



A Palliative Care Needs  
Assessment for Children

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## Foreword by the Tánaiste

In recent years there have been many developments in palliative care. We are all aware that caring for someone with a life-limiting condition can be challenging on both an emotional and practical level. However, caring for a child or adolescent with a life-limiting condition requires specific support and skills. The Report of the National Advisory Committee on Palliative Care, published in 2001, recognised that the requirements of children with life-limiting conditions differ from the requirements of adults. This Paediatric Palliative Care Needs Assessment highlights the need for a coordinated approach to age appropriate care, given in the location of choice, by healthcare professionals specifically educated and trained to care for children and adolescents.

This needs assessment is the first collaborative project undertaken jointly between the Department of Health and Children and the Irish Hospice Foundation. This is an example of how statutory and voluntary partnerships can work together towards the ultimate goal of fully implementing the recommendations of the Report of the National Advisory Committee on Palliative Care.

The needs assessment represents the first step in the development of a nationwide cohesive and equitable palliative care service specifically for children and adolescents. In addition, it provides a foundation upon which a strategy for providing children and adolescents with palliative care services can be developed by the Health Service Executive.

Finally, I would like to thank all those involved in bringing this needs assessment to fruition.

***Mary Harney***

**Tánaiste and Minister for Health and Children**

## Foreword by Eugene Murray

The Irish Hospice Foundation believes that children should benefit from the many recent developments in hospice and palliative care. Service developments in this area should be informed by the needs of the children themselves and their families, by the evidence available and by models of best practice existing in other constituencies.

Consequently, the Irish Hospice Foundation was very pleased to join the Department of Health and Children in sponsoring this needs assessment. The research aims to describe the situation of children with life-limiting illnesses nationwide. The completed work represents a mandate to develop a menu of supports involving many different professionals. It clearly articulates the preference for children to be cared for at home and the range of physical, medical, nursing, psycho-social and practical help required in order for this to happen – including the need for respite care and family support.

I would like to take this opportunity to emphasise the Irish Hospice Foundation's commitment to the ongoing development of services for children with life-limiting conditions.

*Eugene Murray*

**Chief Executive Officer  
Irish Hospice Foundation**

## Glossary of Terms

ACT <sup>1</sup>	The Association for children with life-threatening or terminal conditions and their families.
Adolescence	Describes various age ranges from as young as 10 and up to 24 years <sup>2</sup> . The World Health Organisation (WHO) defines adolescence as 10-19 years <sup>3</sup> .
Child	Person below the age of 18 years <sup>4</sup> .
Children's hospice	Describes both a place and a philosophy of care <sup>1</sup> .
Complementary therapies	Therapies, which are applied in adjunctive fashion to reduce pain and other symptoms. They are non-invasive and include aromatherapy, reflexology, hydrotherapy, art therapy, music therapy, and others.
ICD	International Classification of Disease.
Infant	Child aged less than one year.
Infant mortality	Refers to death under one year of age and can be subdivided into early neonatal death (<7 days), late neonatal death (1 to <4 weeks), or post neonatal death (4 weeks to <1 year).
Hospice care	A term often used to describe the care offered to patients when disease is at an advanced stage. It may be used to describe both a place of care (i.e. institution) and a philosophy of care, which may be applied in a wide range of settings <sup>5</sup> .
Life-limiting condition	Any illness in a child where there is no reasonable hope of cure and from which the child or young adult will die.
Neonate	Aged less than one month.
Palliative care	Is the active total care of patients and their families by a multidisciplinary team when the patient's disease is no longer responsive to curative treatment <sup>3</sup> .
Respite care	The provision by appropriately trained individual(s) of care for children with life-limiting conditions, for a specified period of time, thus providing temporary relief to the usual care-giver <sup>6</sup> .
Terminal care	Refers to care given at the end of life when the child is dying. Terminal care may take place in hospital, at home or in a hospice.
Voluntary organisation	A not-for-profit service and support organisation outside of the statutory sector. Voluntary organisations may operate on a national or local basis and some have particular eligibility criteria (e.g. provide services for children within certain age ranges or diagnostic categories).



## **Palliative care for children**

Many children requiring palliative care have life-limiting conditions...children may survive many years with these conditions... the needs of these children differ from the needs of adults...

*(Report of the National Advisory Committee on Palliative Care, 2001<sup>5</sup>)*

# Executive Summary

## Chapter One – Introduction and Background

The Report of the National Advisory Committee on Palliative Care (2001)<sup>5</sup> published in 2001, highlighted the need for a review of paediatric palliative care services.

Palliative care for children is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family, and includes the management of distressing symptoms, provision of respite and care through death and bereavement<sup>1</sup>.

A life-limiting condition is defined as any illness in a child where there is no reasonable hope of cure and from which the child or young adult will die. Four categories of life-limiting conditions have been identified and children with these conditions will have palliative care needs.

The challenges which must be faced when caring for a child with a life-limiting condition are multiple and specific, and differ significantly from those relating to the care of adults. Adolescents requiring this care have their own unique needs.

A comprehensive paediatric palliative care service needs to function within a cooperative model with close liaison between general practitioner, community paediatrician and nursing services and requires liaison between children's hospitals and hospitals with paediatric units.

## Chapter Two – The Needs Assessment

This needs assessment aimed to identify the number of children in Ireland living with and dying from life-limiting conditions and to identify their needs. In order to achieve this, a multi-method research design was employed involving all stakeholders (hospital, community, families, policy planners and voluntary organisations).

Information on childhood deaths was obtained from the Central Statistics Office. The number of children dying from life-limiting conditions is significantly higher than previous estimates; the average annual death rate is 3.6 per 10,000 (1996-2001). A significant proportion of childhood deaths occurred within the first year of life and the majority of these are within the first week of life.

## Chapter Three – Results: A Description of Current Services

There is inequity in the provision of palliative care services to children with life-limiting conditions; services received are dependent on diagnosis and the geographical location of the child.

Home is the preferred location of care. However, services to support care at home are deemed inadequate by many families. Caring for a child with a life-limiting condition presents numerous challenges – practical, emotional, financial and social. The services currently provided are limited and there is a need for more paediatric-trained staff (e.g. nurses, physiotherapists etc.) to provide care at home. One major source of stress for families is the difficulty encountered in accessing essential aids, appliances and equipment for their child.

Whilst generally positive about hospital care, some families voice concerns relating to poor physical conditions, poor communication, and a lack of psychological support. Hospital environments are deemed inappropriate for respite and adolescent care.

Location of death is also diagnosis dependent, with the majority of children with cancer dying at home and the vast majority of those with other diagnoses dying in hospital.

## Chapter Four – Key Findings

Comprehensive data on children with life-limiting conditions are not currently available but are necessary in order to form the basis for service planning at local and national level. Accurate data collection is essential in order to provide key information on the number, location, diagnostic category and age range of children with life-limiting conditions at any given time.

In this study, the preferred location of caring for a child with a life-limiting condition is the family home with parents receiving adequate professional support. This should include access to 24-hour advice and pain and symptom management. Readily available access to locally-based respite is inadequate at present. The provision of respite is essential in enabling parents to provide care at home.

The majority of families also prefer home as the eventual place of death for their child but according to healthcare professionals, parents do not have sufficient choice regarding the location of their child's death. This is due to a number of factors, which include a lack of facilities and resources, a lack of information, parental fear and a lack of paediatric palliative care experience among professionals.

The development of a children's hospice is not seen as a priority by the respondents in this study, some of whom raised concerns regarding accessibility and cost. There is a degree of ambiguity however, regarding the role of 'hospice' in paediatric palliative care with some respondents associating it only with end-of-life care.

There is a substantial need for ongoing education, training and development of healthcare professionals caring for children with life-limiting conditions.

Palliative care services currently provided to children in Ireland with life-limiting conditions are seen to be inequitable, differing significantly according to diagnosis (malignant versus non-malignant) and according to geographic location. This poses challenges, particularly for parents of children with non-malignant diseases.

Both families and professionals often deem the physical environment for adolescents in hospitals unsuitable. The difficulties encountered in the transition from children's services to adult services have been identified as an issue for adolescents.

The provision of bereavement support varies between services. Professionals have identified the need for a broader range of bereavement services.

## Chapter Five - The Future

Future developments in paediatric palliative care should be shaped by four key principles: inclusiveness, partnership, comprehensiveness, and flexibility.

### **Inclusiveness**

All children regardless of diagnosis, geography or age should be able to access care which is appropriate to their individual need.

All providers of care to children with life-limiting conditions should have an understanding of their role in the provision of palliative care and have access to specialist palliative care as required. There is an urgent need to develop specialist paediatric palliative care posts (initially medical and nursing), to spearhead the establishment of services and education.

Families need to have the 'know-how' to provide care for their child. Information and training should be framed within the unique needs of the child and the family, and should be readily available.

### **Partnership**

The active participation of all stakeholders, including the child, should be promoted. Children should have a voice in matters which affect them and their views should be given due weight in accordance with their age and maturity.

### Comprehensiveness

A holistic approach to the planning of care is required and this should include the child and family and be adaptable to their changing needs. Holistic care requires teamwork including medical, nursing, physiotherapy, occupational therapy, speech therapy, dietetics, play therapy, social work, psychology, bereavement support, and pastoral care. These should be readily accessible in all locations of care. In settings where health professionals do not usually care for children with life-limiting conditions, generic protocols can provide a useful framework.

### Flexibility

The findings of this study suggest the need for a 'key worker' for each child and family to coordinate and implement a plan of care. This role would include:

- ◆ *Assessment, implementation and review of the care plan with the multi-disciplinary team.*
- ◆ *Ongoing contact with the child and family.*
- ◆ *Provision of information and support.*
- ◆ *Liaison, where required, between the family and the service providers.*

Paediatric palliative care services should provide seamless quality care regardless of location or diagnosis with formal links between the different service providers.

Essential to the development of paediatric palliative care services is the establishment of coordinated education and training programmes.





# Chapter One

## Introduction and Background

# Introduction and Background

## 1.1 Introduction

In recent years, there has been a significant growth in interest in, and demand for, the provision of palliative care services for children with life-limiting conditions. In 1999, the Minister for Health and Children established the National Advisory Committee on Palliative Care. The report produced by this committee<sup>5</sup> which was published in 2001, comprehensively reviewed palliative care services focusing mainly on adults and made key recommendations for the future development of palliative care services in Ireland. The report highlighted the distinct needs of children and recommended that the provision of paediatric palliative care services be reviewed. A national paediatric palliative care needs assessment was undertaken by a research team from University College Dublin. The project was jointly funded through a partnership between the Department of Health and Children and the Irish Hospice Foundation. The researchers were guided by a Steering Committee representing paediatrics, palliative care, nursing, public health and the voluntary and statutory funders of the study. This report summarises the findings of this study.

## 1.2 Palliative Care

Palliative care is both a philosophy of care and a practice discipline with the primary goal being the achievement of optimum quality of life for both the patient and his/her family. The practice of palliative care is not dependent on a particular location but should be available in the home, hospital, and hospice or wherever the patient in need of palliative care chooses to be.

### Palliative care

Palliative care improves the quality of life of patients and their families facing the problems 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<sup>3</sup>.

Effective palliative care requires the involvement of a broadly skilled multidisciplinary team that is committed to working together towards the achievement of best practice. Palliative care services need to be structured to accommodate three levels of specialisation<sup>5</sup>.

### Level One – Palliative care approach

Palliative care principles should be appropriately applied by all health care professionals.

### Level Two – General palliative care

At an intermediate level, a proportion of patients and families will benefit from the expertise of health care professionals who, although not engaged full-time in palliative care, have had some additional training and experience in palliative care.

### Level Three – Specialist palliative care

Specialist palliative care services are those services whose core activity is limited to the provision of palliative care.

The principles underpinning the three levels of palliative care<sup>5</sup> are:

- ◆ *Palliative care is an important part of the work of many different healthcare professionals.*
- ◆ *All health care professionals require a basic knowledge of the philosophy of palliative care as well as core skills.*
- ◆ *Primary health care providers play a pivotal role in the delivery of palliative care services to patients being cared for in the community. This includes accessing specialist palliative care services as necessary.*
- ◆ *Specialist palliative care should be seen as complementing and not replacing the care provided by other health care professionals in hospital and community settings.*
- ◆ *Specialist palliative care services should be available to all patients as required, regardless of their diagnosis or the location of their care.*
- ◆ *Specialist palliative care services need to be planned, integrated and co-ordinated; they should assume responsibility for education, training and research in this specialist area of practice.*

## 1.3 Palliative Care for Children

### Definition of palliative care for children

Palliative care for children is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement<sup>1</sup>.

It is well recognised that the needs of children with life-limiting illness differ significantly from those of adults. Whilst there are some similarities, children are not just 'little adults' and caregivers skilled in the care of adults who are dying generally lack the expertise to deal with the unique needs of children.

### 1.4 Definition of Children with Life-Limiting Conditions

A life-limiting condition is defined as any condition in a child where there is no reasonable hope of cure and from which the child or young adult will die. Whilst the majority are unlikely to live beyond 18 years, some whose diagnosis is made in childhood will survive unexpectedly into early adulthood. The categories of children with life-limiting conditions deemed eligible for inclusion in this study are shown below<sup>5,7</sup>.

Categories of life-limiting conditions	
<b>Category 1</b>	Life-limiting conditions for which curative treatment has failed e.g. cancer, irreversible organ failure.
<b>Category 2</b>	Conditions associated with periods of normal childhood activities, which usually require long periods of intensive treatment, but which are often associated with premature death e.g. cystic fibrosis, muscular dystrophy.
<b>Category 3</b>	Progressive conditions without curative option where treatment may ameliorate the condition, which may extend over a number of years e.g. Batten's disease, mucopolysaccharoidosis.
<b>Category 4</b>	Conditions with severe neurological disability that may deteriorate unpredictably but are not usually considered progressive e.g. severe brain or spinal injury, severe cerebral palsy.

The above categorisation serves mainly to identify children who may need palliative care support and also helps with the planning and development of paediatric palliative care services. Some children whose life expectancy is short may need intense involvement over a limited period of time. Others will require intermittent involvement at different stages of their illness before needing active continuous care when they reach the terminal phase.

#### Challenges of Caring for Children with Life-Limiting Conditions

- ◆ *Conditions from which children suffer are often quite rare and may be specific to that age group. This may pose difficulties for professionals whose expertise is often confined to the care of adults.*
- ◆ *Conditions are sometimes familial, which means that other children in the family may be living with, or have died from, the same illness. This will impact on how the family copes during the illness and into bereavement.*
- ◆ *The nature of some life-limiting illnesses in children means that predicting a prognosis may be quite difficult. Their physiological resilience and, as a result, prognostic uncertainty, can make decisions about appropriate therapy difficult.*
- ◆ *The number of children dying is quite small. As a result, the main care-givers may have little experience in the complex management of their care.*
- ◆ *Many life-limiting illnesses are so complex that a child can cross the boundary between episodes of critical illness and back to the management of chronic illness many times before death occurs<sup>1</sup>.*

## 1.5 Adolescence

Adolescence is variously described as ranging from 10, 12 or 13 years to 18,19 or 24 years and is arbitrarily divided into three phases, early, middle and late. The boundaries between these phases may be blurred and obvious differences exist between these phases with regard to key issues such as relationships with peers, behaviour and the impact of a life-limiting illness<sup>2</sup>. Given the difficulties involved in defining this group, some services have adopted more flexible policies in relation to age and have included adults up to the age of 40<sup>8</sup>. As a group this patient population is growing as a result of earlier diagnosis, better nutritional support, clinical interventions and generally better medical care resulting in significantly improved survival rates. This has previously been identified as a major emerging challenge<sup>9</sup>.

### Challenges in Caring for Adolescents with Life-Limiting Conditions

Key issues for adolescents with life-limiting conditions previously identified include<sup>8</sup>:

- ◆ *A need for involvement in decision-making. This can be a source of conflict when parents want to keep information from their child.*
- ◆ *Attention to psychological needs. The needs of adolescents are specific and can be complex. They may be aware of the prognosis yet not be able to deal with the anxiety and the uncertainty of the illness<sup>10</sup>. Psychological support is particularly important at the time of transition to adult services.*
- ◆ *Inexperience of adult services in dealing with the challenge of caring for adolescents.*
- ◆ *Concerns about their parents and siblings.*
- ◆ *The desire for independence.*
- ◆ *The importance of school, college and employment.*
- ◆ *The need for opportunities to do things that other young people do.*

## 1.6 The Irish Service Context

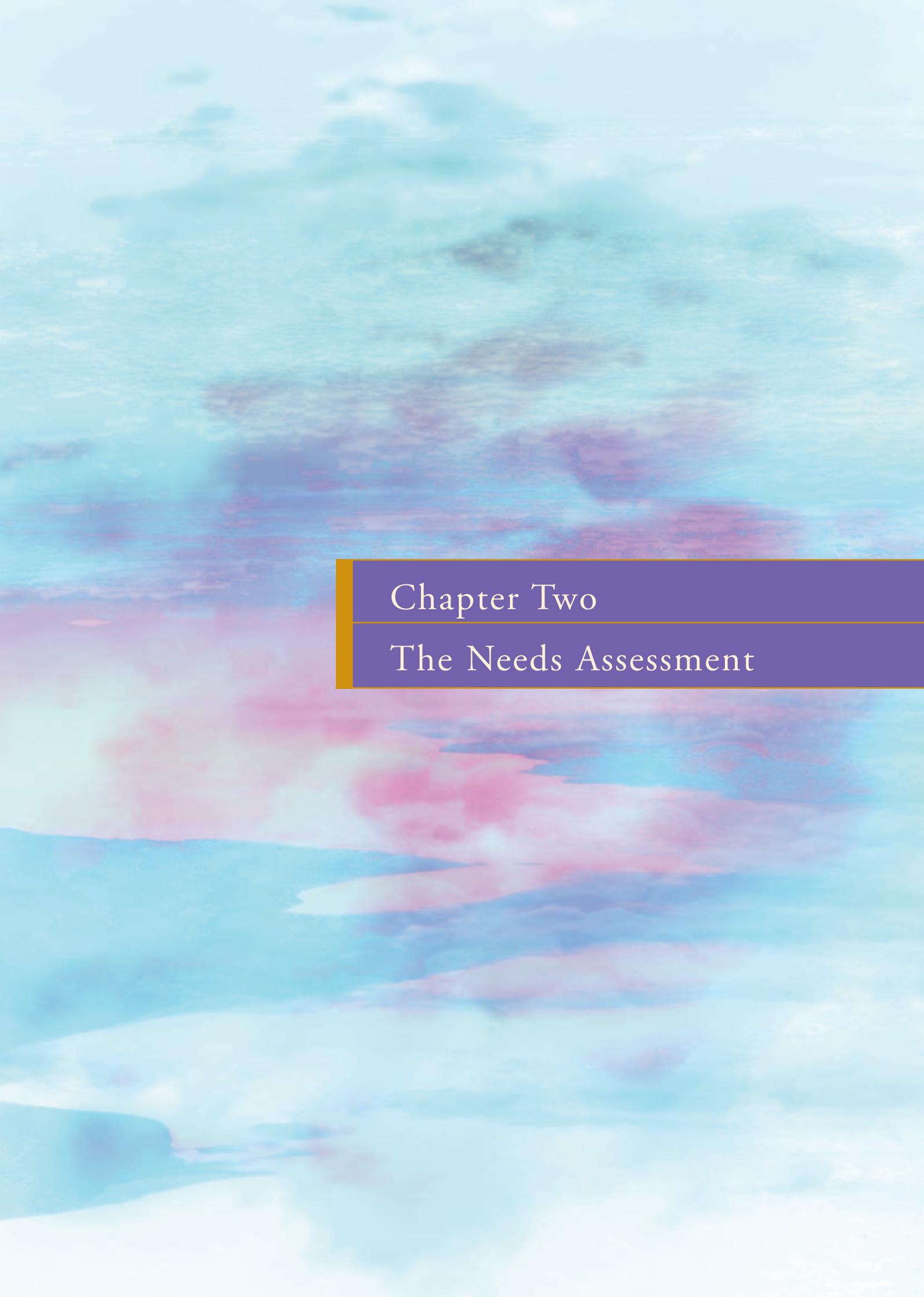
The Report of the National Advisory Committee on Palliative Care<sup>5</sup> is the blueprint for the development of palliative care in Ireland. For the development of paediatric services specifically, the report recommends that:

- ◆ *Palliative care for children is best provided at home, except in extraordinary circumstances, with the family closely supported by the general practitioner and the public health nurse, and also the specialist palliative care team when required.*
- ◆ *The medical and nursing care of children in hospital should be the responsibility of paediatric-trained medical and nursing staff.*
- ◆ *There should be close co-operation and liaison between paediatric and specialist palliative care services in each health board area (now Health Service Executive Area).*

In many countries, children's hospices have a role in the provision of both specialist paediatric palliative care and respite. To date no such facility has been established in this country.

The Primary Care Strategy<sup>11</sup> focuses on the development of multidisciplinary teams to be led by general practitioners. It also recommends the development of community paediatrician and children's nursing posts to support the provision of community-based care. A comprehensive paediatric palliative care service needs to function within this model, with close liaison between community and hospital-based services. Whilst public health nurses provide much of the care to children with life-limiting conditions in the community, only 120 of 2,079 public health nurses registered with An Bord Altranais are also registered sick children's nurses<sup>12</sup>.

Currently in Ireland, those involved in the provision of all palliative care include statutory and voluntary organisations of varying size and remit. It is envisaged that the voluntary sector will be involved in the future planning and delivery of specialist palliative care services for children<sup>5</sup>. The development of a partnership model will help ensure consistency of service nationally.



## Chapter Two

### The Needs Assessment

# The Needs Assessment

## 2.1 Study Objectives

The overall goals of this national assessment were to:

- ◆ *Review the relevant literature on identification and servicing of children’s palliative care needs in other countries.*
- ◆ *Identify the number of children in Ireland currently in need of palliative care and the projected number over the next decade in an evolving multicultural society.*
- ◆ *Identify the current and anticipated palliative care needs of these children over the course of their illness, including all illnesses represented by the four groups referred to in Section 3.8 of the Report of the National Advisory Committee on Palliative Care<sup>5</sup> and originally defined by ACT<sup>7</sup>.*
- ◆ *Compile a comprehensive audit of existing services available to children with palliative care needs.*
- ◆ *Assess current services by accessing the views of those who use and provide the current services e.g. children, families, health professionals and administrators and voluntary groups, with regard to development of this service area.*
- ◆ *Identify the views and concerns of other groups and individuals who deal with children with palliative care needs e.g. teachers.*

## 2.2 Methodology

The study objectives indicated the need for a multi-method approach. Data collection methods included postal questionnaires, focus groups, individual and family interviews, and finally consultation seminars to discuss the implications of preliminary findings with respondents and stakeholders. Mortality data from the Central Statistics Office (CSO) were reviewed for all causes of death in childhood, and for life-limiting illnesses.

As the primary objective of this study was to focus on the care of children with life-limiting conditions the following groups were accessed as key sources of information (Table 1).

Hospital	Community	Families	Policy Planners	Voluntary Organisations
Consultant Paediatricians	Palliative Care Teams	Parents/Guardians	Department of Health & Children	Local and national
Clinical Nurse Managers	General Practitioners		Health Board Policy Planners	Voluntary Hospice Groups
Clinical Nurse Specialists	Public Health Nurses		Hospice Chief Executive Officers	
Medical Social Workers				
Palliative Care Teams				

The samples of health professionals and others involved in the care of children with life-limiting conditions are detailed below (Table 2), along with the methods of data collection used and the number of respondents.

Table 2: Sample, research method and response					
Sample	Location	Method	RESULTS		
			Contacted	Responded	Currently providing care
Consultant paediatricians in all tertiary paediatric hospitals and in all paediatric units in general hospitals	All health board areas	Self-completion postal questionnaire	70	35	34
Clinical Nurse Managers	All health board areas	Self-completion postal questionnaire	51	28	28
Clinical Nurse Specialists in: Palliative Care, Oncology Children's nursing, Intellectual disability	All health board areas	Self-completion postal questionnaire	160	70	70
Medical Social Workers	All health board areas	Self-completion postal questionnaire	22	16	14
Palliative Care Teams	All health board areas	Self-completion postal questionnaire	14	9	7
General Practitioners	Nationwide	Self-completion postal questionnaire	540	241	119
Public Health Nurses	All health board areas	Self-completion postal questionnaire	91	69	60
Voluntary Organisations	Nationwide	Self-completion postal questionnaire	64	34	28
Voluntary Hospice Groups/Committees	Nationwide	Self-completion postal questionnaire	27	16	14
Families	Nationwide	Interviews		Purposive sample n=34	N/A
Hospice Chief Executive Officers	Nationwide	Interviews	6	5	N/A
Health Board Policy Planners	All health board areas	Interviews/self-completion open-ended postal questionnaire	10	7	N/A
Professional Service Providers	Nationwide representing statutory/voluntary, hospital and community-based services	Focus groups	N/A	N/A	15 groups

In addition, four regional consultation seminars were conducted, at which preliminary findings were presented and discussed. These were held in Athlone, Dublin, Cork and Sligo.

## 2.3 Childhood Mortality – All Causes

In Ireland the total number of deaths from all causes in children under 18 years between 1996 and 2001 was 3,380 (mean 563, range 536–592 per annum). The average annual mortality rate was 5.4 per 10,000<sup>13</sup>. Individual rates for those years are shown in Table 3 below.

	1996	1997	1998	1999	2000	2001	Average annual rate
Rate per 10,000	5.0	5.3	5.4	5.7	5.5	5.6	5.4

Data source: CSO<sup>13</sup>, personal communication

## 2.4 Mortality from Life-Limiting Conditions

As children with life-limiting conditions are not currently considered as a discrete group, definitive epidemiological data relating to diagnosis, numbers and place of death at a national level is not being collated.

The categories of conditions identified by ACT<sup>1</sup> as life-limiting and potentially in need of palliative care services are listed in Table 4. These also form the definition of life-limiting conditions for the purposes of this report. All diseases can be categorised into an International Classification of Disease (ICD) group code. The following conditions are excluded, as they are unlikely to have an impact on palliative care services: infections and parasitic diseases (codes 001–139), mental disorders (codes 290–319), acute respiratory infections, pneumonia and influenza (codes 460–487) and sudden infant death syndrome (codes 780–799).

The definition currently excludes childhood deaths from injuries and poisonings (ICD codes 800–999). It has been recommended by ACT<sup>1</sup> that these children be included on local registers, as a proportion of these children will have palliative care needs (e.g. long-term survivors of accidents).

ICD Code	Category	Total number of deaths 1996 – 2001	Average annual number of deaths	Range
140–239	Neoplasms	173	29	24–35
240–279	Endocrine, Nutritional and Metabolic Diseases and Immunity Disorders	100	17	12–27
280–289	Diseases of Blood and Blood-forming Organs	11	2	0–4
320–389	Diseases of the Nervous System and Sense Organs	181	30	26–36
390–459	Diseases of the Circulatory System	60	10	8–11
488–519	Diseases of the Respiratory System (excluding acute respiratory infections 460–487)	49	8	4–11

520–579	Diseases of the Digestive System	28	4	2–9
580–629	Diseases of the Genitourinary System	13	2	1–4
710–739	Diseases of the Musculoskeletal System and Connective Tissue	5	1	0–3
740–759	Congenital Abnormalities	855	142	128–157
760–779	Conditions originating in the perinatal period	747	125	122–129
	<b>Total excluding ICD 800-999</b>	<b>2222</b>	<b>370</b>	<b>354–398</b>
800–999	Injury and Poisoning	665	111	97–123
	<b>Total including ICD 800-999</b>	<b>2887</b>	<b>482</b>	<b>460–519</b>

In Ireland the total number of deaths in children from life-limiting conditions for the years 1996-2001 was 2,222 mean 370 (range 354-398 deaths per annum)<sup>13</sup> (see Table 5). The death rates for each of these years are provided in Table 6 below. The average annual death rate is 3.6 deaths per 10,000. These figures are significantly higher than the estimated figure of 100 childhood deaths from life-limiting conditions per annum cited in the report produced by the National Advisory Committee on Palliative Care<sup>5</sup>.

	Number of deaths	Average annual number of deaths	Range per annum	Average annual death rate per 10,000
All causes	3,380	563	536-592	5.4
Life-limiting conditions	2,222	370	354-398	3.6

Data source: CSO<sup>13</sup>, personal communication

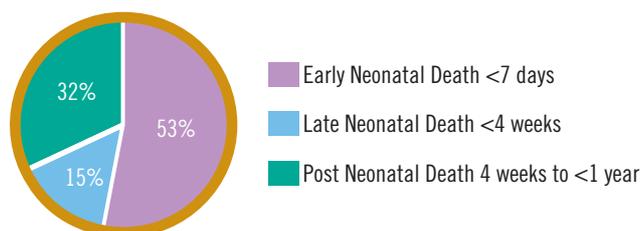
	1996	1997	1998	1999	2000	2001	Average annual rate
Rate per 10,000	3.4	3.3	3.5	3.9	3.6	3.6	3.6

Data source: CSO<sup>13</sup>, personal communication

## 2.5 Infant Mortality

Many childhood deaths occur within the first year of life. The majority of these deaths are caused by congenital abnormalities. While families of children who die in the first four weeks of life may have needs over a relatively short period of time, this support is often significant as it is intensive and extends into bereavement.

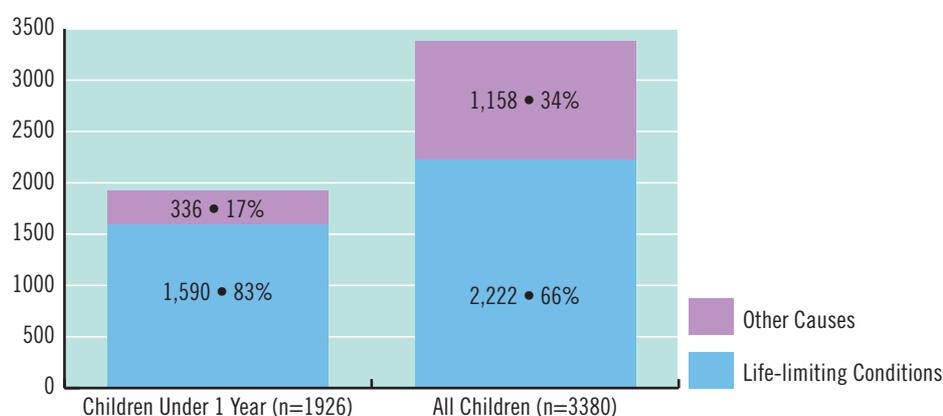
**Figure 1: Percentage distribution of infant deaths 1996-2001**



Infant mortality can be subdivided into early neonatal death (<7 days), late neonatal death (7 days to <4 weeks) or post neonatal death (4 weeks and <1 year). Data are illustrated in Figure 1 above. These figures indicate that 53% of infant deaths occur in the first week of life. It is also noteworthy that of *all* childhood deaths, 57% occur in children under one year, 32% occur within the first week of life, and 9% between one and four weeks of age.

During the period 1996-2001, 83% of deaths occurring in children aged less than one year were from life-limiting conditions. For all childhood deaths the majority (66%) were also from life-limiting conditions.

**Figure 2: Childhood deaths all causes and life limiting conditions 1996-2001**



Data source CSO<sup>13</sup>, personal communication

## 2.6 Estimating Prevalence of Children with Life-Limiting Conditions

One of the aims of the needs assessment was to establish the numbers of children living with life-limiting conditions. Despite attempts to access data relating to prevalence (e.g. recipients of the Domiciliary Care Allowance, Disability Allowance etc.) inaccurate data was obtained due to inappropriate inclusion, duplication or omission of data. Figures on the prevalence of life-limiting conditions in Ireland were therefore formulated by drawing on estimated figures from the UK of 12 per 10,000 children aged 0–19 years<sup>1</sup> and on population data for Ireland in 2002<sup>13</sup>. This yielded a national estimated prevalence of 1,369. However, applying the same prevalence rate for the projected population 0–19 years in 2021 would give an increased figure of 1,610. These figures are estimated and should be treated with caution as they are based on a number of assumptions, for example, that prevalence rates in Ireland are similar to those in the UK, and that prevalence rates across the Health Service Executive areas are similar.



## Chapter Three

### A Description of Current Services

# A Description of Current Services

## 3.1 Families

### 3.1.1 Families' Experiences from the Literature

Published data indicates that parents caring for children with life-limiting conditions can experience many challenges.

- ◆ *Lack of symptom control and pain relief*<sup>4</sup>.
- ◆ *Feeling that their concerns are not being taken seriously*<sup>15</sup>.
- ◆ *Social, financial, mental and physical health repercussions on the entire family*<sup>16</sup>.
- ◆ *Insufficient time with doctors and consultants*<sup>17</sup>.
- ◆ *Poor communication between parents and professionals*<sup>18, 19</sup>.
- ◆ *Worry that their child is not receiving the best possible care*<sup>20</sup>

In the UK, despite the fact that home is the preferred place of care for the majority, children who are receiving potentially curative treatments are more likely to die in hospital<sup>21</sup>. The same applies in Ireland, where in 2001, only 11% (39) of children with life-limiting conditions died in a domiciliary setting (Table 7). The majority of children died either in a hospital or a local authority institution (e.g. a district or county hospital)<sup>13</sup>, whereas the majority of children with cancer died in their own home<sup>22</sup>. The method of classification of location of death in Ireland by the Central Statistics Office (Table 7) means that it is not possible to present accurate data on the number of children who die in their own home.

**Table 7 - Location of death for children in Ireland – 2001**

Location of death	Deaths <sup>13</sup>	Deaths from life-limiting conditions <sup>13</sup>	Deaths from cancer <sup>22</sup>
Hospital (excluding private homes)	281 (50%)	218 (60%)	5 (21%)
Local Authority Institution (including most district and county hospitals)	143 (25%)	93 (25%)	3 (12%)
Domiciliary (home or elsewhere e.g. street, river/lake, pub/hotel)	124 (22%)	39 (11%)	16 (67%)
Private home (registered maternity home, nursing home and convalescent home)	18 (3%)	16 (4%)	0 (0%)
<b>Total</b>	<b>566</b>	<b>366</b>	<b>24</b>

The advantages of being cared for at home are numerous and care at home may

- ◆ *greatly diminish feelings of fear, isolation, and helplessness*
- ◆ *allow care of the child to be shared among family members*
- ◆ *allow the child the chance to participate in family routines*
- ◆ *offer many more opportunities for communication*
- ◆ *enable parents to be satisfied that they have done all they possibly could for their child<sup>20, 23, 24, 25, 26</sup>.*

An important dimension to care at home is that parents know their child and when assisted and supported can provide care that is truly individual. Families require substantial support from professional health and social care networks, though in practice, support is not always available and can be un-coordinated. Supportive home care requires

- ◆ *financial, practical, emotional, psychological and spiritual support*
- ◆ *involvement of a multidisciplinary team<sup>26</sup>*
- ◆ *clear, honest and detailed information and communication about managing their child's care<sup>27</sup>*
- ◆ *24 hour access to expertise in paediatric palliative care*
- ◆ *access to appropriate respite<sup>28</sup>*
- ◆ *immediate access to hospital, if needed<sup>23</sup>*
- ◆ *a key worker to coordinate the care between family, carers in the community, local hospital and specialist centres<sup>1</sup>.*

### 3.1.2 Family Perspective

A total of 34 families were interviewed, ten of whom had at least one child who had died and 24 who were currently caring for a child (children) with a life-limiting condition.

Common themes arising from the interviews were:

- ◆ **Communication** is a key issue for families and **information** should be imparted in a sensitive manner. Families accessed information from a variety of sources and they valued professionals who were clear and open about their child's condition, treatment and prognosis. When information was withheld or only given in a piecemeal fashion, families felt angry and excluded.
- ◆ Families identified that there was often a lack of **coordination** between different agencies and professionals.
- ◆ Families found the **learning** curve steep when first faced with caring for a child with life-limiting illness. They had to become competent in complex care such as suctioning, PEG feeding and administering medication, which they found challenging. They also found that they had to learn what to ask and when.

- ◆ While most families wanted to care for their child at home, the **'burden of care'** – physical, psychological, practical and financial – took a heavy toll on their time and energy.
- ◆ The need for **respite care** to allow for time, free from the 'burden of care'.
- ◆ There are many hidden **financial** costs associated with having a child with a life-limiting condition.
- ◆ Most families interviewed explicitly stated that they wished to **'keep things normal'** at home, despite the obvious constraints that having a very sick or dying child imposes.
- ◆ The needs of **siblings** were a concern for parents.
- ◆ There is a need for **peer contact and professional support** for family members, especially during the terminal phase and after the child's death. Parents spoke of their need for some ongoing contact with professionals who had cared for their child. The need for counselling and the wish to make contact with other parents in the same situation was also raised.

### 3.1.3 Care Settings – Home

- ◆ The availability of **physiotherapy or occupational therapy** in the home, home help/family support services and, in particular, **children's nursing services in the community** were deemed inadequate. Those limited services, where available, were valued. The voluntary sector played a significant role in the provision of services to families.
- ◆ **Practical and emotional support** when caring for a child at home is essential. Flexibility in the availability of this support was also deemed to be important. Home care offered reassurance and support in the isolating task of caring for a very ill child in the home setting.
- ◆ **Limited access to services, entitlements and equipment** was a source of much anger and frustration for many of the parents. Unnecessary bureaucracy, lack of information and delays in provision caused additional and unnecessary stress. Parents spoke of 'battling' for entitlements. Ready access to appropriate equipment was a particular issue.
- ◆ Adequate **pain relief and symptom control** at home on a 24-hour basis was seen as essential by parents, particularly in the terminal phase. Such support would enable them to be more confident in caring for their dying child at home. In some cases this help was available and in other cases parents felt this would be very beneficial but it was not available to them.

### 3.1.4 Care Settings – Hospital

Parents were generally positive about the level of care provided for their children and the professional staff they encountered in hospital.

When criticisms were voiced these related to:

- ◆ *Poor **communication** by professionals with parents.*
- ◆ ***Physical conditions** in some hospital settings – e.g. no privacy or comfort, dirty toilets, dirty laundry and parents sleeping on a fold-up bed or chair.*
- ◆ *Children’s wards were not always suitable for **adolescent care**.*
- ◆ *Follow-up **psychological and bereavement support** for families was not always available through hospital structures.*
- ◆ *Many parents would welcome the opportunity to be put in **contact with other parents** in similar situations, or to participate in a support group.*
- ◆ *The range and level of **available respite** is not felt to be currently sufficient to meet demand. Some hospitals endeavour to provide respite services to families as this service was not available elsewhere.*

### 3.2 Children’s Experiences

One of the study objectives was to gather the experiences of children with life-limiting illnesses and their families. Whilst children were not directly interviewed, their experiences have been well documented in the literature (see below). Children are often acutely aware of the seriousness of their illness although their understanding and sense of death differs according to developmental stage<sup>29</sup>. While communication can be difficult, straightforward discussion with a child with life-limiting conditions is critical and helps to alleviate distress and provide mutual support<sup>30</sup>.

Children requiring palliative care need:

- ◆ *to be in a familiar environment in order to maintain a normal life for as long as possible<sup>23</sup>*
- ◆ *to have the opportunity for education and structured play<sup>31, 32</sup>*
- ◆ *to have access to information and to be involved in all aspects of decision-making about their care. This must be appropriate to their age, understanding and circumstances<sup>14, 33</sup>*
- ◆ *to have access to the services of a multidisciplinary care team to address their physical, psychosocial, emotional and spiritual needs<sup>15, 17</sup> (e.g. access to 24 hour specialist palliative care)<sup>30</sup>*
- ◆ *to have access to respite<sup>34</sup>.*

### 3.3 Adolescents’ Experiences

The needs of adolescents are specific and differ from those of younger children or adults. Adolescence is a time of development physically, emotionally, socially and cognitively. With this development comes the expectation of independence. However, for children with life-

limiting illness the opposite occurs, with progression of their disease often leading to dependency<sup>8</sup>. It is important to view the needs of these young people in the context of a normal adolescence.

In this study, issues were raised by both families and focus group participants regarding the care of adolescents which reflected views previously published<sup>8</sup>. These were:

- ◆ *The need for improved transition from paediatric to adult services<sup>1</sup>*
- ◆ *The need for improved facilities for adolescents when in hospital<sup>1</sup>*
- ◆ *The need for more education for carers who have to deal with adolescents*
- ◆ *Opportunities for privacy*
- ◆ *Interaction and communication with their own peer group*
- ◆ *Open communication with trusted adults, other than parents*
- ◆ *Engagement in collaborative decision-making with parents and professionals<sup>31</sup>.*

### 3.4 Service Provision for Children with Palliative Care Needs

Paediatricians and paediatric units, palliative care teams and voluntary organisations were specifically asked to identify services offered and provided for children with life-limiting conditions/palliative care needs. Services always or usually offered are shown in Table 8. Service managers (hospices and health boards) were also used as a data source. Other data relating to these groups are explored below.

Always or usually offered	Offered by:		
	Paediatricians (n=34)	Palliative care teams (n=7)	Voluntary organisations (n = 28)
Palliative care physician	4	6	N/A
Clinical nurse specialist palliative care	5	7	N/A
Clinical nurse specialist – other	14	1	N/A
Social worker	22	3	13
Psychologist	12	0	11
Physiotherapist	21	3	11
Occupational therapist	5	2	13
Speech therapist	2	1	10
Dietician	23	1	4
Dental care	12	1	2
Play therapist/specialist	7	1	2
Access to respite care	6	3	8
Spiritual care	19	6	5
Complementary therapies	3	2	1
Special facilities in school	9	0	4
Home tuition	2	0	2

Respondents were also asked to identify home nursing services that were available and utilised when caring for a child with a life-limiting condition. The majority of paediatricians referred to public health nursing services (n=21, 61%). Voluntary organisations played a significant role in the support of families at home and services offered included the Jack and Jill Foundation (n=12, 35%), 'Nurse for Daniel' (n=6, 18%) or the Irish Cancer Society (n=3, 9%). Four of the palliative care teams also usually or always offered the services of the Irish Cancer Society. A complete list of voluntary organisations mentioned by respondents as being involved in the care of children with life-limiting conditions is listed in Appendix 1.

Thirteen paediatricians (38%) reported that the services of palliative care physicians and clinical nurse specialists in palliative care were not offered to children with life-limiting conditions and their families. Occupational therapy, play therapy, psychologist and complementary therapies were services seldom offered.

### 3.4.1 Number and Diagnostic Categories of Children Cared for by Health Professionals in the Study

Health professionals could only provide limited data relating to the number and diagnostic categories of children with life-limiting conditions that they had cared for during the previous three years (2000–2002). Respondents gave estimated numbers, as accurate figures were unavailable. The lack of accurate information systems supports the need for a database or register to inform service planning.

### 3.4.2 Responses from Paediatricians and Paediatric Units

Out of the total number of 78 paediatricians and paediatric units surveyed, there was a valid response rate of 34 (44%) from both tertiary paediatric hospitals and paediatric units within university and general hospitals. Clinical nurse managers, clinical nurse specialists and hospital social workers working in paediatric settings were also surveyed (see Table 8). Responses indicated:

- ◆ *There is currently perceived to be a dearth of education and training specifically for healthcare professionals providing care for children with life-limiting conditions.*
- ◆ *Only twelve paediatricians (35%) had experience of referring a child to a specialist palliative care physician or nurse.*
- ◆ *In the majority of cases (n=27, 79%) bereavement support was usually or always offered to parents following the death of a child. The extent or type of service, however, was not assessed.*
- ◆ *Of clinical nurse managers in paediatric units (n=28), clinical nurse specialists (n=70) and medical social workers (n=14), over 70% of each group provided information to children and their families. Psychological support was a core activity for these professionals. Moreover, their pivotal role in linking children and families to other hospital, community and local and national support services was clearly indicated in the data.*
- ◆ *A need was identified to improve arrangements for the transition to adult services for adolescents with chronic life-limiting conditions.*

### 3.4.3 Responses from Community Based Palliative Care Services

Fourteen palliative care teams were sent questionnaires and nine responded.

- ◆ *Seven of these indicated that they had provided care for children with life-limiting conditions in the last three years.*
- ◆ *The need for a comprehensive multidisciplinary team was endorsed — e.g. only three teams had a social worker on their team.*
- ◆ *Where services were provided, both the level and the range were often determined by diagnosis (e.g. more services are available to children with cancer) and by age.*
- ◆ *Four of the seven teams who had cared for children with life-limiting conditions included staff with specific education/training in the care of children with life-limiting conditions.*

### 3.4.4 Responses from Voluntary Organisations

Sixty-four questionnaires were sent to voluntary organisations throughout Ireland. Of these 34 (53%) were returned, with 28 (44%) indicating that they provide services to children with life-limiting conditions and their families. Some organisations provide a range of services to children within specific diagnostic categories over a wide geographical area, whilst other agencies cater for smaller groups with specific needs. In this study voluntary organisations were seen as major providers of respite care and family support services for children with life-limiting conditions and their families.

- ◆ *Twenty-one (75%) of respondents provided services on a national basis, 2 (7%) on a regional basis and 5 (18%) were locally based only.*
- ◆ *Hospitals were the main sources of referral to these groups, followed by self-referral by families and then referral by General Practitioners.*
- ◆ *Thirteen (46%) of the voluntary organisations providing services for children with life-limiting conditions employed professional staff: these included doctors, nurses, social workers, physiotherapists, occupational therapists, psychologists and speech therapists.*
- ◆ *Seven (25%) of the voluntary organisations had plans in place for the development of services including night nursing, information dissemination and training programmes for volunteers.*

Voluntary organisations also suggested there was a need for:

- ◆ *the provision of night-nursing services for children with non-malignant conditions (currently available for children with cancer, funded through the Irish Cancer Society)*
- ◆ *more sibling support following the death of a child*
- ◆ *better financial support and travelling expenses for families*
- ◆ *wider access to specialists in childhood bereavement.*

### 3.4.5 Responses from Service Managers – Hospices and Health Boards

The views of Health Service Executive policy planners (n=7) and hospice chief executive officers (n=5) on current services and their suggestions for the future development of paediatric palliative care services were explored by means of semi-structured interviews. This group recognised that there were deficiencies in service provision, particularly in rural areas. An absence of dedicated funding to support service provision and a dearth of accurate data on the numbers of children with life-limiting illness further compounded the problem.

Issues arising from these interviews were the need for:

- ◆ *the provision of dedicated funding for specialist paediatric palliative care*
- ◆ *consistency in policy development and in the provision of basic services to ensure equity*
- ◆ *the development of collaborative and multidisciplinary approaches to service delivery across all settings (hospital and primary care) including shared care initiatives*
- ◆ *essential services in the community on a 24-hour basis, in particular access to symptom control advice*
- ◆ *the development and provision of respite care — including home-based respite*
- ◆ *the provision of staff training and development in paediatric palliative care*
- ◆ *the development of national standards*
- ◆ *the provision of staff support.*

The development of a dedicated children's hospice was not seen as a priority with issues raised regarding location and cost.

## 3.5 Primary Care Services Supporting Children with Life-Limiting Conditions

### 3.5.1 Responses from General Practitioners

A total of 540 General Practitioners were surveyed, representing 20% of the overall number in practice in 2003. A response rate of 45% (n=242) was achieved. Of those who responded, 119 had cared for a child with a life-limiting condition within the past three years.

Of those GPs who had cared for a child with a life-limiting condition, 115 (97%) considered that care for the child's ongoing medical needs was the primary responsibility of the GP. These GPs provided the following services:

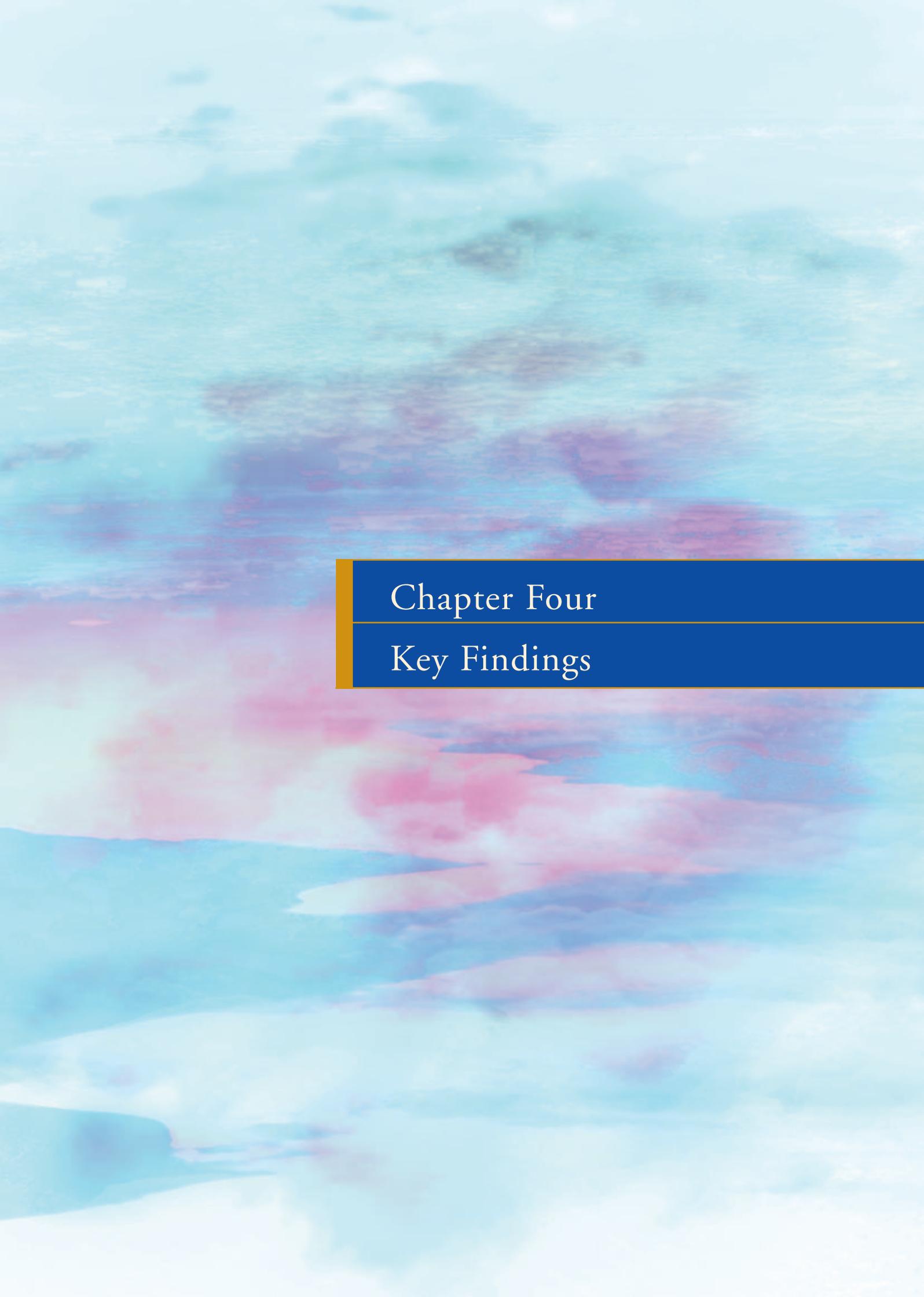
- ◆ *emergency callout (95, 80%)*
- ◆ *referral to other professionals (93, 78%)*
- ◆ *fifty-six (47%) indicated that when caring for a child with a life-limiting condition they visited at least once per week*

- ◆ consultations occurred with equal frequency in either the child's home or the doctor's surgery
- ◆ referral of children and their families to respite care services 26 (22%) or to local voluntary support services and services provided by the Health Service Executive 37 (31%). However, 27 (23%) did not refer to respite services as there were none available and a further 62 (52%) respondents reported that they did not know of any local voluntary support services.

### 3.5.2 Responses from Public Health Nurses

Ninety-one Public Health Nurses were identified by their managers as having cared for a child with a life-limiting condition within the last three years (2000–2002). Sixty-nine nurses responded and of these, 60 (87%) confirmed that they had cared for children with a life-limiting condition.

- ◆ Forty (67%) indicated that when caring for a child with a life-limiting condition they visited at least once per week
- ◆ Twenty-two (37%) referred children and their families to respite care services. 24 (40%) referred children and their families to local voluntary support services and services provided by the health boards
- ◆ Those who did not refer children to voluntary services (n=33, 55%) cited either a lack of availability of necessary services or an absence of knowledge of such facilities as the reason for non-referral
- ◆ Forty-nine (82%) considered the waiting times for Health Service Executive services to be satisfactory.



## Chapter Four

### Key Findings

# Key Findings

### 4.1 Data Collection for Planning Services

Whilst mortality figures for children are available<sup>13</sup>, accurate figures for the prevalence of children living with life-limiting conditions in this country are not. Currently there is no system in place to collect this information. Where figures were available these were far in excess of those previously estimated<sup>5</sup> with significant numbers of deaths occurring in the first week and year of life. This has resource implications for palliative care services (e.g. the provision of palliative care support in maternity hospitals). Ultimately the gathering of this type of data is essential in order to develop an equitable high quality national paediatric palliative care service.

#### Key findings

Currently there is no system in place to collect accurate figures on prevalence of children living with life-limiting conditions.

The lack of accurate information systems supports the need for a database or register to inform service planning.

Childhood mortality from life-limiting conditions is significantly higher than previous estimates.

32% of all childhood deaths occur in the first week of life.

### 4.2 Caring at Home

The preferred location for caring for a child with a life-limiting condition is the family home with parents receiving adequate professional support. The majority of parents would also choose home as the preferred location of death. The service providers also supported this finding. However, preference does not always follow through to choice. Whilst many children dying with cancer are able to die in their own homes, figures indicate that in Ireland the majority of children who die of life-limiting illnesses other than cancer do not die in their own home<sup>13</sup> (Table 7).

Healthcare professionals including paediatricians (41%), clinical nurse managers (57%), clinical nurse specialists (41%) and medical social workers (64%) do not feel that parents have enough choice regarding the location of their child's death. Some factors mitigating against choice include lack of facilities and resources, absence of information, parents' fears, and lack of experience in paediatric palliative care. The majority of palliative care teams perceived that the parents of children they cared for did have a choice regarding location of death (n= 6) (although most of the children cared for by these teams have cancer).

Respondents felt that some families were vulnerable and that this could go unrecognised. The term ‘burden of care’ was used to express some of the challenges. A source of great distress for families was the difficulty that they repeatedly encountered in accessing necessary aids and equipment for their child.

Barriers identified in caring for a child at home were:

- ◆ *access to aids and equipment*
- ◆ *coordination of care and support*
- ◆ *financial support*
- ◆ *help with decision making.*

Identifying a key worker was seen as one way in which these issues could be addressed.

### Key findings

The provision of seamless quality care is required, regardless of location or diagnosis.

Home is the preferred place of care and for the death of a child, yet the majority of children with non-malignant disease do not die at home.

Significant barriers have been identified to caring for a child at home contributing to the overall ‘burden of care’.

A key worker would improve coordination of the care of a child with a life-limiting condition.

## 4.3 The Need for Respite

To enable families to continue to care at home, access to respite care is essential, particularly where the child has needs over an extended period of time. Respite care can occur both within the home and away from the home. At home, it includes the provision of nursing and social support services, which can be short-term or long-term.

Over 80% of clinical nurse managers (n=23, 82%), 31% (22) of clinical nurse specialists, 79% (11) of medical social workers, 23% (27) of GPs, and 45% (27) of public health nurses confirmed that they wished to refer to respite services but that appropriate respite care was not currently available.

### Key findings

Respite is essential to enable parents to care for children with life-limiting conditions at home.

Professionals confirmed that necessary respite services were often not available for children in need of them.

### 4.4 Children's Hospice

The development of a purpose-built children's hospice is not currently seen as a priority. In the interests of establishing an equitable specialist palliative care service nationwide, concerns were raised regarding the potential geographical location, cost and accessibility of any such unit. The development of home-based or home care support initiatives and community-based care were seen as the priority.

Ambiguity existed regarding the role of 'hospice' in paediatric palliative care with some respondents associating the term only with end-of-life care and not as a place of respite. Interestingly, respondents including parents, consistently identified the need to provide respite centres as an essential part of a comprehensive paediatric palliative care service.

#### Key findings

The development of a purpose-built children's hospice is not currently seen as a priority, with concerns expressed regarding accessibility and cost.

The development of home-based or home care support initiatives and community-based care were seen as the priority.

### 4.5 Staff Training, Support and Ongoing Professional Development

In this study, professionals working at all three levels of palliative care specialisation identified a need for further education and training. Specifically, many respondents noted the need to address education and training in the following areas:

- ◆ *defining palliative care and especially palliative care for children*
- ◆ *pain and symptom management*
- ◆ *information on services and how to access them*
- ◆ *counselling and bereavement skills.*

Many healthcare professionals care for children with life-limiting conditions infrequently, and therefore education is required on an ongoing basis to maintain competency and skill-base.

Professional carers spoke of the positive experiences they have had in providing care for children with life-limiting conditions. However, caring for these children can also exert heavy demands, both physically and emotionally. Caring for the carers is now regarded as part of good quality health care. Staff support systems could include debriefing following the death of a child.

#### Key finding

There is substantial need for further education and training for all professionals involved in caring for children with life-limiting conditions.

## 4.6 Extended Care

The level of care a child requires, in combination with family circumstances, may result in the need for extended care. It is difficult to separate the availability and extent of community based supports from the need for extended care. Many of the parents of children who were in extended care, and who were interviewed as part of this study, indicated that they had struggled, sometimes for many years, to care for a child at home with relatively little home based support before opting for extended care. Largely provided by voluntary agencies, the availability of extended care varies according to geographic location and the numbers and level of care offered. Providers of such facilities reported inability to meet demand and uncertainty of funding, which limited the extent and range of their services.

### Key finding

Providers of extended care are limited by excessive demand and uncertainty around funding.

## 4.7 Care in the Hospital Setting for Children with Life-Limiting Conditions

This study has found that despite the best efforts of staff, the absence of suitable accommodation and poor resources are seen as obstacles to providing optimum care for children and their families in hospitals. Lack of privacy for dying children and their families, poor physical conditions and staff shortages were all raised as issues by both parents and hospital staff. Play activities, which are considered an essential element to any paediatric palliative care service, are currently insufficient to meet demand. The provision of family accommodation for parents and siblings is an essential element of providing a service for children with palliative care needs. There is a need for child-friendly surroundings and facilities.

### Key finding

Absence of suitable accommodation and poor resources are obstacles to providing optimum care for children and their families in hospital.

## 4.8 The Special Needs of Adolescents

The physical environment in hospital was often deemed unsuitable for the needs of adolescents and was described as being more child-oriented. Some parents of adolescent children were critical of facilities in acute hospitals as being much more suited to younger children. There is a need to develop more adolescent-friendly facilities, including recreational areas geared to their interests. Some suggested that children and adolescents should be in different but adjacent areas within the hospital setting.

Transition to adult services was identified as an issue, as young people often felt lost in the system when being transferred. Families had often been under the care of paediatric services

for many years and found the move traumatic. Suggestions were made as to how to improve this transition and included an overlap period, where paediatric liaison nurses would accompany the patient to adult clinics for their first few visits until relationships were established.

### Key findings

There is a need to develop more adolescent-friendly facilities.

The transition from paediatric to adult services needs to be improved.

## 4.9 Bereavement

Bereavement care, by definition, is part of the continuum of palliative care. Currently the majority of paediatric units provide bereavement services to parents, although the type and quality of services was not evaluated in this study. Fewer units provided bereavement services for siblings. Some respondents stated that hospital bereavement services need to be expanded to reflect the often close relationships which develop between families and staff. A range of bereavement support should be available, including memorial services, contact with familiar staff and specialist bereavement support for those who require it.

### Key finding

Professionals engaged in the delivery of palliative care require appropriate training to enable them to support bereaved families.

## 4.10 Cultural Issues

In this study staff spoke about their experiences of caring for children from the travelling community — the indigenous minority in the Irish population. While the numbers of children with life-limiting conditions from other ethnic minorities who had been cared for to date were limited, it was recognised that with changing demography these care challenges would increase. Professionals described the steep learning curve in providing care, the pressure on resources and the need for further education and training in meeting the needs of minority groups, an area of growing need in paediatric palliative care.

The particular needs of children from different ethnic groups should be explicitly included in the planning and development of services. Cultural and religious traditions need to be considered in quality paediatric palliative care<sup>24</sup>. Specifically, engagement with principles that foster people's cultural choices and beliefs is important. International evidence suggests that minority ethnic groups have a poorer uptake of palliative care services<sup>35</sup>. The importance of providing care in a manner that is both knowledgeable and respectful of religious and cultural beliefs is central to good practice.

**Key findings**

The particular needs of children from different ethnic groups should be explicitly included in the planning and development of services.

Further education and training is needed to meet the needs of different cultural groups.

#### 4.11 Inequity

Palliative care services currently provided to children in Ireland with life-limiting conditions were seen to be inequitable, differing significantly according to diagnosis (malignant versus non-malignant) and according to geographic location. This poses challenges, particularly for parents of children with non-malignant disease.

**Key finding**

Palliative care services were seen to be inequitable, differing significantly according to diagnosis and according to geographic location.

#### 4.12 Complexity of Defining Palliative Care

There is uncertainty amongst professionals as to what constitutes paediatric palliative care. Despite the fact that three levels of palliative care specialisation have been identified<sup>1</sup>, professional and voluntary groups working with children with life-limiting conditions do not always recognise that they are already providing palliative care at either level 1 (palliative care approach) or level 2 (general palliative care) or that involvement of level 3 (specialist palliative care) may be appropriate.





## Chapter Five

### The Future

# The Future

*Future developments in the area of paediatric palliative care should be shaped by four key principles: inclusiveness, partnership, comprehensiveness and flexibility.*

### 5.1 Inclusiveness

All children regardless of diagnosis, culture, geography and age should be able to access appropriate care.

- a. Palliative care services currently being provided to children in Ireland are inequitable, differing significantly according to diagnosis (malignant versus non-malignant) and according to geographical location.
- b. Non-Irish nationals currently account for approximately 6% of the population of the Republic of Ireland. Of all immigrants to Ireland, 45% originate from outside the EU and the USA, 8% are from central and Eastern Europe, 7% from African countries and an unknown number are born to Irish citizens outside of Ireland<sup>13</sup>. Any developments to meet the varied requirements of multiple cultures will have resource implications in areas such as translation services and the education of health professionals.
- c. All children, from neonates to adolescents, have a right to age-appropriate services.

All providers of care to children with life-limiting conditions should have an understanding of their role in the provision of palliative care and access to specialist palliative care as required.

- d. Currently, there is uncertainty amongst professionals as to what constitutes paediatric palliative care. Many do not recognise that they are already providing palliative care at either level 1 (palliative care approach) or level 2 (general palliative care) or that involvement of level 3 (specialist palliative care) may be appropriate.
- e. There is an urgent need to develop specialist paediatric palliative care posts (medical and nursing initially) to spearhead the establishment of services and education. In Ireland, it has previously been recommended that medical and nursing care should be provided by paediatric trained staff with the close support of a specialist palliative care team<sup>5</sup>.

- f.** Recommendations for medical and nursing training programmes have been made in other countries<sup>36</sup>. In addition, this report has identified the importance of multi-disciplinary teams and consequently, systems of training for professions allied to medicine must also be developed. Education programmes should take into account the support needs of carers and should include reflective practice.
- g.** The family is part of the caring team. Families need the 'know-how' that will allow them to provide care for their child. Information and training should be framed within the unique needs of the child and the family and should be readily available.

## 5.2 Partnership

The active participation of all stakeholders including the child should be facilitated.

- a.** All children should have "a voice in matters which affect them and their views will be given due weight in accordance with their age and maturity"<sup>37</sup>. In order to foster partnership, communication with all children needs to be straightforward and honest. This can be achieved through verbal and non-verbal approaches. Children's understanding may vary, taking into consideration intellectual capacity, personality, ethnic, cultural and religious background. Adolescents have a need for increased autonomy that must be recognised in the decision-making process.
- b.** Parents should be actively incorporated as partners in the process of decision-making and in the planning of care. They should have knowledge of alternatives and have real choices, e.g. about the location of care. Key information about the diagnosis and prognosis of their child is integral to future planning. Practical information regarding services that are available, and information regarding financial issues, should be proactively offered. There should be ready access to aids and appliances as required.

## 5.3 Comprehensiveness

Care should include a focus on psychological, emotional, educational and spiritual needs of a child and his or her family.

Accurate data collection would provide key information on the number, location, diagnostic category, and age range of children at any given time and would form the basis for service planning. A system for identification of children with life-limiting conditions should include

all children who may need palliative care services as recognised and defined by ACT<sup>1</sup>. Experience from other countries has highlighted the difficulties involved in establishing and maintaining accurate databases. Practical issues regarding data protection, maintenance and access need to be clearly defined. Accurate information collection is an essential first step in ensuring provision of and access to necessary services to children with life-limiting conditions.

- a.** Children with life-limiting conditions have many of the same requirements as healthy children, and need to maintain a normal life for as long as possible. Children continue to grow and develop physically, emotionally and cognitively throughout their illness, and regardless of the stage or extent of their illness, have a need for education and play. Provision for these needs must be incorporated into their care plans.
- b.** Holistic care requires teamwork and the input of different disciplines. These include physiotherapy, nursing, occupational therapy, speech therapy, dietetics, play therapy, social work, psychology, bereavement support and pastoral care. These should be readily accessible in all locations of care.
- c.** At the end of life parents need to have a sense of ownership of their child's death and to feel that they did everything possible for their child. A range of bereavement services should be available if required. Parents may need support to restructure their lives after the death of their child. Appropriate involvement and support for siblings, both before and after the child's death, is also an important consideration.

### 5.4 Flexibility

Care should be adaptable to the individual and changing needs of the child and his/her family.

- a.** Thorough assessment is the first step in planning responsive care. The development of a comprehensive, individualised plan of care is the duty of a multi-disciplinary team. This process should include parents and, if possible, the child. Throughout the child's illness this plan provides a framework for care. The plan should be reviewed regularly in order to ensure that the child's complex and changing needs continue to be addressed.
- b.** In some settings, and where health professionals do not usually care for children with life-limiting conditions, generic protocols can provide a useful framework for assessment and planning care. Even so, the individual needs of each child must still be considered. Protocols may be developed for particular life-limiting conditions and for different care settings. In particular, children who have a very limited prognosis require intensive planning of care. A key finding of this study is the significant proportion of infants identified who die within the first month of life. End-of-life care pathways have been successfully implemented in the care of dying adults<sup>38</sup> and similar care pathways may have a role in improving the care of children at the end of life.

- c. Part of the assessment process must focus on the key services required. Appropriate resources, services and equipment should be available when needed and with a minimal level of bureaucracy. Regular review should be a feature of all of these processes. Many life-limiting conditions are so complex that a child can cross the boundary between episodes of critical and chronic illness many times before death. Services need to be flexible and prompt, responding to the child’s changing circumstances.
- d. The findings of this study suggest the need for a ‘key worker’ for each child and family to co-ordinate and implement a plan of care. The key worker is not defined by role and can be any member of the multi-disciplinary team, and should be identified during the initial assessment process. The identification of a key worker to liaise between family and all services would provide families with a single resource to aid in the day-to-day management of their child’s illness.

Tasks of the key worker
Assess, implement and review the plan of care with the multi-disciplinary team.
Maintain ongoing contact with the child and family.
Monitor changing needs.
Provide information and support to child, family and team.
Act as liaison, where required, between the family and the service providers.

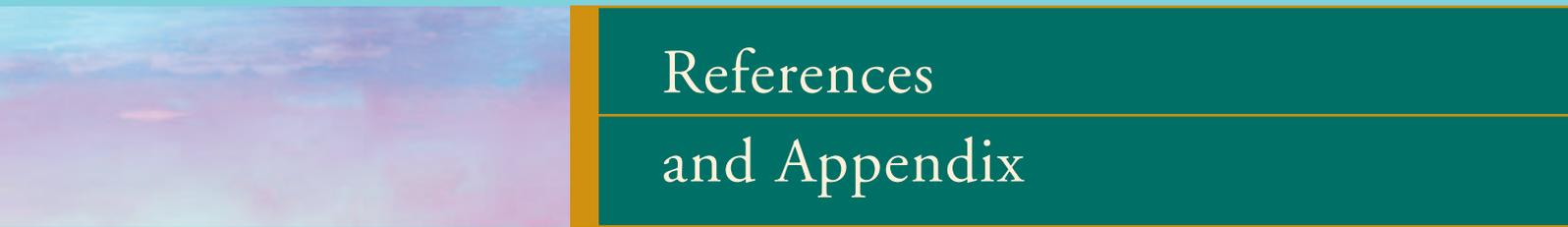
The links between hospital and community based services are of key importance in the continuity of care. Formal links between the different service providers should be encouraged. For example, clearer structures and communication protocols between the different settings and service providers would further facilitate effective liaison.

- a. **Primary Care:** Implementation of *Primary Care: A new direction*<sup>11</sup>, including the creation of multidisciplinary teams would fill an important gap in community-based services for children with life-limiting conditions and their families. This should include the provision of 24-hour a day, seven days a week nursing services where needed. The proposed expansion of community-based posts, for example consultant paediatricians and children’s nurses, would provide a further resource to palliative care development.
- b. **Voluntary Organisations:** Voluntary organisations currently play a crucial role in the provision of paediatric palliative care services. Many of these organisations maintain an age and disease-specific focus. Consequently, children who do not meet specific criteria may not be eligible to receive their services. Voluntary organisations need to be included in the planning of future services. While formal funding mechanisms have done much to ensure continuity of service, further development of a partnership model of service provision would facilitate the voluntary sector to plan and deliver services with greater security and accountability for the funding provided.

- c. Hospital Services:** The role of the hospital is central to the delivery of paediatric palliative care throughout the child's illness, from diagnosis to death. Out-patient clinics provide a currently under-utilised opportunity for access to multiple disciplines, including palliative care. The introduction of a 'one-stop-shop' clinic may reduce the burden on parents who currently need to attend multiple clinics to meet their child's complex medical needs. Attendance at out-patient clinics can also provide an opportunity to meet with other children and families going through a similar experience. Hospital bereavement services need to be expanded to reflect the often close relationships which develop between families and staff.
- d. Respite Care:** Locally based, child-friendly and readily accessible respite facilities must be a priority in the development of a 'seamless' system of care. Familiarity with the child and her/his needs is of the utmost importance when considering respite care. Admission to the hospital unit known to the family is often welcomed for that reason. If respite is offered in a hospital setting, it needs to be in a separate facility that is different in terms of its atmosphere and surroundings to the acute wards.
- e. Coordination of services for children with life-limiting conditions:** Respondents identified some potential structures for the coordination of services for children with life-limiting conditions. These Irish structures included: community paediatric multi-disciplinary teams with access to a range of services including home-based and residential respite facilities; specialist palliative care teams providing support at regional level; and tertiary children's hospitals supporting hospital paediatric units and community-based paediatric services. The provision of essential equipment, aids and appliances when required is essential.

Internationally, different structures have been put in place to promote a coordinated and comprehensive approach to care of children with life-limiting conditions. Coordination may be vested in an individual role (e.g. key worker<sup>1</sup>), a structure (e.g. team<sup>39</sup>) or outside agency.

This needs assessment has identified current service provision to children with life-limiting conditions and their families in Ireland. These findings should form the basis of further work aimed at providing an equitable and seamless service to children with life-limiting conditions and their families regardless of their diagnosis and geographical location.



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and Appendix

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## Appendix 1 - Voluntary Organisations Utilised by Respondents

Aisteoir Beo	Jack and Jill Foundation
ARC House	Learning Disability Agencies
Asthma Association	Local Hospice Voluntary Group
Balbriggan Family Centre	Make a Wish
Barnardos	Marymount Hospice
Barrettstown Gang Camp	Mayo/Roscommon Foundation
Bereavement Support/Counselling	Mucopolysaccharide Disease Society
Brain Tumour Support Group	Muscular Dystrophy Association
Brothers of Charity	NAMI
Canteen Ireland	Nurse for Daniel
Care for Children on Home Dialysis and Gastronomy Feeds (UK service of child sitting — no branch in Ireland)	Palliative Care (adult service)
Cancer Support Group	Parent Child Psychological Support Jobstown
Carers' Association	Parent to Parent Support Group/Planning Group
Chaplain/Religious Services	Rainbow Support Network
Cheeverstown House	Rehab
Clinical Nurse Specialist (Oncology Crumlin)	Respite
Counselling	Sick and Indigent Roomkeepers Society (financial)
Counsellor Irish Heart Foundation	Shima Valley Holiday Home
County Down Family Holiday	Soft
COPE Foundation	St John of God
Cork Leukaemia	St Mary's Baldoyle
Cerebral Palsy Ireland	St Mary's Beaufort Killarney
Central Remedial Clinic	St Mary's of the Angels
CURAM	St Rita's Clonmel (Disability services for respite of neurologically impaired children)
Cystic Fibrosis Association	St Vincents Navan Road
Down's Syndrome Association	Suicide Services
Enable Ireland	Spina Bifida Association
Home Support Services	Society for Blind
Hospice Home Care/support services	Stewart's Hospital
Incontact (British Organisation for persons with spinal needs/incontinence)	Sunshine Home
Irish Cancer Society	Suzanne House
Irish Kidney Association	Web
Irish Wheelchair Association	Western Care Association
	Winstons Wish

