

PALLIATIVE CARE FOR CHILDREN WITH LIFE- LIMITING CONDITIONS IN IRELAND

- A National Policy



©December 2009

FOREWORD BY MARY HARNEY T.D. MINISTER FOR HEALTH AND CHILDREN



As Minister for Health and Children I welcome the publication of this Policy document '*Palliative Care for Children with Life Limiting Conditions*'. It seems so unnatural to think about, or have to plan for, the death of infants and children but hundreds of parents and families go through this tragic experience every year. This Policy is necessary to make sure that we provide coherent support and care to these children and their loved ones at this most difficult time.

The specific needs of children with life-limiting conditions requiring palliative care were highlighted in the '*Report of the National Advisory Committee on Palliative Care*' published by my Department in 2001. Following on from that, an Irish national children's palliative care needs assessment was undertaken and published in 2005. The needs assessment represented the first step in the development of a nationwide cohesive and equitable palliative care service specifically for children and adolescents. This policy aims to address the issues identified in the needs assessment in order to build a responsive service for children and their families and provide a framework within which a seamless service for children with life-limiting conditions and their families can be planned, delivered and accounted for.

I would like to thank and congratulate those involved in the development of this Policy particularly the working group for their time, commitment and hard work. I want also to acknowledge the contribution of the Irish Hospice Foundation towards making the policy a reality, by funding initially the key medical staff necessary to get Phase 1 of this policy up and running. It is an example of how statutory and voluntary partnerships continue to work together towards the goal of enhancing the lives of people in receipt of palliative care.

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Presentations

The following made presentations to the working group:

- Jack and Jill Foundation, Dublin.
- A family's journey through paediatric palliative care, Claire Quinn.
- Palliative Care Team, Our Lady's Children's Hospital, Dublin.
- Community Paediatric Service, Letterkenny Hospital, County Donegal.
- Mark Brierley, Social Information Systems Ltd, Cheshire UK.
- The Children's Sunshine Home, Dublin.

TERMS OF REFERENCE

Having regards to –

- a) The best interests of children with life-limiting conditions and their families.
- b) Relevant national and international research, analysis and standards.
- c) The Report of the National Advisory Committee on Palliative Care (Department of Health and Children, 2001).
- d) The paediatric palliative care needs assessment (Department of Health and Children, 2005), and the palliative care requirements of children with malignant or non-malignant diseases.
- e) The newly developed systems and structures under the Health Service Executive.

To examine and develop policy on:

- The principles underlying the development of specialist and non-specialist palliative care services for children nationally and regionally.
- The organisation and development of an integrated palliative care service for children with life-limiting conditions and their families involving both statutory and voluntary providers, and including the delivery of care in all settings.
- Personnel, education and training.

EXECUTIVE SUMMARY

This policy provides a foundation upon which children's palliative care services can be developed in Ireland. It is divided into three sections. The first section defines and describes palliative care for children with life-limiting conditions and draws on national and international developments in this small and highly specialised field of health care. The second section describes services as they are currently provided. The third section gives clear direction for the future development of palliative care for children.

Children's palliative care has evolved from the specialty of paediatrics rather than adult palliative care and is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancing the quality of life for the child and providing support for the family, and includes the management of distressing symptoms, provision of respite and care through death and bereavement. 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 palliative care have their own unique needs.

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 (Table 1). Children with these conditions are likely to have palliative care needs.

In Ireland there are approximately 1400 children living with a life-limiting condition and in the region of 490 childhood deaths per year. Of childhood deaths due to life-limiting conditions, the majority occur in the first year of life, with approximately 350 deaths per year from life-limiting conditions.

The *Report of the National Advisory Committee on Palliative Care* published in 2001, highlighted the need for a review of children's palliative care services. A *Palliative Care Needs Assessment for Children* was undertaken and the results published in 2005. The findings of the needs assessment in Ireland were consistent with those undertaken in other countries.

This policy aims to address the issues identified in the needs assessment in order to build a responsive service for children and their families. A comprehensive children's palliative care service needs to function within a cooperative model with close liaison between general practitioner, paediatrician, nursing services, therapists and the voluntary sector. Children's hospitals and hospitals with paediatric units are central to the ongoing care and management of children with life-limiting conditions. This policy recommends that there should be a hospital-based specialist palliative care team led by a Consultant Paediatrician with a Special Interest in Palliative Care. The palliative care service should move to the new paediatric hospital when it is operational. The consultant should have access to inpatient beds.

In order to provide support to children with life limiting conditions and their families primary care services need to be developed including the provision of a Consultant Paediatrician with a Special Interest in Palliative Care and Outreach Nursing posts, therapy posts, Hospice-in-the-Home and respite care (both in home and away from the home) in each of the HSE regions. These developments would be in line with primary care/network developments. In order to plan and develop services, data collection is required and it is envisaged that the Health Service Executive will collect information on children living with and dying from life-limiting conditions.

The needs assessment clearly identified a need for staff to develop the competencies required to address the palliative care needs of children. This policy identifies developments required in the education and training of health care staff and carers. Bereavement services developments are also required.

A National Development Committee for Children's Palliative Care should be established by the HSE in order to provide a national forum for the cohesive, integrated development of children's palliative care services based on population need and to ensure geographical uniformity in the provision of services.

This national palliative care policy for children aims to provide a foundation upon which service development can take place. In developing this policy the Department of Health and Children aims to provide a framework within which a seamless service for children with life-limiting conditions and their families can be planned, delivered and accounted for by the Health Service Executive (HSE).

Table 1 - Four Groups of children who are most likely to have palliative care needs.

Group 1

Life-threatening conditions for which curative treatment may be feasible, but can fail. Where access to palliative care services may be necessary when treatment fails children in long term remission or following successful curative treatment are not included. (Examples: cancer, irreversible organ failures of heart, liver, kidney.)

Group 2

Conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. (Example: cystic fibrosis.)

Group 3

Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. (Examples: Batten disease, mucopolysaccharidoses, muscular dystrophy.)

Group 4

Irreversible, but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. (Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord insult.)

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SECTION ONE

Defining and describing
palliative care
for children

SECTION ONE - Defining and describing palliative care for children

1. Introduction

This section defines children's palliative care and briefly describes its development both in Ireland and internationally. The findings of 'A Palliative Care Needs Assessment for Children' (2005) underpin the development of future policy direction for children with life-limiting conditions and the key findings are synthesised and discussed in this section. Best practice in children's palliative care is described and set in the Irish context. Throughout this document the term life-limiting will be used to encompass both life-limiting and life threatening conditions. The term 'child' refers to any person under the age of eighteen years and will include all young people including adolescents.

2. Definition of children's palliative care

Palliative care for children is a developing area of care that is not yet widely recognised as a speciality in its own right. Palliative care aims to support children with life-limiting conditions and their families to maintain quality of life. It has been defined by the World Health Organisation (WHO) as follows:

Table 2 – WHO definition of Palliative Care for Children

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

2.1 The difference between palliative care for adults and palliative care for children

Palliative care for adults is a well-established medical speciality. The majority of adults currently in receipt of palliative care have cancer and thus a somewhat predictable disease trajectory and prognosis. The needs of children with life-limiting conditions differ significantly from those of adults (Table 3). There is an overlap between some of the needs of children with life-limiting illnesses and the care that children with disabilities will require. Not all children with palliative care needs will require **specialist** palliative care input.

Table 3 - Childrens palliative care differs from adult palliative care as:-

- The number of children dying is small.
- The conditions are extremely rare with diagnoses specific to childhood.
- Predicting a prognosis can be difficult.
- The palliative phase is often much longer and can be episodic and unpredictable.
- Children may experience several apparently terminal phases.
- Care embraces the whole family and uses a model of family-centred care.
- Parents require adequate resources to support them with the heavy responsibility for personal and nursing care.
- Siblings are vulnerable and parents must continue to provide care for them while often providing 24 hour care to a sick child.
- Conditions are sometimes familial - other children in the family may be living with, or have died from, the same condition.
- Childrens ability to communicate and understand varies according to their age or stage of development.
- The provision of education and play when a child is sick is essential.

2.2 Children's palliative care

Childhood deaths are still a rare event; therefore specialist palliative care for children is a very small and highly specialised field of healthcare. Palliative care aims to maintain quality of life for the duration of the child's illness which may be days but can be months and sometimes years. Children's palliative care is holistic in nature where the child and their family are viewed as one unit. Most children with palliative care needs will have these needs met by their family supported by locally provided services. This may sometimes, but not always, require the support of a specialist palliative care team.

Ideally support for children with palliative care needs starts at the time of diagnosis, and for many children with life-limiting conditions this can be at birth. Palliative care support can be given alongside active treatments aimed at cure or prolonging life and should, where possible, be provided in the location where the child and family choose to be. Families vary in how strongly they wish to pursue treatments aimed at cure or prolonging life. Decisions about moving away from active care are difficult for both the family and staff and should only be made following full discussion. A care plan, once decided, should include details of what, if any, emergency treatment measures should be taken. The child's comfort should always be central to the decision-making process. Parents' wishes should be documented and care should be planned accordingly. Clear communication between parents and all healthcare professionals involved in the care of the child is essential.

2.3 Adolescence

Adolescents are distinct from children with differing needs. Adolescence is variously described as ranging from as young as 10 to 24 years and is arbitrarily divided into three phases, early, middle and late. The boundaries between these phases can be blurred and obvious differences exist with regard to key issues such as relationships with peers, behaviour and the impact of a life-limiting condition. More adolescents with life-limiting conditions are now being cared for. This is as a result of better medical care including earlier diagnosis, better nutritional support and improved clinical interventions which have significantly improved outcomes. The care of adolescents with life-limiting conditions is challenging and requires the availability of services to meet their specific needs.

Whilst not all children, will be able to participate in decision making about their health and care needs, where possible children should have a voice. This is dependent on the child's understanding, intellectual capacity, personality, ethnic, cultural and religious background. Adolescents have a need for increased autonomy and this must be recognised in the decision making process.

Children will have a voice in matters which affect them and their views will be given due weight in accordance with their age and maturity.

National Children's Strategy 2000

2.3.1 The specific needs of adolescents

Challenges in caring for adolescents with life-limiting conditions include:

- 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. Psychological support is particularly important at the time of transition to adult services.
- 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.
- Inexperience of adult services in dealing with the challenge of caring for adolescents.

2.3.2 Findings of the needs assessment on adolescents

In *A Palliative Care Needs Assessment for Children* the issues that were raised regarding the care of adolescents were:

- The need for improved transition from paediatric to adult services.
- The need for improved facilities for adolescents when in hospital.
- The need for more education for carers who have to deal with adolescents.
- Opportunities for privacy.
- Interaction and communication with trusted adults other than parents.
- Engagement in collaborative decision-making with parents and professionals.

2.3.3 Transition to adult services

When making decisions with adolescents and their families about appropriate care, it is essential that emotional and developmental age is taken into consideration. Use of chronological age alone is too simplistic. Special services are needed in order to bridge the gap between child-based and adult-based services. Where bridging services is not possible or appropriate, it is essential that necessary arrangements are in place to ensure continuity of service provision designed specifically to meet the needs of each individual young person with a life-limiting condition.

KEY POINT

Adolescents are distinct from children and have differing and specific needs.

Special services are needed to bridge the gap between child-based and adult-based services.

3. International perspective

Internationally, children's palliative care has evolved from paediatrics rather than adult palliative care. This is in keeping with the *United Nations Convention on the Rights of the Child*, which insists that those working with children should first and foremost be trained in the care of children and young people. Irish palliative care policy also recommends that ideally children with life-limiting conditions should be cared for by staff who are trained in paediatrics.

Whilst many countries are in the process of developing children's palliative care, the United Kingdom (UK) has led on many of the developments in this area of care. In the UK palliative care services specifically for children have developed, initially from paediatric oncology services and more recently as palliative care teams in their own right. The Association for Children with Life-threatening or Terminal Conditions and their Families (ACT) and the Royal College of Paediatrics and Child Health in the UK have been instrumental in producing several key documents regarding the palliative care needs of children which include key recommendations for the care of children with life-limiting conditions (Appendix 1). More recently an extensive review of palliative care services for children has been undertaken in England and a national strategy has been developed. Standards for children's palliative care services have also been developed in Wales. These documents have informed the development of this children's palliative care policy in Ireland.

KEY POINT

It is recommended that ideally, children with life-limiting conditions should be cared for by staff trained in paediatrics.

3.1 International needs assessments

Several countries or jurisdictions, including Ireland, have undertaken needs assessments aimed at identifying the requirements of children with life-limiting conditions and their families. Regardless of country of origin, healthcare system or stage of development of palliative care services, the findings of the needs assessments already performed have been remarkably consistent (Table 4).

Table 4 – Common findings of international needs assessments

- Location of choice for both children and their families is home through illness and ultimately death.
- Community resources currently provided are inadequate to support children at home.
- There are insufficient essential respite services available.
- Services are dependent often on geographical location and diagnosis, with the better developed services often only available to children with cancer.
- Communication between professionals is poor and needs vast improvement.
- There is a need for better education for all professionals and volunteers involved in the care of children with life-limiting conditions.

4. Irish context

Palliative care services for children should be accessible, equitable, flexible and appropriate and should meet the needs of any child with a life-limiting condition and their family. Development of services should be in line with recommendations of strategy documents and national policy including the Health Strategy and the Primary Care Strategy.

4.1 The Primary Care Strategy (2001)

'Primary Care – A New Direction (2001)' focuses on the development of inter-disciplinary teams working in the community. Members of the primary care team and wider primary care network will provide services for an enrolled population. This model of primary care represents a change in emphasis from secondary care to more appropriate primary care services and requires new ways of working to deliver the range of services envisaged. This policy aims to provide appropriate care in the appropriate setting and to provide a service that is responsive to the needs of individuals or families when problems or acute needs are experienced. This should include the development of further community paediatrician posts and the development of community children's nursing services. Children's palliative care needs to function within this model.

4.2 Government policies in relation to children

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 play and education. Meeting the play and educational needs of children with life-limiting conditions can pose particular challenges and parents and teachers may need support from healthcare professionals around issues that may arise relating to the child's condition and how to address these. In an effort to maintain normality, where possible the child's education should continue for as long as possible at the usual location.

4.3 Report of the National Advisory Committee on Palliative Care (2001)

The *Report of the National Advisory Committee on Palliative Care* is seen as the blueprint for the development of palliative care in Ireland and has been adopted as national policy. In the report, three levels of specialisation for the structuring of palliative care services are identified (Table 5). These levels may play an important part in defining palliative care for children as they clearly delineate the different roles and levels of palliative care being offered to children with life-limiting conditions.

Table 5 – Levels of Palliative Care Specialisation**Level One – Palliative Care Approach**

Practice at this level involves engagement in the principles of palliative care, where required, by all health care professionals. At this level many patients will have their care needs met without the necessity of referral to specialist palliative care.

Level Two – General Palliative Care

At this level of practice those providing palliative care will have additional training and expertise. This is viewed as intermediate level expertise, where engagement in palliative care is part of the health professional's caring role but does not define it.

Level Three – Specialist Palliative Care

This level refers to those whose core activity is limited to the provision of palliative care. Caring for patients with complex and demanding palliative care needs requires a greater degree of training, staff and other resources.

4.3.1 National Advisory Committee recommendations on children's palliative care

Palliative medicine was recognised as a medical specialty in Ireland in 1995. Children's palliative care is a more recent development and is not currently recognised as a distinct medical specialty. Although the National Advisory Committee report focused mainly on adult services, the committee also made recommendations for children's palliative care (Table 6).

Table 6 - Report of the National Advisory Committee recommendations for children's palliative care

- Palliative care for children is best provided at home, except in extraordinary circumstances, with the family closely supported by the GP and the PHN 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 with the support of specialist palliative care services.
- There should be close co-operation and liaison between paediatric and specialist adult palliative care services.
- Palliative care services for children, including respite care, should be provided as close to the child's home as possible.
- Each paediatric unit should review its requirements for the provision of palliative care and respite care for children in its local area.

Furthermore the report suggested that the issues that need to be addressed in the future planning of palliative care services for children include:

- Access to specialist palliative care services.
- Home nursing care.
- Access to allied health professional services in the community.
- Locally based respite.
- Family support.
- Bereavement support.
- Education and training of children's health care professionals.
- Educational needs of children.

KEY POINT

Effective palliative care requires the involvement of an interdisciplinary team that is committed to working together towards the achievement of best practice.

5. A Palliative Care Needs Assessment for Children (2005)

The findings of the Irish national children’s palliative care needs assessment were published in 2005. This document was based on the findings of a research project supported by the Department of Health and Children and the Irish Hospice Foundation which was undertaken by a team of researchers from University College Dublin. The needs assessment highlighted the issues that have to be addressed in order to provide palliative care services for children in Ireland (Table 7).

Table 7 – Key findings of the children’s palliative care needs assessment

The need for:

- Equity in service provision.
- Co-ordination of and access to services.
- Home care and community support services to be developed.
- Accurate data collection on prevalence and mortality.
- A ‘key worker’ to improve co-ordination of and access to services.
- Education, training and development of health care professionals.
- Readily available access to locally based respite.
- Planning of the development of services.
- The specific needs of adolescents to be considered.
- A broader range of bereavement supports to be available.

5.1 Childhood deaths

The Children’s Palliative Care Needs Assessment provided information on childhood deaths in Ireland between 1996 and 2001 (Table 8) and identified that of all deaths in children up to one year, 83% are due to life-limiting conditions with 53% occurring in the first week of life. Of all childhood deaths 66% are due to life-limiting conditions. Of childhood deaths due to life-limiting conditions, 71% occur in the first year of life.

Table 8 – Mortality data for children under 18 years in Ireland 1996-2001

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

The latest information provided by the Central Statistics Office for 2002-2004 shows that since the publication of the needs assessment there has been a decrease in the number of childhood deaths from all causes, whilst the number of deaths from life-limiting conditions remains almost the same at 3.5 per 10,000 (Table 9). Information also indicates the majority of childhood deaths continue to occur in the first year of life.

Table 9 – Mortality data for children under 18 years in Ireland 2002-2004

	Number of deaths	Average annual number of deaths	Range per annum	Average annual rate per 10,000
All Causes	1474	491	462-516	4.8
Life-limiting conditions	1061	354	346-368	3.5

5.2 Prevalence of children with life-limiting conditions

To date, no country has a national database identifying children with life-limiting conditions, therefore information on the prevalence of children who need palliative care is limited. In the absence of this data, most documents and needs assessments rely on estimates of the prevalence of life-limiting conditions. It was estimated in the needs assessment that there are approximately 1,400 children currently living in Ireland with a life-limiting condition. There are now indications that the Association for Children with Life-threatening or Terminal Conditions and their families (ACT) document and the Irish needs assessment contain figures that are very likely to be underestimated.

KEY POINT

Figures on the prevalence of children with life-limiting conditions are likely to be underestimated.

Of childhood deaths due to life-limiting conditions, 71% occur in the first year of life.

5.3 Data collection

European guidelines on the development of standards for paediatric palliative care stress the importance of standardisation in the collection of information on all aspects of children's palliative care so that comparisons and generalisations can be made between and across countries.

Combinations of two methods of information are currently used:

1. The International Classification of Disease (ICD) codes are the preferred method of collecting data on childhood death (Appendix 2).
2. The categories of life-limiting conditions described by the ACT (Table 1).

Children in the four categories described by ACT are most likely to have palliative care needs at some stage in their illness. Some will have long periods of relatively good health whilst others may need active palliative care support at an earlier stage of their disease.

KEY POINT

As children's palliative care deals with relatively small numbers of cases it is important to ensure standardisation in the collection of information so that comparisons and generalisations can be made between and across countries.

6. Evidence Based Practice

In order to ensure that children with life-limiting conditions and their families receive appropriate and timely palliative care, best practice must be defined. In the UK, the basic requirements of children and families receiving palliative care are defined in the ACT charter (Table 10).

Table 10 – Every child with a life-limiting condition and their family should expect to:

1. Have individual needs assessed and receive care according to a care plan which is regularly reviewed.
2. Be included in the process of care planning.
3. Be provided with appropriate and timely information.
4. Have access to a 'key worker' who will co-ordinate their holistic care and link services to ensure co-ordination and continuity of care.
5. Have access to medical support from their GP and a paediatrician in their local area.
6. Where possible, be under the care of a specialist consultant paediatrician expert in the child's condition.
7. Have access to a local based inter-disciplinary team with knowledge about the range of services available.
8. Be supported in the management of their child's physical and emotional symptoms.
9. Have access to 24-hour care/advice in the terminal stages of their child's condition.
10. Receive help in meeting the needs of parents and siblings during the child's illness and through death and bereavement.
11. Be offered regular and reliable respite, either in the home or away from home as required. This should include direct care or 'hands on' care and symptom management if required.
12. Be provided with supplies of medications, oxygen and specialised feeds and have all disposable items such as feeding tubes, suction catheters and stoma products supplied regularly and efficiently as required.
13. Have access to housing adaptations and specialist aids and equipment for use at home and school in an efficient and timely manner.
14. Be given assistance with financial matters including eligibility and access to benefits and grants.

6.1 Who should work in children's palliative care?

Professionals providing care for children with life-limiting conditions and their families should be appropriately educated and possess the knowledge, skills and competencies in both caring for children and palliative care. The U.K. Association of Children with Life-Threatening or Terminal Conditions and their Families (ACT) recommended the following competencies: (Table 11).

Table 11 – Competencies required to work with children with life limiting conditions

The ability to:

- Comprehensively assess the needs of the child and family.
- Listen to and respect parents' knowledge, skills and choices.
- Deal with the specific problems of childhood illnesses and their management.
- Communicate with children and young people.
- Provide care and support for the whole family.
- Advocate on behalf of families to secure services from other agencies.
- Work with families from different ethnic or cultural backgrounds, family structures and beliefs, acknowledging how each influences the care of children.
- Maximise the child's developmental potential and quality of life.
- Proactively plan for likely problems in the near future.

A team of staff working in children's palliative care also need the skills to assess and manage:

- Symptoms during illness and at the end of life.
- Psychosocial problems of children with life-limiting conditions and their families.
- The spiritual needs of children with life-limiting conditions and their families.

And to:

- Have knowledge of the facilities available and how families can access them.
- Work effectively as a member of an interdisciplinary team.

KEY POINT

Professionals providing care for children with life-limiting conditions and their families should be appropriately educated and possess the knowledge, skills and competencies in both caring for children and palliative care.

6.2 Education, training and development of staff

In *A Palliative Care Needs Assessment for Children* the need for further education and training of staff was consistently raised as an issue and the need for inter-disciplinary education and training in the following areas was identified:-

- Defining palliative care and especially palliative care for children.
- Symptom management and symptom control.
- Information on services and how to access them.
- Counselling and bereavement skills specific to children and families.

Palliative care is an interdisciplinary speciality. The education and training requirements of all members of the inter-disciplinary team should be addressed. Education and training should include how to assist and empower families, extended families and friends to help care for their child.

Caring for a child with a life-limiting condition is a rare event for many healthcare professionals. The challenge is then to ensure that when their professional competencies, skills and knowledge are needed these are maintained and reflect current best practice. This requires ongoing education and training which is often best provided by hospital staff working with the child with a life-limiting condition prior to their discharge to their home or to a local paediatric unit. Clear protocols around clinical governance and scope of practice need to be established.

The need for differing levels of palliative education for health care professionals has been established by the European Association for Palliative Care Taskforce (Table 12). The level of education should be adapted to the degree of palliative care involvement in their practice.

Table 12 – The three levels of palliative education adapted from ‘A Guide for the Development of Palliative Nurse Education in Europe’		
Level A	Basic Undergraduate Post graduate	New health care professionals during their initial training Qualified health care professionals working in a general healthcare setting who may be confronted with conditions and situations requiring a palliative care approach.
Level B	Advanced (post graduate)	Qualified health care professionals who either work in a specialised palliative care or any general setting where they fulfil the role of resource person. Qualified health care professionals who are frequently confronted by palliative care situations e.g. oncology, community care, paediatrics and elderly care.
Level C	Specialist (post graduate)	Qualified health care professional specialists who are responsible for palliative care units, or who offer consultancy service and/or who actively contribute to palliative education and research.

KEY POINT

Further education and training of all staff working with children with life-limiting conditions must be an integral part of service provision.

6.3 Quality of care

Quality and continuous improvement must be embedded in daily practice to ensure consistently high standards. Quality of care is one of the four guiding principles of the Health Strategy which supports the development of evidence based standards of care, externally validated and set in partnership with consumers. The development of a quality culture throughout the health care system is the ultimate aim, integrating an inter-disciplinary approach to care and incorporating the continuous evaluation of the system using techniques such as clinical audit. In order to ensure the provision of high quality effective services which meet the needs of children with life-limiting conditions and families, it is important to put in place robust quality assurance measures in conjunction with clinical governance structures.

The Irish Health Service Accreditation Board (IHSAB) developed standards for adult palliative care services in 2005. IHSAB has now been subsumed into the Health Information and Quality Authority (HIQA) which was established in early 2007. One of the functions of the Authority is to develop National Standards for Quality and Safety across service settings, linked to their work on safety, quality and excellence in service provision. The Authority will continue to work with service providers, and will monitor compliance against the National Standards, to ensure the provision of the highest standard of service possible.

KEY POINT

In order to ensure that palliative care for children conforms to best practice, it would be desirable that protocols and standards, specifically in relation to palliative care for children, be developed.

6.4 Integration and Co-ordination of services

A child with a life-limiting condition almost always has to pass through several different areas of the health services. Often these services are not connected, and this fragmentation can lead to difficulties in the child receiving appropriate, responsive and timely care. The integration and co-ordination of services is a vital prerequisite to providing an effective and efficient seamless palliative care service for children with life-limiting conditions and their families. Providing continuity of care through the integration of neonatal, acute paediatric through to primary care, secondary and tertiary hospitals, voluntary services and respite centres requires knowledge of the healthcare system. A 'key worker' is identified as fulfilling this role by assisting in the navigation through the services.

6.4.1 Locally based support systems

Best practice dictates that there is a need to ensure that appropriate structures are put in place to enable children with life-limiting conditions gain access to care at home with priority given to those approaching the end of life (Table 13).

Table 13 – Support at home for children with life-limiting conditions and their families

- Support of a key worker.
- Medical support (GP and/or paediatrician).
- Provision of care as required (registered nurses, registered children's nurses, PHN, Therapists or healthcare assistants).
- 24-hour advice and support at the end of life such as a 'hospice at home' team.
- Specialist palliative care advice.
- Timely provision of aids and equipment.
- Range of flexible respite care including respite at home, or as an in-patient.

KEY POINT

The integration and co-ordination of services is a vital prerequisite to providing an effective and efficient seamless palliative care service for children with life-limiting conditions and their families.

A key worker is needed to link and co-ordinate care and services.

There should be locally based children's palliative care support available at network level.

6.5 Bereavement care

Bereavement support is a recognised component of palliative care and part of a continuum which should span pre-death to post-bereavement care (Figure 1). Grieving may start long before the time of death and support may be needed from the time of diagnosis. Although not all families will require professional support, a range of options and services should be available to them. Grief is a normal process and whilst most families will need a caring listener, most will not require specialist help. Bereavement care should respect and support natural coping.

Caring for a child with a life-limiting condition impacts on the whole family and can create enormous strain on parents, siblings and other family members. After the death of a child, bereavement services need to be responsive to this need. Bereavement support is ideally provided by a person known to the family, such as a key worker, who has the appropriate training, supervision and support and who is able to assess and refer on to specialist bereavement services if required. Bereavement education and training should be provided for all staff involved in the care of children with life-limiting conditions and their families.

Figure 1 – The Bereavement Support Continuum



KEY POINT

There is a need to provide bereavement support for the whole family including siblings and to provide access to specialist bereavement services if required.

Bereavement training and education for all staff involved in the care of children with life-limiting conditions and their families should be an integral part of training.

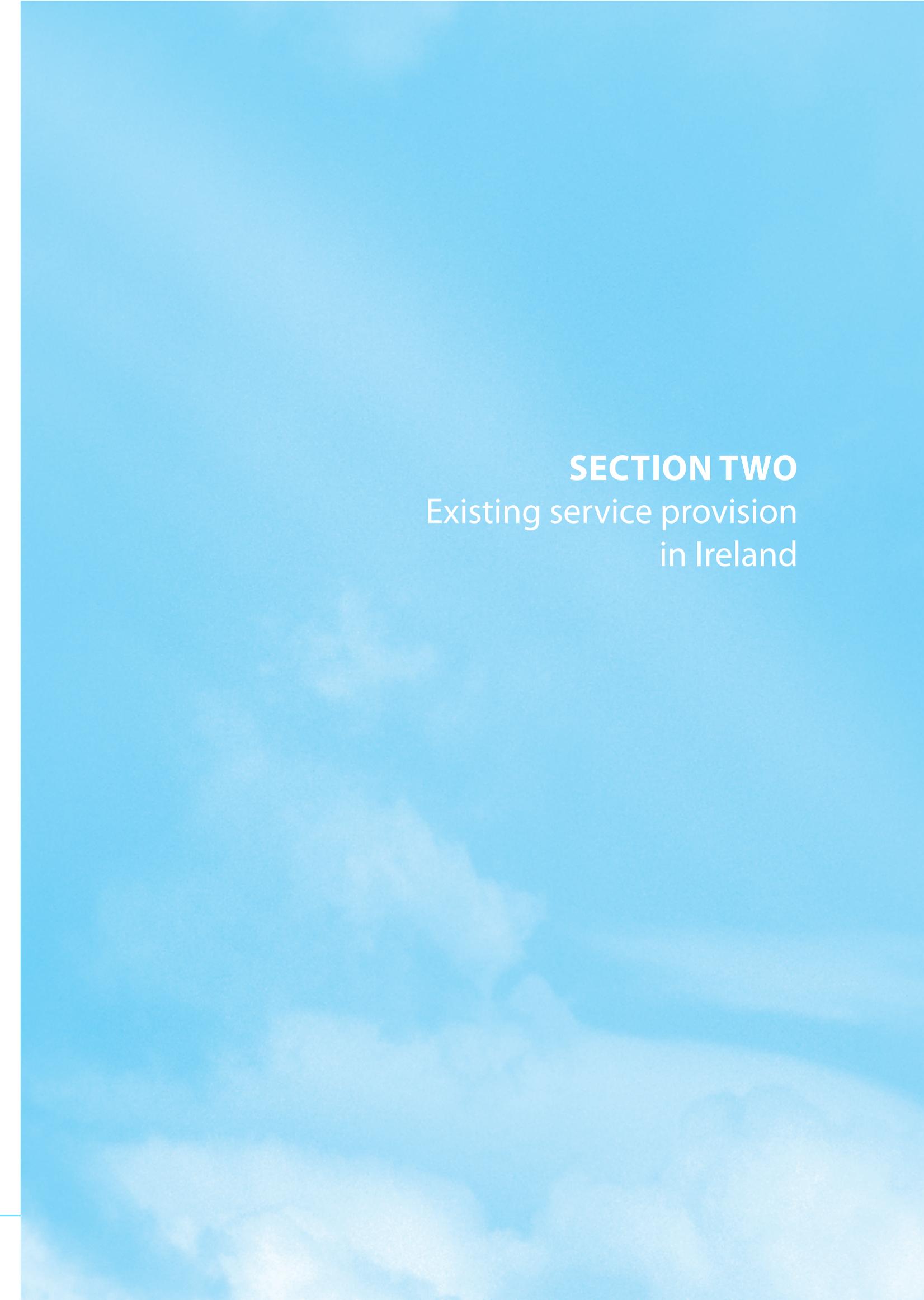
Specialist bereavement services may be required.

6.6 Care of children with life-limiting conditions from ethnic minorities

The provision of good local services can provide families from a wide range of cultural and ethnic backgrounds with the care which they require. Specific needs of children from different ethnic and religious groups should be explicitly included in the planning and development of services. The HSE has recently developed an *Intercultural Health Strategy* which amongst other things aims to ensure that nationally there are adequate numbers of suitably trained interpreters available.

KEY POINT

The needs of children with life-limiting conditions and their families who are from ethnic minority communities need to be considered and addressed.



SECTION TWO
Existing service provision
in Ireland

SECTION TWO - Existing service provision in Ireland

1. Introduction

Currently paediatricians are providing palliative care to children with life-limiting conditions within the existing acute and community services. Palliative care is often delivered through and integrated with the existing child health services and in many cases this includes the disability services. Geographically across the HSE services in the community have evolved and developed differently. This has resulted in regional disparities in the delivery of service to children with palliative care needs and their families. Some services are delivered directly by the HSE and others contracted out to voluntary agencies. Historically there has been a reliance on the voluntary sector to fill gaps in the palliative care services provided for children. In many cases both statutory and voluntary agencies currently providing palliative care to children are very willing but some may lack the experience and competencies to provide the level of palliative care required.

2. Collecting data

A *Palliative Care Needs Assessment for Children* identified the need for comprehensive data on children with life-limiting conditions to form the basis for service planning at local and national level. The needs assessment stressed the importance of developing an information system, at a strategic level, of the number and characteristics of children with life-limiting conditions.

A study was recently undertaken in Ireland to assess the feasibility of setting up a database of children living with and dying from life-limiting conditions. This study concluded that by using a combination of the HSE 'Hospital Information Patient Enquiry' (HIPE) system coupled with an examination of death certificate data it would be possible to set up a database.

3. Palliative care for children in hospitals

There are currently twenty two children's units attached to acute hospitals in Ireland and three tertiary hospitals in Dublin all providing care to some children with life-limiting conditions. At present there is a children's palliative care team based in Our Lady's Children's Hospital, Crumlin. Children's palliative care is provided by an adult palliative care consultant supported by a whole time equivalent children's palliative care clinical nurse specialist. In 2007, the 'Hospice Friendly Hospitals' programme was launched. This project aims to integrate hospice principles into hospital practice; Our Lady's Children's Hospital, Crumlin is one of the pilot sites for this project.

3.1 Child and family friendly hospitals

Child and family friendly hospitals are vital if children with life-limiting conditions and their families are to receive appropriate care.

In 2005 the Children's Palliative Needs Assessment identified:-

- An absence of suitable accommodation.
- A lack of resources.
- A lack of privacy for dying children and their families.
- Poor physical conditions.
- Staff shortages.
- Insufficient play activities to meet demand.
- A need to provide accommodation for parents and siblings.

In recent times efforts have been made to improve hospital accommodation for children with life-limiting conditions and their families. Examples of this are the 'step-down' accommodation facility for children and their families ('Ronald MacDonald House') and the planning of a new adolescent unit - both at Our Lady's Children's Hospital, Crumlin.

3.2 Play needs

Many of the children's units in acute hospitals have play specialists and some have teachers working in the unit or as part of a school within the hospital setting. The importance of continuing play and education for children with life-limiting conditions and the need to engage in normal childhood activities is recognised.

3.3 Education needs

Educational needs of children should not be location dependent. Currently there are nineteen specialist teachers providing education for children and young people with medical needs (including palliative care) in children's hospitals and wards around Ireland. Children with life-limiting conditions by the nature of their condition are frequently admitted to hospital and many attend as pupils at hospital school during these repeated admissions.

Children with life-limiting conditions who are at home also have a need for continuing education. Many children with life-limiting conditions go back to school, even for reduced hours, in an effort to maintain normality and to socialise with their peers.

3.4 National Paediatric Hospital

In June 2006, the HSE announced the findings of the joint HSE/Department of Health and Children taskforce set up to determine the most suitable location for the new National Paediatric Hospital. This taskforce recommended that the hospital should be developed on the Mater Misericordiae University Hospital site in Dublin's north inner city. In the high level framework brief a number of stakeholders have suggested a need for a facility within the national paediatric hospital for children who are dying and their families that would be larger than the standard bedroom and more domestic in scale.

3.5 Maternity Hospitals

The *Palliative Care Needs Assessment for Children*, (2005) identified that most childhood deaths occur in the first year of life. The majority are related to congenital abnormalities and occur in the first week of life. Currently there is no formal specialist palliative care support for any of the maternity units in Ireland.

KEY POINT

At present there is one specialist children's palliative care team in Ireland.

Child and family friendly hospitals are vital if children with life-limiting conditions and their families are to receive appropriate care.

As the majority of childhood deaths occur in the first week of life, there is a need to provide palliative care support in maternity hospitals.

4. Palliative care for children in the community

Currently the provision of palliative care services for children in the community is reflective of the child's diagnosis and care options available rather than the needs of children with life-limiting conditions. This care is being provided by healthcare professionals across a number of disciplines that are employed in the statutory or voluntary sectors.

4.1 Children with cancer

Our Lady's Children's Hospital, Crumlin is the national treatment centre for children with cancer. The hospital collaborates with sixteen local children's units on a shared care basis to treat children with malignancy. Children with a cancer diagnosis and with palliative care needs usually have the support of specialist adult palliative care services. This is often initiated during treatment through the oncology/haematology team. Children's Oncology Liaison Nurses work as part of these teams and provide a link to local adult palliative care teams. All children have access to the support of an adult specialist palliative care service. This includes advice, homecare visits and in exceptional circumstances some adult hospices, although not ideal, will consider admitting a child with a life-limiting condition.

Direct care of children with a cancer diagnosis in the community is usually provided by the family with the support of the Public Health Nurse (PHN). A palliative care nursing service may also be provided by voluntary agencies such as the Irish Cancer Society who, in the five years 2002 to 2007 provided night nursing services to 93 children and young people mainly with a cancer diagnosis aged 0-20 years. This service is usually only provided for a short period of time (up to 10 nights). In most cases this nursing care is provided by registered general nurses with either palliative care experience or a qualification in palliative care. Respite admissions are arranged at the oncology/haematology ward at either Our Lady's Children's Hospital, Crumlin or at the local children's unit.

4.2 Children with a diagnosis other than cancer

Children with palliative care needs who do not have cancer may have complex disabilities and are often involved with local physical/sensory and learning disability services. Delivery of and access to these services varies throughout the country. Services may be provided directly by the HSE or by voluntary agencies. Services provided include: therapy (physiotherapy, occupational therapy, speech-language therapy, and psychology), preschool, respite away from home, nursing, and home support. Some services have special schools attached that are funded by the Department of Education and Science. Whilst some receive the support of adult specialist palliative care teams, they are less likely to do so than children with cancer. Since 2007, the Irish Hospice Foundation has collaborated with the Irish Cancer Society to provide funding of a night nursing service to children with life-limiting conditions other than cancer at the end of life.

Implementation of the Primary Care Strategy, which commenced in 2002, will improve and enhance the development of children's healthcare in the community. Following a detailed mapping exercise of the entire HSE it is envisaged that there will be 530 Primary Care Teams and 134 Health and Social Care Networks upon full implementation. These teams will in time comprise a range of healthcare professionals who will be involved in the care of children with life-limiting conditions.

At present there are three Community Nursing Posts that provide input to children with palliative care needs. These positions also carry responsibilities for a wide range of children with complex medical problems. These positions should complement any proposed development of palliative care nursing posts for children but not replace them.

4.3 Preferred location of death

A key finding of *A Palliative Care Needs Assessment for Children* was that the preferred location of caring for a child with a life-limiting condition is the family home with parents receiving adequate professional support. Home was also the preferred location as the eventual place of death for a child. The majority of children with cancer die at home. However due to a number of factors the majority of children who do not have cancer continue to die in hospitals and other healthcare institutions (Table 14).

Location of death (CSO categories)	Total number of Deaths	Deaths from all life-limiting conditions	Deaths from cancer
Hospital	143	106	13
Local Authority Institution (Including most district and county hospitals)	140	110	0
Private homes (Registered nursing home, maternity home or convalescent home)	6	4	0
Dublin Maternity Hospitals	83	81	0
Homes for the aged, community care, and hospices	2	2	0
Domiciliary	66	40	26
Elsewhere	22	3	0
Total	462	346	39

4.4 Barriers to caring at home

The *Palliative Care Needs Assessment for Children* identified significant barriers to caring for a child at home that contribute to the overall “burden of care” for parents and carers (Table 15). Currently, for children requiring complex medical and palliative care at home, securing homecare support funding can be a cumbersome and lengthy process. Funding may need to be sourced through multiple agencies within both the voluntary and statutory sectors and this process can be difficult for parents and families. Funding for nursing or carer’s providing respite in the home may be supported by voluntary agencies in addition to statutory agencies. Additional home support such as nursing or a carer is provided by HSE community services. However, in many cases the onus is on the parents to find the carer or registered nurse or provide the care themselves. Parents and family members caring for a child with complex care needs at home will need education and support from healthcare professionals.

General Practitioners (GP) and Public Health Nurses (PHN) are the backbone of caring for children with life-limiting conditions in the community. As caring for a child with a life-limiting condition is often a rare event, it may be a challenge for these healthcare professionals to maintain the required skills and competencies. For example the majority of PHN’s are not Registered Children’s Nurses and many have no formal training in palliative care. According to An Bord Altranais, of 2,286 PHN’s on the live register, only 129 are also Registered Children’s Nurses. Recent changes in nurse education in Ireland and the removal of the requirement for a midwifery qualification to become a PHN may result in more Registered Children’s Nurses working in the community in the future.

Table 15 – Barriers to caring for a child at home

- Access to aids and equipment.
- Coordination of care.
- Support, help with decision making.
- Financial support.

Some children, (particularly those with a diagnosis placing them in ACT category 3 or 4) have an unpredictable course of illness and often progress to end-of-life phase following an acute illness such as infection. These children tend to be admitted to hospital with acute deterioration and die in hospital as they have nursing needs that cannot be supported in the community or in local respite centres.

The results of the quantitative data in the *Palliative Care Needs Assessment for Children* demonstrated that the range and availability of disciplines in different hospitals is not sufficient to provide children and their families with a timely comprehensive palliative care service. The findings identified inadequacy in the numbers and geographical distribution of disciplines such as physiotherapy, speech and language therapy, occupational therapy, dietetics, play specialists, psychology and social work.

4.5 Providing co-ordination and support

Currently services for children with life-limiting conditions and their families vary considerably with the majority cared for by the family General Practitioner (GP), local Public Health Nurse (PHN), Paediatrician and staff at the local children’s unit. Children may also receive care from several other services, for example a tertiary children’s hospital, a voluntary organisation, the local adult palliative care teams etc. Accessing therapy services such as Dietetics, Occupational Therapy and Speech and Language Therapy is often difficult. The need for co-ordination and linking between these groups was identified in *the Palliative Care Needs Assessment for Children*.

KEY POINT

For children requiring palliative care at home, securing homecare support funding can be a cumbersome and lengthy process.

Funding may need to be sourced through multiple agencies within both the voluntary and statutory sectors and this process can be difficult for parents and families.

Children tend to be admitted to hospital with acute deterioration and die in hospital as they have healthcare needs that cannot be supported in the community.

There is a lack of professional support for staff, caregivers and families in the community in dealing with children with palliative care needs.

5. Respite

Definition of Respite

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.

Currently the availability of appropriate, child-friendly and accessible respite for children with life-limiting conditions is limited. There are a small number of centres both public and voluntary providing some respite care to children with life-limiting conditions. Respite admissions are also provided by local children’s units in the acute hospitals.

5.1 Respite for children with disabilities

Respite services for children with disabilities are provided in respite centres or in the home for children who are clinically unwell.

Respite for children with disabilities

Respite care supports people to live with their families in the community and is provided in residential and non-residential settings. It includes recreational and social activity programmes, summer camps and holiday/family breaks.

Specific admission criteria vary countrywide, but on the whole in order to be eligible for respite through the disability services the child has to be:

- Assessed as having a physical/intellectual, sensory disability, autistic spectrum disorder or a combination of these.
- The disability results in reduction of independent function to the extent that ongoing support is required.
- Additional care needs due to the level of disability are such that support services are necessary.

Where services are operated by voluntary agencies, individual agency admissions criteria also apply. Referral for services can come from a variety of sources including parents, self-referral, therapy teams, PHN's, GP or schools. Provider agencies assess the child's needs through social work or service coordinators. Some agencies have standard assessment mechanisms in place that aim to assess for provision and subsequently meet need on an equitable basis.

In general respite provision for children with disabilities supports children who are medically well. Very few respite centres are currently able to provide respite to children who require intensive medical or nursing input. In-home services for children with disabilities who are unwell maybe provided by a combination of PHN's, care assistants, and registered nurses. In both of these cases an individual package of care is required to meet the specific needs of the child and their family. Currently demand outstrips supply for respite services for children with disabilities and most services have waiting lists for new children or for children who are receiving services but who require additional help.

KEY POINT

Respite is an integral part of providing care at home for children with life-limiting conditions and their families.

6. National Children's Hospice

At this time there is no National Children's Hospice in Ireland. The recent *Palliative Care Needs Assessment for Children* found mixed views amongst respondents and did not identify the provision of a National Hospice as a current priority.

7. Education and training of staff

The *Children's Palliative Care Needs Assessment* consistently identified a need for the further education and training of all staff working with children with life-limiting conditions and their families.

In order to meet these educational requirements an educational framework has been developed by the HSE to meet the differing levels of need. Initially a programme (Level A) aimed at registered nurses and midwives to create an awareness of the special needs of children with life-limiting conditions was introduced and more

recently a more advanced programme (Level B) has been delivered. Future plans include providing education to all members of the inter-disciplinary team. The first six months of the basic programme delivered by the Centre for Education at Our Lady's Children's Hospital, Crumlin, received a positive evaluation in 2007.

Currently there is no formal educational input on children's palliative care to medical students or allied health professionals during their undergraduate programme. All undergraduate nursing programmes have palliative care as part of their curriculum, although this is not specific to the care of children with life-limiting conditions.

Several universities around Ireland deliver postgraduate Higher Diploma Programmes in Palliative Nursing, but again these are not specific to the care of children with palliative care needs. The Irish College of General Practitioners currently runs a postgraduate certificate course in palliative medicine for general practitioners and other doctors with an interest in palliative care provided in the community.

Education programmes aimed at the development of skills and competencies to FETAC Level 5 for healthcare assistants are available, although currently there is no specific children's palliative care module.

8. Bereavement Support

In Ireland some major hospitals have dedicated bereavement services and many hospitals have posts that include a bereavement remit. Social work departments in the tertiary children's and some acute hospitals have a range of bereavement care for families, including information, memorial books and services, and one-to-one and group counselling. Some voluntary organisations also provide bereavement services and information.

KEY POINT

Bereavement services and support need further development.

9. The role of the voluntary sector

In Ireland those currently involved in the provision of palliative care for children include statutory and voluntary organisations of varying size and remit. Voluntary (non-statutory) organisations have been at the forefront in identifying and responding to the healthcare and other needs of children with life-limiting conditions in the community and at national level. They have played a key role in the development of palliative care and many of these developments have been in co-operation or partnership with statutory care providers. The voluntary sector provides a wide range of services to children with life-limiting conditions and their families. The ongoing involvement of the voluntary sector in the planning and delivery of specialist palliative care services in Ireland should be encouraged and facilitated by the development of a structured framework for the planning and implementation of future palliative care services for children.

KEY POINT

The voluntary sector plays a large role in the planning and delivery of children's palliative care services in Ireland. The ongoing involvement of the voluntary sector in the planning and delivery of specialist palliative care services in Ireland should be encouraged and facilitated.



SECTION THREE
Future provision of services

SECTION THREE - Future provision of services

1. Introduction

This section outlines the direction for the future provision of services for children with life-limiting conditions and their families. In order to meet their needs services must function within a primary care model, with integrated community and hospital-based services.

2. Transition from policy to practice

Ultimately this policy aims to ensure that all children with life-limiting conditions will have the choice and opportunity to be cared for at home. This is currently possible for some, but not all children. The care of children with complex medical needs in the community cannot always be facilitated due to a number of factors:

- Assessed level of individualised care need exceeds locally available resources.
- A lack of suitably trained and qualified staff in the community (even in the presence of adequate resources).
- A lack of access to appropriate medical support and equipment.

Medical care for children with life-limiting conditions in the community should be delivered through the primary care model and within the context of services and resources that are available.

Children approaching the end of life will be prioritised. Whilst assessing prognosis can be problematic, children thought to have the shortest prognosis will be given the greatest priority. Children ready for discharge from a tertiary hospital should ideally be transferred to a local hospital or paediatric unit under the care of a locally based paediatrician prior to being discharged home. Parents should be included in the decision-making process and should be able to make an informed choice regarding the discharge home of their child. An assessment of needs should be made prior to discharge and these should be matched with services available locally. Discussions with parents regarding care issues and what measures are to be taken in the event of an emergency should form the basis for the child's detailed care plan. Decisions regarding provision of this care will be made on a case by case basis.

Whilst ideally this policy should be implemented in full with immediate effect, within the context of current financial constraints it is necessary to have phased implementation of the policy. The priority for this policy is to appoint key staff who will lead and develop children's palliative care services. The second phase of implementation will explore models of supporting children with life-limiting conditions throughout the disease trajectory.

Following publication of this policy the HSE should develop an implementation plan. Prior to and during the transition from policy to practice children with life-limiting conditions requiring palliative care will continue to receive available services from paediatricians and other healthcare professionals. It is implicit that the community services personnel currently involved in the delivery of care to children with life-limiting conditions remain central to the care of these children. This includes the Community Paediatrician, GP, PHN and some of the voluntary groups. Some adult specialist palliative home care teams also provide support and advice and this is especially valued particularly in the area of symptom management and end of life care. It is envisaged that this will continue during the transition between publication of this policy and its full implementation and in some areas adult specialist teams may continue to have a role in the care of children requiring palliative care.

RECOMMENDATION

Children with imminent palliative care needs will be prioritised, especially those nearing the end of life.

Following publication of this policy the HSE should develop an implementation plan.

3. Clinical governance

Clinical governance is a systematic approach to maintaining and improving the quality of patient care. In line with the recommendations of the Commission on Patient Safety and Quality Assurance (2008), children with life-limiting conditions and their families should be:

- Informed and knowledgeable about their care.
- Receiving safe and effective care from skilled professionals in appropriate environments with assessed outcomes.
- Receiving care from organisations with a governance framework in place that:
 - Clearly describes responsibilities, delegated levels of authority, reporting relationships and accountability within the organisation.
 - Places particular emphasis on the clear assignment and documentation of responsibility within and between clinical teams involved in the care of individual patients.

This is especially important in children's palliative care as it is likely that a child with a life-limiting condition will pass through and between several services (e.g. neonatal, tertiary children's hospital, local paediatric unit, locally-based respite services, primary care etc.) during their life-time. It is envisaged that the development of the Outreach Nurses post will assist in the safe transfer and movement of children throughout the health services.

RECOMMENDATION

There should be clear assignment and documentation of responsibility within and between clinical teams involved in the care of the child with a life-limiting condition and their family.

4. Principles underpinning the development of Children's palliative care

The *Palliative Care Needs Assessment for Children* suggested four principles that future service developments for children with life-limiting conditions should encompass (Table 16) and these principles underpin the recommendations in this section.

Table 16 - Four key principles upon which all future developments in children's palliative care should be based

1. Inclusiveness	All children regardless of culture, geographical location and age should be able to access appropriate care. All providers should have access to specialist palliative care as required.
2. Partnership	The active participation of all stakeholders including the child should be facilitated. Parents should be incorporated as partners in the process of decision-making and in the planning of care.
3. Comprehensiveness	Care should include a focus on psychological, emotional, educational and spiritual needs of a child and his or her family.
4. Flexibility	Care should be adaptable to the individual and changing needs of the child and his or her family. High quality care for children with palliative needs should be provided regardless of location or diagnosis.

5. Delivery of care

In order to provide a palliative care service to children with life-limiting conditions that adheres to the principles highlighted in the needs assessment (Table 16), some key healthcare professional appointments need to be made.

5.1 Consultant Paediatrician with a Special Interest in Paediatric Palliative Medicine

The development of a new post of Consultant Paediatrician with a Special Interest in Paediatric Palliative Medicine would provide the necessary leadership and direction for the future development of children's palliative care in Ireland and will provide integration nationally within children's services. In order to develop and sustain a consultant-led service, the appointment of a further consultant may be required. The consultant post will ultimately be based at the new National Paediatric Hospital and pending that, at Our Lady's Children's Hospital, Crumlin.

The consultant will:-

Clinical

- Be responsible for the development of a comprehensive interdisciplinary palliative care service at the New Paediatric Hospital.
- Provide clinical support and advice to healthcare professionals and liaise with the lead paediatrician responsible for the care of the child and their family.
- Act as a further resource/support for the Children's Outreach Nurses (Section 5.3).

Research and Education

- Develop and assist in the delivery of education and training programmes.
- Develop and lead on a research agenda for children's palliative care.

Service Development

- Provide clinical leadership for future development and professional recognition of children's palliative care in Ireland, both in hospital and community settings.
- Be involved in decisions relating to and the development of an integrated children's palliative care service.

The consultant should be supported by an interdisciplinary team including a paediatric registrar in training.

RECOMMENDATION

A Consultant Paediatrician with a Special Interest in Paediatric Palliative Medicine should be appointed.

The consultant should ultimately be based at the new National Paediatric Hospital, Dublin.

5.2 The Children's Palliative Care Team

The primary location of the Consultant Paediatrician with a Special Interest in Paediatric Palliative Care should be at the New Paediatric Hospital. This is likely to be the source of referral of most children with life-limiting conditions with complex care needs. A Children's Palliative Care Team should be developed. This team should be interdisciplinary with a minimum staff complement of the Consultant Paediatrician with a Special Interest in Paediatric Palliative Care and medical team, a hospital-based clinical nurse specialist, a social worker and administrative support, but with ready access to the wider range of team members (e.g. occupational therapy, physiotherapy, music therapy, play specialist, dietetics, speech and language therapy etc.). The Children's Palliative Care Team should provide a service for children

and their families facing any life-limiting condition ensuring the best quality of care, during living, dying and bereavement.

The Consultant should have admitting rights at the National Paediatric Hospital for patients requiring palliative care such as complex pain and symptom management. In the new National Paediatric Hospital there should be dedicated rooms (with family facilities) for children with life-limiting conditions.

The Children's Palliative Care Team should be:-

- Committed to close partnership and joint working with colleagues within the National Paediatric Hospital, community based services and regional hospitals to facilitate comprehensive care planning for children throughout their illness including care within the home. This would include the provision of consultation with maternity hospitals, regional hospitals, paediatricians based at the tertiary hospital, primary health care teams, and community based services including respite and /or direct care to families on quality of life, symptom management, psychosocial, spiritual care and bereavement follow-up.
- Dedicated to the professional development of health care providers caring for children with life-limiting conditions and this would include a commitment to high quality research, evidence based practice and advocacy on behalf of children and families facing life-limiting conditions.
- Provide clinical leadership, professional development and a mentoring role for the regionally based Children's Outreach Nurses (Section 5.3). Each family of a child with life-limiting condition would have contact through the Outreach Nurse to the Children's Palliative Care Team to help co-ordinate care.

The team, in line with international best practice, should develop clinical pathways for children requiring palliative care which should be overseen/rolled out locally by the Children's Outreach Nurse and local service providers. Guidelines for children requiring palliative care would also need to be developed for the following settings – home, local community services, secondary and tertiary hospitals.

Parents/carers and health care workers providing care to children with palliative care needs would have access to advice on palliative care issues. This would be provided by the Children's Palliative Care Team/Children's Outreach Nurses on a rota basis with a national number for service out-of-hours.

RECOMMENDATION

A Children's Palliative Care Team should be established at the National Paediatric Hospital.

The Consultant Paediatrician with a Special Interest in Paediatric Palliative Care should have dedicated rooms in the new paediatric hospital.

5.3 Children's Outreach Nurses for Children with Life-limiting Conditions - Clinical Nurse Specialist

A new clinical nurse specialist post, Children's Outreach Nurse for children with life-limiting conditions, has been developed. Throughout this section this role will be referred to as Children's Outreach Nurse.

The *Palliative Care Needs Assessment for Children* highlighted the need for co-ordination of services, with improved communication and linking of services and referred to this co-ordinating role as a 'key worker'. A network of Children's Outreach Nurses to support patients and families in the community should be developed to fulfil this role. These posts should be developed to ensure equity of access to services throughout the country for children with life-limiting conditions and their families, regardless of geographical location.

The Children's Outreach Nurses should be based in Regional Children's Units in hospitals throughout Ireland and would be supported clinically by a named locally based paediatrician with an interest in palliative care. Further clinical support would be provided nationally by the Consultant Paediatrician with a Special Interest in Paediatric Palliative Care and the wider network of Outreach Nurses nationally. National team guidelines and protocols for care management should be developed. All appointments would be in line with a nationally agreed job description. Interim reporting relationships would be in accordance with local governance arrangements.

All children with life-limiting conditions should have their needs individually assessed and a care plan developed by the Children's Outreach Nurse as part of the process of meeting their palliative care needs.

The role of the Children's Outreach Nurse for children with Life-limiting conditions will include the following:

- Co-ordinate a service that provides continuity of care and improves quality of life for children with life-limiting conditions and their families.
- Plan, implement, deliver and evaluate care for a caseload of children with life-limiting conditions and their families, in collaboration with local healthcare professionals/carers. This role will apply to both acute and community care settings.
- Facilitate education and training for health and social care professionals in collaboration with relevant stakeholders.
- Support the collection of data in relation to children with life-limiting conditions.
- Act as an informed resource and link person for children and family carers and for health and social care professionals involved in the care of children with life-limiting conditions.
- Link with PHN, Community Paediatric Link Nurses, Adult Specialist Palliative Care Teams and Voluntary organisations (e.g. Jack and Jill Foundation Nurses).

Initially eight Children's Outreach Nurses should be appointed. Evaluation of these initial posts, workload of similar posts, Central Statistics Office (CSO) data on current population by age and figures contained in the *Children's Palliative Care Needs Assessment* may result in further appointments being necessary. These posts should be allocated to ensure geographical equity of access to this service. As the role of Clinical Nurse Specialist - Children's Outreach Nurse develops further there may be opportunities for some to develop to the higher level of Advanced Nurse Practitioner.

Further development must happen in conjunction with developments in primary and community care, such as the development of primary care teams/networks and in particular, community children's health care services and the appointment of more community paediatricians. In some instances the community paediatrician is ideally placed as the local lead clinician in the care of children with life-limiting conditions.

The appointment of Outreach Nurses should be in line with a nationally agreed job description. Interim reporting relationships will be in accordance with local governance arrangements. For medical clinical support children should substantively remain under the care of the treating consultant from their paediatric unit of the local hospital or a community paediatrician where available. Care should be supported by the GP and the local adult palliative care physician when needed. Ultimately, a network of support and an advisory structure should be established under the guidance of the Consultant Paediatrician with a Special Interest in Paediatric Palliative Care.

A team approach to the delivery of care should ensure a co-ordinated approach and would help to avoid confusion between and duplication of services for both providers and recipients. In particular, an integrated approach to care between the Children's Outreach Nurses and the support available from voluntary groups is required. In order to achieve this integration, the HSE may need to facilitate a re-defining of roles and funding arrangements for some voluntary providers.

RECOMMENDATION

Regionally based Children's Outreach Nurses for children with life-limiting conditions should be appointed to facilitate service delivery in the community and facilitate integration between hospital, community services and specialist palliative care.

5.4. Children's 'Hospice at Home' Service

International experience has shown that there are several different models of hospice care for children. In order to provide an equitable service with access to services across all geographic locations the recommended model for children with life-limiting conditions in Ireland is 'Hospice at Home'.

Hospice at home differs from hospital at home. Hospital at home is a health care model that provides hospital-level care in a patient's home as a full substitute for acute hospital care. Hospice at home provides care to children with palliative care needs and their families in their own home which according to the *Children's Palliative Care Needs Assessment* is the location of choice. Hospice at home provides an alternative to inpatient care for children who have been appropriately assessed and for whom a detailed care plan has been established with the input of the child (where appropriate) and the parents. This care plan should include details of what, if any, emergency measures should be taken. Hospice at home is predominantly a nursing service with interdisciplinary team input providing care and support aimed at meeting the assessed needs of a child with a life-limiting condition and their family. It is a service that is not exclusively confined to the end of life but primarily provides more intensive care and support at this time.

In addition to this service, inpatient hospice beds specifically for respite should be developed as part of the children's palliative care service. This model aims to meet the physical, psychological, developmental, emotional and spiritual needs of the child and their family and the service can be supported with a mix of day care, respite and community nursing support. The co-ordination of the various stakeholders is fundamental to the implementation of this policy. This model of care will be supported by specialist governance procedures to cater for shared care planning and service delivery.

Children's community nursing support is required to ensure that this model of care is able to meet the palliative care needs of children with life-limiting conditions and their families. Family members are often the primary carers of children with life-limiting conditions and they often need access to direct nursing care, and respite, depending on the complexity of diagnosis and related symptoms. Children may go through periods of severe illness requiring additional intensive support. Family and carers require access to the support of registered nurses, care assistants and home helps. Access to continuous nursing may also be required, particularly when a child is in the terminal phase of illness. Some aspects of this care would be co-ordinated by the Children's Outreach Nurse.

The Children's Outreach Nurse may in certain emergency situations provide direct nursing care during patient visits. However in the main, care should be provided by:

- A core 'bank' of registered nurses or carers to provide direct nursing care identified in each HSE region.
- Access to the expertise and skills related to the last 24 hours of life (including access to advice and support of the adult specialist palliative care team if required).
- Out of hours telephone support.

These services should be provided by either primary care teams/networks, directly by the HSE or through HSE funding.

The development of teams by the HSE would take into consideration the needs of the local population served and the number of children with life-limiting conditions likely to avail of this service. Some of this information would be provided by the proposed database (see 12 below). These teams should be developed to ensure equity of access to services throughout the country for children with life-limiting conditions and their families, regardless of geographical location.

5.5 Therapy Services

Physiotherapy, Occupational Therapy, Dietetics and Speech and Language Therapy services should be available in both the tertiary referral centre and in the community via the Primary Care Team/Network. It is essential that both sectors are resourced adequately to allow for appropriate and timely assessment and intervention from these therapy services. Whilst full time posts designated to the speciality may not be required, an appropriate level of commitment should be factored in with other development posts in service planning activities.

RECOMMENDATION
Hospice at home teams should be developed by the HSE.
Inpatient hospice beds specifically for respite should be developed as part of a children's palliative care service.
Family and carers may require access to:- <ul style="list-style-type: none">• The support of qualified nurses, care assistants and home helps according to their child's assessed needs.• Direct nursing care, and respite, depending on the complexity of diagnosis and related symptoms.• Twenty-four hour nursing, particularly when a child is in the terminal phase of illness.
The Children's Outreach Nurse should liaise with the Primary Care Team and Network services in order to plan appropriate care.
Children should have access to therapy services at both hospital and primary care level.

Figure 2 – The people providing care to children with life-limiting conditions

6. Location of care

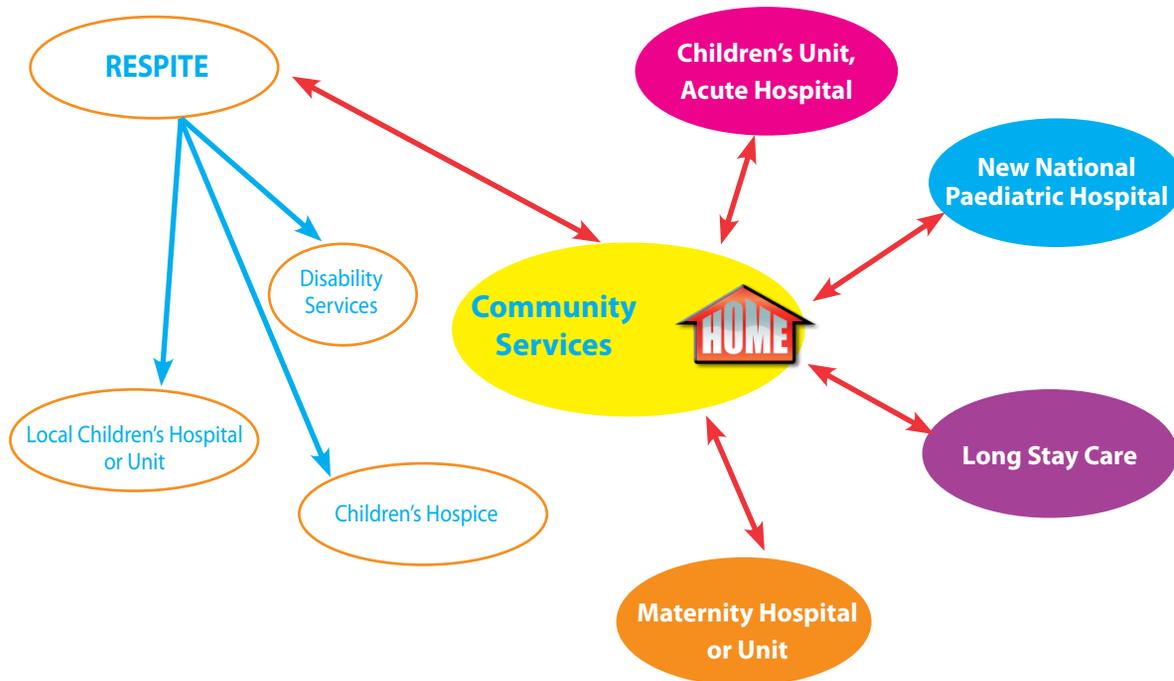
The location of choice of care for a child with a life-limiting condition is the family home. In order for children to be cared for at home it is necessary to put in place as much community support as possible (Figure 2). Whilst acknowledging that the home is the location of choice for most children with life-limiting conditions and their families, many children with life-limiting conditions require practical options for care elsewhere (Figure 3).

In order for children and their parents to make informed choices it is essential that key information about diagnosis and prognosis is given in a format that can be understood and allows parents to make decisions. In particular for a child with a life-limiting condition, decisions regarding location of care are often dependent on the parents and their ability as primary carers. Practical information about the type and level of services available should be provided.

RECOMMENDATION

Parents should be actively involved in the decision making and planning of location of care for their child.

Figure 3 - Location of care for children with life-limiting conditions



6.1 Children's units in acute hospitals

Access to hospital care for children with palliative care needs should be flexible. Hospitals should provide a suitable physical environment for children including appropriate accommodation for the child and carers, and facilities for education and play. Children should also be given information on their condition that is appropriate for their age.

During hospital admission there should be interdisciplinary involvement of professionals to plan and deliver care. On admission to hospital, it is vital that all team members involved in the care of the child and family are aware of the care plan and ensure that the child and their family's wishes are observed. Detailed discharge planning should take place and involve the hospital, community personnel and the Outreach Nurse. The family and child should be involved and be at the centre of discharge planning at all stages.

RECOMMENDATION

Hospitals should provide an appropriate environment for children with palliative care needs. This includes physical environment – facilities and ward space, and professional environment such as staff education and training.

6.2 Palliative care support to maternity hospitals

As the majority of childhood deaths occur in children under the age of one year consideration needs to be given to the provision of palliative care support to maternity hospitals/units. The majority of deaths in the first year of life are from congenital abnormalities. Neonatologists require the following palliative care support:

- Outreach support from the Children's Palliative Care Team providing clinical guidance and advice to doctors, nurses, therapists and family members caring for the child including out of hours telephone support.
- Clinical Guidelines on symptom control and end of life care.
- Comprehensive discharge planning with neonatal, palliative care, primary care and community services involved.

RECOMMENDATION

The Consultant Paediatrician with a Special Interest in Paediatric Palliative Care and the team will act as a resource providing support to maternity hospitals and neonatologists.

6.3 Services available for children with life-limiting conditions at home

6.3.1 Primary Care Teams/Network Services

In both the established and proposed primary care teams/network services, some grades of staff are of particular relevance to caring for children with life-limiting conditions (Table 17). The primary care teams and network services would be involved in the direct care of the child with a life-limiting condition with palliative care needs, will require the involvement of existing and additional inter-disciplinary personnel. It is proposed that the specific roles, responsibilities and governance procedures for staff involved would be agreed with acute hospital paediatric services. Children are likely to avail of the services of the allied health care professionals attached to the Primary Care Teams/Network Services. In particular, prompt and uncomplicated access to aids and appliances via occupational therapy services would provide children and their families with much needed support in the community.

Table 17 - Health and Social Care Personnel of relevance to children's palliative care in each proposed Primary Care Team/Network Service

General Practitioner
Nurse/Midwife
Health Care Assistant
Home Help
Occupational Therapist
Physiotherapist
Social Worker
Also available in some teams/networks <ul style="list-style-type: none"> • Psychology. • Speech and Language Therapy. • Dietetics.

6.3.2 Funding of care at home

In order to provide care at home there needs to be clarity regarding the funding available to those caring for a child with a life-limiting condition (e.g. Long-term illness book, Domiciliary Care Allowance, Carers Benefit, Tax Credits etc.). This should apply to all children with life-limiting conditions and not only to those from

specific disease categories. Access to services and funding should be streamlined and standardised nationally so that regardless of geographical location funding for home care support is available in a timely and equitable manner. Each local health office should be provided with budgets and have protocols in place to facilitate the provision of such supports. Whilst many children with life-limiting conditions will already be in possession of a medical card, some are not. Under the *Health Act, 2004*, determination of eligibility for medical cards is the responsibility of the HSE. The HSE has discretion, in cases of exceptional need, to provide assistance to individuals where undue hardship would otherwise be caused. The HSE will continue to view applications from children with life-limiting conditions and their families in as sensitive and compassionate a manner as possible.

6.3.3 Specialist Respite Care

In order to help families and carers to keep a child with a life-limiting condition at home, access to locally based respite is required. A range of respite services should be developed for children with life-limiting conditions and palliative care needs. This includes access to a range of flexible respite options, both within and outside of the home. There is a need for new or extended services to be developed and these should include statutory/voluntary partnership models. Respite services may mirror some of those already provided through disability services and indeed some children with life-limiting conditions (generally those in ACT Categories 3 and 4) already access disability respite care.

6.3.3.1 In-Home Respite

Respite at home may be provided for a number of hours or days and should be inclusive of overnight provision. Specifically trained personnel (registered nurses and carers) should be available for this service which should be provided according to the identified or assessed needs of each child and family. Current in-home respite services with additional resources may be expanded to include children with life-limiting conditions with palliative care needs.

6.3.3.2 Centre Based Respite

Centre-based respite should take account of the medical needs of the child including the management of symptoms. Each HSE area should audit their children's respite facilities to explore the possibility of providing dedicated palliative care respite. This may include upgrading of current facilities and staff education, training and development.

The development of non-specialist hospice units dedicated to the provision of respite care for children with life-limiting conditions will also be required, particularly in urban areas with high density populations. Facilities should be designed, equipped and made available for defined periods to provide planned respite. Where these are provided by the voluntary sector, service level agreements should be reached with the HSE.

Children with life-limiting conditions who have palliative care needs requiring medical care may also in some cases avail of respite admissions in their local paediatric unit or tertiary paediatric hospital if appropriate.

Using data from the database and international experience the HSE will decide: (See 12 below.)

- The appropriate bed numbers in each of the four HSE administrative areas according to population need.
- Staffing levels.
- Education and training of staff.

Each of the HSE areas should develop a plan for respite facilities for children with life-limiting conditions and their families. These plans should be presented to the National Development Committee on Children's Palliative Care.

RECOMMENDATION

A range of respite services should be developed for children with life-limiting conditions and palliative care needs.

Each HSE area should develop a plan for respite facilities for children with life-limiting conditions and their families.

7. Bereavement care

Bereavement supports for children's palliative care should be developed according to a bereavement care continuum. Support should be offered at a level appropriate to the service user. The three levels described below require that specific goals and measurable objectives are developed.

Level 1: Good pre-death care, information and planning**Goals:**

- Interventions geared towards preparing the family for the death and strengthening the natural network should be addressed.
- Access to accurate information about the illness and about the grieving process should be available for all sibling and family members.
- The role of primary care/community based carers in providing level 1 bereavement support should be further explored.

Specific actions

- *Training:* Specific bereavement training is required.

Level 2: Support services**Goals:**

- Provide bereavement support to siblings and other family members.

Specific actions

- No cost telephone and 'face to face' support by well-trained volunteers could be developed and expanded as part of a comprehensive bereavement service for both adults and children.
- Providers should demonstrate that they are working to an accepted code of practice.

Level 3: Professional and specialist bereavement services**Goals:**

- Bereaved siblings and families, assessed as needing professional intervention, should be provided with this service.
- Services should be delivered promptly, by appropriately trained professionals. Services should be offered in a location convenient to the service user, at little or no cost.
- A standard of training and a code of practice must be demonstrated.

Specific actions

- Services for adolescents and siblings need to be developed.
- Existing service providers may need to be up skilled to facilitate and further develop the competencies to meet this service need.
- Identify experts in the field both in Ireland and the UK who can provide this level of support.

Funding should be made available to develop services for those families identified as needing access to appropriate bereavement care. The Children's Outreach Nurse has a role in bereavement assessment.

RECOMMENDATION

Bereavement supports for children's palliative care should be developed relative to defined levels and encompasses child, adult and family support.

Funding should be made available to develop services for those families identified as needing access to appropriate bereavement care.

8. Play for children with life-limiting conditions

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 play. Play should continue for as long as possible and should be incorporated into the child's care plan.

9. Education for children with life-limiting conditions

As with play, education should continue 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 and their location of care, have a need for play and education which must be met as part of a comprehensive palliative care service.

RECOMMENDATION

In an effort to maintain normality, where possible the child's education should continue for as long as possible at the usual location.

10. Education and training of staff

10.1 Professional education and training

In order to ensure that children with life-limiting conditions receive appropriate care, both basic and ongoing education and training of staff is essential. A framework exists upon which children's palliative care education programmes for all healthcare workers, professional and non-professional can be based. Education programmes should extend to all members of the interdisciplinary team and where possible, a multi-professional approach to education should be implemented. This could include the development of a core module of integrated learning for all healthcare professionals.

- There has been a concerted effort to create and implement a cohesive and structured education programme for nurses and this should be extended to all healthcare professionals.
- E-learning and online learning should be incorporated into a programme of education.
- Clinical practice is an important and essential component of any education programme, but has cost and travel implications for those who require specific levels of expertise, with limited opportunity to gain same in Ireland.
- Specific credence needs to be given for clinical practice requirements (or otherwise) at level C (Table 11).
- Children's palliative care education should be incorporated in the children's education strand in existing academic programmes.

10.2 Support staff education and training

It is envisaged that all healthcare assistants would undertake education and training programmes. Whilst there is no specific module on children's palliative care, programmes are available to FETAC level 5 on 'caring for children in hospital' and 'palliative care support' either of these modules provides a good foundation for healthcare assistants wishing to work with children with life-limiting conditions.

- Practical 'hands-on' training is needed for non-professional carers to support families in the home according to the care plan and under the direction of the care team responsible for the needs of the child and family.
- There is a need to engage with Social Care and Health Care Assistant education providers about modules within existing programmes to prepare workers for this area of care.
- Ideally healthcare assistants working with children with life-limiting conditions should be either working towards or educated to FETAC level 5.

RECOMMENDATION

All relevant hospital and community staff should be facilitated to partake in education and training on children's palliative care.

10.3 Family carers

The education and training needs of families, extended family members, neighbours and friends need to be considered by healthcare professionals. For many families caring for a child at home allows for maintenance of privacy and avoids the sometimes overwhelming intrusion of strangers on family life. Healthcare professionals need to educate, empower and support families who choose to care for their child themselves.

10.4 Evidence based practice

Research ensures both the appropriate use of resources and the provision of high quality cost effective health care. In order to develop an evidence base with contributions from medicine, nursing and other disciplines further research is needed in children's palliative care. The development of a research culture is essential and it is important that front line clinical staff support research and understand its importance.

Charitable organisations play an important role in funding education and research in palliative care. All health care professionals working in palliative care should have the opportunity to engage in research in order to develop evidence based practice, leading to improved quality of care for children with life-limiting conditions and their families.

RECOMMENDATION

All health care professionals working in palliative care should have the opportunity to engage in research.

10.5 Quality assurance

Ensuring that services provided to children with life-limiting conditions and their families are provided to the highest standard and in an equitable and timely fashion, is part of the role of all healthcare professionals. Given that children's palliative care is such a small and highly specialised field of care, services for children with life-limiting conditions should be provided on the basis of standardised and nationally agreed assessments. To ensure uniformity and equity in the provision of care, assessments for services, standards and protocols should all be agreed nationally and this process should be overseen by the National Development Committee on Children's Palliative care.

RECOMMENDATION

In order to ensure that palliative care conforms to best practice, protocols and standards specifically in relation to palliative care for children, should be developed and should be overseen by the National Development Committee on Children's Palliative care.

11. National Development Committee for Children's Palliative Care

A National Development Committee for Children's Palliative Care should be established. The function of this committee would be:

- To provide a national forum for the cohesive, integrated development of children's palliative care services.
- To address the regional administrative area variations in service provision to children with life-limiting conditions and their families.

11.1 Membership

There should be 16 core members of the National Development Committee on Children's Palliative Care and these should be constituted as follows:-

- The HSE senior official with national responsibility for Children's Palliative Care should be both a member and Chairperson of the Committee.
- One member should be a present or past user of children's palliative care services.
- Consultant Paediatrician with a Special Interest in Paediatric Palliative Medicine.
- 12 representatives from within the HSE, four from each region including;
 - 1 Regional Director of Operations (with responsibility for palliative care), or his/her nominee;
 - 1 Statutory agency (clinical and professionals);
 - 1 Voluntary organisation involved directly or indirectly in the provision of children's palliative care services with a Service Level Agreement with the HSE who is able to represent the views of the voluntary sector. Invited by the Regional Director of Operations (with responsibility for palliative care) and nominated by individual groups.

The CEO of the HSE would be responsible for the appointment of the National Development Committee for an agreed period of time. One member should also sit on the HSE Children's Expert Advisory Group. The Committee should meet not less than twice each year. Secretarial support for the committee should be provided by the HSE.

11.2 Terms of reference

The terms of reference for the National Development Committee should include:-

- Prepare and agree a national development plan based on the assessment of need and national policy as set out in this policy document – Palliative Care for Children with Life-Limiting Conditions in Ireland.
- Participate in the estimates process and make recommendations to the CEO on the allocation of all statutory resources (capital and revenue) provided by the Department of Health and Children for new and developing services.
- Encourage and participate as appropriate in the evaluation of service delivery nationally in accordance with the agreed mission statement.
- Provide an annual national commentary on children's palliative care to the CEO and appropriate National Director, HSE.
- Consider the establishment of any appropriate supporting administrative area structures and their remit.

RECOMMENDATION

A National Development Committee on children's palliative care should be established.

12. Collecting data on children with life-limiting conditions

A key finding of the *Palliative Care Needs Assessment for Children* was that a database would help to establish the number of children living with and dying from life-limiting conditions. Despite the inherent challenges, following the findings of a feasibility study undertaken in Ireland, a database of children with life-limiting conditions should be compiled. This will primarily use HIPE data (measuring the number of hospital visits made by each child) and CSO death data. It is envisaged that information will be collected annually and that it would inform strategic service planning, map service delivery and assist in workforce planning.

In line with international best practice, the International Classification of Disease ten diagnostic codes (ICD-10) (Appendix 2) and the four categories identified by ACT (Table 1) would be used. This would enable international comparisons to be made. Once the database is operational, it is envisaged that data collection would be further refined and tailored specifically to reflect the Irish context.

12.1 Dataset Implementation Proposals

The HSE should establish a working group to assess implementation of the recommendations of the feasibility study report and would address such issues as:

- Timeframe and membership.
- The recommended data items.
- The relevance of different ICD-10 codes.
- Calculation for extracting data from HIPE system.
- Processes for engaging with the Health Information Unit/Economic and Social Research Institute to extract HIPE data.
- Processes for engaging with the Central Statistics Office for Death Certificate data.

The Health Intelligence Unit (HIU) in the HSE would be responsible for extracting defined data on children with life-limiting conditions. This data should remain within the HSE structures and be used proactively to plan services for children with life-limiting conditions.

The resources required to progress this include:

- HIU - Required resources would need to be put in place, the terms of reference for this piece of work implies that the activities would be embedded in HSE activity. If required, an initial start-up grant to the HIU with the intention of the HIU incorporating these data exercises into their usual work in the long term may be explored.
- A secretariat and administrative support for the meetings and consensus building exercises of the subgroup.
- Consultation with international experts on the development of children's palliative care services for Ireland.

The HIU is part of HSE Population Health Intelligence Department and the normal HSE governance would apply. Reports would be made to the Management Team through the Assistant National Director (Chronic Illness and Palliative Care).

RECOMMENDATION

Data on children living with and dying from life-limiting conditions should be collected by the HSE.

13. The interface between voluntary and statutory agencies.

The HSE and the voluntary agencies need to continue to develop closer working relationships. This is particularly important in deciding how local priorities are to be decided and delivered. The voluntary sector while retaining their autonomy should form part of an integrated framework for health care provision for the administrative areas. Service level agreements should form the basis of future working relationships between the HSE and all voluntary providers of palliative care to children with life-limiting conditions. The use of service level agreements should provide a means to establish safeguards and reassurances for both. The process should respect the independent identity and operational autonomy of individual voluntary services providers and respect the statutory, regulatory and public accountability responsibilities of the HSE and the Minister for Health and Children.

RECOMMENDATION

The HSE and the voluntary agencies should continue to develop closer working relationships around caring for children with life-limiting conditions.

The voluntary sector while retaining their autonomy should form part of an integrated framework for the administrative areas.

Service level agreements should form the basis of future working relationships between the HSE and all voluntary palliative care service providers.

14. Workforce planning

Future developments in children's palliative care must take account of the need for structured workforce planning in order to provide equitable, effective, sustainable and safe service delivery to children with life-limiting conditions and their families. An integrated approach to workforce planning is needed to link strategic policy objectives and focus on the skills and competencies required to achieve these objectives. The supply and demand for staff should be examined together with the existing and any additional training requirements, which should be met by the education systems both at undergraduate and postgraduate level.

The introduction of a database of children with life-limiting conditions would assist in workforce planning. At present Ireland has insufficient numbers of suitably educated and experienced professionals available to take up lead positions in this specialised and developing area of children's health care. In order to begin the process of developing palliative care services for children with life-limiting conditions and to sustain the development of the speciality, key medical and nursing appointments need to be made in the first instance.

RECOMMENDATION

The supply and demand for staff should be examined together with the existing and any additional training requirements which should be met by the education systems both at undergraduate and postgraduate level.

15. Integrated care pathway for children and families with palliative care needs

15.1 Developing an Irish integrated care pathway for children & families with palliative care needs

This integrated care pathway outlines the key stages in delivery of care in hospital and community settings to children and young people with palliative care needs and is based on the work of ACT and adapted to reflect the Irish healthcare setting.

This pathway is divided into 3 stages:

- Diagnosis or recognition of a life-limiting condition (Figure 4).
- Ongoing care that may last weeks, months, years (Figure 5).
- End of the child's life, including bereavement care (Figure 6).

The pathway highlights some of the crucial points for families around the delivery of care where difficulties arise with communication and a lack of integrated working by professionals. In the UK, standards have been developed around each of these points. The development of similar standards here in Ireland, would address some of the recurring issues for children with life-limiting conditions and their families and ensure equal access to high quality care.

The care pathway is a broad template for service delivery. Each HSE region would need to adjust the pathway and develop their own service delivery plan taking into account existing services, geographical area and available resources.

Figure 4. Diagnosis or recognition of life-limiting condition

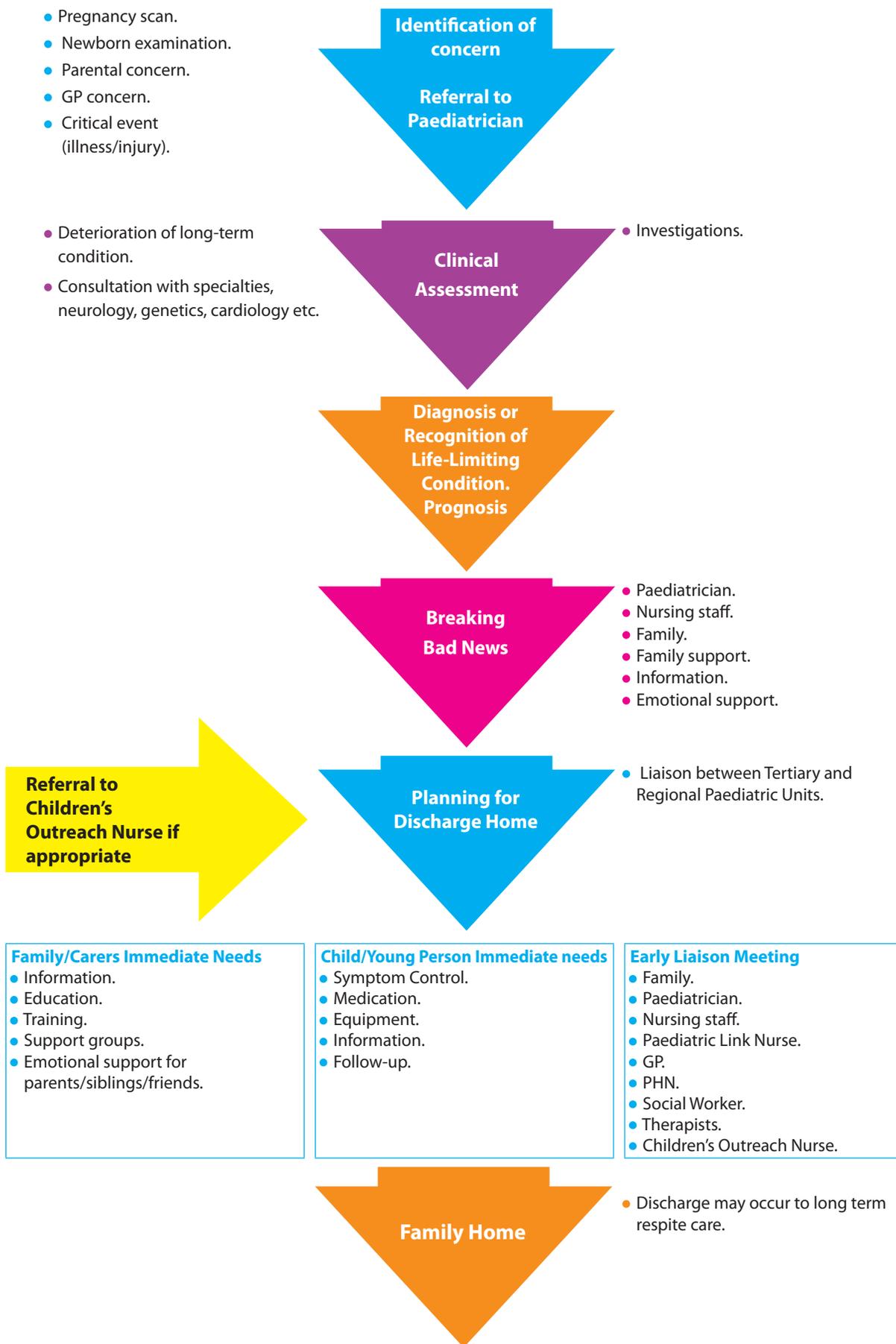


Figure 5. Living with a Life-limiting condition

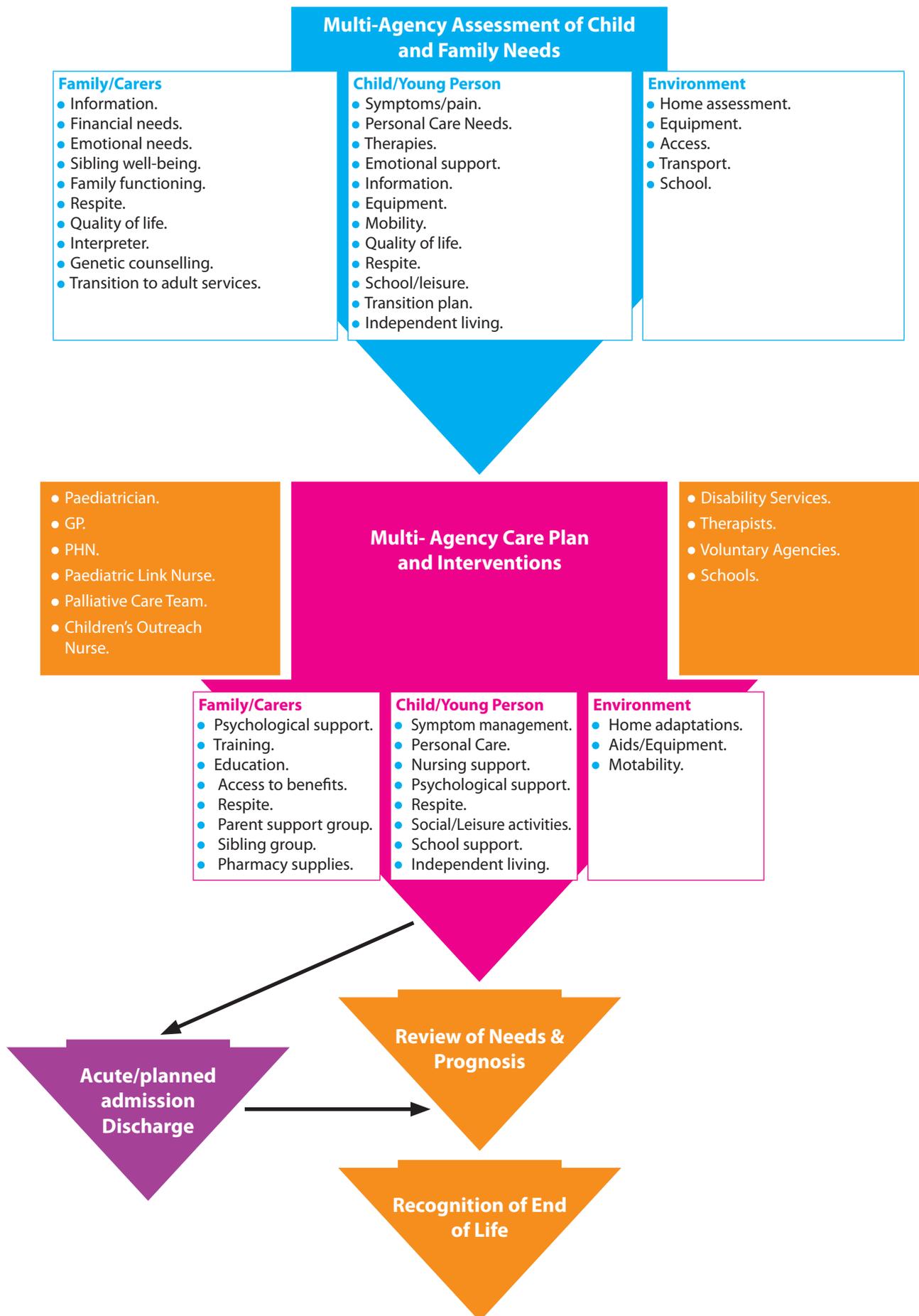
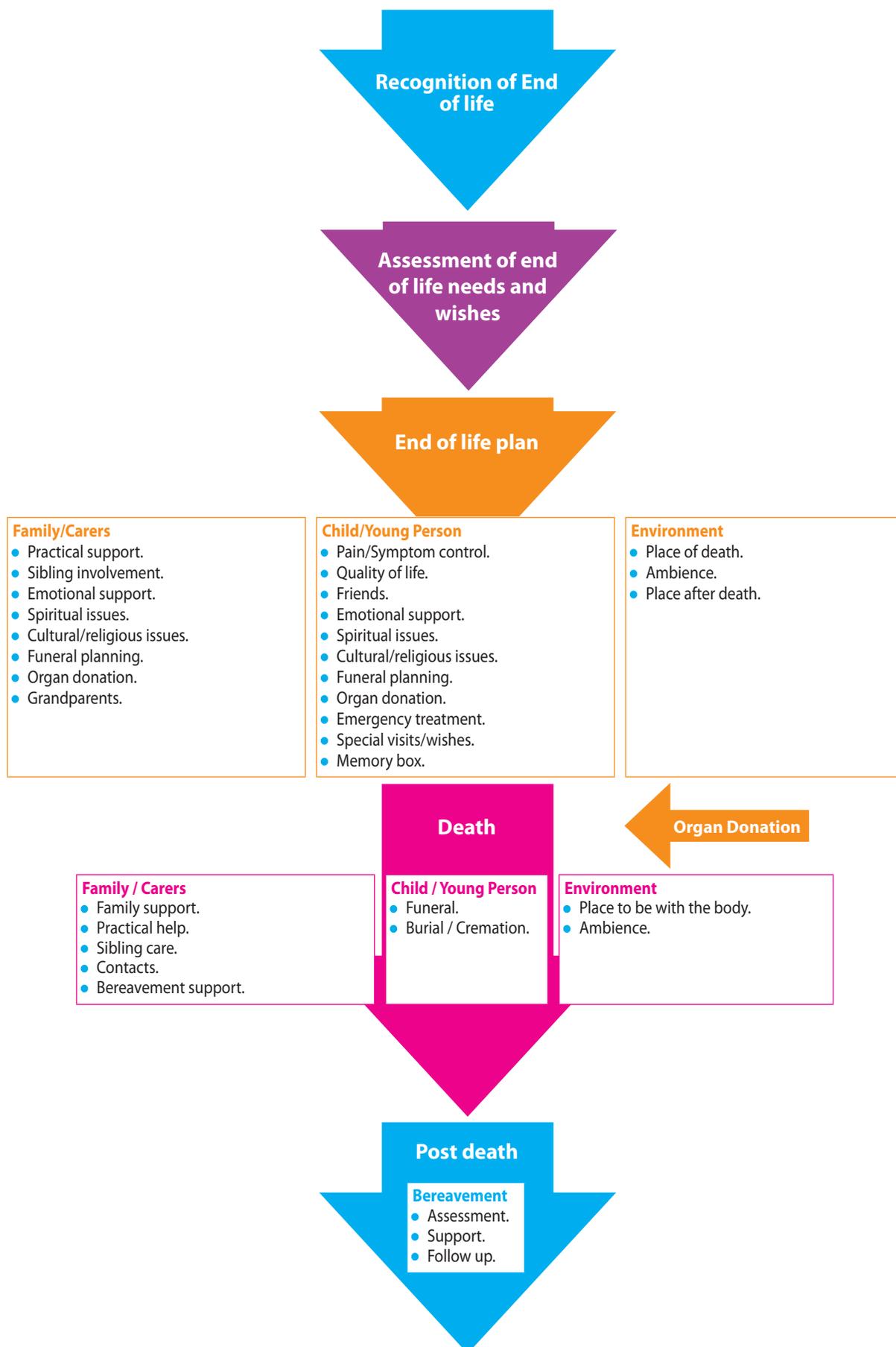


Figure 6. Recognition of End of Life



16. Priorities and timeframes

It is proposed that this policy will be implemented in phases. The policy development group have identified the following priorities and timeframes in the first phase of implementation of the development of children's palliative care services in Ireland:

PHASE ONE

	Priority	Time frame	Responsibility
1.	The appointment of a Consultant Paediatrician with a Special Interest in Paediatric Palliative Care	One year from availability of funding	HSE
2.	Initially the appointment of eight Children's Outreach Nurses with plans for further appointments if necessary	Four months from availability of funding	HSE
3.	Education and training for staff working with children with life-limiting conditions	Ongoing	HSE
4.	Development of a database/register of children with life-limiting conditions	End 2010	HSE
5.	Setting up a National Development Committee for Children's Palliative Care	Spring 2010	HSE

17. Estimated cost of funding Phase one of implementation

It is estimated that it will cost €2.25m to implement Phase 1 of this policy over the next five years. This includes:-

The appointment of Ireland's first **Consultant Paediatrician with a Special Interest in Paediatric Palliative Care**. It is recommended that there should be one whole time equivalent (WTE) post.

Appointment of 8 **Clinical Nurse Specialists – Children's Outreach Nurses for Children with life-limiting conditions**. Following evaluation of this role and taking into consideration the findings of the National Database and CSO figures for population, the number of Outreach Nurses may, in time, need to be adjusted.

The Education programmes include the following:

- Level A and B Paediatric Palliative Care Education programmes
- Bereavement education programmes
- Development of Certificate Children and Loss programme (20 places per annum) at an ongoing cost of €350,000 approx.

It is envisaged that the National Database would be developed over a period of three years at an estimated cost of €150,000 and will be funded from within existing HSE resources.

PHASE TWO

The focus of phase 2 of implementation of the children’s palliative care policy is on the development of models of care for children with life-limiting conditions and their families. Implementation of Phase 2 will fall within the remit of the National Development Committee for Children’s Palliative Care, progress will be contingent on the availability of funding.

	Priority	Time frame	Responsibility
1.	Development of hospital based palliative care team.	Six months from approval and availability of funding.	HSE
2.	Respite <ul style="list-style-type: none"> • Audit of existing facilities. • Provision of locally based or ‘at home’ respite. 	Commence March 2010 dependent on findings of audit.	HSE (Disabilities/ PCT/PCCC)
3.	The provision of ‘hands on` patient care and the development of ‘Hospice at Home’ services for children with life-limiting conditions who have palliative care needs	Six months from approval and availability of funding.	HSE (PCT/ PCCC)

Development of a hospital-based palliative care team

Following the appointment of a Consultant Paediatrician with a Special Interest in Paediatric Palliative Care, the following key appointments would be required to develop a hospital-based palliative care team. In addition to the Clinical Nurse Specialist in Palliative Care currently working in Our Lady’s Children’s Hospital, Crumlin:

Administrative Support

Palliative care team administrative support would be provided by a Grade 4.

Medical Social Worker

One WTE medical social worker with a special interest in children’s palliative care.

Respite audit and developments

This policy recommends that a flexible range of respite care services be available to children with palliative care needs. Respite care should be delivered within the home and on an in-patient basis. To facilitate a costing exercise for development of this model it is recommended that the following initiatives take place:

- An audit be undertaken of existing respite facilities to define the capacity in the current system to support additional respite facilities for children with life - limiting conditions.
- A sub-group with relevant expertise be established to examine the audit findings and define further what is required to provide additional respite requirements including specialist and centre based respite.
- Data derived from the ICD coding extract be analysed to assist in respite need projections.

Recommendations for the future development of children's palliative care.	
Implementation of policy	
1.	Following publication of this policy the HSE should develop an implementation plan.
2.	Children with imminent palliative care needs requiring Hospice at Home will be prioritised, especially those nearing the end of life.
Clinical Governance	
3.	There should be clear assignment and documentation of responsibility within and between clinical teams involved in the care of the child with a life-limiting condition and their family.
Children and their parents	
4.	Family and carers should have access to:- <ul style="list-style-type: none"> • The support of qualified nurses, care assistants and home helps according to their child's assessed needs. • Direct nursing care, and respite (depending on the complexity of diagnosis and related symptoms). • Twenty-four hour nursing, particularly when a child is in the terminal phase of illness.
5.	Children should have access to therapy services at both hospital and primary care level
6.	Parents should be actively involved in the decision making and planning of location of care for their child.
Consultant	
7.	A Consultant Paediatrician with a Special Interest in Paediatric Palliative Care should be appointed.
8.	The consultant should ultimately be based at the new National Paediatric Hospital, Dublin.
9.	The consultant should have dedicated rooms in the new National Paediatric Hospital.
10.	A Children's Palliative Care Team should be established at the National Paediatric Hospital.
Outreach Nurses	
11.	Regionally based Children's Outreach Nurses for children with life-limiting conditions should be appointed to facilitate service delivery and integration between hospital, community services and specialist palliative care.
12.	The Children's Outreach Nurse should liaise with Primary Care Teams and Network Services in order to plan appropriate care.
Acute and maternity hospitals	
13.	Hospitals should provide an appropriate environment for children with palliative care needs. This includes the physical environment such as facilities and ward space, and professional environment such as staff education and training.
14.	The Consultant Paediatrician with a Special Interest in Paediatric Palliative Care and team should provide palliative care support to maternity hospitals and neonatologists.
Respite	
15.	Inpatient hospice beds specifically for respite should be developed as part of children's palliative care service.
16.	A range of respite services should be developed for children with life-limiting conditions who have palliative care needs.

17.	Each HSE administrative area should plan and develop respite facilities for children with life-limiting conditions and their families.
18.	'Hospice-at-Home' teams should be developed by the HSE.
Bereavement services	
19.	Bereavement supports for children's palliative care should be developed relative to defined levels and encompasses child, adult and family support.
20.	Funding should be made available to those families identified by the team as needing access to appropriate bereavement care.
Education	
21.	Children continue to grow and develop physically, emotionally and cognitively throughout their illness and regardless of the stage or extent of their illness and their location of care, have a need for education and play which must be met as part of a comprehensive palliative care service.
22.	In an effort to maintain normality, where possible the child's education should continue for as long as possible at the usual location.
Healthcare staff education and research	
23.	All relevant hospital and community staff should be facilitated to partake in education and training on children's palliative care.
24.	The supply and demand for staff should be examined together with the existing and any additional training requirements which should be met by the education systems both at undergraduate and postgraduate level.
25.	All health care professionals working in children's palliative care should have the opportunity to engage in research.
National Committee for Children's Palliative Care	
26.	A National Development Committee for Children's Palliative Care should be established by the Health Service Executive.
27.	In order to ensure that palliative care conforms to best practice, protocols and standards specifically in relation to palliative care for children should be developed, agreed nationally and be overseen by the National Development Committee on Children's Palliative Care.
28.	Data on children living with and dying from life-limiting conditions should be collected by the HSE.
Working with voluntary agencies	
29.	The HSE and the voluntary agencies should continue to develop closer working relationships around caring for children with life-limiting conditions.
30.	The voluntary sector while retaining their autonomy should form part of an integrated framework for the HSE administrative areas.
31.	Service level agreements should form the basis of future working relationships between the HSE and all voluntary palliative care service providers.

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GLOSSARY OF TERMS

Adolescence

Describes various age ranges from as young as 10 and up to 24 years. The World Health Organisation (WHO) defines adolescence as 10-19 years.

Child

Person below the age of 18 years.

Children's palliative care

Palliative care for children and young people with life-limiting conditions 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.

Children's Hospice

A children's hospice is an organisation which provides palliative care for a child or young person with a life-limiting condition and their family and aims to meet all needs – physical, emotional, social and spiritual – through a range of services including children's palliative care, specialist respite care, terminal and emergency care, 24 hour telephone support, practical help, advice and information and bereavement support for all family members.

Hospice at home

This document describes 'Hospice at Home' which is an integral component of children's palliative care. Hospice at home is a term commonly used to describe a service which brings skilled, practical children's palliative care into the home environment, especially in the last weeks and days of life. Hospice at home works in partnership with parents and families and provides hands on expert nursing care on a 24-hour basis, along with other elements of palliative care including:

- Emotional, psychological and social support.
- Access to specialist colleagues in other disciplines, such as physiotherapy, as required.
- Provision of information, support, education and training where needed to all carers both lay and professional.
- Close collaboration and communication with the primary care team, the child's acute hospital specialists if appropriate and other agencies.
- Specialist respite care.
- 24 hour end-of life care.
- Bereavement support.

Hospital at home

Hospital at home is a health care model that provides hospital-level care in a patient's home as a full substitute for acute hospital care.

Life-limiting conditions

Life-limiting conditions are those for which there is no reasonable hope of cure from which children or young people will die.

Life-threatening conditions

Life threatening conditions are those for which curative treatment may be feasible but can fail such as cancer. Children in long term remission or following successful curative treatment are not included.

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.

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.

Specialist palliative care

Specialist palliative care services are those whose core activity is limited to the provision of palliative care. These services are involved in the care of patients with more complex and demanding care needs which require a greater degree of training, staff and other resources. Specialist palliative care services because of the nature of the needs they are designed to meet are analogous to secondary or tertiary health care services.

Specialist respite care

Specialist respite care refers to a setting of care, a programme of care or a service that provides additional services. It may take place in the child's home or in a setting outside of the home such as a hospital, long term care facility or hospice. Specialist respite care provides the support required to meet the child's holistic care needs and enables children and families to access short break services. Specialist respite care will often address some aspects of symptom management.

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 and is a continuum of palliative care.

Voluntary body/organisation

A not-for-profit service and/or 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). Some of these non governmental organisations are either partially or in some cases fully funded by the state.

ABBREVIATIONS

ACT	Association for children with life-threatening or terminal conditions and their families
GP	General Practitioner
ICD	International Classification of Disease
HIPE	Hospital Information Patient Enquiry System
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
PHN	Public Health Nurse
WHO	World Health Organisation

APPENDIX ONE

Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT)

Recommendations:

Every child and family should expect to:

1. Receive a flexible service according to a care plan, which is based on individual assessment of their needs, with reviews at appropriate intervals. Children and families should be included in the process of care planning.
2. Be provided with appropriate and timely information.
3. Have their own named key worker to co-ordinate their holistic care and provide access to appropriate professionals across the network.
4. Have access to a local paediatrician in their home area and have access to a local interdisciplinary children's palliative care team with knowledge about the whole range of relevant services.
5. Be in the care of an identified lead consultant paediatrician expert in the child's condition.
6. Be supported in the day-by-day management of their child's physical and emotional symptoms and to have access to 24- hour care in the terminal stages.
7. Receive help in meeting the needs of parents and siblings, both during the child's illness and during death and bereavement.
8. Be offered a range of regular and reliable respite, both in the home and away from home and over varying periods of time. This should include nursing care and symptom management.
9. Have available appropriate supplies of medications, oxygen and specialised feeds and have all disposable items such as feeding tubes, suction catheters and stoma products supplied regularly, efficiently and preferably through a single source.
10. Have access to housing adaptations and specialist equipment for use at home and school, in an efficient and timely manner without recourse to several agencies.
11. Be given assistance in order to access benefits, grants and other financial help.

APPENDIX TWO

International Classification of Disease (ICD) Codes used to define life-limiting conditions.

ICD Codes/Categories identified by ACT*	
ICD Code	Category
140 - 239	Neoplasms
240 – 279	Endocrine, Nutritional and Metabolic Diseases and Immunity Disorders
280 – 289	Diseases of Blood and Blood-forming Organs
320 - 389	Diseases of the Nervous System and Sense Organs
390 – 459	Diseases of the Circulatory System
488 – 519	Diseases of the Respiratory System (excluding acute respiratory infections 460 – 487)
520 – 579	Diseases of the Digestive System
580 – 629	Diseases of the Genitourinary System
710 – 739	Diseases of the Musculoskeletal System and Connective Tissue
740 – 759	Congenital Abnormalities
760 – 779	Conditions originating in the perinatal period

*Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT)

