:20).

Palliative Care: Report of the Palliative Care Expert Working Group to the Cancer Control Steering Group (Ministry of Health 2003b)

This report quotes the gaps identified in *Through the Eyes of a Child*, but it also identifies the following issues for families and providers:

- lack of awareness of when palliative care should begin
- the need for clear information and support, preferably from a key worker and lead paediatrician
- problems associated with night-carer relief
- the considerable financial burden for families
- the importance of acknowledging appropriate spiritual and cultural aspects of caring for a dying child
- under-treatment of pain and other symptoms

- services for children affected by terminal illness of family members.

The report notes the employment of the first paediatric palliative care specialist and the establishment of a multidisciplinary palliative care team at Starship Children's Hospital in Auckland.

New Zealand Cancer Control Strategy (Ministry of Health 2003a)

The purpose of the *New Zealand Cancer Control Strategy* is to:

- reduce the incidence and impact of cancer
- reduce inequalities with respect to cancer.

The high-level Strategy is underpinned by the principles of the Treaty of Waitangi, reduction of health inequalities, timely and equitable access, high quality, sustainability, an evidence base, person-centred approaches, active involvement of consumers and communities, respect for cultural diversity, and a planned, co-ordinated and integrated approach.

The Strategy has six goals. While most of these are oriented to cancer treatment, Goal 4 explicitly addresses palliative care. Goal 4 is to improve the quality of life for those with cancer, their family and whānau, through support, rehabilitation and palliative care. The goal includes several objectives. Of these, Objectives 6 and 7 have particular relevance for paediatric palliative care and are described below.

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

Broad areas for action

- Ensure that each region has at least one palliative care service.
- Build on existing services, including primary care services.
- Develop appropriate support services.
- Improve access for those with limited or difficult access (eg, Māori and Pacific people, children, and those living in rural areas).
- Provide equality of access to hospital-based palliative care teams.
- Ensure equality of access to palliative care services.
- Ensure information on available services is readily available.

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

Broad areas for action

- DHBs need to work on co-ordinating and integrating the broad range of professionals and services involved in the care of a person with cancer. These include: primary care; hospital services and hospital palliative care teams; community-based services, including district nurses and allied health services; hospice services (community and in-patient); Māori and

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Pacific people's services and groups; long-term residential care and support services; and social support provided by voluntary agencies (Ministry of Health 2003a).

The New Zealand Cancer Control Strategy Action Plan 2005–2010 (Cancer Control Taskforce 2005)

The Action Plan was developed to realise the goals of the *New Zealand Cancer Control Strategy*. Objectives 6 and 7 (described above) are elaborated in the Action Plan. As well as identifying general palliative care gaps – such as uneven use of a palliative care approach by some cancer providers, uneven distribution of palliative care services and access barriers for Māori and Pacific people – the Action Plan identifies a lack of services specifically designed for children and adolescents (Cancer Control Taskforce 2005).

The Action Plan prioritises the development of palliative care services for all New Zealanders, including:

- assessment (initial and ongoing)
- care co-ordination
- clinical care (community nursing and medical management)
- inpatient care
- bereavement and spiritual care
- support care (in the home or in long-term residential care).

The outcomes, actions and milestones required to achieve the outcomes are identified. These integrate adult and children's palliative care and are described in Table 3.

Table 3: Action table for achieving Goal 4, Objectives 6 and 7, New Zealand Cancer Control Action Plan 2005–2010

Outcomes/results	Specific actions	Milestones/measures
The New Zealand Palliative Care Strategy will be implemented	Ensure the goals and strategies are incorporated into DHB annual plans.	Palliative care plans are developed and implemented in each DHB. Phase 1
Access to palliative care for people with cancer from specific under-served populations will increase and will be delivered in an appropriate manner	Identify and address barriers to accessing palliative care services for those with limited or difficult access (eg, Māori, Pacific people, children, those living in rural areas). Involve Māori, Pacific people and members of other significant ethnic groups in the planning of local/regional palliative care services.	A strategy to reduce barriers to access is included in DHB/cancer networks plans. Phase 1 Access rates for those groups identified as having poor access are monitored locally and nationally. Phase 1

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	<p>Involve paediatric services and consumers in the planning of local/regional palliative care services. The option of centralised national planning for paediatric and adolescent palliative care is explored.</p> <p>Involve rural primary professionals and consumers in the planning of local/regional services, where appropriate.</p> <p>Ensure the public are adequately informed about the extent of palliative care services through local and national information campaigns.</p>	<p>Systems for informing providers and the public about the availability of palliative care services are in place in each DHB/cancer network. Phase 1</p>
<p>Access to and for palliative care services will be appropriately monitored</p>	<p>Develop and implement a national minimum palliative care data set.</p>	<p>Data collection to facilitate the building of a national minimum data set on palliative care services is completed. Phase 1</p> <p>A national minimum data set is used to monitor outcomes in DHBs and cancer networks. Phase 2</p> <p>A service gaps and prioritisation benchmarking system is in place. Phase 2</p>
<p>A system for national leadership in palliative care will be developed for the Cancer Control Strategy</p>	<p>Form a group to ensure implementation of the New Zealand Palliative Care Strategy and the relevant objectives of the Cancer Control Strategy</p>	<p>The group is established. Phase 1</p>

Source: Cancer Control Taskforce 2005

Specialist Palliative Care Tier Two Service Specification (Ministry of Health 2008b)

The draft specialist palliative care service specification covers services delivered to children, adolescents and adults, as well as their families and whānau, and utilises a model based on levels of care that includes both generalist and specialist provisions. The specification is intended to be flexible enough to enable adaptation to meet local need and to integrate specialist and generalist services.

Generalist palliative care is palliative care that is:

- delivered to people who have a life-limiting illness
- delivered as an integral part of standard clinical practice
- provided in the community by general practice teams, Māori and Pacific providers, district nurses, residential care staff, community support providers and community paediatric teams
- provided in hospitals by general adult and paediatric medical and surgical teams, as well as by disease-specific teams (such as oncology and renal)
- provided in an ongoing or episodic manner
- linked with specialist service support and advice
- supported by education and training.

Specialist palliative care, provided by community hospice teams, hospital-based palliative care services and paediatric specialist palliative care teams, is palliative care that:

- is provided by those who have undergone specific training and/or accreditation in palliative care/medicine, working in the context of an expert interdisciplinary team of palliative care health professionals
- is provided according to developed national standards
- is built on generalist palliative care provision
- reflects a higher level of expertise in complex symptom management, spiritual support, psychosocial support, cultural support, and grief and loss support
- involves either:
 - direct provision of care to a person whose need exceeds the resources of the generalist provider; or
 - indirect provision of care, including advice, support, education and training to generalist providers and volunteers.

The minimum requirements for a specialist paediatric service are:

- an accredited and registered paediatric palliative care medical specialist

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- a specialist paediatric nurse with specific training in paediatric palliative care
- paediatric psychological and allied health professionals (with paediatric palliative care training, where available)
- a remit to work across the hospital–community continuum
- administrative support.

Integration of generalist and specialist levels of care is emphasised. The service specification states that where there is no specialist palliative care service, formal links should be established to external palliative care services. Specialist service objectives are to be achieved in three ways.

1. Develop clinical services that are responsive to people with palliative care needs (particularly of a more complex or difficult nature) by:
 - utilising best practice in clinical assessment, care and service delivery
 - delivering care in an environment and cultural context of the person's choice, whenever possible
 - providing some specialist services that are available 24 hours a day, 7 days a week.
2. Promote and support the provision of collaborative and integrated models of care provision with generalist providers by:
 - implementing mechanisms for integrating and co-ordinating care for generalist clinical and support services, including referral criteria and out-of-hours cover
 - participating in the development of integrated models/frameworks of palliative care provision that recognise the roles of specialist and generalist clinical and support services
 - providing education programmes, advice and support for generalist services in order to build their capacity and capability to respond to palliative care need.
3. Improve safe and effective clinical services by:
 - participating in professional development, audit, credentialling/benchmarking and research/evaluation
 - adopting palliative care clinical practice that is evidence-based and shown to make a difference
 - supporting the development and maintenance of an appropriately skilled and resourced specialist palliative care workforce for the population served.

Access to specialist palliative care services is advocated for:

- people who have a diagnosis of a life-limiting illness with little or no prospect of cure and when death is the likely outcome, with needs that are beyond the resources of the generalist provider

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- family or whānau who have needs beyond the resources of generalist providers
- generalist providers who require education, support or advice.

Discharge occurs when a person no longer needs specialist palliative care, self-discharges, moves or dies.

The service specification recommends providing services 24 hours a day, 7 days a week. These services include telephone consultancy to generalist (nurse and doctor) providers in any care setting and specialist inpatient care. Service components, purchase units and reporting requirements are identified, and include initial referral assessment, ongoing follow-up care, inpatient care, a last-days-of-life care programme, grief and loss support, and an education programme for generalist and support services.

The National Paediatric Palliative Care Working Group responded to the service specification. Noting that, outside of Auckland, paediatric palliative care is delivered by primary paediatric services with a range of local services, leading to a lack of co-ordination and inequitable quality of care, the Working Group proposed:

- the development of a national framework for paediatric palliative care
- national leadership of the framework to be provided by the Starship-based Paediatric Palliative Care Team
- key workers/co-ordinators in Auckland, Wellington and Christchurch, who would be responsible for service delivery in the Northern, Central and South Island regions, respectively.

It was recommended that key workers be situated as part of a multidisciplinary team, with access to both adult and paediatric specialist palliative care providers for knowledge and support, along with generalist paediatric providers. The following roles for the key worker/co-ordinator were proposed:

- collaborate across services
- plan care and co-ordinate care processes
- understand local needs and the provision of a local response
- provide clinical advice on the management of distressing symptoms, including pain
- understand, have resources for, and link families with practical support, including financial support, respite options and equipment
- link families with available emotional and psychological support/services
- help facilitate decision-making, thereby preventing crisis-oriented management
- link with a national network for continued professional development, and develop standards of care, guidelines for practice and professional support

- take responsibility for education within regions (National Paediatric Palliative Care Working Group)

Gap Analysis of Specialist Palliative Care in New Zealand (Ministry of Health 2009)

This overview of hospital and hospice-based services confirmed the uneven provision of hospice and other specialist palliative care services at the local and regional levels. It notes that there are opportunities for resource sharing between services, which would increase equity of access.

With reference to paediatric palliative care, the report points out that clear referral guidelines and formal links between palliative care and paediatric services have yet to be developed. It suggests that this is because the number of children with palliative care needs seen by some services is very small. The report concludes that such referral guidelines and formal links are central to ensure equitable service delivery. The Starship Paediatric Palliative Care Team is situated as the national resource.

Positioning Palliative Care in New Zealand: A review of government health policy in relation to the provision of palliative care services in New Zealand (Palliative Care Council of New Zealand 2010)

This review notes that some population groups, including children, have inequitable access to high-quality palliative care services. It suggests that, despite the coverage in a number of related policy documents, the role of palliative care is sometimes not explicit and there is little guidance on meeting the palliative care needs of the population. The report suggests this may be because of lack of information on palliative care and population need, current service availability and utilisation, and a lack of understanding and awareness of palliative care.

The report points out that the *New Zealand Palliative Care Strategy* has not led to any monitoring and evaluation, and that there has been no national stocktake of service provision. The report emphasises the following challenges:

- inequity 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 and/or 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 (Palliative Care Council of New Zealand 2010:5).

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Significant gaps in paediatric palliative care service provision are noted, especially for people with non-cancer diagnoses. The report points out that the national service model recommended in 1998 has been only partially implemented. As a result, the following recommendations are made.

- Develop an outcomes-focused monitoring and evaluation framework, based on the *New Zealand Palliative Care Strategy* and relevant outcomes of the *Cancer Control Strategy Action Plan 2005–2010*, to enable monitoring and evaluation at a strategic level.
- Evaluate palliative care service provision that utilises the above framework, in order to establish the state of current service provision and to accurately identify achievements, gaps and opportunities for improvement.
- Undertake a population needs assessment that uses an established methodology, ensures meaningful results and enables international comparisons.

The following actions are proposed.

- Urgently address service gaps, especially for groups currently underserved by palliative care, and who would most benefit from improved access.
- Review the *New Zealand Palliative Care Strategy* to ensure it addresses the contemporary issues facing palliative care.
- Raise public, professional and government awareness of palliative care and the services available, especially in non-cancer groups.
- Ensure that palliative care is fully incorporated into overarching health policy and chronic disease strategies.

8 THE WIDER POLICY ENVIRONMENT

Any development in paediatric palliative care services must be aligned with changes in the overall New Zealand policy environment. This section identifies and briefly discusses major shifts in the health sector. With the exception of the Whānau Ora initiative, reforms in other sectors are out of the scope of this analysis.

The health sector in New Zealand is currently undergoing considerable change. In response to an environment of rising costs, an ageing population, increased demand and an expensive, scarce and international workforce, the goal of the Minister of Health is a sustainable, high-quality, patient-centred health service which provides equitable opportunities for good health (Ministry of Health 2010; Minister of Health 2010).

The recent specialised paediatric services review (Ministry of Health 2010) proposes:

- the development of an overarching plan to guide decisions about what paediatric sub-specialties services New Zealand will invest in, and their configuration and distribution
- national planning of many of the sub-specialties, and improving service co-ordination and planning through clinical networks.

The Paediatric Society of New Zealand (2008) has proposed that seamless care for children requires links across a continuum of care, via managed clinical networks and programmes that link self-care, primary, secondary and tertiary care. The shared infrastructure that would facilitate such care includes:

- linking DHBs, and implementing policy across DHBs
- leadership (information technology, nursing, medical, allied health)
- training and nationwide training resources (medical, nursing and allied health)
- planning
- staff (medical, nursing and allied health, with national roles)
- workforce planning and recruitment
- on-call rosters
- facilities and equipment
- communication and peer support
- quality standards, accreditation, up-skilling and outreach
- promulgation of best practice (protocols, guidelines, policies, care pathways and referral pathways)
- patient education and health promotion materials
- population health initiatives
- evaluation and audit
- IT solutions and clinical information systems

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- transport systems and policies.

Health and social policy, which is currently being developed by several groups, is likely to have an impact on the future of paediatric palliative care. In the health sector, of central importance are the decisions of the National Health Board, Health Workforce New Zealand and the Health Quality and Safety Commission.

The National Health Board has been established to provide greater leadership, support and monitoring to the sector. Health Workforce New Zealand will lead workforce planning, education and training, development and purchasing. This body will address strengthening clinical leadership and the involvement of clinicians in policy development and expanded clinical networks. The Health Quality and Safety Commission will lead and co-ordinate sustained improvement in safety and quality (Minister of Health 2010).

The Whānau Ora strategy presents opportunities to deliver flexible, culturally anchored and inclusive services to whānau. The strategy requires government agencies to work together. A key component is the appointment of a navigator, or key worker, to assist whānau according to their own priorities. The strategy has yet to be fine-tuned. However, Whānau Ora providers across the country have recently been identified (Te Puni Kōkiri 2010).

The Cancer Control Council is currently conducting a national palliative care needs assessment. This is reported on section 9.3.

9 POPULATION NEED

9.1 Data requirements

Like other countries, New Zealand lacks comprehensive data to inform an assessment of palliative care need. Quantification of need presents difficulties because raw data and rates are often not accurately assessed (Goldman 1998) and indicators have not been universally agreed.

The ACT has noted that in the UK the best data are for cancer and that reliable data are largely absent for other conditions. This is also true for New Zealand (L Craig, personal communication, November 2011). The ACT suggests there is an urgent need for robust databases and recommends that the following disease groups be included:

- metabolic diseases (such as mucopolysaccharide diseases)
- diseases of the blood and blood-forming organs (such as thalassaemia major)
- diseases of the nervous system and sense organs (such as severe cerebral palsy, Batten's disease, spinal muscular atrophy, Duchenne muscular dystrophy, and progressive and non-progressive neurological disorders such as tuberous sclerosis)
- diseases of the cardiovascular system (such as inoperable congenital anomalies of the heart)
- diseases of the digestive system (such as chronic liver failure)
- diseases of the genito-urinary system (such as chronic renal failure)
- congenital anomalies and chromosomal disorders (such as trisomy 18)
- undiagnosed diseases of assumed metabolic or neurological origin
- malignant diseases
- non-malignant brain tumours
- diseases of the immune system (such as HIV)
- trauma – accidental and non-accidental injuries such as brain injuries following road traffic accidents, drowning, etc (ACT and RCPCH 1998).

9.2 Defining 'child'

In June 2009 there were 891,200 children aged 0–14 years in New Zealand, comprising 20.7 percent of the total New Zealand population. The child population grew by a modest 1.6 percent in the decade from 1999 to 2009 (Statistics New Zealand 2010).

In New Zealand a person is legally classed as a child until the age of 20, when they are considered to have full capacity to make their own decisions (Office of the Children's Commissioner 2010). This is despite the fact that the United Nations Convention on the Rights of the Child, to which New Zealand

is a signatory, defines a child as ‘a human being below the age of 18 unless under the law applicable to the child, majority is gained earlier’ (United Nations 1989).

For the purposes of health services, the New Zealand *Child Health Strategy* defines children as:

being between birth and 14 years. Young people up to the age of 18 should, however, be given care within the most developmentally appropriate services, as most young people generally do not have the cognitive and psychological maturity to be cared for in adult settings.
(Ministry of Health 1998a)

The Paediatric Society of New Zealand considers children to be those aged from birth to 15 years, and young people to be those aged from 16 to 24 years (Craig et al 2007), while the Child and Youth Mortality Review Committee includes data for the population aged 4 weeks to 24 years (Child and Youth Mortality Review Committee 2009).

In practice, health services variously define (and provide services to) children. For example, Starship Children’s Health provides transition to adult services at different ages, depending on the service and the prognosis. Some patients, such as those with paediatric cancers or congenital cardiac conditions, remain in the care of paediatric services for life (K Bycroft and R Drake, personal communication, October 2011).

9.3 Current and proposed data collection

Two agencies currently collect and analyse child and youth health data: the Child and Youth Epidemiology Service and the Child and Youth Mortality Review Committee. The former, based at the University of Otago, provides annual reports to participating DHBs, which address health outcomes, determinants of health, and chronic conditions and disabilities for the population aged 0–24 years; in addition, two specific topics are selected for more in-depth review. The purpose of these reports is to inform local needs assessment and service development. The monitoring framework used by the service does not include specific palliative care indicators (New Zealand Child and Youth Epidemiology Service 2010).

The Child and Youth Mortality Review Committee is an independent body which is appointed by, and reports to, the Minister of Health on ways to reduce preventable deaths, collect standard information for every child and youth aged 4 weeks to 24 years who dies, and identify trends and their implications for service delivery agencies (Child and Youth Mortality Review Committee 2010). The last comprehensive analysis of child and youth mortality conducted by the Committee is for the period 2002–2004. However, it is intended that a report addressing paediatric palliative care provision will be published in 2011.

The Palliative Care Council of New Zealand is currently conducting a national population-based needs assessment of palliative care need, which includes children and adolescents. The project employs a methodology developed in Australia (see Rosenwax et al 2005). Utilising mortality data for a core group of malignant and non-malignant diseases, the methodology makes three estimates of need: minimal, mid-range and maximal. No prevalence studies are planned. Phase 1 of the needs assessment project was completed by March 2011, after which a second project phase will map palliative care services and make recommendations for future development. (W Naylor, personal communication, November 2011).

9.4 Child and youth mortality

Child deaths may be categorised as sudden (such as accidents, perinatal death and sudden infant death syndrome) or anticipated. Anticipated deaths include those that follow life-limiting illnesses in which death is likely to occur in childhood, or those that carry a high risk of mortality in childhood (Goldman and Burne 1999).

Child and Youth Mortality Review Committee analyses of child and youth deaths for the period 2002–2004 have been categorised as follows:

- medical (35.2 percent of all deaths)
- unintentional (34.5 percent)
- intentional (18.8 percent)
- unexplained (11.5 percent).

Of the total 4089 deaths in that period, 1438 (35.2 percent) were categorised as medical. This category includes the conditions likely to require palliative care. Medical mortality is broken down by age and cause in Table 4.

Table 4: Medical mortality, by age group and cause, 2003–2008

	< 1 year	1–4 years	5–9 years	10–14 years	15–19 years	20–24 years	Total	%	% all deaths
Infectious and parasitic disease	56	41	13	8	14	25	157	10.9	3.8
Neoplasms	12	39	41	59	91	96	338	23.5	8.3
Diseases of the blood and blood-forming organs, and disorders of the immune system	1	3	1	1	1	4	11	0.8	0.3
Endocrine, nutritional and metabolic diseases	10	18	4	7	7	7	53	3.7	1.3
Mental and behavioural disorders	–	–	–	1	–	1	2	0.1	0.0

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Diseases of nervous system	23	21	19	25	35	42	165	11.5	4.0
Diseases of eye and adnexa	-	-	-	-	-	-	-	0.0	0.0
Diseases of ear and mastoid process	-	-	-	-	-	-	-	0.0	0.0
Diseases of circulatory system	21	16	8	16	33	34	128	8.9	3.1
Diseases of respiratory system	12	11	8	7	20	22	80	5.6	2.0
Diseases of digestive system	10	6	1	2	2	1	22	1.5	0.5
Diseases of skin and subcutaneous tissue	-	-	-	-	1	-	1	0.1	0.0
Diseases of musculoskeletal system	-	-	1	-	1	4	6	0.4	0.1
Diseases of genitor-urinary system	3	-	1	1	5	4	14	1.0	0.3
Pregnancy, childbirth and puerperium	-	-	-	-	-	-	-	0.0	0.0
Certain conditions originating in the prenatal period	73	13	10	12	12	4	124	8.6	3.0
Congenital abnormalities	123	49	14	24	36	23	269	18.7	6.6
Symptoms and abnormal findings not elsewhere classified	11	5	2	1	3	8	30	2.1	0.7
Unknown	6	1	1	2	16	12	38	2.6	0.9
Total medical	361	223	124	166	277	287	1438	100.0	35.2

Source: Child and Youth Mortality Committee 2009:41

9.5 Estimating population palliative care need

In the absence of accurate prevalence estimates, extrapolation of population estimates provides one way of assessing need. Utilising New Zealand mortality data, Jones et al (2002) have estimated that the rate of children aged 1–17 years who die from a life-limiting illness in one year is 1.14 per 10,000 children. Of a total of 2122 cases during the period 1996–1998, 16 percent (348 deaths) were considered to have required palliative care. Cancer accounted for 37 percent of these, cardiac conditions 11 percent, congenital abnormalities 24 percent and other conditions 24 percent (Jones et al 2002).

While et al (1996) and the ACT and RCPCH (1997) have proposed an estimation method, using UK data, as follows.

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The annual mortality rate for children aged 1–17 years with life-limiting conditions is 1 per 10,000. This covers all four palliative care groups described above. Morbidity is estimated at 10 per 10,000 children aged 0–19 years per year. Therefore, in a population of 250,000 people, with a child population of approximately 50,000, in one year:

- five are likely to die of a life-limiting condition
- of these two die from cancer, one of heart disease and two from other life-limiting conditions
- 50 are likely to have a life-limiting condition, about half of whom will need active palliative care at any one time.

Tables 5 and 6 show extrapolations of the estimation of While et al to the New Zealand child population.

Table 5: Estimated annual mortality from life-limiting conditions in the New Zealand population aged 0–19 years

Condition	Estimated number
Cancer	35.6
Cardiac disease	17.8
Other causes	35.6
All life-limiting conditions	89

Table 6: Estimated annual prevalence of life-limiting conditions and children with palliative care need in the New Zealand population aged 0–19 years

Category	Estimated number
Children with life-limiting conditions	890
Children who require palliative care	445

When these extrapolations are compared with actual mortality shown in Table 4, it appears need may be underestimated. Further analysis is clearly required.

10 THE NEEDS OF THE FAMILY

10.1 Introduction

This section uses project consultation data to identify current issues for families providing care for children with palliative care needs. The issues identified by providers have changed little from those identified in policy documents over the last decade.

10.2 Family needs identified by providers

The needs of families identified in policy documents produced since 1998 can be summarised as follows:

- respite care
- care co-ordination
- clear information and support, preferably from a key worker and lead paediatrician
- equity of access to services
- alleviation of financial burdens
- appropriate responses from services to spiritual and cultural needs
- adequate symptom relief
- services for affected siblings.

Despite the policy development over the last decade, little appears to have changed for families caring for a child with palliative care needs. Providers consulted for this project reported the following key areas of need for families.

Place of care and death

There are no robust data concerning place of care and death in New Zealand. However, providers report that most families wish to care for their children at home. Hospital or hospice care is generally requested when there is inadequate primary care and community support, and/or when the burden of care exceeds family resources. Māori and some other ethnic groups may seek the sense of hope or optimism that is conferred by being in a hospital environment.

Financial burden and poverty

The financial burden of caring for children with long-term life-limiting illnesses is a key concern of providers. One or both parents may have to stop work, and the extra costs associated with care create major pressures for families. Poverty is amplified in low-income families and created in middle- or high-

income families. Providers see financial burden and the associated poverty as a central issue for whānau.

Work and Income New Zealand provides some support options, including the Caring for the Sick Allowance, Domestic Purposes Benefit, Sickness Benefit and Accommodation Allowance. However, many families appear to have substantial problems accessing financial support within a reasonable time.

Access to services

According to providers, access to palliative care services remains inequitable. Children with cancer consume much of the palliative care resource, while some children with long-term disabilities and palliative care needs may never come to the notice of providers.

Geographic location also affects access to services. Families living near secondary or tertiary services are likely to receive care from paediatricians and paediatric outreach nurses, while in remote locations district nurses and GPs are likely to provide palliative care services. Children and families in the northern region are advantaged in terms of access to the Starship team: team members undertake home visits and provide direct support to other providers.

Funding silos affect equitable access to services. Depending on how a child's diagnosis is classified, financial support may be provided via the Accident Compensation Corporation (ACC), disability or personal health funding streams. Those with ACC or disability funding are reported to receive higher levels of financial and equipment support than those dependent on other sources of funding.

In Auckland, providers identified access problems for families who are illegal residents. These families are unable to access public services, although providers often find informal ways to support them. Throughout the country there are families that are not registered with a primary health organisation, which has a direct impact on their ability to access primary care services. Although it has not been formally identified, Māori providers consider this may be a particular problem for whānau.

Respite care

Respite care is a key concern for providers. While in some DHBs (Waikato and Lakes, for example), hospice or in-home respite services are available, in much of the country there are no respite facilities for children. It is noted that children with disabilities are able to access disability-funded and provided respite. For families who may be engaged in frequent care tasks such as heavy lifting or regular suctioning, a lack of respite options adds to the burden of care.

The Family Options programme provides respite and relief funding and services to families with medically fragile children. It is only provided in

Auckland, Northland, Waitemata, Counties Manukau and Lakes District Health Boards. If the child's needs are as a result of a disability they should receive support from the local DSS NASC agency. The support offered by Family Options is intended as an additional "top up" to any supports already in place i.e. carer support. It is intended to be used when families can not cope with their current situation and need extra support.

Funding is based on the assessment of need and the cost of the care required with allocation determined for periods of 3 to 12 months. Families can choose a private caregiver as long as there are no parenting or safety issues but Family Options will not accept any responsibility for that caregiver's competence. Family Options can assist in coordinating training for a family chosen caregiver if required. Alternatively families can work with their Key Worker and the Respite Nurse Coordinator to arrange care through an agency.

After-hours support

There is no systematic after-hours support for families in New Zealand. However, DHBs with formalised links with hospices and/or 24-hour district nursing services are able to offer after-hours contact. In other locations, families are encouraged to contact an on-call paediatrician at the local hospital. Care plans and anticipatory prescribing are often utilised.

Primary care involvement in after-hours care appears to be mixed. Because of changed general practice models and financial imperatives, GPs are likely to be involved in after-hours care only in peripheral locations. Families that have been linked to secondary providers for long periods of time develop relationships of trust with those providers, and so are likely to prefer a hospital as an after-hours service.

Care co-ordination

The family of a child under palliative care is potentially burdened by inputs from multiple agencies and providers. In many DHBs where this need is recognised, one provider (usually a nurse) acts as a point of contact for the family. However, this role is often negotiated on an informal, case-by-case basis and may not be supported by shared records and formalised memoranda of understanding. Where there is case co-ordination, it usually comprises information sharing and resource sharing between public sector providers. Although GPs and practice nurses may be kept informed, they are usually not formally included in the care co-ordination process.

Māori providers report that the nature of whānau is changing, such that the whānau is increasingly considered to be a network of relationships of trust rather than kinship relationships. Māori providers emphasise the need for longstanding, trusting relationships with a key worker/co-ordinator as a central

requirement for whānau, and point out the requirement under the Whānau Ora initiative for such relationships.

Adolescent services

For children with palliative care needs who survive childhood, transition to adult services is usually required. Transition from generalist paediatric care, with its longstanding relationships of trust, to adult services, which are organised as 'single organ' services, presents particular issues for adolescent developmental and health needs. The True Colours Charitable Trust in Hamilton provides an adolescent space and facilitates adolescent peer support groups.

Sibling services

The needs of siblings who are affected by a child with palliative care needs, and by the death of that child, are not supported in a systematic way. In some DHBs, hospices provide sibling support, while in others clinical staff attempt to meet that need. An exception is MidCentral, which contracts services to a psychological service run by Massey University.

Grief and loss support

The burden of care for a child with palliative care needs presents multiple problems for parents, and the loss of a child affects families permanently. Grief support and bereavement counselling for parents and other family members are not systematically developed. In some locations, counselling services are provided by the private sector, while in others paediatric service providers ensure that one post-death visit is paid to a grieving family. In the absence of other services, some medical and nursing clinicians undertake to provide counselling themselves.

11 SERVICE DELIVERY: CURRENT ISSUES

11.1 Introduction

This section describes the range of service delivery models in New Zealand and then discusses current service delivery issues in four subsections: levels of care, collaborative and integrated services, safe and effective services, and service enablers. Services are reviewed against the policy documents described earlier in this report, and the results of consultations with providers are discussed.

11.2 Service models

Throughout the last decade policy documents have noted the range of paediatric palliative care service delivery models in New Zealand. In the absence of a national framework, diverse local delivery systems persist. These illustrate the present varied levels of engagement between hospice, public health and primary care services and different applications of co-ordination processes. Several examples of diverse service delivery models are briefly described below.

Counties Manukau DHB

Counties Manukau DHB provides paediatric palliative care services to a large and growing multicultural population. Most of these services are delivered through the DHB. Kidz First, the paediatric service, comprises inpatient and community services. Most children with palliative care needs are linked with Starship, and so Counties Manukau DHB providers have close links with the Starship Paediatric Palliative Care Team.

The consultant and the clinical nurse specialist are available for home visits. The clinical nurse specialist meets with the Kidz First outreach nurses each fortnight to discuss ongoing care and to plan care for new referrals. The community team values the opportunity to engage with specialist advice and support.

Although the South Auckland Hospice has a mandate to provide care for all ages, public sector providers consider that hospice care is not appropriate for children. Relationships with GPs depend on GP interest and engagement. Practice nurses often act as an intermediary between home care nurses and GPs, but are otherwise not directly involved in service provision.

The Counties Manukau population utilises Middlemore Hospital as its after-hours service. This is considered to be because of widespread poverty, which

precludes GP involvement, along with a community sense of ownership of the hospital.

Northland DHB

Northland DHB, as part of the Northern region, has formal links with the Starship team. However, unlike Counties Manukau DHB, Northland paediatric providers have formalised relationships with two hospices.

The secondary paediatric service at Whangarei Base Hospital is the focus for paediatric palliative care. The MidNorthland Hospice in Whangarei provides after-hours nursing care and an after-hours contact for families caring for a child at home. The hospice is able to accommodate children and whānau, if required, for respite or end-of-life care. In practice this rarely happens. The Kerikeri Hospice service links with primary and community providers in the Far North.

To provide equitable services to a scattered rural population, interested GPs are creating hubs of palliative care expertise. Despite the large Māori population in Northland, iwi providers are not usually involved in palliative care for children.

Waikato DHB

Waikato DHB provides a unique constellation of palliative care services to children. Paediatricians and community nurses link with two non-government organisations: Rainbow Place and True Colours Charitable Trust. Rainbow Place, the children's hospice attached to Hospice Waikato, provides family rooms for respite and end-of-life care. A small team at True Colours provides a range of support services and a day-stay respite facility. It provides palliative care support to staff at Waikato Hospital and works closely with DHB outreach nurses. Rainbow Place receives some public funding as part of the hospice, but True Colours is entirely community-owned.

After-hours services are provided by the True Colours nursing service, and the paediatric registrar or on-call paediatrician is available for consultation. In rural locations, district nurses and GPs provide direct care. However, providers report that expertise and inclination among GPs is variable.

Lakes DHB: Taupo

In Taupo, paediatric palliative care providers have established a multidisciplinary team. The team includes the community paediatrician, paediatric outreach nurses and allied health providers, and the Taupo Hospice team. Services, which are provided to a wide geographic area, include nursing (including night nursing), care co-ordination, education, and bereavement counselling.

Despite the fact that records and electronic information are not accessible to all providers, nursing teams share care plans and decide how to share care between the community and hospice services. The community paediatrician is available for support. After-hours care is usually provided by the on-call paediatrician at Rotorua Hospital.

Tairawhiti DHB

The population of Tairawhiti DHB is geographically scattered and is younger than the general New Zealand population. Paediatric palliative care is provided by the paediatric service at Gisborne Hospital and by paediatric outreach nurses. Children with palliative care needs are referred to and from several centres, including Starship.

For an individual family the key worker is likely to be a paediatric outreach nurse, supported by a lead paediatrician. The hospice service is reluctant to extend its work to children, and GPs are not often directly involved in care. In remote locations the use of locum GP services results in inconsistent primary care for families. To compensate for this, paediatricians conduct outreach clinics in remote locations, and rural health nurses and Māori nurses provide much direct care.

Eight paediatric sub-specialists provide outpatient services in Tairawhiti DHB. Providers value regular visits and the opportunity for phone consultation and support. Support from the Starship team is sought when required.

Respite is a major issue for Tairawhiti providers. Skilled respite caregivers are not widely available, so patients are sometimes admitted for weekend respite in Gisborne Hospital.

11.3 Levels of care model

The levels of care model, which distinguishes service provision by specialist and generalist providers, appears not to have been adopted in the field of paediatric palliative care. This possibly reflects the under-development of the field in New Zealand, and the inequitable representation of paediatric palliative care in policy decision-making and funding allocation.

Specialist services

The only provider team that conforms to specialist criteria is the Paediatric Palliative Care Team based at Starship. Established in 1998, the Starship team meets the requirement for a multidisciplinary team with specific training and experience. It currently comprises: one paediatric palliative care and complex pain management specialist (1.0 FTE); two paediatric palliative care nurse specialists (1.6 FTE), one of whom is completing nurse practitioner registration; one social worker (1.0 FTE) and psychological/grief and bereavement support (0.4 FTE). A Fellow is based with the team for a 12

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month period. No formal administrative support is provided to the team: currently, administration support is provided by the ACC Patient Support Liaison Worker attached to the Complex Pain Service.

Working across the hospital–community continuum, the team is funded to provide paediatric palliative care services in the Northern Region. Services include direct care, support and advice to other providers, and the provision of education and training (Ministry of Health 2010). The team also provides advice and support to providers across New Zealand on an informal and unfunded basis. In order to meet growing national need, team members are often available on a 24/7 basis.

From 2005 to 2009, 331 patients were admitted to the paediatric palliative care team. Of these, 142 (42.9 percent) had malignant conditions and 189 (57.1 percent) had non-malignant conditions. Classification by secondary diagnosis is shown in Table 7. At the time of writing no other service data were available.

Table 7: Number of patients admitted to Starship Paediatric Palliative Care Team between 1 January 2005 and 1 January 2009, by primary and secondary diagnosis

Primary diagnosis	Secondary diagnosis	Number	%
Malignant disease	Leukaemia/lymphoma	38	
	CNS tumour	52	
	Neuroblastoma	12	
	Sarcoma	27	
	Other	13	
Total malignant		142	42.9
Non-malignant disease	Cardiology	43	
	Chromosomal/syndrome	18	
	Infection/immunology	11	
	Gastroenterology/hepatology	7	
	Metabolic	24	
	Neurology	63	
	Renal	3	
	Respiratory	16	
	Other	4	
Total non-malignant		189	57.1
Total admissions		331	100.0

Source: Auckland District Health Board 2010

Paediatric palliative care-specific services are provided in two other DHBs. In Waikato DHB two NGOs (Hospice Waikato and True Colours) provide palliative care services to children. In Canterbury DHB a nurse specialist has been recently appointed to co-ordinate services for the South island, and 0.2 FTE paediatric oncologist time is allocated to palliative care. These services do not meet the criteria of specialist services.

In some DHBs, including Northland and Lakes, adult hospice services are involved in care. Because they do not take a formal specialist role, but instead supplement hospital and community services, they cannot be considered specialist providers for children.

Generalist services

Palliative care is provided by a range of generalist providers. These include hospital- and community-based primary paediatric teams, disease-specific paediatric specialists, paediatric outreach nurses, Māori providers, NGOs and, in some DHBs, adult hospices. Varied models of care and constellations of service providers are used in each DHB. Some examples are described section 11.4.

11.4 Development of a national paediatric palliative care framework and network

Progress towards developing a national framework has been slow. Since 1998 the single national specialist paediatric palliative team has been at Starship in Auckland, and a paediatric palliative care specialist has been appointed as part of that team. A national network, regional paediatric palliative care co-ordinators and a national grief and bereavement support programme have not been established.

Drake (2010) suggests that lack of progress in this area is due to:

- lack of a national paediatric palliative care strategy
- absence of mandated paediatric representation on the Palliative Care Council and of specific paediatric palliative care working groups
- poor attention given by DHBs to this area
- funding inequity for paediatric palliative care.

The paediatric oncology shared care model provides an example of an effective clinical network. The model utilises a continuum of care and clinical partnerships established between primary-, secondary- and tertiary-level providers to deliver safe, effective and appropriate treatment closer to the patient's home (Ministry of Health and DHBNZ 2010).

Secondary centres designate a local paediatrician as the shared care consultant responsible for guidelines-based conduct of care, and a senior nurse to act as the oncology link nurse, responsible for regular contact with the patient, direct care and co-ordination between the tertiary centre and community-based nursing teams. Strong links with primary providers are encouraged.

Tertiary centres take responsibility for initial management, diagnosis and treatment, and discharge planning. They keep secondary providers informed and provide advice to them on a 24-hour, 7-day-a-week basis. Outreach clinics are conducted by secondary centres and attended by consultants from the tertiary centre in order to provide diagnosis, management and continuity of care. A senior shared care link nurse liaises with secondary-level shared care nurses. Tertiary centres host an annual update meeting for shared care consultants, link nurses and other interested clinicians. A shared care policy folder is developed and maintained by the tertiary centre (Ministry of Health and DHBNZ 2010).

Providers see the value of the oncology shared care model and there is strong support for a national service delivery network. Providers especially appreciate the nursing links, the attendance of paediatric oncologists at outreach clinics, and good communication with the two tertiary oncology centres, which are facilitated by the oncology model. There is strong support for formalising a national role for the Starship team. Providers believe that a national network would enable support from the Starship team and facilitate improved communication flow.

However, providers do feel that a national network should be developed carefully, with guidance from the Paediatric Society of New Zealand and leadership by the Starship team. Concerned that a national network could erode local autonomy, providers want a national framework and network to facilitate local assessment of need and the development of local services.

There is universal scepticism among providers regarding unfunded network and local service development. Providers strongly believe that the health system is under considerable stress and that for a network to be successful and sustainable it would require appropriate funding.

11.5 Development of collaborative and integrated services

As we have seen, collaborative and integrated services that are embedded in a national framework and linked via clinical networks have not yet been established. However, there is wide provider support for services that are locally developed and better utilise existing resources. The features of co-ordinated services identified by Goldman et al (2006) frame a review of service components in New Zealand:

Multi-agency teams that can deliver care in a variety of settings, but predominantly at home

Multi-agency teams are rare in New Zealand. With the exception of DHB-hospice relationships in some DHBs (eg, Northland, Lakes, Waikato and Canterbury), most multidisciplinary teams are made up of DHB medical, nursing and, sometimes, allied health professionals. GPs are not formally involved in these teams. The Starship team provides services across the

hospital–community continuum, but, with some exceptions, other teams are located in either the hospital or the community.

The ability to deliver care in a variety of settings requires education and training. Outside of Auckland few providers have formal paediatric palliative care training, although many nurses have attended an annual study day conducted by the Starship team.

Specialist palliative care teams that support primary and secondary care teams delivering palliative care

The one specialist paediatric palliative care team, based at Starship in Auckland, is funded as a service to the regional team. Its national role is an informal one. Clinicians throughout the country seek advice and support from the Starship team clinical nurse specialist and consultant on a 24/7 basis. The resources of the team are stretched, and increasing numbers of national requests puts added pressure on the team.

In many DHBs paediatricians provide palliative care advice to outreach nursing teams, GPs and (sometimes) hospice services. Where hospices take a formal palliative care role, such as in Northland, hospice staff provide after-hours support to community providers.

Comprehensive assessment of needs for both the child and family

Palliative care assessment is conducted by providers as part of care plan development. Although assessments may be shared between teams and across disciplines, services usually conduct their own assessment. Hence, when more than one agency is involved, multiple assessments are common.

Practical and explicit care planning

Care plans are used in most local settings. When a child is discharged from Starship, care plans are sent to local providers by the paediatric palliative care team. Despite widespread use, the quality and effectiveness of these plans is unknown.

Because of delays in achieving shared electronic records, care plans are often shared between providers by email or fax and are often maintained in hard-copy form. Patient-held records appear not to be widely used.

Issues relating to the definition of palliative care and the appropriate timing of its implementation concern a number of providers. Hence it is likely that most palliative care plans are, in fact, end-of-life care plans.

Planning ahead for expected complications and crises

In a number of DHBs, hospital-based clinicians ensure that anticipatory prescribing and care plans are in place, which anticipate complications. Providers consider that this partially addresses the lack of after-hours care.

A key worker to act as a co-ordinator and advocate on behalf of families

Although the key worker concept is used in several DHBs, the role appears to be informal and negotiated on a case-by-case basis with families and other providers. Key workers are usually nurses, a role which is supported by both nurses and medical clinicians. Providers support the concept of key workers, but they see the need for extra resources for a formalised role to have an impact on normal practice.

24-hour access to a service delivered in a setting that is desired and/or appropriate to their needs

As discussed above, little is known about preferred place of care and death in New Zealand. Providers report that most families wish to provide care at home but are concerned about the inadequacy of health service supports that enable high-quality home-based care. At present, 24-hour access to paediatric palliative care services is not universally available with out-of-hours GP service and 24hr district nursing services variable across locations. However, in developing an individualised care package for children and their families the key people, as identified by the child and family, should be involved including the GP and other primary care providers. Individual GP's have shown a willingness to provide after hours local response when included in the planning for co-ordinated care.

Good co-ordination of care

As discussed above, care co-ordination is variable across the country. Without designated key worker responsibilities, assessment and reassessment, shared care plans and after-hours care, co-ordination at any particular moment in time is not achievable. Drake (2010) reports the results of a questionnaire regarding child health, and including palliative care, which was sent in 2003 by the Paediatric Society of New Zealand to all DHBs. DHB responses indicated both a poor understanding of the palliative care needs of children and young people and a reluctance to appoint co-ordinators.

A nurse co-ordinator was appointed in late 2010 to co-ordinate paediatric palliative care services for the South Island. The nurse co-ordinator is based in the Nurse Maude district nursing service and has close links with DHB services and with the Starship clinical nurse specialist.

Facilities for respite care

Although a need for respite facilities has been identified since 1998, co-ordinated respite policy has not been developed. As discussed in section 10, respite facilities are available in one designated children's hospice service (Rainbow Place in Hamilton) and several adult hospices. It can be difficult for children with a disability or a life-limiting condition who have been referred to a palliative care service to access disability support services through NASC agencies.

Many paediatric providers are sceptical about the appropriateness of palliative care services delivered by adult hospice services, yet hospices receive public funding to provide palliative care services to all – including children. Most are willing to provide community, respite and end-of-life services to children and adolescents. It is reported that they consider education and formalised support from paediatric services is required to deliver high-quality care. At present, patients are admitted to hospice services if they have a life expectancy of less than 12 months. If hospices were to be engaged in care provision for children, the admission criteria would require re-consideration.

New Zealand's small population size precludes the development of children's hospices. Providers are broadly in favour of the development of in-home respite care, which relieves pressure on hospitals, but such development requires an appropriately skilled and reimbursed workforce.

Continuity of care over the lifetime of the child, including transitions and into the bereavement period

There is an apparent lack of agreement among providers as to what palliative care is and when it should be introduced. For many, palliative care is end-of-life care, to be introduced when curative care is withdrawn. Some tertiary providers consider that specialist palliative care, a relatively new paediatric sub-specialty, encroaches on the scopes of practice of other providers. Conversely, specialist paediatric palliative care providers note reluctance by some tertiary providers to refer patients with palliative care needs to the Starship team.

The extent of involvement of GPs and practice nurses in paediatric palliative care is unknown. Many public sector providers are sceptical about the capability and capacity of primary care teams to be involved. However, some of the few primary care providers consulted for this project identified paternalistic attitudes on the part of paediatric services, which act as a disincentive for families to establish relationships with primary care.

As discussed in section 10, bereavement services are patchy and inadequate, and continuity of care is unlikely to be achieved until these issues are resolved.

Easy access to hospital

Hospital access by children and families has not been measured, but it is clear that access is affected by geographic location and by diagnosis. Ethnicity and age may be other factors.

11.6 Development of safe and effective services

Goldman et al (2006) identify clear standards and quality assurance of services as key components of safe and effective services. The Service Specification (Ministry of Health and DHBNZ 2010) calls for national standards in which to embed the work of specialist providers. Such standards have not yet been developed. However, the Starship team has recently begun adapting the Palliative Care Australia standards (described earlier, in section 6.2) for the New Zealand context.

The Starship team has developed protocols, which include an end-of-life care plan and a plan for decision-making at the end of life named *Allow Natural Death: Te Wa Aroha*. Several clinical symptom management guidelines are in the process of development.

A quality assurance agenda, and data systems to support such an agenda, have yet to be developed. No national or co-ordinated programme of research has been identified or developed. The development of safe and effective services depends on adequate funding, but consultation indicates that the delivery system is under considerable stress. A system cannot therefore be implemented at nil extra cost.

Palliative care for children has no discrete funding stream. Compared with adult palliative care services, children's services are extremely underfunded. A recent report points out that paediatric palliative care services receive \$450,000 (primarily staff costs) compared with funding for adult services of \$45 million (Ministry of Health 2010).

Development of safe and effective services depends on a system that has good leadership and a 'clear line of sight' from top to bottom: that is, from the policy development environment to the service delivery context. Although paediatric palliative care providers are represented on some national policy groups, there is widespread concern that representation is not equitable.

In summary, New Zealand has some way to go before the requirements for a functioning paediatric palliative care system, identified by ACT and RCPCN (1998) can be met. These requirements are:

- a system to identify and keep track of children
- identification and recognition of a provider team/network, which comprises both a multidisciplinary network and the core provider group
- overall service co-ordination
- service co-ordination for families.

11.7 Service enablers

Project consultation indicates that, although paediatric palliative care services are enabled by some local systems, the most significant enabler is professionalism and collegiality in the paediatric sector. This is true both between and within disciplines.

In locations where providers have developed relationships of trust, care co-ordination and information-sharing is continual and, to a degree, informal. Providers in these settings share care, information and resources. Co-location of staff is considered to assist these relationships. In some smaller communities, providers are known to each other and deeply understand community dynamics.

Paediatric services are delivered by committed and interested providers, who engage in close collegial networks. Palliative care is enabled by both the generalist nature of paediatrics and its family-centred models of care.

PART C: GUIDANCE FOR THE DEVELOPMENT OF PAEDIATRIC PALLIATIVE CARE SERVICES

12 OVERVIEW

The aim of Part C is to clearly set out a direction for paediatric palliative care services in New Zealand. The direction is informed by:

- the needs and gaps identified in New Zealand policy documents over the last 12 years
- international best practice
- the views of providers consulted for this project regarding service enablers, gaps and future direction
- the health and welfare reform context.

The guidance provided is implementation focused but is necessarily high level. Once agreed, implementation strategies should be subjected to a rigorous project delivery methodology which identifies, in more detail, implementation components, milestones, risks and costs.

The guidance proposes a service delivery system that builds on existing resources and is implemented at minimal extra cost. The proposed system utilises clinical networks and collaborative approaches to create a coherent structure that is nationally led and co-ordinated, but enables local DHB development and ownership. It also provides for the development of a national evidence base.

Strong leadership from the Ministry of Health and the national specialist service is required to implement the proposed guidance. Services and systems will need to be closely aligned with the development of the reform agenda, with particular regard given to workforce planning, safety and quality, primary care development, regionalisation and Whānau Ora.

The guidance is presented as follows. A vision and a set of principles are identified, and a proposed national service delivery framework, which identifies and links levels of care, is described. The responsibilities of provider and support agencies are identified, and each of the principles is broken down into a set of recommendations. Proposed agency involvement for each recommendation is identified, and a phased implementation process is proposed.

13 PRINCIPLES AND FRAMEWORK

13.1 Principles

The principles for paediatric palliative care in New Zealand are adapted from the vision of the *New Zealand Palliative Care Strategy* (Ministry of Health 2001):

All children with palliative care needs and their families/whānau have timely access to high-quality palliative care services

The proposed guidance adheres to the following six key principles.

- 1 A service framework utilises a paediatric palliative care network and links levels of care.
- 2 Services are co-ordinated and flexible.
- 3 Services are equitable and needs-based.
- 4 Services are of high quality.
- 5 Services are culturally anchored.
- 6 Services are fiscally responsible and appropriately resourced.

13.2 Framework

The proposed national framework positions the Starship Paediatric Palliative Care Team as the national specialist service. They will continue to provide direct specialist palliative care to the Northern Region, but will also take a formal advisory role and will lead national service development.

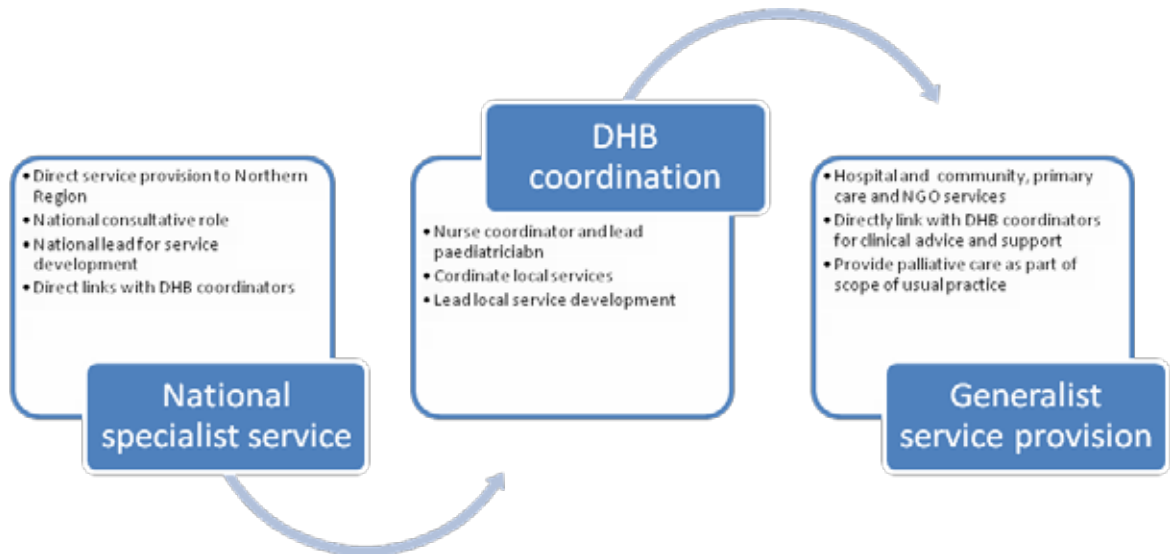
A network of co-ordinators in each DHB or region will provide a system of linkages between the national specialist service and local DHB providers. DHB or regional co-ordination will be the responsibility of a nurse co-ordinator, who may be located in a hospital or community team, and a lead paediatrician, who is a specialist or generalist paediatrician with an interest in palliative care. (The nurse co-ordinator may also be the oncology shared care nurse.) Both will have specific education and training in paediatric palliative care and may undertake short-term training positions with the national specialist team.

Co-ordinators will directly link with the national specialist service and provide advice and support to generalist providers. The co-ordination roles will be a proportion of FTE. Co-ordinators will lead local needs assessment, data collection and service development. Local development and ownership of local services will be emphasised.

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Generalist services will be provided as a component of usual practice by primary, secondary and tertiary providers, including allied health providers and NGOs. Generalist providers will participate in, and may take key worker roles in, co-ordinated delivery of care. Hospice services are included as generalist providers of paediatric palliative care. This is because where hospice services are utilised, providers consider them appropriate, and in a context of constrained resources every resource must be utilised.

Figure 1: Paediatric palliative care system relationships



To guide and support the framework, a National Paediatric Palliative Care Network should be established. The Network would most likely comprise the Palliative Care Special Interest Group of the Paediatric Society of New Zealand, as well as representation from the Ministry of Health, DHBs, Hospice NZ, NGOs and consumers. The work of the Network would intersect with that of the Palliative Care Council and other policy groups.

Table 8 describes in more detail the proposed activities conducted at each level of service delivery.

Table 8: Proposed paediatric palliative care service responsibilities

National specialist service	Responsibilities
Starship Paediatric Palliative Care Team	<ol style="list-style-type: none"> 1. Provide direct specialist care to the Northern Region. 2. Take a lead role in the development of national services, including adolescent services, standards, clinical guidelines, and care co-ordination / shared care models. 3. Co-ordinate national clinical services. 4. Directly link with DHB/ regional co-

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	<p>ordinator(s).</p> <ol style="list-style-type: none"> 5. Facilitate clinical advice and support on a 24/7 basis to the DHB/regional co-ordinator. 6. Co-ordinate and develop a national education and training programme. 7. Co-ordinate and develop a national research programme. 8. Develop and conduct own research programme. 9. Collate national service data. 10. Develop and maintain professional networks, including the National Paediatric Palliative Care Network, Paediatric Society of NZ, Ministry of Health advisory groups, and Child and Youth Epidemiology Service.
DHB co-ordination	Responsibilities
<p>Paediatric palliative care nurse co-ordinator</p> <p>Lead paediatrician</p>	<ol style="list-style-type: none"> 1. Based in each DHB or region. 2. Role is a component of usual practice. 3. Participate in role-specific education and training. 4. Accept and disseminate discharge information from paediatric and other centres. 5. Lead the collaborative development of local services, including service mapping, care co-ordination / shared care models, care planning, 24/7 clinical advice for generalist providers, and respite services. 6. Co-ordinate local services. 7. Provide some direct care as a key worker. 8. Provide support and clinical advice to generalist providers. 9. Request specialist clinical advice from the national specialist service. 10. Develop and/or deliver local education and training. 11. Collect local data and submit these to the national specialist service.
Generalist service provision	Responsibilities
<p>Generalist paediatric services</p> <p>Specialist paediatric services</p> <p>Primary care teams</p> <p>Hospice services</p>	<ol style="list-style-type: none"> 1. Provide palliative care to children and adolescents as part of scope of usual practice. 2. Participate in the development and implementation of co-ordinated care initiatives.

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Māori and ethnic-specific providers	3. Directly link to DHB/regional co-ordinators for clinical advice and support.
Community nursing teams	4. Access a designated on-call paediatrician for 24/7 clinical advice.
Allied health services	5. Provide information to the DHB/regional nurse co-ordinator.
Non-government organisations	6. Participate in local education and training initiatives.

Support for the service delivery framework would be provided by the Ministry of Health, DHBs and the National Paediatric Palliative Care Network. Table 9 explains the anticipated responsibilities of each.

Table 9: Proposed paediatric palliative care support responsibilities

Ministry of Health	Responsibilities
	<ol style="list-style-type: none"> 1 Support paediatric palliative care representation on national advisory committees. 2 Ensure equitable funding for the national specialist service and local services. 3 Develop information systems, with the national specialist service. 4 Navigate high-level links with emerging health and social sector policy.
District Health Boards	Responsibilities
	<ol style="list-style-type: none"> 1 Ensure equitable funding for the development of local services and links with the national specialist service. 2 Ensure paediatric palliative care representation in local palliative care and in paediatric services policy development and advisory groups.
National Paediatric Palliative Care Network	Responsibilities
	<ol style="list-style-type: none"> 1 Participate in national policy development and advisory groups. 2 Provide a peer review mechanism. 3 Further develop the framework and service development.

14 GUIDANCE

In this section, the principles of the organising framework are broken down into sets of discrete, but linked, recommendations.

Principle 1: A service framework utilises a paediatric palliative care network and links levels of care

Recommendations

- 1.1 Develop terms of reference and establish a National Paediatric Palliative Care Network.
- 1.2 Develop and implement new terms of reference for the Starship Paediatric Palliative Care Team, including a national support and service development role and 24/7 support to DHB co-ordinators.
- 1.3 Appoint DHB/regional nurse co-ordinators and lead paediatricians.
- 1.4 Develop and implement an education and training programme for nurse co-ordinators and lead paediatricians.
- 1.5 Develop and implement local services.
- 1.6 Ensure alignment with emerging health and social policy.

Principle 2: Services are co-ordinated and flexible

Recommendations

- 2.1 Conduct local needs assessments and service mapping.
- 2.2 Develop and implement DHB key worker roles.
- 2.3 Develop and implement DHB shared records and/or information-sharing mechanisms.
- 2.4 Develop and implement a DHB 24/7 paediatric service (or other) support for generalist providers.
- 2.5 Develop and implement local education and training.

Principle 3: Services are equitable and needs-based

Recommendations

- 3.1 Develop and disseminate an agreed definition of paediatric palliative care and the timing of its introduction.
- 3.2 Conduct local needs assessments and service mapping.
- 3.3 Develop and implement services that meet Māori need.
- 3.4 Develop and implement services to meet the needs of rural children and their families/whānau.
- 3.5 Ensure family representation in service development.

- 3.6 Develop high-level relationships with social welfare, education and disability sectors to progress funding and supportive care issues.

Principle 4: Services are of high quality

Recommendations

- 4.1 Develop and implement national standards.
- 4.2 Develop and implement clinical guidelines for key areas, such as symptom control and end-of-life care.
- 4.3 Develop a quality improvement framework.
- 4.4 Develop an evaluation framework and data collection system.
- 4.5 Develop and implement a research programme and a national evidence base.

Principle 5: Services are culturally anchored

Recommendations

- 5.1 Align all initiatives with the principles of the Treaty of Waitangi.
- 5.2 Ensure Māori representation on the National Paediatric Palliative Care Network.
- 5.3 Ensure that Māori and other significant ethnic groups are represented in local service development decision-making.
- 5.4 Link with local Whānau Ora developments.

Principle 6: Services are fiscally responsible and appropriately resourced

Recommendations

- 6.1 Develop clear funding mechanisms.
- 6.2 Ensure that service development adheres to funding constraints.

15 IMPLEMENTATION OF GUIDANCE

In this section the principles and recommendations provided in section 14 are re-presented, along with an indication of which organisation(s) would take the lead role in implementation and any other groups that may be involved. A suggested timeline for implementation is then provided.

15.1 Who will be responsible?

Table 10: Agencies involved in implementing the recommendations

Principle 1: A service framework utilises a paediatric palliative care network and links levels of care			
	Recommendation	Lead	Also involved
1.1	Formalise the terms of reference and membership of the National Paediatric Palliative Care Network (PPCN).	National Specialist Service (NSS)	Paediatric Society of NZ (PSNZ)
1.2	Develop and implement new terms of reference for the Starship Paediatric Palliative Care Team, including a national support and service development role and facilitation of 24/7 support to DHB or regional co-ordinators.	NSS	PPCN Ministry of Health Auckland DHB
1.3	Appoint DHB or regional nurse co-ordinators and lead paediatricians.	DHBs	HSS PPCN
1.4	Develop and implement an education and training programme for nurse co-ordinators and lead paediatricians.	NSS	DHBs Ministry of Health PPCN Universities/ training institutions
1.5	Develop and implement local services.	DHB/regional co-ordinators	NSS PCCN DHBs NSS
1.6	Ensure alignment with emerging health and social policy.	Ministry of Health	PPCN DHBs

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Principle 2: Services are co-ordinated and flexible			
	Recommendation	Lead	Also involved
2.1	Conduct local needs assessments and service mapping.	DHB/regional co-ordinators	DHBs NSS NSS
2.2	Develop and implement DHB key worker roles.	DHB/regional co-ordinators	NSS
2.3	Develop and implement DHB shared records and/or information-sharing mechanisms.	DHB/regional co-ordinators	DHBs PPCN NSS
2.4	Develop and implement a DHB 24/7 paediatric service (or other) support for generalist providers.	DHB/regional co-ordinators	DHBs NSS PCCN
2.5	Develop and implement local education and training.	DHB/regional co-ordinators	
Principle 3: Services are equitable and needs-based			
	Recommendation	Lead	Also involved
3.1	Develop and disseminate an agreed definition of palliative care and the timing of its introduction.	NSS	PCCN Ministry of Health DHBs
3.2	Conduct local needs assessments and service mapping.	DHB/regional co-ordinators	NSS
3.3	Develop and implement services that meet Māori need.	DHB/regional co-ordinators	NSS DHBs Māori providers
3.4	Develop and implement services to meet the needs of rural children and their families/whānau.	DHB/regional co-ordinators	NSS DHBs
3.5	Ensure family representation in service development.	NSS	DHBs
3.6	Develop high-level relationships with social welfare, education and disability sectors to progress funding and supportive care issues.	Ministry of Health	NSS PPCN

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Principle 4: Services are of high quality			
	Recommendation	Lead	Also involved
4.1	Develop and implement national standards.	NSS	PPCN DHBs
4.2	Develop and implement clinical guidelines for key areas, such as symptom control and end-of-life care.	NSS	PPCN
4.3	Develop a quality improvement framework.	NSS	PPCN
4.4	Develop an evaluation framework and data collection system.	NSS	PPCN
4.5	Develop and implement a research programme and a national evidence base.	NSS	DHBs Universities Other identified national and international partners
Principle 5: Services are culturally anchored			
	Recommendation	Lead	Also involved
5.1	Align all initiatives with the principles of the Treaty of Waitangi.	NSS	PPCN DHBs
5.2	Ensure Māori representation on the National Paediatric Palliative Care Network.	PPCN	NSS
5.3	Ensure that Māori and other significant ethnic groups are represented in local service development decision-making.	NSS	DHB coordinators Maori GMs
5.4	Link with local Whānau Ora developments	DHB/regional co-ordinators	Ministry of Health
Principle 6: Services are fiscally responsible and appropriately resourced			
	Recommendation	Lead	Also involved
6.1	Develop clear funding mechanisms.	Ministry of Health	PPCN NSS
6.2	Ensure that service development adheres to funding constraints.	NSS	PPCN Ministry of Health

5.2 Phased implementation

The development of paediatric palliative care services is complex and will require good management of many implementation strands. Given that such development must be achieved at minimal extra cost, the appointment of a project manager is unlikely. A phased implementation is therefore recommended.

Phased implementation could be achieved over a three-year period. The proposed milestones are described below.

Table 11: Implementation milestones for the proposed guidance

Year 1	<ul style="list-style-type: none"> • National Paediatric Palliative Care Network is established. • National Paediatric Palliative Care Specialist Service is established and resourced. • DHB/regional nurse co-ordinators and lead paediatricians are appointed and trained. • Standards and some agreed clinical guidelines are developed and disseminated. • DHB needs assessments and service mapping are completed. • DHB after-hours support for community providers is developed and implemented.
Year 2	<ul style="list-style-type: none"> • All clinical guidelines are developed and disseminated. • Local care co-ordination resources and mechanisms are developed. • All clinical guidelines are developed and disseminated. • Quality and research programmes are developed.
Year 3	<ul style="list-style-type: none"> • All guidance components are implemented. • Framework and guidance components are evaluated.

APPENDIX 1: PROJECT IMPLEMENTATION GROUP MEMBERS

Name	Position
Karyn Bycroft	Clinical Nurse Specialist Paediatric Palliative Care Team Starship Children's Health
Ross Drake	Clinical Director Paediatric Palliative Care Team Starship Children's Health
Naida Glavish	General Manager, Māori Health Chief Advisor Tikanga Auckland DHB
Mata Forbes	Co-ordinator/ Advisor Māori Health Service Auckland DHB
Lisa Gestro	Planning and Funding Manager Palliative Care and Older People's Health Auckland DHB
Belinda Coulter	Community Paediatrician, Lakes DHB Paediatric Society of New Zealand
John Forman	Executive Director New Zealand Organisation for Rare Disorders Consumer representative

APPENDIX 2: PEOPLE CONSULTED FOR THE PROJECT

Name	Position
Northland DHB	
Laeonie McKinnon	Nurse Paediatric Community Nursing Service
Bridgette McLean	Nurse Paediatric Community Nursing Service
Noelene Brown	Nurse Paediatric Community Nursing Service
Yvonne Hunter	Clinical Nurse Manager Northland DHB
Catherine Bremner	Paediatrician Northland DHB
Sam Boyd	Palliative Care Education Facilitator NorthHaven Hospice
Robbie Robinson	Team Leader, IPU NorthHaven Hospice
Mary Death	Clinical Services Manager NorthHaven Hospice
Christine Brownlee	Social Worker NorthHaven Hospice
Warwick Jones	Palliative Medicine Specialist NorthHaven Hospice
Liz Clark	Counsellor NorthHaven Hospice
Douglas Mearns	General Practitioner Kaikohe
Jenny Coleman	Nurse MidNorthland Hospice
Lyn Rastern	Population Health Strategist Northland DHB
Ellie Berghan	Population Health Strategist, Māori Health Northland DHB
Kim Tito	GM, Service Development and Funding and Māori Health Northland DHB
Auckland DHB	
Ross Drake	Consultant Starship Paediatric Palliative Care Team
Karen Bycroft	Clinical Nurse Specialist Starship Paediatric Palliative Care Team
Jess Jamieson	Social Worker Starship Paediatric Palliative Care Team
Karen Mikkelson	Clinical Nurse Specialist

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	Starship Paediatric Palliative Care Team
Jessie Butler	Nurse Specialist, Oncology Starship
Jane Skeen	Paediatric Oncologist Starship
Scott MacFarlane	Paediatric Oncologist Starship
Naida Glavish	GM Māori Health, Chief Adviser Tikanga Auckland DHB
Mata Forbes	Advisor, Māori Health Service Auckland DHB
Jan Nichol	CEO Mercy Hospice
Counties Manukau DHB	
Shirley Lawrence	Specialty Clinical Nurse, Kidz First Counties Manukau DHB
Kay Doherty	Specialty Clinical Nurse, Kidz First Counties Manukau DHB
Chris Holt	Specialty Clinical Nurse, Kidz First Counties Manukau DHB
Kerry Lote	Specialty Clinical Nurse, Kidz First Counties Manukau DHB
Heather Marmont	Specialty Clinical Nurse, Kidz First Counties Manukau DHB
Jean Jackson	Specialty Clinical Nurse, Kidz First Counties Manukau DHB
Leanne McMillan	Play Therapist, Kidz First/Medical/NICU Counties Manukau DHB
Tenari Jackson	Community Health Worker Counties Manukau DHB
Faasoa Aupa'au	Specialty Clinical Nurse, Kidz First Counties Manukau DHB
Linda Duncan	Specialty Clinical Nurse, Kidz First Counties Manukau DHB
Ambigay Ramsamy	Charge Nurse Manager, Kidz First Counties Manukau DHB
Bernard te Paa	GM Māori Health Counties Manukau DHB
Louise Porteous	Paediatrician Counties Manukau DHB
Adrian Trenholme	Paediatrician Counties Manukau DHB
Jessie Maravcich	Manager South Auckland Hospice
Willie Landman	Palliative Care Consultant South Auckland Hospice
Waikato DHB	
Renee Streatfield	CNS, Paediatric Homecare

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	Waikato DHB
Dave Graham	Community Paediatrician Waikato DHB
Cynthia Ward	CEO True Colours Charitable Trust
Stephen Parkinson	Psychotherapist True Colours Charitable Trust
Penny Parsons	Manager Rainbow Place, Hospice Waikato
Lakes DHB	
Shelley Kirk	Social Worker, Women Child & Family Lakes DHB
Bridget Wilson	Clinical Nurse Manager, Children's Unit Lakes DHB
Belinda Coulter	Paediatrician Lakes DHB
Christine Payne	Clinical Nurse Director Lakes DHB
Catherine Mott	Children's Outreach Nurse Specialist Lakes DHB
Vanessa Russell	Planning and Funding Portfolio Manager Lakes DHB
Phyllis Tangitu	GM Māori Health Lakes DHB
Eru George	Māori Health Lakes DHB
Carmelle Waiariki	Hunga Manaaki Lakes DHB
Carol Burton	Social Worker Lakes DHB
Karen Fox	Visiting Neurodevelopmental Therapist Lakes DHB
Beth Malcolm	Visiting Neurodevelopmental Therapist Lakes DHB
Suzie Kuper	Clinical Nurse Manager Lake Taupo Hospice
Justine Pereka	Children's Nurse Lakes DHB
Penny Brewer	Practice Nurse Pihanga Health
Jan Pook	Practice Nurse Pihanga Health
Yvonne Steeds	Practice Nurse Pihanga Health
Nola Cowan	General Practitioner Pihanga Health
Jo McArthur	Practice Nurse Pihanga Health

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Rene Lenoir	General Practitioner Pihanga Health
Frank Liaw	General Practitioner Pihanga Health
MidCentral DHB	
Robyn Williamson	Service Manager, Child and Women's Health MidCentral DHB
Jeff Brown	Clinical Director, Child Health MidCentral DHB
Joanne Briggs	Paediatric Social Worker MidCentral DHB
Nicki Twigge	Palliative Care Co-ordinator and Team Leader MidCentral DHB
Tracy Stone	Charge Nurse, Paediatric Services MidCentral DHB
Renee Clements	Clinical Nurse Specialist MidCentral DHB
Kirsty Ross	Clinical Psychologist Massey University Psycho-oncology and Health Conditions Psychology Services
Te Aira Henderson	Manager, Māori Health Services MidCentral DHB
Tairāwhiti DHB	
Maaka Tibble	GM, Māori Health Tairāwhiti DHB
Hein Stander	Consultant Paediatrician Tairāwhiti DHB
Robert Hunter	Manager, Maternal, Child and Youth Tairāwhiti DHB
Shaun Grant	Consultant Paediatrician Tairāwhiti DHB
Sue Cranston	Registered Nurse/ Paediatric Quality and Education Co-ordinator
Mary Stonehouse	Paediatrician Tairāwhiti DHB
Canterbury DHB	
Jane Rollings	Clinical Nurse Manager Nurse Maude Hospice Palliative Care Service
Rachel Teulon	Paediatric Palliative CNS Nurse Maude Hospice Palliative Care Service
Dawn Anderson	CNS, Paediatric Neurology Canterbury DHB
Viv Patton	GP Liaison Canterbury DHB
Trudy Brown	CNS, Paediatrics Canterbury DHB and Nurse Maude
Amanda Lyver	Paediatric Oncologist and Paediatric Palliative Care (all diagnoses)

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	Canterbury DHB
Nicola Scott	Paediatric Oncology Shared Care Nurse Canterbury DHB
Viv Isles	CNS, Respiratory Children's Outreach Canterbury DHB
Other	
Elizabeth Craig	Epidemiologist NZ Child and Youth Epidemiology Service
Wayne Naylor	Cancer Control Council Ministry of Health
John Forman	CEO NZ Organisation for Rare Disorders

GLOSSARY

ACT	The Association for Children with Life Threatening or Terminal Conditions and their Families subsequently changed its name to ACT (The Association for Children's Palliative Care) and since 2008 has been known simply as ACT.
care co-ordination	a service delivery process that links children and families with services in co-ordinated ways, and is facilitated by a key worker
clinical network	a multidisciplinary group of clinicians that work together in non-hierarchical ways as a collaborative team
DHB	District Health Board
GP	general practitioner
key worker	a service provider who takes a co-ordinating role for children and families
life-limiting illness/condition	a condition for which there is no cure and which is likely to lead to premature death
NGO	non-government organisation
RCPCH	Royal College of Paediatrics and Child Health
respite care	provision of temporary relief for those caring for a person with health and/or disability needs
service provider	a clinician or service agency that provides services to a population or client group
WHO	World Health Organization

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