

# Strengthening care for children with a life-threatening condition

A policy for health, palliative care, disability, children's services and community care providers 2008–2015





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Victorian Government, Department of Human Services, Melbourne, Victoria

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## Ministerial foreword

In a society which values children highly and aims to ensure that all children reach their potential, the serious disability or illness and death of a child is distressing for everyone. From parents, siblings and extended family members to friends, acquaintances and teachers, as well as health, disability, children's services and community care providers, the death of a child is confronting and challenging.

In developed countries the death of a child is now fairly uncommon. This has implications for how confident health and community care providers feel in supporting children with a life-threatening condition and their families. Many families report feeling isolated from friends, extended family and social networks at this time. This often reflects society's fear of death and the discomfort people feel in talking about death and dying, particularly when it involves children.

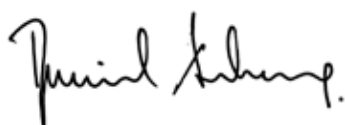
Because of the particular needs of children with a life-threatening condition and their families it is important that there is a policy framework that takes into account the different illness trajectories, diverse illness types and involvement of a broad range of services which are associated with providing paediatric palliative care.

This policy, '*Strengthening care for children with a life-threatening condition: a policy for health, palliative care, disability, children's services and community care providers 2008-2015*,' outlines the principles that underpin care for neonates, infants, children and adolescents with a life-threatening condition, and their families and the relationships that are critical to providing care in an appropriate and timely way.

With the growth of specialist palliative care services, significant progress has been made in ensuring that all Victorians have access to quality palliative care. In Victoria, the government has built the foundations for a collective and coordinated effort to improve care for children with a life-threatening condition and their families. This has been achieved through the establishment and growth of a statewide paediatric palliative care program. In addition to this, a wide range of government funded programs including health, palliative care, disability, early childhood, bereavement and community services also provide care and support to children and their families.

This policy, developed in conjunction with the paediatric palliative care policy advisory group, was informed by over 100 organisations and individuals who took part in consultations for the policy, and commented on the draft policy.

The Victorian Government is committed to ensuring the principles identified in this policy are implemented. We look forward to working with you towards achieving the vision that all Victorian children with a life-threatening condition and their families receive high quality care which is delivered in a timely and coordinated way in the best interests of the child.



**The Hon. Daniel Andrews MP**  
**Minister for Health**

## Acknowledgements

This policy has been produced by Cancer and Palliative Care, Programs Branch, Metropolitan Health and Aged Care Services Division, Department of Human Services (the department) in consultation with the Disability Services Division of the department and the Office for Children and Early Childhood Development in the Department of Education and Early Childhood Development.

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The Department would like to acknowledge the work of Dr Jenny Hynson, who generously allowed her PhD thesis '*The Palliative Paediatrician. Understanding the doctor-parent relationship in paediatric palliative care*' (November 2007) to form the basis of the literature review underpinning this policy.

The department also thanks the stakeholders who supported the development of this document through their participation in workshops, interviews and meetings and their feedback on the consultation version of the draft policy. The department particularly thanks the parents who shared their personal experiences of caring for a child with a life-threatening condition and provided feedback on the draft policy.

The policy document was developed and written by Amanda Bolleter and Brooke Blogg (Cancer and Palliative Care, Programs Branch Metropolitan Health and Aged Care Services Division, Department of Human Services).

## Contents

<b>Executive summary</b>	<b>1</b>
<b>Introduction</b>	<b>4</b>
<b>Relationships underpinning paediatric palliative care</b>	<b>9</b>
<b>Principles for caring for children with a life-threatening condition</b>	<b>11</b>
Principle one: information and decision making	11
Principle two: support for families	13
Principle three: best possible care at all times	15
Principle four: specialist advice and consultation	19
Principle five: coordinated care	23
Principle six: quality care	24
Principle seven: community awareness and support	26
<b>Glossary</b>	<b>27</b>
<b>Appendix one</b>	<b>28</b>
<b>References</b>	<b>29</b>





## Executive summary

With improvements in hygiene and medical technology, child and infant mortality rates have fallen steadily over the last century. However, there remain a number of children who will live with and die from a wide range of life-threatening conditions. Many of these children will die in the first month or year of life.

When providing care for children with a life-threatening condition, it is important to take into consideration the developmental differences between infants, children, adolescents and adults, which may affect diagnosis, prognosis, treatment strategies, communication and decision-making.<sup>1</sup> It is important to also consider the needs of children in rural areas, Aboriginal children and children from culturally and linguistically diverse backgrounds. A core defining aspect of paediatric palliative care is that family-centred care is provided for the child and their family.

The nature of paediatric palliative care means that children and families often need to access services from a range of sectors, including disability, acute health, community, early childhood and palliative care services. Effective coordination of these services, and the provision of case management where appropriate, is important in ensuring that care meets the continuously changing needs of the child and their family throughout illness and bereavement.

In order to ensure clarity about the use of terminology throughout this policy document, some key definitions are provided below:

### Life-threatening condition

The term 'life-threatening condition' is defined as any illness or condition developed in childhood whereby the child is likely to die prematurely.<sup>2</sup> It includes life-threatening disabilities as well as life-threatening illnesses. It is important to note that palliative care may be required for children with a range of life-threatening conditions such as cystic fibrosis, muscular dystrophy or other

neurodegenerative conditions, as well as children with cancer. It should also be noted that while all children with life-threatening conditions will require elements of palliative care to be integrated into their management, not all will require referral to a specialist paediatric palliative care service.

### Paediatric palliative care

Paediatric palliative care is an active and total approach to care for neonates, infants, children and adolescents with a life-threatening condition and their families. Paediatric palliative care includes physical, emotional, social and spiritual elements. It focuses on enhancing quality of life for the child and their family and includes management of physical symptoms such as pain, and psychosocial issues such as the impact of loss and grief and feelings of fear or isolation. Paediatric palliative care includes provision of respite, and ongoing support through death and bereavement to enable the family to remain functional and intact.<sup>3,4</sup>

### Family

Family is defined as parents and siblings and other family members such as grandparents, as well as extended family and social networks, or people the family identify as being of particular significance. The particular needs of siblings should be considered during a child's illness and death and into bereavement. Families should be supported to meet these needs wherever possible.

### Family centred care

Family centred care recognises services that work with children must take into account their families, the relationships within their families and the relationships between families and their communities. Family centred care employs a holistic and sensitive approach and aims to identify the family's strengths and capabilities and build on these to strengthen and empower the family.<sup>5</sup>



This document is based on feedback from the consultations undertaken as part of the policy development. Feedback provided in the consultation sessions is used throughout the document to inform each principle. It is also based on the literature review and policies cited throughout the document. The feedback from the consultations was consistent with the key themes in the literature review.

Regardless of the differences across developmental age groups or conditions, the consistent message from the consultations and research undertaken in developing this policy is that children with a life-threatening condition and their families need high quality, coordinated care that responds to their particular needs.

This policy document aims to strengthen care for children with a life-threatening condition and their families through:

- defining paediatric palliative care in the Victorian context
- outlining principles for the delivery of quality paediatric palliative care
- defining the relationships that underpin the effective delivery of paediatric palliative care.

The vision underpinning this policy is:

All Victorian children with a life-threatening condition and their families will receive high quality care which is delivered in a timely and coordinated way in the best interests of the child.

The paediatric palliative care policy is based on the seven key principles outlined in *Strengthening palliative care: a policy for health and community care providers 2004–2009*. Each principle represents a key element of providing the best possible care for children with a life-threatening condition and their families.

## Principle one: information and decision making

Children with a life-threatening condition and their families have information about options for their future care and are actively and appropriately involved in those decisions.

### Expected outcomes

- Children and their families are consulted about who is informed about their care and who makes decisions about their care.
- Children are informed about, and involved in, making decisions about their care as appropriate to their age and developmental stage.
- Families of children with a life-threatening condition are informed about and involved in decision making about their child's care.
- The unique needs of the child with a life-threatening condition and their families are addressed through developing and implementing an agreed care plan.

## Principle two: support for families

Families of children with a life-threatening condition are supported by health and community care providers.

### Expected outcomes

- Families are adequately supported by health and community care providers so that they can provide the best possible care for their child.
- The health and wellbeing of the family is maintained and enhanced by improved access to appropriate respite care, education facilities and support services.
- Families' ability to navigate the system will be strengthened through the timely provision of information about available services and supports.

### Principle three: best possible care at all times

Children with a life-threatening condition and their families receive the best possible care at all times.

#### Expected outcome

- The primary treating team caring for the child and their family is supported by specialist services to remain actively engaged in the child's care throughout their illness and into bereavement.

### Principle four: specialist advice and consultation

Children with a life-threatening condition and their families have access to specialist palliative care services when required.

#### Expected outcomes

- Children with complex needs have appropriate and timely access to specialist paediatric palliative care through specialist advice and secondary consultation for primary treating teams and palliative care services.
- Family members assessed with complex grief and bereavement needs are provided with information about and access to appropriate counselling and support.

### Principle five: coordinated care

Children with a life-threatening condition and their families have treatment and support that is coordinated across the continuum of care.

#### Expected outcomes

- Children and their families receive care which is seamless and continuous.
- Children and their families have a key contact person who assists in management of their care.

### Principle six: quality care

Children with a life-threatening condition and their families have access to quality services and skilled staff to meet their needs.

#### Expected outcomes

- Children and their families have access to care and support from suitably qualified service providers and trained volunteers.
- Children and their families receive care based on child and family needs and current research evidence.

### Principle seven: community awareness and support

Children with a life-threatening condition and their families are supported by their communities.

#### Expected outcomes:

- Communities, including family, friends, neighbours, work and social contacts are able to actively support children with a life-threatening condition and their families as appropriate.
- Community awareness about the needs of children with a life-threatening condition is enhanced through community promotion and education.

The rationale for these principles and the expected outcomes and key objectives for each principle are outlined in the body of this policy document.



## Introduction

### Background

A significant reduction in the infant and child mortality rates of developed societies has been achieved over the last century.<sup>6</sup> Members of developed societies now expect to bear healthy children, live long lives and be treated successfully for their illnesses. Parents do not expect to outlive their children.<sup>7</sup>

In Australia, the number of deaths occurring in infants and children has fallen in recent decades. Between 1984 and 2003 the death rate for Australian children aged 1-14 years decreased from 30 to 15 deaths per 100,000 children.<sup>8</sup> Between 1986 and 2006, the infant mortality rate for Australian children also declined significantly.<sup>9</sup>

It is important to acknowledge that the mortality rates for Aboriginal children remain substantially higher than for non-Aboriginal children. In the period 2004 to 2006, the infant mortality rate for Aboriginal children was more than double that of the non-Aboriginal rate.<sup>9</sup>

In developed countries the death of a child is now fairly uncommon, with health professionals rarely encountering the death of a child. A nurse working on a general paediatric ward would be likely to experience the death of a patient only once in every five years of full time work.<sup>10</sup> While the death of a child remains devastating for the family, the reduced exposure to child mortality has implications for how providers understand and feel confident to respond to the needs of children and their families. Many families report feeling isolated by community reactions, which often reflect society's fear of death and the discomfort people feel in talking about death and dying, particularly when it involves children.

Palliative care provides a holistic approach that seeks to provide specialist health care and address the physical, psychological, social and spiritual needs of people with a life-threatening condition and has the potential to improve the experience of children and their families.

Palliative care provided for children differs substantially to palliative care provided for adults. It is important to recognise that a child's life-threatening condition impacts upon the whole family. Children with a life-threatening condition and their families have particular and varying needs depending on the child's developmental stage, the nature of the condition, and the significant uncertainty that may accompany the prognosis and medical treatment. Specific strategies need to be employed to support children, parents, siblings and other family members. The term life-threatening condition refers to a range of illnesses and disabilities including muscular dystrophy and neurodegenerative conditions as well as cancer. A significant majority of children with a life-threatening condition will have a non-malignant disability or illness. In contrast, a significant majority of adults accessing palliative care services will have a malignant condition.

The impact of developmental differences for individual children can influence treatment strategies and make communication and decision making processes more complex. As a result, the issue of discussing impending death may be a challenge for the child and their family, as well as for service providers.<sup>11</sup>

While the general principles of palliative care apply to both adults and children, as with other special needs groups, there are specific needs and care approaches in which generalist or specialist service providers may have limited experience.<sup>12</sup> This policy outlines how the seven principles of the *Strengthening Palliative Care* policy apply specifically to children with a life-threatening condition and their families.

## Why do the needs of children with a life-threatening condition require special consideration?

Childhood is a time of rapid physical, psychological, emotional and spiritual development. From the tiniest newborn to the adolescent, children cannot be viewed as ‘little adults’. The diverse range of life-threatening conditions experienced by children and the uncertainty associated with many of these conditions means different requirements are needed in the provision of palliative care for children. Adolescents, neonates, Aboriginal children and children from culturally and linguistically diverse backgrounds also require special consideration.

## What are the rights of children with a life-threatening condition?

Children with a life-threatening condition have the same rights as all children. The rights of children (including those with a life-threatening condition) are addressed in a range of legislation and policy documents including the *Charter of Human Rights and Responsibilities Act 2006*, the *Child Wellbeing and Safety Act 2005*, ‘*Every Child Every Chance – a strategic framework for Family Services 2007*’ and the *Victorian State Disability Plan 2002-2012*.

In particular, children with a life-threatening condition and their families have the right to receive effective pain and symptom management, appropriate, timely and affordable services, and treatment which is in their best interests. Children with a life-threatening condition have the right to be respected and the right to equal opportunities to participate in the social, economic, cultural, political and spiritual life of society, including the right to an education. They have the right to live free from discrimination, including both active and passive forms of discrimination.<sup>13</sup>

All children with a life-threatening condition, including Aboriginal children and children from culturally and linguistically diverse backgrounds, have the right to have their cultural and spiritual needs met as part of their care.

## Pathways to palliative care: how children access palliative care

Many previously fatal conditions of childhood can now be either prevented or cured. However, advances in technology also mean that children who once died early of congenital anomalies, prematurity and other conditions now live for longer periods in states of high dependency. Many children with life-threatening conditions have uncertain prognoses characterised by recurrent relapses and remissions. This means that many will continue to pursue treatment until very late in their illness.

The life-threatening conditions which most commonly affect children can be classified in four key groups:

- conditions for which curative treatment is possible but may fail (for example, leukaemia)
- diseases where premature death is likely but intensive treatments may prolong good quality of life (for example, cystic fibrosis and muscular dystrophy)
- progressive conditions where treatment is exclusively palliative and may extend for many years (for example, neurodegenerative conditions)
- conditions, often with neurological impairment, causing weaknesses and susceptibility to complications (for example, cerebral palsy).<sup>6</sup>

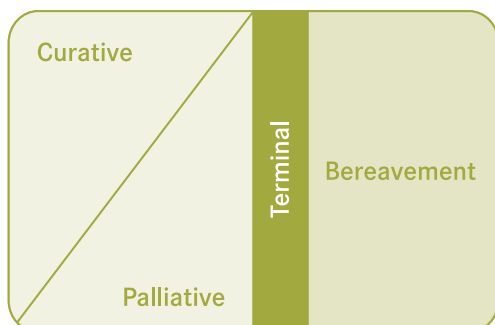
Not all children with a life-threatening condition will require support from a specialist paediatric palliative care service. The need for specialist palliative care intervention should be assessed according to the complexity of the child’s needs. In some cases, the child and



family's needs may be met by the combined expertise of paediatric health professionals and those working in palliative care. The input of specialists in paediatric palliative care is usually required when the complexity of the child's and family's needs exceeds the capacity of the health professionals already involved.

There is often no clear point of transition between curative and palliative care so a model in which the patient is receiving one mode of care or the other is unworkable. Instead, an integrated approach is required in which elements of palliative care are provided in conjunction with ongoing efforts to cure or modify the underlying disease process. This is represented diagrammatically in Figure 1.<sup>14</sup>

**Figure 1: Transition between curative and palliative care services**



### Where should palliative care be provided to children?

The question of where care is best delivered depends on the options available, the needs of the child and the family, and the capacity of the service system to respond to those needs in various care settings. The majority of families caring for a child with a life-threatening condition opt for care at home as this is where normal routines can be maintained, privacy achieved and social supports accessed. These children and their families may seek hospital care when their needs cannot be met at home.

This will depend on the nature of the condition, the level of medical care required and the level of support available in the home. In Victoria, a children's hospice is available as a third option, and children and their families may use this for respite, end of life care or both.

In rural areas, where access to specialist services may be more limited, support is provided to health services and paediatricians to assist them to care for the child and their family as close to home as possible. If it is necessary for the child and their family to travel to a major centre for treatment or respite, consideration needs to be given to the travel, accommodation and other support needs of the family during this time. This can be particularly stressful for families (both personally and financially) if they are physically separated for long periods of time.<sup>15</sup>

Metropolitan services that provide care for children and families who live in rural areas need to maintain contact with the child and the family once they return home as well as establish links with local support services to ensure the child and family's care needs are met.<sup>15</sup>

### Models of paediatric palliative care

Internationally, over the last two decades, various models of paediatric palliative care have evolved and there has been increasing recognition of the needs of children with non-malignant conditions.<sup>16, 17</sup> Many hospitals and health authorities in developed countries around the world now have dedicated palliative care services for children.<sup>17, 18, 19</sup> A range of models exist and are being developed in Australia. Mindful of the desire of most children and their families to be cared for at home, these have focused on the provision of community-based care.<sup>20</sup>

Recognition of paediatric palliative care as a medical specialty is relatively new, both nationally and internationally. The Royal Australasian College of Physicians (RACP) developed a training path for paediatric palliative care in 2005 and at present there is one accredited training position in Australia.

### Victorian models of care

Victorian children with life-threatening conditions utilise a range of services and supports. These include those provided through the paediatric, palliative care and disability sectors, as well as community-based support agencies and general practitioners. Components of the Victorian paediatric palliative care service system are listed below:

- Victorian Paediatric Palliative Care Program (VPPCP) (see below for more information)
- Paediatric services – tertiary: Royal Children’s Hospital (RCH) and Monash Medical Centre (MMC), secondary: major regional health services
- Very Special Kids (VSK) – VSK House and family support services
- Palliative care services – community and inpatient
- General practitioners and paediatricians
- Other services – education, disability services, early childhood intervention services, family support groups, equipment services, welfare organisations.

### The Victorian Paediatric Palliative Care Program (VPPCP)

The VPPCP functions as an alliance between the RCH, the paediatric program at Southern Health and VSK. It is auspiced by the RCH and staffed by paediatricians, consultants, allied health professionals and case management liaison nurses. It operates using a consultation-liaison model of care. The VPPCP works to ensure families have access to information and resources, and supports health professionals

from both the paediatric and palliative care sectors in the provision of care. The program also takes an active role in advocacy, training and research, and holds discretionary funding to purchase equipment and support that cannot be provided by other programs for children requiring end of life care.

### How does this policy fit with other relevant policies?

Due to the broad range of services involved in providing care for children with a life-threatening condition and their families, a wide range of legislation and policy documents from across Victoria have been consulted in developing this policy. Relevant documents which have been consulted include:

- *A Fairer Victoria*
- *A Strategic Framework for Family Services*
- *Care in Your Community: a planning framework for integrated ambulatory health care*
- *Charter of Human Rights and Responsibilities Act 2006*
- *Child Wellbeing and Safety Act 2005*
- *Children and Young Person’s Act 1989*
- *Children, Youth and Families Act 2005*
- *Disability Act 2006*
- *Every Child Every Chance – a strategic framework for Family Services.*
- *Growing Victoria Together*
- *Palliative Care Australia Standards 2005*
- *Protecting Children – the next steps white paper*
- *Review and redevelopment of Support for Children with a Disability and their Families – Final Report*
- *Statewide Paediatric Plan*
- *Strengthening Palliative Care; a policy for health and community care providers 2004-2009*
- *Victorian State Disability Plan 2002 – 2012*

This policy seeks to make links with all these relevant policies as appropriate.



### How has this policy been developed?

The Cancer and Palliative Care Unit in the department has worked in collaboration with Disability Services Division (DSD) and the Office for Children and Early Childhood Development, Department of Education and Early Childhood Development (DEECD) and the VPPCP to develop this policy. An advisory group comprising the above groups, plus community palliative care services, guided the development of the policy.

Other key stakeholders involved in developing this policy include palliative care services, specialist children's medical services, a broad range of other service providers, such as education, early intervention and disability services, and consumers.

As part of the consultations to develop this policy over 100 representatives from health, community, early intervention, disability, education services, consumer groups and support groups provided feedback on the principles of paediatric palliative care and the relationships which are important in providing effective paediatric palliative care.

This policy is based on feedback from these consultations. Feedback provided in the consultation sessions is used throughout the document to inform each principle. It is also based on the literature review and policies listed above, as cited throughout the document. The feedback from the consultations was consistent with the key themes in the literature review.

This policy document is written to support service providers in providing care to children with a life-threatening condition.



### Implementation of this policy

Services are currently working together to implement and enact these principles. Some of these principles require the development of a more focussed implementation plan to achieve. In order to ensure that all principles are fully implemented across the state by 2015, a concerted focus will be required from across government, as well as health, palliative care, disability, children's services and community care providers.

The department will develop an implementation plan for 2008-2015 that will guide service responses and focus on key priorities for action. The implementation plan will address the key objectives outlined for the principles in this policy.

The development of the implementation plan will be guided by a state-wide advisory group for paediatric palliative care.

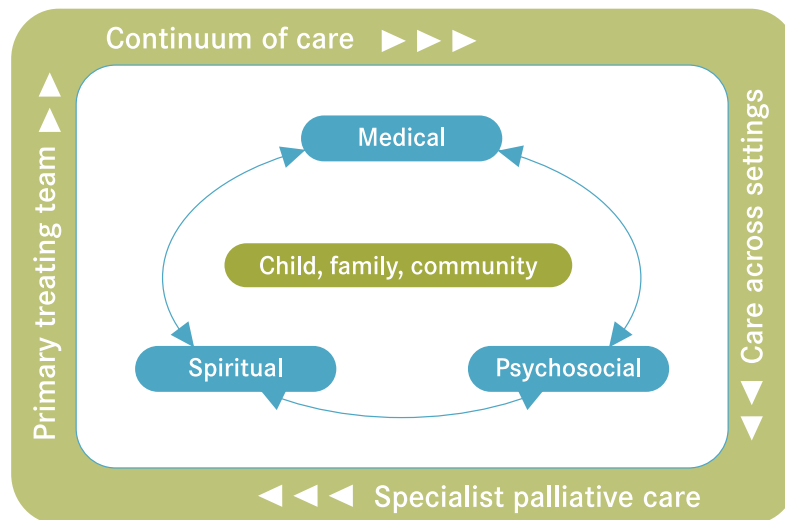


## Relationships underpinning paediatric palliative care

Children and their families have the right to receive comprehensive, well-coordinated care from multiple service providers that is empathetic, competently and consistently delivered.<sup>1</sup>

As outlined in figure 2, paediatric palliative care is centred around the child and their family, and involves a broad range of services and is more than just healthcare. Paediatric palliative care adopts a child and family centred approach, integrating all aspects of care in the provision of a holistic service which may extend beyond the time of the child’s death.

Figure 2: Relationships underpinning paediatric palliative care



**Continuum of care**

- Diagnosis
- Acute care – changes in care
- Crisis points
- Transition
- Terminal phase
- Bereavement

**Care across settings**

- Family home
- Alternative home (e.g. foster care)
- Inpatient hospice
- Hospital

**Specialist Palliative Care (may include)**

- Palliative care services
- Paediatric palliative care services
- Specialised bereavement
- Specialist paediatricians
- Specialised respite services

**Primary Treating Team (may include)**

- Aboriginal health services
- Allied health services
- Bereavement services
- Case management
- Community support
- Counselling
- Disability services
- Early childhood intervention services

**Equipment (provision of)**

- General practitioners
- Midwives
- Neonatologists
- Neonatal nurses
- Nurses
- Obstetricians
- Occupational therapy
- Paediatricians
- Personal care attendants
- Pharmacy services
- Physicians
- Physiotherapy
- Respite services
- Speech pathology
- Social work

Adapted from Children’s International Project on Palliative/Hospice Services 2001, *A call for Change: Recommendations to Improve the Care of Children Living with Life-threatening Conditions*, National Hospice and Palliative Care Organisation, Alexandria, Virginia



There are many care providers and support groups that are important in the provision of paediatric palliative care, these include, but are not limited to:

- palliative care (predominantly in the community but also in the inpatient setting)
- specialist paediatric (including neurology, and respiratory)
- paediatric palliative care (including hospice services)
- general practitioners
- general paediatricians
- case management
- disability
- early childhood
- education (for example, kindergartens and schools)
- mental health
- Aboriginal health
- early childhood
- home and community care
- religious groups
- bereavement counselling and support
- support groups (including peer support groups and cultural groups)
- community groups.

The types of services involved, their level of involvement, and their role in providing care will vary significantly depending on the child and their families' needs and the stage of the child's condition. It is therefore important that services are flexible and respond to individual needs and communicate clearly with the child and their family, as well as with other services about changes in their role in providing care for the child.

Wherever possible, care for children with a life-threatening condition and their families should be provided through the child's primary treating team. This helps to maintain continuity of care for the child and build effective relationships between services and the child and their

family. Such care ensures a comprehensive and streamlined patient journey that minimises duplication and coordinates patient information and service delivery.

In rural areas, where there is limited access to specialist services, including specialist palliative care and specialist paediatric services, it is important that effective relationships between tertiary paediatric services such as RCH and MMC support rural health services and rural paediatricians to care for children with a life-threatening condition as close to home as possible. This support may take a number of forms, including specialist consultation, mentoring, education and training.

Continuity of care and coordination requires:

- effective communication between service providers at all stages of the child's care
- the involvement of the child's general practitioner or paediatrician at all stages of the child's care
- building effective and efficient links between specialist paediatric palliative care services and other relevant community, health and allied health providers, including disability services.

In summary, the types of services and relationships that support a child with a life-threatening condition and their family are very broad and include health, disability and community services as well as education and other networks and support groups. Because of the broad range of services involved it is critical that there is continuity in service provision and services are well-coordinated.

The following section of the policy document outlines seven principles for providing care for children with a life-threatening condition and their families. The principles include the expected outcomes and key objectives necessary to achieve best possible care for children with a life-threatening condition and their families.

# Principles

## for caring for children with a life-threatening condition

### Principle one: information and decision making

**Children with a life-threatening condition and their families have timely information about options for their future care and are actively and appropriately involved in those decisions**

#### Principle one: expected outcomes

Children and their families are consulted about who is informed about their care and who makes decisions about their care.

Children are informed about, and involved in, making decisions about their care as appropriate to their age and developmental stage.

Families of children with a life-threatening condition are informed about and involved in decision making about their child's care.

The needs of the child and their family are addressed through developing and implementing an agreed care plan.

The right to dignity and self determination should be upheld for all children with a life-threatening condition.<sup>13, 21</sup> Children with a life-threatening condition and their families should be provided with timely information about options for future care and supported to make decisions in a way that is appropriate to their age and individual needs. Children can be involved in a number of ways. They can be informed about their situation and treatment, consulted about their preferences and, when competent, adopt the role of primary decision-maker. Services should take the child's developmental stage, as well as issues such as the child's life and illness experience and their guardianship, into consideration when determining how best to involve the child, and their family in decisions about their care.<sup>5, 12, 22</sup>

Sometimes families may not want the child to be fully informed about their prognosis even if it is appropriate to the child's age and developmental stage. In this situation services should attempt to communicate and mediate in order to achieve an outcome that is right for the family and child.

It may be difficult for the child or family to accurately recall information provided when the child's prognosis is first discussed with them. It may be more appropriate to provide information on multiple occasions and if necessary, to repeat information or provide it in several different formats. When providing information, services should explore with the child and their family how they would like to receive information about prognosis and future care. Care plans should identify key points at which information should be provided or refreshed. Services should ensure that interpreters are provided for children and families where English is not the first language.

It is important that services are sensitive to the child and family's preferences about their care and exercise a non-judgemental approach in responding to the child and family's needs.<sup>4</sup> Children and their families should be given adequate time, opportunity and appropriate support to process information and make decisions about treatment and care.



Planning and support for children with a life-threatening condition is critical to care planning, which should be based on a child and family centred approach, and the identification of formal and informal supports to respond to individual and family needs. The types of needs identified may include physical, emotional, spiritual or financial needs.<sup>3, 5</sup> Care plans should be updated at transition points in the child's care (for example, moving from hospital to home) and when the child and family's needs change.

While many children and their families prefer that care is provided at home options such as hospice and hospital care may also be appropriate at different points in the child's care.<sup>23, 24, 25, 26</sup> The impact for families of providing 24 hour care to a child at home should not be underestimated and appropriate supports including respite should be put in place.

### Achieving principle one

#### Key objectives

Children and their families will be actively and appropriately involved in making decisions about and planning their care.

Children and their families are empowered to make the best decision about their care.

All children with a life-threatening condition will have an up to date care plan which reflects the child's and families needs, preferred care arrangements and identifies formal and informal supports for meeting those needs.

## Principle two: support for families

### Families of children with a life-threatening condition are supported by health and community care providers

#### Principle two: expected outcomes

Families are adequately supported by health and community care providers so that they can provide the best possible care for their child.

The health and wellbeing of the family is maintained and enhanced by improved access to appropriate respite care, education facilities and support services.

Families' ability to navigate the system will be strengthened through the timely provision of information about available services and supports.

In addition to parents and siblings, the definition of family also includes family members such as grandparents and extended family and social networks, or people the family identify as being of particular significance. A child's life-threatening condition impacts not only upon their family but also upon the community. Ideally, children with a life-threatening condition should be cared for by a supportive family within a supportive local community.<sup>3,5</sup>

The needs of siblings of a child with a life-threatening condition should be included as part of the care plan and as part of the identified support provided to the family. Siblings require information and support that takes into consideration their age, developmental stage and family relationships. It is important that their needs are identified and addressed as are the special needs of brothers or sisters who share genetically inherited conditions (for example, muscular dystrophy).<sup>27,28</sup>

Services should adopt family centred approaches that support, strengthen and build the capacity of the whole family to care for a child with a life-threatening condition.<sup>3,5</sup> In order to do this an accurate assessment of the current support available to the family is important. Support that is provided for families may include information and education about the child's illness, case management, emotional support and counselling, accommodation in or near to the facility where the child is being cared for, assistance with domestic duties or respite care. Support groups that are specific to the child's condition can provide valuable support and information for family members.

Support for families should extend throughout the child's illness and into bereavement.<sup>3</sup> Ongoing bereavement support from skilled professionals and people with similar lived experience may be needed. Services should have a transition plan for withdrawal of services after the child dies and should consider gradually changing service provision to avoid a sudden withdrawal of support from the family.



Families of children with a life-threatening condition may face significant financial issues related to the difficulty of remaining in employment and providing full time care for a child with a life-threatening condition. This may be compounded by the cost of medical treatment and equipment related to the child's condition. Financial assistance should be provided where appropriate.<sup>3, 12, 29</sup>

In order to access services and negotiate an often complex set of services during a very stressful time, families should be provided with timely information about relevant services. The family's need for support and assistance is likely to vary over time and the information provided about available services should also change to reflect this.

### **Achieving principle two**

#### **Key objective**

A range of supports are available to meet the needs of families, including information, respite, psychosocial support, financial and practical supports

## Principle three: best possible care at all times

### Children with a life-threatening condition and their families receive the best possible care at all times

#### Principle three: expected outcomes

The primary treating team caring for the child and their family is supported by specialist services to remain actively engaged in the child's care throughout their illness and into bereavement.

Children with a life-threatening condition often experience a longer duration of illness than adults with a life-threatening condition.<sup>30</sup> This heightens the importance of maintaining care and support over an extended period of time.

Wherever possible, care for children with a life-threatening condition and their families should be provided through the child's primary treating team. This helps to maintain continuity of care for the child and build effective relationships between services and the child and their family. The primary treating team may include health, disability and community services, as well as the child's paediatrician or general practitioner.

Primary treating teams are not expected to be experts in palliative care or experts in paediatric palliative care. This is the role of specialist palliative care services, which provide specialist advice and consultation to the primary treating team (see principle four).

The primary treating team should be a multidisciplinary team with the expertise to address the physical, emotional, psychological and spiritual needs of the child and family. This team should include a locally based paediatrician who works in collaboration with a general practitioner and a lead clinician who has detailed knowledge of the child and their condition.<sup>3, 37</sup> Ideally, the lead clinician will be identified by the family and be involved in the care of the child and their family throughout their illness.

It may be difficult for the primary treating team to acknowledge that the involvement of palliative care services is now an appropriate element of the child's care. Education and training about palliative care can assist with appropriate and timely referral to palliative care services and enable primary treating teams and specialist palliative care services to work effectively together in providing holistic care for the child and their family.

Children with a life-threatening disability often have special needs related to their disability, which need to be considered by services when planning and providing care. Those with cognitive disabilities or severe communication needs for example, may have difficulties with mobility or feeding or be unable to express their needs concerning pain management or the side effects of medication or psychosocial issues such as anxiety.<sup>12</sup> Services should make use of specific tools and approaches to assist in meeting these needs.

In summary, some of the key types of needs which should be addressed in order to ensure that the best possible care is provided include pain and symptom management, psychosocial care, practical assistance for the child and their family, respite, spiritual care and bereavement support.



## Pain and symptom management

There is substantial evidence to indicate that some children with a life-threatening condition experience significant pain, although it may be difficult for the child to communicate the extent and nature of the pain.<sup>32, 33, 34, 35, 36, 37, 38</sup> Therefore effective pain relief is a core element of optimal paediatric palliative care. Careful assessment of pain and other symptoms is essential. As part of managing pain and symptoms experienced by children with a life-threatening condition, access to appropriate medication as well as timely medication review is critical.<sup>3</sup> Specialist advice from a palliative care service or pain team should be sought in circumstances where symptoms are not quickly and easily controlled.

## Psychosocial care

There is substantial evidence to indicate that children with a life-threatening condition experience fear and grief, although it may be difficult for the child to communicate this to families or health professionals.<sup>32, 33, 34, 35, 36, 37, 38</sup> Psychosocial interventions to assist with communication and provision of support may assist children to express their fears and to develop strategies for addressing them. Children who are thought to have anxiety disorders or depression should have timely access to a mental health worker or service.

Families, particularly parents and siblings, will also have psychosocial needs which will vary according to the composition and coping style of the family, the nature and progression of the child's illness and the extent of the child and family's support networks. Assessment of psychosocial needs should be included in the care planning and delivery of the family's care. Services may also consider the use of complementary therapies for the child and family such as music, art, massage and other forms of diversional therapy.

Families may need a range of information about how to look after their own physical and emotional health over an extended period in order to fully understand the role of psychosocial support and respite care.

## Spiritual care

Spiritual issues can be particularly important to children with a life-threatening condition and their families. Spiritual needs may be independent of religious needs and will vary from person to person. Some of the ways in which people may understand spirituality include their views about identity, values and healing, as well as religious views.<sup>39</sup>

The spiritual needs of children are as real and important as those of adults, and services may need to pay particular attention to ensuring that the child's spiritual needs are identified and addressed as part of their care. Families should be supported to discuss their own understanding of spirituality and to encourage children to talk about their own doubts, beliefs and values. Sometimes the child or family may prefer that a member of the primary treating team talks to them about their spiritual beliefs while other families may prefer spiritual support to be provided within their local community.<sup>15</sup>



## Practical assistance

Practical assistance may take a variety of forms, from the timely provision of housing adaptations and aids to assistance with household chores or financial assistance.<sup>3</sup>

As noted in principle two, caring for a child with a life-threatening condition can place a significant financial burden on families.<sup>40</sup> Financial assistance may be required to cover the cost of equipment, medications or lost income.

Flexible funding mechanisms that can be employed when required during the child's illness and after the child dies are important in ensuring that the necessary care and support is provided in a timely way to the child and their family.

Timely access to specialised equipment should be provided to assist in managing the child's needs, and where appropriate helping them to remain at home.

## Respite

Respite is a key element of care for children with a life-threatening condition and their families. Families need to be confident that they can take a break from their primary care role and that their child will continue to receive the best possible care in their absence. Respite may be required for many reasons, such as maintaining care for other siblings, meeting parents' work, family and social commitments or providing a complete rest for parents and families.

Access to a diverse range of options (such as in-home, inpatient, residential and overnight respite) is a vital component of care that should be available when required in order to enhance family functioning and alleviate pressure on families. Respite for children and adolescents should be appropriate to the child's age and developmental stage.<sup>3, 4, 5, 12, 31</sup> In order to provide timely access to respite effective coordination between services and respite providers is required.

## Grief and bereavement support

In addition to the feelings of bereavement experienced by families, friends and other people involved in the child's life when the child dies, children and families experience feelings of grief throughout the child's illness as a result of losses related to the illness itself and anticipatory grief at the prospect of the child dying.

Grief and bereavement support is a core element of caring for children with a life-threatening condition and their families. Wherever possible this support should be provided by services with expertise in grief and bereavement such as palliative care or community health services, with specialist advice and consultation sought from groups such as specialist bereavement services where required. It is also important that families are given the opportunity to receive support and share their experiences with other families who have experienced the loss of a child. For many families, this level of support is important in the healing process following the death of a child.<sup>29</sup>



If bereavement support can be provided by services that were involved with the care of the child this also helps to maintain continuity of care from the service after the child's death. Bereavement support may address emotional, economic, spiritual or social needs.<sup>37</sup> Support to and from the child's school, the parents' workplaces and the family's community may be an important part of providing bereavement support.

### Achieving principle three

#### Key objective

The child's primary treating team is supported to provide the best possible care for the child and their family, including pain and symptom management, psychosocial care, spiritual care, practical assistance for the child and their family, respite and bereavement support.

## Principle four: specialist advice and consultation

### Children with a life-threatening condition and their families have access to specialist palliative care services when required

#### Principle four: expected outcomes

Children with complex needs have appropriate and timely access to specialist paediatric palliative care through specialist advice and secondary consultation for primary treating teams and palliative care services.

Family members assessed with complex grief and bereavement needs are provided with information about and access to appropriate counselling and support.

Children with a life-threatening condition and their families should have access to specialist palliative care services when required. This may take the form of direct care from a specialist palliative care service such as a community palliative care service, or it may be advice and consultation to the child's primary treating team from the VPPCP.

As stated in principle three, where possible, children should receive ongoing care from their primary treating team. Secondary consultation and advice from a specialist paediatric palliative care service such as the VPPCP should be sought at the following points:

- when developing or revising care plans for the child
- at transition points in the child's care (for example moving from hospital to home or a significant change in the disease process)
- if the child or their family experiences a crisis (for example a crisis in physical or psychosocial well-being)
- if the child is believed to be in the terminal phase of their illness
- at any point in the child's illness if the primary treating team requires advice or support in relation to symptom management or psychosocial, grief or bereavement issues.

#### Timeliness

Children with a life-threatening condition can experience unpredictable illness trajectories. The illness trajectory is often characterised by a series of health crises rather than a steady decline, which can make it more difficult to accurately assess prognosis.<sup>47</sup>

Referral to, or advice from, specialist palliative care services should be based on the child's need for complex symptom management, psychosocial and bereavement issues, not on the estimated time to death.<sup>47</sup> If in doubt about the need for referral to palliative care, services should discuss this with a palliative care service as early as possible.



Twenty-four hour access to advice and support is key to helping families meet the child's physical and emotional needs during crisis or terminal care phases.<sup>3</sup> The primary contact for after hours care does not need to be a specialist paediatric palliative care clinician, but the primary contact should have access to their advice if required.<sup>3</sup> Rigorous care planning will identify potential needs for 24 hour assistance and how to access it if required.

### Specialist bereavement support

As noted in principle three, bereavement support can be provided by a range of generalist health services, including general practitioners and community health counsellors. For most people who experience bereavement, this level of support (as well as support from family, friends and communities) will meet their needs. However, parents whose child dies (and other family members, including siblings and grandparents) are at risk of more complicated or prolonged bereavement.<sup>42, 43, 44, 45</sup>

The Statewide Specialist Bereavement Service (SSBS) is available to provide counselling and support for bereaved families. This Victorian Government funded service is operated by the Australian Centre for Grief and Bereavement (ACGB). The role of the SSBS is to provide specialist bereavement counselling and support as well as secondary consultation for other service providers. In addition to this, the SSBS undertakes quality, leadership and health promotion initiatives to strengthen the provision of bereavement support in Victoria.

Most experiences of bereavement are not associated with enduring consequences such as negative impacts on immediate family and extended family relationships.<sup>29, 45, 46, 47, 48, 49, 50, 51</sup> For people who are experiencing complicated or prolonged bereavement, there is a need for specific grief interventions that should be flexible, responsive to individual needs and available in a timely way. Services should provide a range of different types of support to meet the varying needs of family members (research shows that men are less likely to seek support in traditional forms such as counselling), Aboriginal people and people from culturally and linguistically diverse backgrounds.<sup>45</sup>

Siblings may experience bereavement very differently from other family members. The grief of young children and adolescents is influenced by levels of conceptual understanding, which are related to stages in development and life experience.<sup>52, 53</sup> Children are known to revisit losses in different ways at each new developmental stage.<sup>29</sup> It is important that families and other support networks are informed about different ways in which children may experience loss and bereavement, and that support is provided to siblings in a way which meets individual needs. Siblings may benefit from external support at different times throughout the child's illness and during bereavement.

Particular consideration should be given to supporting grieving families in rural areas as they may not have the same access to support services as parents living in metropolitan areas.

## Special needs groups

Within paediatric palliative care there are some groups whose needs require particular consideration. These include, but are not limited to:

### Neonates

The needs of infants aged 0–28 days (neonates) with a life-threatening condition require special consideration as the circumstances of their illness and death may be different from other children with a life-threatening condition.

Extreme prematurity, birth asphyxia and congenital abnormalities account for most deaths in the neonatal period.<sup>54</sup> Some parents may have been aware of the potential for difficulties before delivery of the child but for most, events unfold quickly and unexpectedly.

The exact nature of the condition is often unclear at birth and treatment is generally intense until a clearer idea of the child's diagnosis and prognosis can be obtained. As a result, death often occurs in the acute setting of the neonatal intensive care unit where decisions must be made, sometimes with little time for parents to reflect or spend time with their child, particularly if the mother is physically recovering from a difficult birth.<sup>55, 56, 57, 58, 59, 60</sup> There may be insufficient time to arrange care at home.

Specialist paediatric palliative care services can assist in this area by providing specialist advice and secondary consultation to staff working in neonatal units to support them in meeting the physical needs of the child and the psychosocial, spiritual and bereavement needs of parents and siblings.

There may also be a role for palliative care services to provide education, training and support to staff such as radiologists and midwives who conduct antenatal screening, to assist them in communicating with and supporting parents if a life-threatening condition is diagnosed. Services should be sensitive to the needs of parents whose child has died and initiate follow up support in a timely way. Parents may require specialist bereavement support and counselling at this time.

### Adolescents

The needs of adolescents with a life-threatening condition require special consideration as the illness or disability may create dependency at a stage where they are seeking greater autonomy and can also isolate the young person from their peers.<sup>61</sup> Many adolescents are acutely aware of issues relating to body image and the loss of their future. For these reasons, peer support groups may be a valuable component of palliative care for adolescents.

Services should also consider the needs of the adolescent in providing age appropriate respite, involving the adolescent in decision-making and how to help the adolescent and their family transition to adult health care services.<sup>17</sup> Decisions about transition of care to adult services should be made on a case by case basis according to the adolescent's treatment and support needs, developmental stage, life and illness experience, and the adolescent and family's preference for place of care.



The needs of teachers and peers at the adolescent's school or other educational facility need to be considered as they may require advice about how to manage the effects of the condition and provide support to the adolescent to enable them to remain at school for as long as possible.

Careful planning and involvement of the adolescent about their preferences should be undertaken in deciding whether adolescents aged 17 or 18 years who are newly diagnosed with a life-threatening condition should commence their care in a paediatric or an adult service.

### Aboriginal children and families

Culturally sensitive services should be available for Aboriginal children with a life-threatening condition and their families.<sup>22</sup> Services and practices should be respectful of cultural views about health, community, death and dying, particularly as they relate to children, and should develop tailored approaches to meet the particular needs of Aboriginal children and their families.<sup>5</sup>

Services should work with Aboriginal Health Workers such as Aboriginal Liaison Officers in health services to help ensure good communication with the child and their family and the development of a culturally appropriate care plan for the child, their family and their community.

Some of the particular considerations that services should discuss with the child and their family include whether there are family or community members who should be consulted when making important decisions about the child's care. The child and their family may also prefer to return to their traditional land to be cared for or include traditional medicine or ceremonies as part of their care plan.<sup>15</sup>

### Children and families from culturally and linguistically diverse groups

Children and families from culturally and linguistically diverse backgrounds may have different attitudes towards illness, medical treatment, death and dying and customs relating to burial, cremation and bereavement. Services should actively seek information from children and their families about how their cultural and religious beliefs can be incorporated into their care plan. Families who have recently arrived in Australia may have few family and social support networks. Assistance should be provided to these families to help them to link with appropriate support groups and other networks.<sup>15</sup>

Where English is not the first language of the child or their family, professional interpreters should be provided. Professional interpreters should also be able to assist in translating complex medical information. It is not appropriate for family members to interpret on behalf of other family members.

## Achieving principle four

### Key objectives

Specialist paediatric palliative care services and bereavement services are available when required.

The needs of children and families who may have special requirements, such as neonates and adolescents and children from Aboriginal and culturally and linguistically diverse backgrounds are actively considered and included in their care.

## Principle five: coordinated care

**Children with a life-threatening condition and their families have treatment and support that is coordinated across the continuum of care**

### Principle five: expected outcomes

Children and their families receive care which is seamless and continuous.

Children and their families have a key contact person who assists in management of their care.

Effective coordination is essential in paediatric palliative care as a large number of services are likely to be involved in the child's care. Case management should be provided for all children with complex care needs and multiple care providers in order to support the family to care for their child. Children with a life-threatening condition may receive care across a range of settings, including hospitals, respite facilities and their own home. It is important that transition points are planned and coordinated so that the care provided to the child remains consistent.

Wherever possible, the primary treating team should remain closely involved in the child's care whilst palliative care is incorporated into the child's primary care. This helps to ensure continuity of care for the child and their family. This is particularly important if the child is already being cared for by one or more disability services, if Children's and Family Services are involved in the child's care or if the child is moving from paediatric to adult services.

In order to maintain effectiveness and continuity of care, the management of the relationship between services and between services and the family is critical. This relationship may last for the course of the child's illness and into bereavement. It may vary over time dependent on the child's health and the family's needs. Advocacy for the child's and families' needs should continually inform the relationship between services.

Effective coordination and timely referral is hampered when clinicians are reluctant to refer to palliative care because they are concerned that it will unnecessarily alarm the child and/or the family or because they are concerned that they will lose their involvement in the child's care once a palliative care team 'takes over.' Education about the role of palliative care services, especially in the paediatric context, and encouraging ongoing involvement of the primary treating team are some strategies which may help to address this reluctance to refer.

### Achieving principle five

#### Key objectives

Children receive care that is coordinated and responsive to individual child and family needs.

Services coordinate with each other in order to meet the needs of children and their families.

Services make use of Primary Care Partnerships and Service Coordination Tool Templates to support their coordination of the child and family's care.

There is a key contact or case manager who can assist with coordinating the child and family's care.



## Principle six: quality care

### Children with a life-threatening condition and their families have access to quality services and skilled staff to meet their needs

#### Principle six: expected outcomes

Children and their families have access to care and support from suitably qualified service providers and trained volunteers.

Children and their families receive optimal care based on child and family needs and current research evidence.

#### Education, training and support for staff

Services need to address the ongoing professional development and support needs of staff who work with children with a life-threatening condition and their families. This may include access to formal internal or external education and skills development programs. Given the nature of paediatric palliative care and its potential impact on staff, formal and informal support including the use of a range of staff support strategies and professional supervision is a critical element of professional development.<sup>12</sup> This should include training about how to communicate with children at different development stages and their families about death and dying.<sup>12</sup>

Health professionals who do not specialise in paediatric palliative care may not have extensive experience of caring for a child with a life-threatening condition and managing their own responses to the child's illness and death. For this reason, timely access to information, education, secondary consultation and support from specialists in this area should be available. This information and education can be either child specific and relate to elements of the child's care plan or generic, such as how to incorporate paediatric and palliative care philosophies into their care.

#### Volunteers

Volunteers make a significant contribution to caring for children with a life-threatening condition and their families. It is important that volunteers are appropriately selected for the role and have appropriate training and ongoing supervision and support including debriefing and counselling.<sup>12</sup>

#### Research

Due to the relative 'youth' of paediatric palliative care as a specialty, there has not been extensive research undertaken in Victoria or in Australia to extend the evidence base for paediatric palliative care.

As this field develops, so too should the focus on and commitment to research and education.<sup>4</sup> In particular, a greater focus on hearing about the experiences of children with a life-threatening condition and their families and learning from these experiences is needed in order to inform practice so that the best possible care is provided.



## Quality care

Particular attention needs to be given to providing information that outlines the pros and cons of particular treatments and therapies in order for families and providers to make a judgement about what approach is in the best interest of the child. Children should be included in age appropriate discussions about the advantages and disadvantages of particular treatments.

Children should not be subjected to treatments for which there is no evidence of effectiveness. Nor should they be subjected to treatments for which the expected burdens outweigh the anticipated benefits. Where the child is unable to communicate or make a decision about their treatment, particular care should be taken to inform and actively involve families in making a decision about treatment for their child.

### Achieving principle six

#### Key objectives

Staff who are skilled in providing care for children with a life-threatening condition and their families are recruited and retained.

Volunteers to support children and their families are recruited, trained and supported.

The research and evidence base in paediatric palliative care is strengthened.



## Principle seven: community awareness and support

### Children with a life-threatening condition and their families are supported by their communities

#### Principle seven: expected outcomes

Communities, including family, friends, neighbours, work and social contacts are able to actively support children and their families as appropriate.

Community awareness about the needs of children with a life-threatening condition is enhanced through community promotion and education.

Support from the community is a key element of providing effective care for children with a life-threatening condition and their families. A child's community may include neighbourhood groups, child care centres, kindergartens or schools, parents' workplaces, religious or cultural groups, friends and extended family and support groups which are specific to the child's condition.<sup>62, 63, 64</sup>

The nature of the support provided can extend from simply being welcoming and inclusive of the child and their family to providing practical support such as child minding for siblings or transport to attend medical and health related appointments.<sup>5</sup> Ideally, this type of support extends into bereavement. This is particularly important for the workplaces of parents (and other family members) in terms of providing flexibility and support for parents as they experience their child's illness and likely death.<sup>29</sup> It is also important to consider the privacy needs of children with a life-threatening condition and their families.

Some children with a life-threatening condition and their families become isolated during the child's illness. This can be related to friends, family and other parts of the community not knowing how to cope or react. Sometimes this is due to the communities' fear of death. Community education about paediatric palliative care and grief and bereavement support can assist people to support families who have a child with a life-threatening condition.

In rural areas a greater degree of support may potentially be provided for the child and their family due to the smaller and more 'close-knit' nature of the community. However it may also be more difficult to maintain confidentiality and privacy in these communities and it may be more difficult to access condition-specific support groups.

#### Achieving principle seven

##### Key objectives

The capacity of the community to provide support and understanding to children and their families throughout the child's illness and into bereavement is strengthened through information and community awareness raising activities by services.

## Glossary

### Definitions

#### Paediatric

The term 'paediatric' refers to children including neonates, infants, children and adolescents up to the age of 19 years (that is, 18 completed years).

#### Life-threatening condition

The terms life-threatening and life-limiting, illness and condition are often used interchangeably in palliative care. Consultations with consumers in the development of this policy identified that the term life-threatening condition is preferred in this context. Refer to appendix one for more information about life-threatening conditions.

In this policy document, the term 'life-threatening condition' is defined as 'any illness or condition developed in childhood whereby the child is likely (probability of greater than 50 per cent) to die prematurely (before the age of 40 years)<sup>2</sup>. It includes life-threatening disabilities as well as life-threatening illnesses.

#### Paediatric palliative care

Paediatric palliative care is an active and total approach to care for children with a life-threatening condition and their families. Paediatric palliative care includes physical, emotional, social and spiritual elements. It focuses on enhancing quality of life for the child and their family and includes management of physical symptoms such as pain, and psychosocial issues such as grief and loneliness. Paediatric palliative care includes provision of respite, and ongoing support through death and bereavement to enable the family to remain functional and intact.<sup>3, 4</sup>

#### Specialist palliative care

For the purposes of this policy, specialist palliative care is defined as specialist health care and practical support that provides expert symptom control and psychosocial, spiritual and bereavement support. Depending on the patient and their family's needs and the model of care employed by the service, specialist palliative care providers may work in three ways:

- providing consultancy services to other generalist service providers, supporting their care of the person and their family
- undertaking shared care arrangements with primary treating teams
- providing direct care and practical support to people with a life-threatening condition and their families.<sup>65</sup>

Palliative care may be required for children with a range of life-threatening conditions such as muscular dystrophy or other neurodegenerative conditions, as well as children with cancer. While all children with life-threatening conditions will require elements of palliative care to be integrated into their management, not all will require referral to a specialist paediatric palliative care service.

#### Primary treating team

The primary treating team may include health, disability and community services, as well as the child's paediatrician or general practitioner.

Primary treating teams are not expected to be experts in palliative care or experts in paediatric palliative care. This is the role of specialist palliative care services, which provide specialist advice and consultation to the primary treating team.



## Appendix one

### How many children have life-threatening conditions?

Estimates of how many children have life-threatening conditions range from 10 to 16 children in 10,000.<sup>3, 6, 55, 66, 67</sup> Extrapolating estimates of 16 per 10,000 children to the Victorian context means that at any one time, up to 1,972 children aged between 0-19 years may be in need of palliative care (16 per 10,000 of 1,232,338 children).<sup>3, 68</sup>

Table one provides a breakdown of age and cause of death for children in Victoria in 2005 where the death may have been anticipated and therefore the involvement of palliative care services may have been appropriate.<sup>4, 54</sup>

**Table 1: Anticipated deaths of children in 2005**

<b>Neonates (0-28 days)</b>	
Prematurity	88
Congenital anomalies	84
Hypoxic ischaemia encephalopathy*	20
<b>Total</b>	<b>192</b>
<b>Infants (29 days-1year)</b>	
Birth defects, genetic conditions	32
Conditions determined at birth	17
Malignancy	5
<b>Total</b>	<b>54</b>
<b>1-4 years</b>	
Birth defects, genetic conditions	14
Malignancy	8
<b>Total</b>	<b>22</b>
<b>5-9 years</b>	
Malignancy	10
Birth defects, genetic conditions	3
Other conditions determined at birth	3
Other acquired disease	4
<b>Total</b>	<b>20</b>
<b>10-14 years</b>	
Birth defects, genetic conditions	10
Malignancy	7
Other acquired disease	5
<b>Total</b>	<b>22</b>
<b>15-17 years</b>	
Birth defects, genetic conditions	7
Malignancy	4
Other conditions determined at birth	4
Other acquired disease	2
<b>Total</b>	<b>17</b>
<b>Total for all age groups</b>	<b>327</b>

In the 12 months since June 2005, 116 patients were identified by or referred to the Victorian specialist paediatric palliative care service.

Children with non-malignant conditions such as neurodegenerative disorders, congenital anomalies and genetic conditions comprised more than half this group. Rural regions accounted for 21 children. Of the 64 deaths in this 12-month period, 38 (60 per cent) occurred in hospital. Twenty-two (34 per cent) children died at home and four children (6 per cent) died at the children's hospice.

\* brain injury resulting from birth asphyxia

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