

Guidance for Integrated Palliative Care Services in New Zealand – Summary



September 2012

HP 5545

Executive summary

This document provides a summary of the key recommendations from the *Guidance for Integrated Paediatric Palliative Care Services in New Zealand* (the Guidance) including:

- extending the role of the Starship Paediatric Palliative Care Team to include national support services; specifically facilitating 24/7 support to DHB nurse coordinators
- confirmation of DHB nurse coordinators and lead paediatricians
- developing and implementing an education and training process for nurse coordinators and lead paediatricians
- establishing a National Paediatric Palliative Care Network.

This document should be read in conjunction with the Guidance.

Introduction

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

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 paediatric palliative care is inequitable. At the local level, the delivery of paediatric palliative care services is variable. Teams of public health service providers are sometimes supported by hospice services, with primary care providers rarely involved in a systematic way.

The Ministry of Health commissioned the development of implementation-focused guidance to improve integration of palliative care service delivery to children and young people in New Zealand. The Guidance examines existing paediatric palliative care services, both in New Zealand and internationally, and uses the results in the proposed framework. The proposed framework provides structure for developing a coherent, integrated and coordinated system of paediatric palliative care service delivery.

Key recommendations of the Guidance

Extending the role of the Starship Paediatric Palliative Care Team

The Guidance positions the Starship Paediatric Palliative Care Team as the national specialist service for paediatric palliative care. The Guidance recommends that the Starship Paediatric Palliative Care Team continue to provide direct specialist palliative care to the Northern Region, and also take a formal advisory role alongside leading national service development.

The Starship Paediatric Palliative Care Team will facilitate 24/7 support for DHBs and will link directly with nurse coordinators and lead paediatricians. As the national specialist service, the Starship Paediatric Palliative Care Team will coordinate education and training for nurse coordinators. This may include short-term training positions with the Starship Paediatric Palliative Care Team.

Confirmation of DHB nurse coordinators and lead paediatricians

A network of coordinators in each DHB or region will provide a system of linkages between the national specialist service and local DHB providers. DHB or regional coordination will be the responsibility of a nurse coordinator, 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 coordinator 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 Starship Paediatric Palliative Care Team.

Coordinators will directly link with the national specialist service and provide advice and support to generalist providers. The coordination roles will be a proportion of a full time equivalent (FTE). Coordinators will lead local needs assessment, data collection and service development, relevant to local services.

Generalist services will be provided as a component of usual practice by primary, secondary and tertiary providers, including allied health providers and non-government organisations. Generalist providers will participate in, and may take key worker roles in, co-ordinated delivery of care.

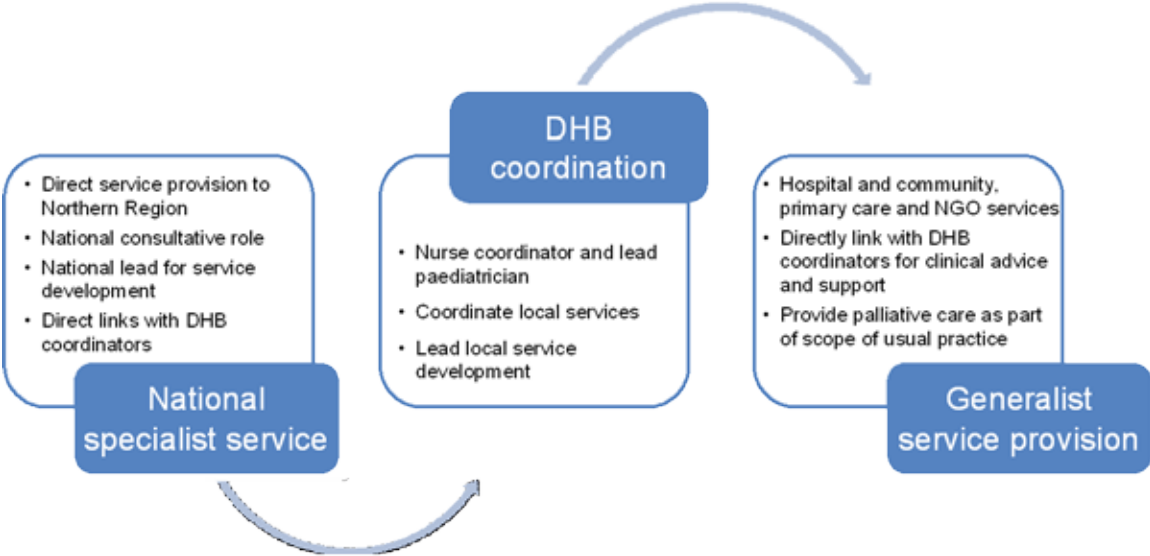
Hospice services are included as one of the generalist providers of paediatric palliative care. Hospice services traditionally provide specialist palliative care services for adults, and the services needed by paediatrics are different. Hospice services can be utilised to provide generalist paediatric palliative care where appropriate, and with support.

Establishing a paediatric palliative care network

To guide and implement the recommendations of the Guidance, a National Paediatric Palliative Care Network (the 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 New Zealand, non-government organisations and consumers. The work of the Network would intersect with that of the Palliative Care Council and other policy groups.

Figure 1 shows the paediatric palliative care system relationship.

Figure 1: Paediatric palliative care system relationships



Support for the implementing the framework will be provided by the Ministry of Health, DHBs and the National Paediatric Palliative Care Network. Table 1 shows the anticipated responsibilities of each.

Table 1: Proposed paediatric palliative care support responsibilities

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

Implementation of the Guidance

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 recommended.

Phased implementation of the Guidance could be achieved over a three-year period. Table 2 shows the proposed implementation milestones.

Table 2: Implementation milestones proposed

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

