



# A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions

Third edition



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**A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions**  
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Together for Short Lives is the leading UK charity that speaks for all children with life-threatening and life-limiting conditions and all those who support, love and care for them. When children are unlikely to reach adulthood, we aim to make a lifetime of difference for them and their families.

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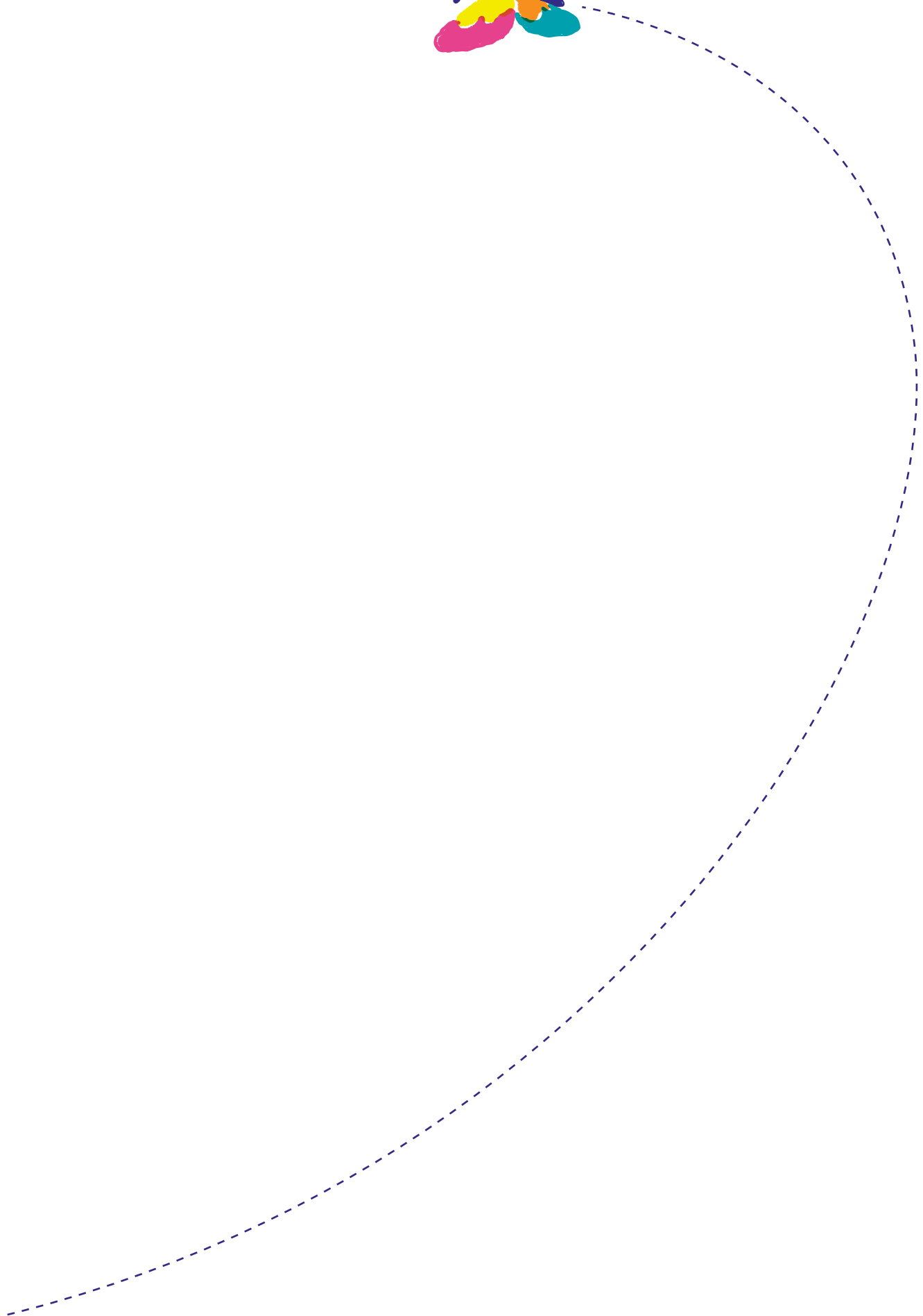
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# Foreword

This Core Care Pathway has been developed as a tool for professionals who support children with life-limiting and life-threatening conditions and their families throughout their care journey, from diagnosis through to end of life care and bereavement support.

It provides a clear framework for all practitioners and aims to facilitate a care process, supported by good communication between professionals across all care settings. It places the child and family at the centre of the planning process, and provides practical guidance at key stages of a child's care journey.

I encourage all professionals who support babies, children or young people with palliative care needs to use this resource as the framework for tailoring service development and provision to support families' needs.

Parents and children know what they would like and professionals know what children and families need, but it is the commissioners and providers of services who can ensure that every child and young person has the necessary services and support to make the most of the precious time that they have together.

I recommend this pathway as an important tool in ensuring children and families receive high quality, personalised, responsive, co-ordinated and sustainable care.



**Angela Thompson**  
Chair of Care Pathway Steering Group



# Introduction

*The Core Care Pathway for Children with Life-limiting and Life-threatening Conditions* is a revision of the world's first care pathway for children with palliative care needs, *Integrated Multi-agency Care Pathways for Children with Life-limiting and Life-threatening Conditions*, which was published by ACT (now Together for Short Lives) in 2004 and re-issued in 2007.

Since the publication of the first pathway there have been many developments in children's palliative care, as well as a range of changes to health and social care structures across the four UK nations. This updated pathway aims to embrace and reflect these changes and the advances in our knowledge.

Over the past eight years, we have been repeatedly told how much this care pathway approach, now widely adopted in many settings delivering services across the UK and beyond, has helped to improve the family's journey throughout their child's life, eventual death and their own bereavement.

The care pathway approach enables the delivery of individualised care focusing on the child's needs wherever they are receiving that care. The child's needs may differ according to individual circumstances, and it recommends that care assessments should take into account the needs of the wider family, and carers. The care pathway approach can also help to support commissioning processes throughout the child or young person's whole journey and help ensure they receive the best possible care, wherever and whenever they need it.

Readers will note that stage three of the revised *Core Care Pathway* now includes a new standard for bereavement, which addresses this critical part of the family's journey in more depth. Professionals will be able to use the pathway to help make sure that the family's needs are addressed beyond the death, ensuring that everything is in place for them to access the appropriate support when and where it is needed.

A key theme that has emerged from the Together for Short Lives Square Table discussions that have taken place across the UK with a range

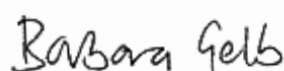
of stakeholders in children's palliative care, including parents and young people (Children's Hospices UK and ACT, 2011), has been that families experience poor care co-ordination, with many parents and professionals reporting that health, education and social care agencies work independently of each other, creating considerable difficulties for families in navigating the maze of services available.

This revised *Core Care Pathway* provides a framework for care delivery across health, education and social care and is therefore a critical tool for creating the improved integration of care that Together for Short Lives continues to advocate.

We encourage you to use this *Core Care Pathway* alongside the suite of Together for Short Lives pathways which are designed for more specific circumstances:

- *The Transition Care Pathway for young people* (2007)
- *A Neonatal Pathway for Babies with Palliative Care Needs* (2009)
- *A Care Pathway to Support Extubation within a Children's Palliative Care Framework* (2011)

More information on all these resources is available at [www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)



**Barbara Gelb**  
Chief Executive  
Together for Short Lives







# Background

The focus of the Together for Short Lives pathways is to put children and families at the centre of a planning process, with the aim of delivering integrated services in response to individual needs.

Together for Short Lives advocates a care pathway approach to delivering care and support to children and families throughout their journey; from diagnosis to end of life and into bereavement. This pathway is guided by standards at each different stage of the journey, which aim to improve the provision and consistency of care and support to children and families. Each standard is supported by a series of goals, which combine to achieve the standard.

It is estimated that there are at least 49,000 children under 19 years across the UK living with a life-limiting or life-threatening condition who may require palliative care services (Fraser, L. K., 2012). There are over 300 conditions which fall into the life-limiting and life-threatening category. The *Core Care Pathway* provides a process which is relevant to any condition as it focuses on the child's needs rather than the disease trajectory.

Where a detailed care pathway or protocol associated with a particular disease or condition has been devised for clinical care, it can be used alongside this pathway. This will ensure the inclusion of all the additional elements needed for a comprehensive multi-agency pathway.

This pathway aims to ensure that families experience a co-ordinated approach to family-centred care throughout their child's life, regardless of their child's diagnosis, with clear and open communication and support to enable the family to build up and maintain access to an appropriate network of support, regardless of where they are cared for, whether that is in hospital, in their home, or in a children's hospice.

Many children's palliative care journeys begin in hospital. This pathway is designed to be started either prior to or after discharge from hospital and follows the child through to the community care setting, either at home or in a children's hospice. The pathway can also be started at any appropriate point for children already receiving community based care.

The Together for Short Lives philosophy has always been to promote the best possible quality of life and care for every child with a life-limiting or life-threatening condition and their family. Giving families real choice has been key to this approach; a choice of place of care, a choice of place of death, a choice of emotional and bereavement support; and putting the child and family at the centre of decision making to produce a plan for care that is right for them.

This document will be of use to those working to improve the provision and consistency of care and support to children and families, and will help in providing a clear pathway from diagnosis or recognition, through ongoing care to the child's end of life and into bereavement.

The main aim of this pathway is to provide a core framework for professionals working with children to support the local development of an integrated care pathway for children diagnosed or recognised as having a life-threatening or life-limiting condition.

Local pathways, reflecting local resources which support best practice should be accompanied by readily accessible local tools and resources to support safe and effective care.







When a child is diagnosed with a life-limiting or life-threatening condition, their care is often provided by a wide range of professionals from different disciplines and specialties. The *Core*

*Care Pathway* is relevant for all members of that team, including those who work regularly in children's palliative care and those providing more generalist services. The pathway provides an opportunity to draw on all care team members' expertise and experience to work together to provide individualised, responsive care, reflected in the child's care plan.

### Who will benefit from the pathway?

Together for Short Lives has developed this *Core Care Pathway* for use with all babies, children and young people who have either a life-limiting or life-threatening condition and who may need palliative care.

Children's palliative care is an approach to care which can be used exclusively or in conjunction with curative treatments. The diagram below explores the relationships between palliative care and those treatments aimed at prolonging life.

Relationship between palliative care and treatments aimed at cure or prolonging life	
	As the illness progresses the emphasis gradually shifts from curative to palliative treatment.
	Highly technical invasive treatments may be used both to prolong life and improve quality of life alongside palliative care, each becoming dominant at different stages of the disease.
	No cure is possible and care is palliative from the time of diagnosis.
	At first it is not apparent that this will be a terminal illness and palliative care starts suddenly once that realisation comes.
Key:  curative  palliative	

Together for Short Lives has developed two widely established tools to help professionals plan for and assess the needs of children. These are four categories of life-limiting and life-threatening conditions and a diagram that explains the relationship between palliative and curative treatment. You can also see the definitions of children's palliative care, life-threatening conditions and life-limiting conditions in the glossary at the end of this document.

## Categories of life-limiting and life-threatening conditions

Together for Short Lives recognises that four broad groups of life-threatening and life-limiting conditions may be delineated. Categorisation is not easy and the examples used are not exclusive. Diagnosis is only part of the process; the spectrum of disease, severity of disease and subsequent complications as well as the needs of, and impact on the child and family need to be taken into account.

These four categories outline the four types of illness trajectory which will require children's palliative care provision. The categorisation is

important for the purpose of planning and needs assessment. The categories demonstrate the range of conditions children have and show how children may benefit from palliative care, or elements of palliative care during their journey. The need for palliative care should always be assessed on an individual basis.

Children from all four of these categories would benefit from some, if not all, elements of this pathway.

<b>Category 1</b>	<p><b>Life-threatening conditions for which curative treatment may be feasible but can fail.</b></p> <p>Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services.</p> <p><i>Examples: cancer, irreversible organ failures of heart, liver, kidney.</i></p>
<b>Category 2</b>	<p><b>Conditions where premature death is inevitable.</b></p> <p>There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.</p> <p><i>Examples: cystic fibrosis, Duchenne muscular dystrophy.</i></p>
<b>Category 3</b>	<p><b>Progressive conditions without curative treatment options.</b></p> <p>Treatment is exclusively palliative and may commonly extend over many years.</p> <p><i>Examples: Batten disease, mucopolysaccharidoses.</i></p>
<b>Category 4</b>	<p><b>Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death.</b></p> <p><i>Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, complex health care needs, high risk of an unpredictable life-threatening event or episode.</i></p>

## Principles of good practice within the Core Care Pathway

There are a number of overarching elements of good practice and themes which should be considered at every stage of the care pathway.

### Best interest

The overriding legal and ethical principle is that all treatment decisions must be taken in the child's best interest.

### Diversity and cultural issues

Culturally appropriate care which respects diversity helps maintain the quality of family centred care for all. An understanding of specific cultural and religious practices around death,

dying and bereavement assists in providing culturally appropriate palliative care, identifying and supporting individual family needs and preferences and preventing assumptions that all people from the same culture or religion practice the same rituals or share the same beliefs. The Together for Short Lives *Diversity Toolkit* (Children's Hospices UK, 2009) is a useful resource to support professionals and organisations as they consider diversity and cultural issues in children's palliative care.

### Consent, confidentiality and capacity

Confidentiality, consent and capacity issues must be addressed throughout the care pathway. A number of resources are available to support professionals, including the *Mental Capacity Act Tool Kit* (BMA, 2008).

## **Communication**

There should be an honest, open and timely approach to all communication with parents and carers, who should be treated as equal partners in any discussions with the care team. It is crucial to remember the importance of talking to parents and the family, giving them choices and maintaining a flexible, 'can-do' attitude to support their choice. If they choose to allow their child to die at home or at a local children's hospice, then the pathway should be followed to support the child's rapid discharge from hospital. At such times, it is vital that one practitioner is identified to take the lead, so they can act as the family's first point of contact for communication, and to ensure that information flows to all services.

## **Uncertainty and losses**

Families often experience repeated uncertainty and losses: first the loss of the 'normal' child, followed by the anticipated loss of a child predicted to die. At times, the child may defy medical expectations and survive episodes of life-threatening deterioration, only for the family to face their death in the future. Some families may also face multiple losses with more than one child having the same medical condition. Often the only honest answer to a family's questions about how long the child will live, is simply that you don't know.

## **A unique bereavement journey for every child and family**

Family life for everyone is affected when a child is diagnosed with a life-limiting illness, and of course, when they die. Grief is an individual concept, experienced very differently. Choice is therefore vital. It is important to ask the family what they want to ensure the whole family focus is retained while ensuring a professional approach, underpinned by theory. All types of support should be available throughout the family's journey. Sometimes a professional approach, over-reliant on theories and ideas, can lead to inappropriate support for families. For example, support groups suit some, but not all. Couple support can be helpful because of the strain the parent's relationship is under when caring for a seriously ill or dying child.

## **Emotional and psychological support**

This is needed throughout the family's experience, from diagnosis, through end of life care and following the death of the child. Families should be enabled to access support when they want to, rather than having their needs assessed at pre-set intervals. The specific needs of siblings should be considered throughout this care pathway.

## **Spiritual support**

Every child and family should receive spiritual support to meet their individual needs. This should begin at diagnosis and continue throughout the child's lifetime, death and during bereavement.

## **Multiple admissions**

Children with life-limiting or life-threatening conditions often experience multiple admissions to hospital. Professionals should prepare the family for this possibility and the potential for their child being cared for in different environments, possibly different hospitals under different care teams.

## **Co-ordinated care**

Children and their families should receive co-ordinated care, where services work together to deliver integrated, child-centred, life-long care to improve quality of life.

## **24 hour support**

Every child should have a local GP and access to a 24 hour multi-disciplinary children's palliative care team for flexible support in the home, and be under the care of a local paediatrician.

## **Ability to respond quickly and flexibly**

Some children will have a very short life expectancy and the normal planning meetings may not happen.

## **Parallel planning**

It is often hard to predict what the future holds for children requiring palliative care. For some, periods of relatively good health are associated with the potential for an unpredictable, and potentially terminal event. For others, a period of deterioration may be observed, yet the child may have considerable time to live when the quality of their life should be maximised. Parents quickly experience the uncertainty that living with a child requiring palliative care brings, and with support, value a 'parallel planning' approach. Discussions with the child (where appropriate) and the family enable various options for care in response to a range of potential outcomes to be considered and written down in advance. Although children

may be assessed as deteriorating or approaching the end of their life, it is sometimes the case that children survive these episodes. Parallel planning for life while also planning for deterioration or death allows a child's full potential to be achieved and primes the mobilisation of services and professionals where necessary. Planning for the future at times of great uncertainty can also be comforting for children and parents. These plans often include the development of an Advance Care Plan.

### Advance Care Plan

Advance Care Planning (ACP) is a process of discussion between an individual and their care provider and often those close to them. The End of Life Care Strategy (Department of Health, 2008) clearly states that ACP and clarity about resuscitation decisions are essential to quality care. This is as important for children and families as it is for adults receiving end of life care. ACP may lead to actions such as advance statements about wishes and preferences, preferred place of care, withdrawal of treatment and resuscitation status. For children and families this will include decisions relating to care in the case of acute deterioration and may also address preferences for organ and tissue donation.

### Care for the team around the child

Everyone who is called upon to support the child and their wider family throughout this care pathway journey will at times, find this journey emotionally challenging. Every member of the team around the child and family should receive support and an opportunity to feedback and discuss what is happening. Professionals should also have access to ongoing support and supervision.

### Risk assessment

Risk assessment and risk management play an important part in ensuring that children and young people with life-limiting or life-threatening conditions can enjoy the kind of activities that many others take for granted. By identifying risks and looking proactively at risk management, professionals can be more effective in supporting families.

"When my daughter became ill I wouldn't consider taking her home, my energy was completely concentrated on getting her well again. That didn't happen and she spent most of her short life in hospital. When it was clear that my son had the same condition I decided that he must have a life – we must have a life together. So I took him home and we took risks. We went to the park, on a train ride, to Disneyland... ..He is still with me and has just started school. I think – how much more of a life my daughter could have had – but we're making the most of our time together and we're a family now."

**Parent of two children with a degenerative condition**







# The Core Care Pathway

*The Core Care Pathway for Children with Life-limiting and Life-threatening Conditions* suggests a broad outline of the key events or processes that happen during the journey made by children with life-limiting and life-threatening conditions and their families. It is divided into three stages:

- Stage one: Diagnosis or recognition
- Stage two: Ongoing care
- Stage three: End of life

Each of these stages begins with a key event that is significant to the family. Although this is shown as a linear process, children may move backwards and forwards between the different stages, or miss stages out in their care journey, depending on individual circumstances.

Within the stages of the pathway, there are six standards, which are described in more detail in the following sections. They identify the key points for many families in their patterns of care. These are the points at which there are sometimes difficulties achieving consistent best practice, leading to children and families experiencing confusing messages about what might happen next.

The standards set down the level and quality of care that every family should expect during their journey.

The six standards are:

## **Within Stage one – Diagnosis or recognition:**

1. The prognosis – sharing significant news
2. Transfer and liaison between hospital and community services

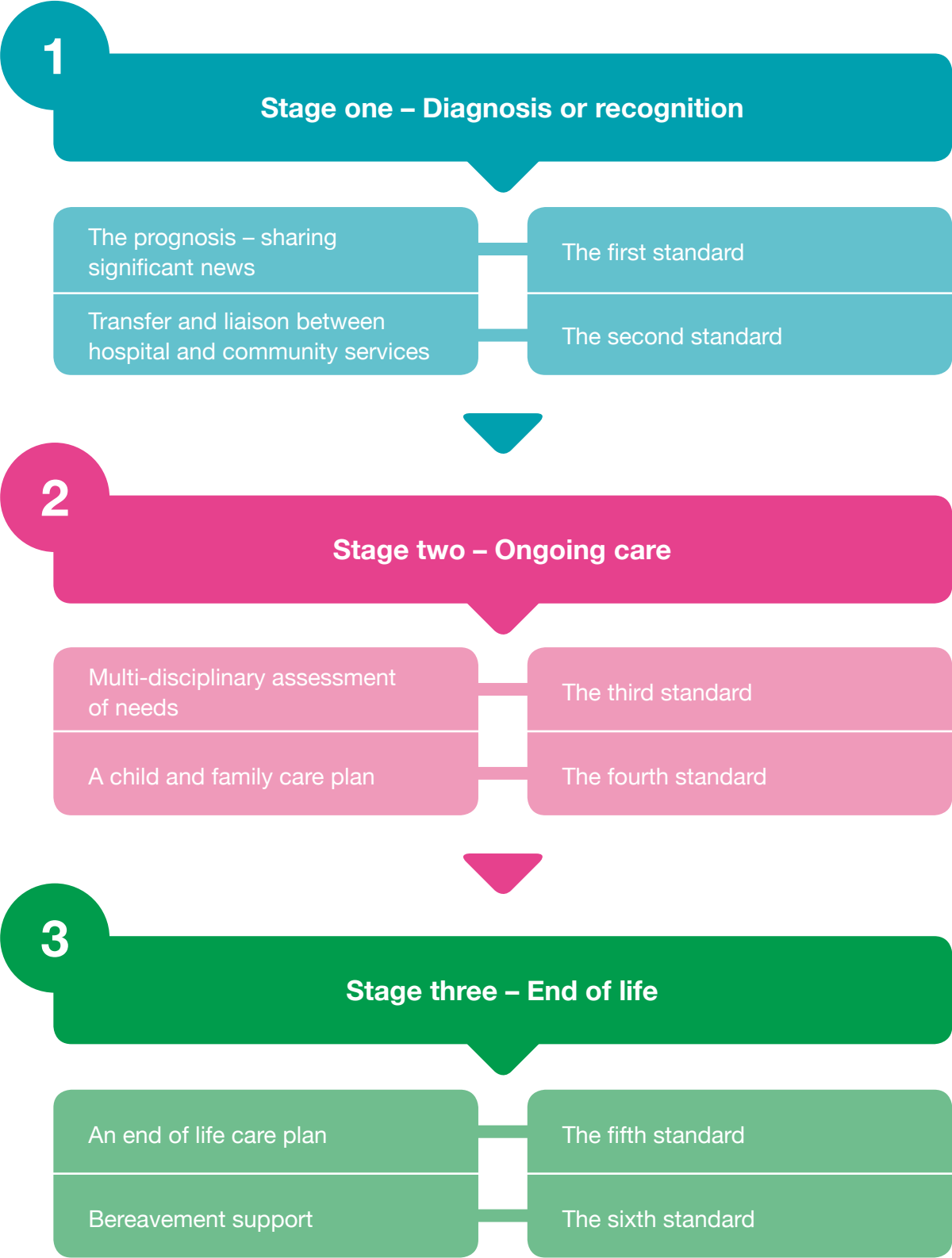
## **Within Stage two – Ongoing care:**

3. Multi-disciplinary assessment of needs
4. A child and family care plan

## **Within Stage three – End of life:**

5. An end of life plan
6. Bereavement support

Figure 1: Pathway summary diagram: A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions





## 1

## Stage one: Diagnosis or recognition

The start of the journey for many children (figure 1) is likely to be attendance or admission to hospital following a professional concern, a parental concern or a critical event, although this may not always be the case. It is important that all children have equal access to high quality medical assessment in order to achieve the best possible chance of a diagnosis. Medical assessments are likely to involve investigations and contact with a number of different professionals before any diagnosis is made.

For families in these circumstances the *Core Care Pathway* will begin with the news that their child has been diagnosed with a life-threatening or life-limiting condition. Sharing this news with the family will require great skill and sensitivity.

For a significant proportion of children, recognition of the likelihood of premature death may come considerably later than the diagnosis of a health condition. Or, the diagnosis in itself may not be an indication that the child has a life-limiting condition, for example cerebral palsy. For other children, recognition may be the point at which all attempts to prolong life have failed.

The common element will be that there has been deterioration to the extent that it has become evident that the long-term prognosis is poor and that the child has needs that could be best met by children's palliative care services.

Some children may be given a diagnosis of a named condition, while others never receive this kind of diagnosis. This lack of a named condition can leave the family feeling in limbo without access to appropriate services. Although there may not be a clearly defined diagnosis, it may be that the paediatrician has identified a shortened life-expectancy but feels reluctant to discuss this with the family. At the point when it has been recognised that the prognosis is poor for a child with a previous health condition, whether named or not, this recognition should be communicated to the family with the same degree of care and sensitivity as with children for whom the prognosis was clear from the start.

SWAN UK (Syndromes Without A Name) offers useful support and information to families of children with undiagnosed genetic conditions.  
[www.undiagnosed.org.uk](http://www.undiagnosed.org.uk)

At whatever point the diagnosis or recognition of a life-limiting condition is made in a child's life, the first stage of the pathway is likely to be relevant. How families proceed along the pathway will then depend on their individual circumstances. The key is that the family is aware that their child has a life-limiting condition and sharing this news marks the first important milestone along the pathway. Some children will have a very short life expectancy and will move to the final stage of the pathway quickly, while others will have long-term conditions that will require many years of support as set out in the middle stage.

### The first standard: The prognosis – sharing significant news

**Every family should receive the disclosure of their child's prognosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity. Information should be provided for the child and the family in a form that they can understand.**

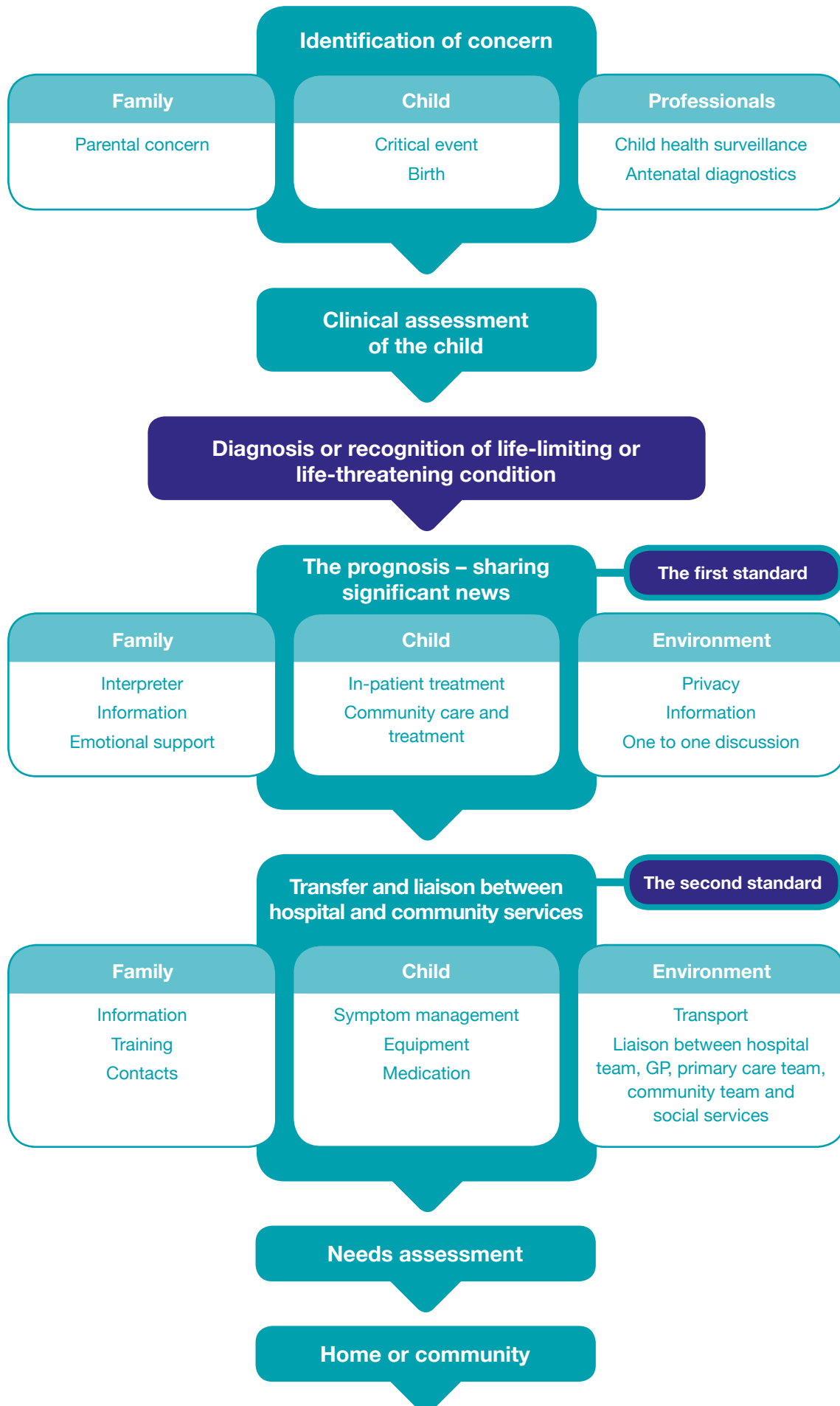
#### What this means

Sharing the news with a family that their child is expected to die prematurely is undoubtedly one of the most difficult tasks that any professional has to face. Despite considerable efforts to improve this area of care, many parents still report that they are treated clumsily or insensitively and this negative experience stays with them for a very long time.

At this point families need honesty, respect and, above all, time from professionals sharing the news. If the disclosure of information is avoided or postponed, parents are likely to stumble upon the truth at a later stage and their trust and confidence in professionals is damaged. Research (Hunt, A, et al., 2012) also confirms that both children and families need information at this stage and that it needs to be provided in a way they can understand. Written information should be used as a back up to face-to-face discussion; not as a substitute for personal communication. Providing details of support groups at the earliest possible stage can also be beneficial to families, who often feel a sense of isolation following the starkness of a diagnosis. Contact a Family can provide information to families about this and many other issues.

[www.cafamily.org.uk](http://www.cafamily.org.uk)

Figure 2: Core Care Pathway stage one: Diagnosis or recognition



From the point of diagnosis, parents and professionals should recognise that they will be entering into a partnership of caring for the child. The training and preparation of staff who will have to handle this situation should be a high priority.

At this point, families should have access to an appropriate specialist and should have the opportunity to have a second opinion if requested.

### Key goals for the prognosis – sharing significant news

- News should be shared in a face-to-face discussion in privacy.
- Written information should be provided to support verbal communication.
- Emotional support should be available to families when significant news is being shared.
- Information conveyed should be easy to understand for the individual.
- Parents should be treated with openness and honesty.
- If possible, families should be together to receive the news.

## The second standard: Transfer and liaison between hospital and community services

**Every child and family diagnosed in the hospital setting should have an agreed transfer plan involving hospital, community services and the family, and should be provided with the resources they require before leaving hospital.**

### What this means

It has long been recognised that home is usually the best place for children and that they should be admitted to hospital only if the care they require cannot be provided in the community or on a day care basis. Following a diagnosis in hospital it is likely that families will want to return home or to

their community as soon as possible. The timing of this will depend on whether or not the child needs hospital treatment. It must be recognised that families are all different, and they do not always feel that home is the best place for their child.

This may be the first major event and it can be one of the hardest times, with families feeling scared, alone or isolated. They may be trying to get used to medical language, meeting new teams and dealing with feeling that their family privacy is being invaded. Support is vital at this time and it can be beneficial to offer ongoing support from an independent, psychosocial support provider.

However long the stay in hospital, the point at which the child returns home represents another significant event along the pathway. This can be a time when communication breaks down, so a detailed handover to community staff should always take place to avoid this.

Taking a child home with a life-limiting diagnosis, sometimes with complex medical procedures to follow and possibly with medical equipment, can be a daunting task for parents. Risk management and careful planning for this stage of the pathway is essential.

Going home from hospital will require an initial needs assessment meeting involving key staff, for example, hospital staff, community staff, social services, the family GP and the family. The hospital team will provide vital input to the discharge planning process. Ongoing liaison between hospital and community teams will be important for the future care of the child. In some cases the hospital may provide an outreach service. The child and family's needs should be discussed and a plan of care agreed to enable a smooth transfer home, such as training in complex procedures, sourcing and availability of equipment, pharmacy supplies, and transport. Clear lines of communication should be agreed and the family should be told who to contact for out of hours support.

Sometimes a rapid discharge pathway may need to be in place to facilitate a smooth transition between care settings for children who are in the final stages of their lives e.g. from hospital to home or children's hospice, where this is the family's preferred place of care. (see stage three).

## Key goals for transfer and liaison between hospital and community services

- Community services should be notified as soon as it is practical to do so. This may include children's hospice services.
- There should be community in-reach to the family in hospital in person if possible, or via telephone if not.
- Planning should begin as soon as possible and a clear plan for transfer should be agreed with the child, family, hospital and community services.
- A lead community children's nurse should be agreed before transfer, and the child's GP should be included. Clear plans should be in place for shared medical care.
- Equipment and supplies should be provided before transfer.
- Transport needs should be arranged.
- Training should be provided for parents and carers prior to transfer.
- Clear lines of communication should be agreed.
- A home visit should be arranged within three days of transfer.
- A 24 hour contact number should be provided to the family.
- If transfer to a children's hospice is planned, a member of the team should meet the family at the hospital before discharge where possible.

## Diagnosis or recognition: Resources to help

**Bliss** is the UK charity working to provide the best possible care and support for all premature and sick babies and their families. They produce leaflets explaining a wide range of issues affecting premature and sick babies. [www.bliss.org.uk](http://www.bliss.org.uk)

Buckman, R. A. (2005) 'Breaking bad news: the S.P.I.K.E.S. Strategy'. *Community Oncology* 2(2): 138-142.

Buckman R. (1992) *How to Break Bad News: A Guide for Health Care Professionals*. Baltimore: John Hopkins University Press.

**Contact a Family** are a national charity providing advice, information and support for any family with a disabled child. Their helpline staff can answer queries on all aspects of raising a disabled child. [www.cafamily.org.uk](http://www.cafamily.org.uk)

Department of Health, Social Services & Public Safety (2003) *Breaking Bad News – Regional Guidelines Developed from Partnerships in Caring* [www.dhsspsni.gov.uk/breaking\\_bad\\_news.pdf](http://www.dhsspsni.gov.uk/breaking_bad_news.pdf)

Farrell M., Ryan S., Langrick B. (2001) 'Breaking bad news' within a paediatric setting: An evaluation report of a collaborative education workshop to support health professionals'. *Journal of Advanced Nursing*, 2001 December; 36(6):765-775.

Goldman, A. Hain, R. and Liben, S. (2012) *Oxford Textbook of Palliative Care for Children*, Chapter three.

Lomas, D. (2004) 'The development of best practice in breaking bad news to patients'. *Nursing Times*; 100(15):28.

Royal College of Paediatrics and Child Health, 2004; *Withholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice (Second Edition)* [www.bapm.org/publications/documents/guidelines/Withholding&withdrawing\\_treatment.pdf](http://www.bapm.org/publications/documents/guidelines/Withholding&withdrawing_treatment.pdf)

Together for Short Lives (2011) *A Parent's Guide: Making critical care choices for your child* [www.togetherforshortlives.org.uk/criticalcare](http://www.togetherforshortlives.org.uk/criticalcare)

ACT (2011) *Children's Palliative Care Handbook for GPs* [www.togetherforshortlives.org.uk/gphandbook](http://www.togetherforshortlives.org.uk/gphandbook)

**SWAN UK** (Syndromes Without A Name) is a project run by Genetic Alliance UK offering support and information to families of children with undiagnosed genetic conditions. [www.undiagnosed.org.uk](http://www.undiagnosed.org.uk)

## 2

## Stage two: Ongoing care

Fraser et al (2011) identified that there are now over 49,000 children and young people living with a life-limiting or life-threatening condition in the UK. Whether the child's condition involves active treatment aimed at cure, or palliative symptom management, care and support will move from the initial stages of diagnosis to ongoing child and family centred care.

Palliative care has its foundations in a holistic approach to care. Positive health approaches look at and build on the strengths and networks of families. In palliative care this approach is particularly pertinent in developing and enhancing quality of life. Therefore an approach of parallel planning where there is a plan for living life to the full, including accepting risks to enhance quality of life, and a plan for the end of life, is most appropriate. Therefore the care pathway through this stage must build on family strengths and supporting families to give their children the very best life possible. This ongoing care can continue for weeks, months or even years.

The reality is that the whole family is living with the uncertainty of a life-threatening condition. Recent studies have shown that despite all the difficulties, with careful assessment and planning, family life can become enriched, purposeful and fulfilling as they reframe their lives to make the most of the time they have with their child.

Many children will live their whole life during this stage of the pathway. It is therefore particularly important to help children and their family seize every opportunity to build memories and experiences. The use of an Advance Care Plan (ACP) may help to identify the child and family's wishes throughout this stage of the pathway.

The common theme in this stage is that care tends to be based around the child, their family and friends in their home and community. Initially families may feel particularly vulnerable. Unrealistic expectations not discussed with the family on discharge can lead to increased feelings of isolation, exhaustion, stress or depression.

Throughout a child's illness a wide variety of health, social services, education and voluntary agencies will become involved. Key working principles involve one agency taking a lead role, developing a crucial element of partnership working with the child and family (Better Care, Better Lives, 2008), enabling them to take control

of their situation and identify their needs. For many children the community children's nursing team take on this role of helping to co-ordinate care, liaising with the discharging hospital and providing a vital link with the child's consultant, GP and other key professionals.

In order for these teams to help families access the care and support best suited to their individual situation, it is essential that a full assessment of the child and family's needs takes place. This process should begin as soon as possible and should involve all disciplines and all agencies, involving assessment of health, psychosocial, practical, educational, spiritual and cultural needs.

### The third standard: Multi-disciplinary assessment of needs

**Every family should receive a child and family centred multi-disciplinary and multi-agency assessment of their needs as soon as possible after diagnosis or recognition, and should have their needs reviewed at appropriate intervals.**

#### What this means

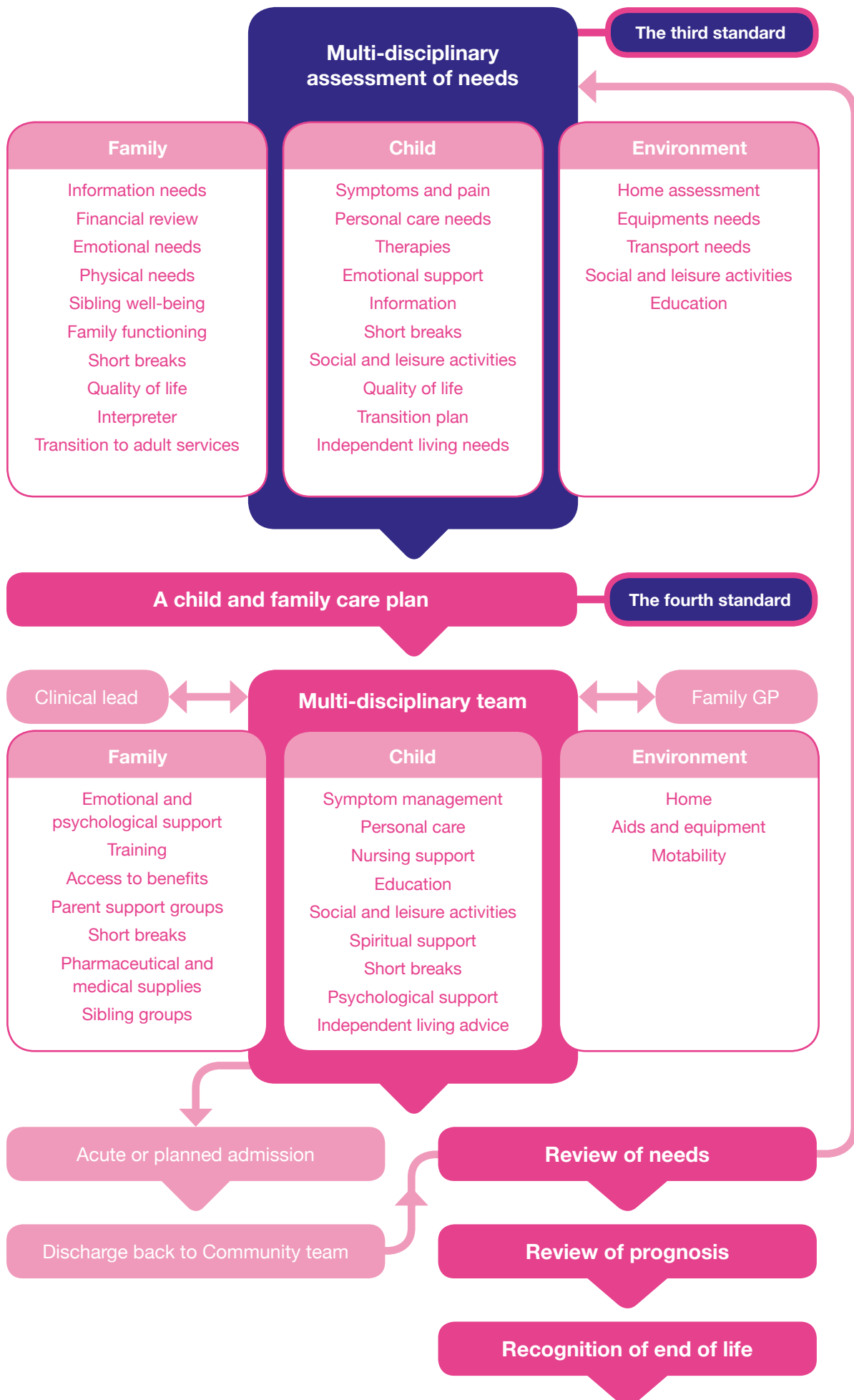
Assessments should take into account the child and family's preferences, the results of a holistic assessment and input from the wider multi-disciplinary team assessments.

#### Assessment of needs as soon as possible after diagnosis or recognition

The importance of the needs assessment cannot be understated. It forms the introduction to the care team that will play a central co-ordinating role. It provides an important foundation for building trust, partnership and support for future care. Assessment of the family's needs involves ongoing, in depth gathering, recording and sharing of information, with the child and family at the heart of the process.

The needs assessment will provide the opportunity for the child and family's hopes, wishes and concerns to be heard and for their full range of needs to be explored. It should empower the family and ensure that they can take control of their lives. It should reframe the relationship between professionals and families from professionally-led care to family-led care, where families are enabled to deliver the care their child needs to make the very most of the opportunities and time they have together. The ultimate goal should be for the family to have the very best life possible.

Figure 3: Core Care Pathway stage two: Ongoing care



### Lead role of one agency

It is important to be clear about which agency is taking lead responsibility for co-ordinating the care package. This will most often be the community children's nursing team or multi-disciplinary community team. The role of this team will be of vital importance to the family.

The multi-disciplinary needs assessment should enable staff to:

- Assess the full range of medical, nursing, practical, social, educational, psychological and spiritual needs.
- Explore the wishes, feelings and concerns of the child and family members.
- Reach an understanding of the individual situation and the impact on the child and family.
- Explore options within local provision.
- Culminate in an agreed plan for action.
- There may be a need to acknowledge that some of these needs will remain unmet.

The assessment should cover the needs of the whole family including fathers, siblings, grandparents and others identified by the child or young person.

The information to be gathered will include:

- Details of the professionals and services involved with the family.
- Medical information.
- Functional abilities of the child.
- Nursing and personal care needs.
- Emotional needs.
- Educational needs.
- The family's home circumstances.

Assessment should be seen as an ongoing process rather than a single event and, depending on the family, may take days or even weeks to complete. Information should be recorded systematically and stored securely.

The aim of the assessment is to examine how all the individual factors that have an impact on the child and family's quality of life, and guide the delivery of specific services to meet the needs of the family.

In figure 3, the types of need have been set down in three sections: the needs of the child in the central column; the needs of family down the left side; and factors concerning the family's environment down the right side.

For many families, the management of the child's symptoms will be their prime consideration. They need to be assured that their child's pain and symptoms will be minimised, and they will require ongoing support and assistance to achieve this. For children whose symptoms are stable, other issues may be of greater importance. Most children will want to enjoy some kind of 'normality' with their peers, so education, social and leisure opportunities are an essential part of the assessment process.

Many families find little time either for themselves or for their other children. The needs of all family members should be carefully considered, particularly their emotional needs and the need for short breaks. The family home may need adaptations to accommodate items such as wheelchairs, bath hoists, or other large apparatus. The child's school may need support, and the needs of the staff should be considered to enable them to manage the child's care.

It is important to remember that the needs of young people are different from those of younger children and should be considered accordingly. Their emotional needs are likely to be more acute and they will have additional issues such as body image, sexual needs and a need for independence. For more information, see the *Transition Care Pathway (Together for Short Lives, 2007)*.

### Key goals for multi-disciplinary assessment of needs

- Those undertaking assessments should be skilled in the assessment of children with palliative care needs.
- Children and families should have their strengths, needs and wishes assessed as soon as possible after diagnosis or recognition in partnership with the family.
- A holistic, multi disciplinary and multi-agency approach should be used to avoid the need for multiple assessments.
- The child or young person should be the central focus of the assessment.
- Care should be taken to include the strengths and needs of fathers, siblings and the wider family.
- To enable shared assessment, consent needs to be gained and confidentiality assured.
- Assessment information should be part of a family held document.

## The fourth standard: A child and family care plan

**Every child and family should have a multi-disciplinary, multi-agency care plan, developed in partnership with them for the delivery of co-ordinated care to enhance family strengths and meet need. A multi-disciplinary and multi-agency team should be identified in agreement with the family and use key working principles. Wherever possible this should involve all agencies involved in supporting the child and family, including the child's community nursing team, allied health professionals, hospice, local acute and tertiary hospital services, education, social care and short break services.**

### What this means

Multi-agency and multi-disciplinary care plans should be comprehensive and include the following elements:

- ✓ Details of the professionals involved plus contact details and identified lead professional duties.
- ✓ Identified multi-agency and multi-disciplinary team.
- ✓ Step by step goal-focused protocol for each aspect of clinical care.
- ✓ Personal care including a privacy and dignity plan.
- ✓ Dietary plan.
- ✓ Allied health professional plans.
- ✓ Emotional, spiritual and psychological care plan for the child and family.
- ✓ An outline of what will be provided by each service.
- ✓ Details of how to access services in and out of hours.
- ✓ Advance care plan including symptom management plan.
- ✓ Emergency care plan or escalation plan.
- ✓ Risk assessments, including moving and handling.

### Principles

The care plan should be a working document that reflects the needs of the child and the wishes and strengths of the child and family. The care plan should be shared with the family and with all organisations and services contributing to the child's care, to the level necessary in order to fulfil their contribution to care.

Parents need to know how to access services, and how to contact the different professionals participating in their child's care. An important principle will be for access to the services and professionals to be organised and co-ordinated for the family. They also need full information about services and the reassurance that their needs and wishes are understood by those with whom they come into contact.

- ✓ Environmental assessments.
- ✓ Agreement of care including parent and staff responsibilities.
- ✓ Information pertinent to the child's needs.
- ✓ Equipment information including manuals and guidelines.
- ✓ Stock lists.
- ✓ Competency based education plan for parents and staff.
- ✓ Play and education plans.
- ✓ Short breaks plan.
- ✓ Communication diary.
- ✓ Clinical updates.
- ✓ Policies where appropriate, for example on washing hands.
- ✓ Checklists for daily routine.
- ✓ Family strengths.

The plan should address both acute and chronic changes and deterioration in the child's condition. For some children it could be helpful to introduce specific local documentation around advance or emergency care planning during this stage of the pathway.



## Key working

Key working is one of the most important elements of support for children, young people and families – it helps them to live ‘ordinary’ lives and enables the growth of strong and resilient families. The overall aim of key working is to ensure the provision of holistic care and support to meet the individual requirements and aspirations of the child and their family. The care and support should be family-centred, not just child-centred. The individual offering key working support should strive for an open and supportive relationship with the child and their family, and this should be developed through regular and proactive contact.

Key working has developed from a role to a function so that it becomes integral to everyone’s role and all professionals and organisations supporting children and families are clear about what the key worker functions are.

### Key working functions

Taken from *In Early Support: Key working: improving outcomes for all* (Early Support, 2012) 2.2.

#### • Emotional and practical support

- Providing emotional and practical support as required, as part of a trusting relationship.
- Enabling and empowering the child or young person and their family to make decisions and use their personalised budgets in a way that is most effective for them.

#### • Co-ordination

- Being a single point of regular and consistent contact for the child or young person and family.
- Facilitating multi-agency meetings.
- Co-ordinating services and professionals around the child, young person and family.

#### • Planning and assessment

- Supporting a single planning and joint assessment process.
- Identifying the strengths and needs of all family members.

#### • Information and specialist support

- Providing information and signposting where necessary.
- Advocating on the child or young person’s and their family’s behalf where appropriate.
- Facilitating clinical care that is seamlessly integrated with specialist and universal services, where appropriate.

## Advance Care Planning

The Advance Care Plan (ACP) or emergency healthcare plan is a plan for life, giving information and guidance about the best way to care for the child, and to fulfil the child and family’s wishes in the event of intercurrent acute illness, and sudden deterioration in the child’s condition. It is more than just a wishes document; it has the status of a medical care plan. In addition it will provide a useful framework to support future discussions around care at the end of life. See the section on page 29 to read more about ACP.

Planning care in advance is helpful and often vital to ensure that a child receives the best care possible. Such plans may be documented locally as Advance Care Plans (which contain plans both for the emergency care if a child has intercurrent illnesses and also plans around care at the end of life) or as Emergency Care Plans (regarding care around a child’s acute deterioration, both reversible and irreversible), depending upon which format is recognised and used locally.

“I wanted them to write him a resuscitation plan because he was so vulnerable. I was terrified that they might not do anything if he had a sudden collapse, but they thought I wanted an end of life care plan and they just kept saying it wasn’t necessary because they would always resuscitate him anyway. What I wanted was a plan that said they were going to do everything they could – an emergency care plan would have been brilliant – it would have set my mind at rest.”

**Mother of a child with a complex respiratory condition**

## Information Support

Information is a vital part of a family’s needs. Initial information is often given at a time of intense emotional distress. Retention of information during stressful experiences can be extremely limited, and therefore the ongoing giving of information is essential. This information should also re-cap foundation knowledge. It is inevitable that families will have access to information via the internet, from contact with other families, through the professionals that they meet and from books and other literature. A key skill for the team will be helping families to understand the information they receive and to sift and prioritise it. Each team should have access to interpreters. The child and siblings should also be given information relevant for their age and level of understanding. Play specialists can often help both the child and their family make sense of the information they are given and should be introduced to the child and family as soon as possible.

“I never really fully understood how her central line worked until I sat in with the play specialist explaining it to my daughter.”

**Parent of a child with an oncology condition**

### **Transport issues**

Assessment of transport needs is essential for providing safe and practical care for children with complex and/or palliative care needs. Bulky equipment presents substantial issues in relation to transportation and the instability of the child's condition may require immediate access to transport.

Some families may have appropriate transport arrangements in place but they may require assistance in making them more practical, for example Blue Badge applications and choice of appropriate car seating.

For other families transport may need to be completely re-thought. Parents may need assistance in learning to drive and in looking into benefits such as the Motability scheme to access transport. Currently the mobility component of disability living allowance does not cover children under three, which can present significant difficulties for children with palliative care needs in this group.

Some important issues that may not always be included within a care plan but are vital to comprehensive care are discussed below.

### **Access to benefits**

The financial cost of illness and disability is significant. A child with a severe disability is estimated to cost twice as much to support as a child without a disability. (Contact a Family, 2012) Families may lose one income to facilitate caring and the lack of appropriate childcare can prevent families from finding alternative paid work. It is important that the family has information and support to assist them in accessing benefits. Not all benefits are means tested and all families have the right to apply. Complex and rare conditions often require considerable supporting evidence from health professionals to convince benefit agencies. The charity Contact a Family has developed an overview of all the main benefits and tax credits available, focusing on those aspects that affect families with disabled children.

[www.cafamily.org.uk](http://www.cafamily.org.uk)

The role of the children's Disability Social Worker may play a key part in the support of families who are struggling to cope. Parents and carers can

request a Carers Assessment and this alongside the child's initial and/or core assessment will provide the evidence for social workers to be able to ask managers for support services to be provided.

### **Access to short breaks**

The benefits of short breaks for children with life-limiting and life-threatening conditions and their families are widely recognised. Both children and families gain enormous benefit from short breaks that can provide time for children to have fun and try new experiences, their parents to rest and spend time together, or have space away from each other, or from the professionals who support the child's care at home. Services provided by the voluntary or statutory sector, including children's hospices for short breaks away from the home could be incorporated within the plan.

### **Access to education**

All children have a statutory right to education and this includes children with health conditions. Enabling school attendance for some will require support staff and highly complex planning while for others, physical needs may not be an issue. Community Children's Nurses can provide a vital link for this group of children. Direct contact between the child's lead teacher or Special Educational Needs Co-ordinator (SENCO) and the community health team is particularly useful.

### **Protection of carers' health**

With improvements in health treatments and techniques, life expectancy for many conditions has improved dramatically. This means many more children are living longer and the number of children reaching their teens has increased greatly (Fraser, L.K. et al., 2012). This has the result that some families are caring for many years, and long-term stress and exhaustion can seriously affect the health of carers. Lifting and transporting older children also takes its toll as carers themselves get older. Primary care services and the multi-disciplinary community team should work together to ensure that carers' health is considered. This should include psychological support and the care of siblings.

### **Access to aids and equipment**

Many families find that obtaining equipment or aids for their children is fraught with difficulties, with agencies seeming unwilling to co-operate. However there has been significant progress towards more integrated working, for example with sharing commissioning of equipment stores and Occupational Therapy posts across health and social care teams.

It is essential that families' needs for aids, equipment and adaptations are met in a timely manner. Teams should make every effort to advocate on behalf of families and assist with forms and meeting the appropriate agencies.

### Planning for transition to adult services

Timely and thorough planning for the transition from children's to adult services is essential. A clear framework to help young people, families and professionals adjust to, prepare for and move on to adult services is available within the *The Transition Care Pathway* (ACT, 2007).

### Continuous review of needs

Throughout this stage of the care pathway, the needs of the family will fluctuate. There are likely to be periods when there is relative stability but there are also likely to be events or developments when a greater level of active support and intervention is required. This could be an acute episode in the child's health or a planned intervention. These events may affect the family's ability to cope and there will be a period of adjustment to the new situation. The loss of what was their 'normality' and acceptance of the new and sometimes painful reality of changes in their child can be an emotional struggle. For many families, the need to review may relate to issues other than the health of the child. Services need to be able to provide sensitive, timely and appropriate support at times of change and instability to enable families to re-establish control.

Additional support and intervention may be required to support the family through an anticipated event such as their first family holiday away from home. Professionals should be available to support risk assessment and liaison with relevant agencies, ensuring that the family have appropriate support networks in place.

Regular reviews of the child and family's needs are necessary due to the uncertain prognosis and the increasing life expectancy of many children with life-limiting and life-threatening conditions. This means that it is important to maintain parallel planning throughout the child's life to ensure that appropriate support is being provided. The stability of the child may dictate the frequency of such reviews or there may be other factors which impact on the family's ability to cope. Families have different thresholds for managing complex issues that occur as the child grows up, such as the child starting nursery or school, transitioning from primary to secondary school or college, as well as challenges such as redundancy, marital

breakdown or family illness. Those professionals working closest with the family will need to be sensitive to their changing needs. Some families may need reviews only every six months, while others may need them much more often. It should also be possible for a family to request a review at any time.

The possibility that a review may be needed after a hospital admission should be acknowledged as the child's needs may have changed. In this case liaison between hospital and community staff for the transfer home will again be vital. For example, the child may go into hospital with complex needs, but the addition of a gastrostomy, which might appear to be a beneficial change, could prove overwhelming as parents feel that they have lost the important role of feeding and nurturing their child. This could also be a time when the child's prognosis could have changed. Care should be taken to consider the child's future and discuss the prognosis with the family. A change in prognosis may mean that the family makes different decisions and considers end of life scenarios. After each review, changes should be documented and incorporated into a revised care plan.

Regular multi-disciplinary and multi-agency review meetings are essential to ensure that co-ordination continues to be effective and that services and professionals are delivering the agreed care plan. The family's view of the delivery of their services will be a crucial part of this review.

### Key goals for a child and family care plan

- Every family should have a team that uses key working principles to co-ordinate the plan.
- Relevant and timely information should be available for the child and family.
- The plan should take account of the whole family's need and wishes.
- The plan should be comprehensive.

## Ongoing care: Resources to help

### Information on benefits:

[www.cafamily.org.uk/advice-and-support/resource-library/parent-guide-benefits-tax-credits-and-other-financial-help](http://www.cafamily.org.uk/advice-and-support/resource-library/parent-guide-benefits-tax-credits-and-other-financial-help)

### Community equipment services:

[www.communityequipment.org.uk](http://www.communityequipment.org.uk)

### Blue Badge Scheme:

[www.gov.uk/browse/driving/blue-badge-parking](http://www.gov.uk/browse/driving/blue-badge-parking)

Scottish Government (2007) *Getting it right for every child: Guidance on the Child's or Young Person's Plan* [www.scotland.gov.uk/Publications/2007/01/22142141/0](http://www.scotland.gov.uk/Publications/2007/01/22142141/0)

DCSF (2006) *Common Assessment Framework* (England) [www.education.gov.uk/childrenandyoungpeople/strategy/integratedworking/caf](http://www.education.gov.uk/childrenandyoungpeople/strategy/integratedworking/caf)

level of uncertainty. A cautious approach should be taken in predicting when a child may die, so that families do not miss out on precious moments with their child.

Parallel planning can help families prepare for the future and can make it feel acceptable to hope for the best alongside preparing for the worst. Many families have little time to acknowledge the reality of their situation and some may have been there many times before. Parallel planning provides a safety net in this situation. Parallel planning is also important in certain circumstances, for example a planned extubation, when there needs to be a plan for the child dying and one for continued support if the child lives for longer. This may be for hours, days, weeks or months longer than expected. Parents may become accustomed to their child being 'taken to the edge of life' and find it difficult to accept when death actually occurs. See *A Care Pathway to Support Extubation within a Children's Palliative Care Framework* (ACT, 2011) for more details.

## 3

## Stage three: End of life

Recognition of end of life is an important step within the care pathway and enables families and professionals to focus and plan for the death of the child. Multi-agency care planning and joint working is fundamental to the care of the child at this stage.

### Care before death – Recognition that end of life is approaching

Predicting the time when a child is likely to move into the end of life phase is not easy. For some, there may have been a series of peaks and troughs in the child's condition and it is not uncommon for children to return to greater stability following a period of serious decline. Very often after an illness the child does not return to their previous level of health. Health changes can be so subtle they may not always be easy to detect, and it is often helpful to support families by reflecting on the previous year. This will help clarify the level of deterioration, in order to make plans and prepare. Other conditions can make a child's condition so unstable that it can be difficult for health professionals to predict accurately what the future holds. For example, when an acute event occurs it may seem likely that the child will die, but they may unexpectedly rally. Professionals should not be worried about telling parents what they expect to happen, but should frame this with the correct

The realisation that death is imminent may be quite sudden: in some cases only days or just hours before death. The families of these children may have had little time to acknowledge this reality or plan for the death.

Transition into the end of life phase is perhaps clearer when there has been a decision to stop all life-prolonging treatment. In these situations the family will be aware that their child's death is inevitable and ideally they will receive care and support from professionals who are experienced and who know them. They will need reassurance that pain and other symptoms will be well controlled and that family-centred care will continue in the place of their choice if it is practical.

Professionals working with children and families at the end of life should be honest and open at all times. This may mean acknowledging professional uncertainty, while demonstrating an ongoing commitment to acting in the child's best interest and planning for all possible outcomes. Families should not be given false hope but instead be given realistic expectations of what may happen.

The term 'good death' is difficult to define, as it is personal to each individual. The important principle is that the child and family should be able to exercise choice and receive quality care and support. It is advisable to agree a plan in advance, based on the family's needs and wishes.

**Supporting the family's choices for quality of life**

Parents, siblings, grandparents and other significant family members should be encouraged and supported to continue their caring role with the child. Depending on the age of the child, the school community may continue to be involved and informed. The child may wish to continue with school work and this should be facilitated. He or she may want to continue seeing friends and carry on with other activities for as long as possible.

Emotional support is vital at this time and is best if it is provided by someone the family already knows and trusts. Some families find the thought of discussing death with their child extremely distressing and feel it is better to shield them from the truth. In all but the very youngest it is most likely that the child already knows that death is possible, and some can feel responsible for the distress this will cause the family. Planning together for death may provide a positive experience for both the child and the family at an otherwise unhappy time.

There may be special wishes or goals the child wants to achieve, or they may have an idea for the funeral or their belongings after death. They may want to provide a memory box for friends or family or they may have views about spiritual issues that they want to share. It is important that there is someone on the team, or known to the team, with the skill and compassion to support the family in approaching the discussion of death, and opening the possibility for the child or young person to make their own plans.

The person who is working with the family needs to be compassionate, have a good relationship with the family, understand of some of the issues they face, and able to stay alongside them throughout.

**Advance care plans**

Good communication and co-ordination between all relevant professionals and local services is essential to ensure that staff and families are aware of what care is available and that they are able to make informed choices. All staff should be aware if a child has an ACP, to inform them of their wishes around care and place of care and death.

An Advance Care Plan (ACP) is a record of the most sensitive thoughts and feelings that a child and family have about the care they wish to receive throughout their life and end of life. ACPs allow children, young people and their families to communicate their wishes for life and wishes for end of life, alongside management of acute and intercurrent illnesses. The difficult conversations

are best carried out by professionals with advanced communication skills, ideally who are known and trusted by the family.

An ACP can help families and professionals think about choices at the end of life. It can set out what actions should be taken when a child develops potentially life-threatening complications. Actions will be discussed and agreed by the child (when appropriate) and the family. It is important that children and their families have choices in the care they receive, and their place of care as they approach the end of their life. An ACP can help minimise inappropriate admissions and interventions, as well as facilitate choice. It is important to discuss the different models and approaches to care across different settings: hospice, home and hospital. It is essential that all available options are explored fully so that families are able to make realistic choices.

Advance care planning should involve decisions about resuscitation status and precise details about what the family want and do not want should be explored. It may be possible to develop a written Personal Resuscitation Plan with the lead consultant and other people looking after the child, to assist in communication between different professionals in different settings. This plan should also be shared with the local ambulance service.

An ACP should also address important issues such as:

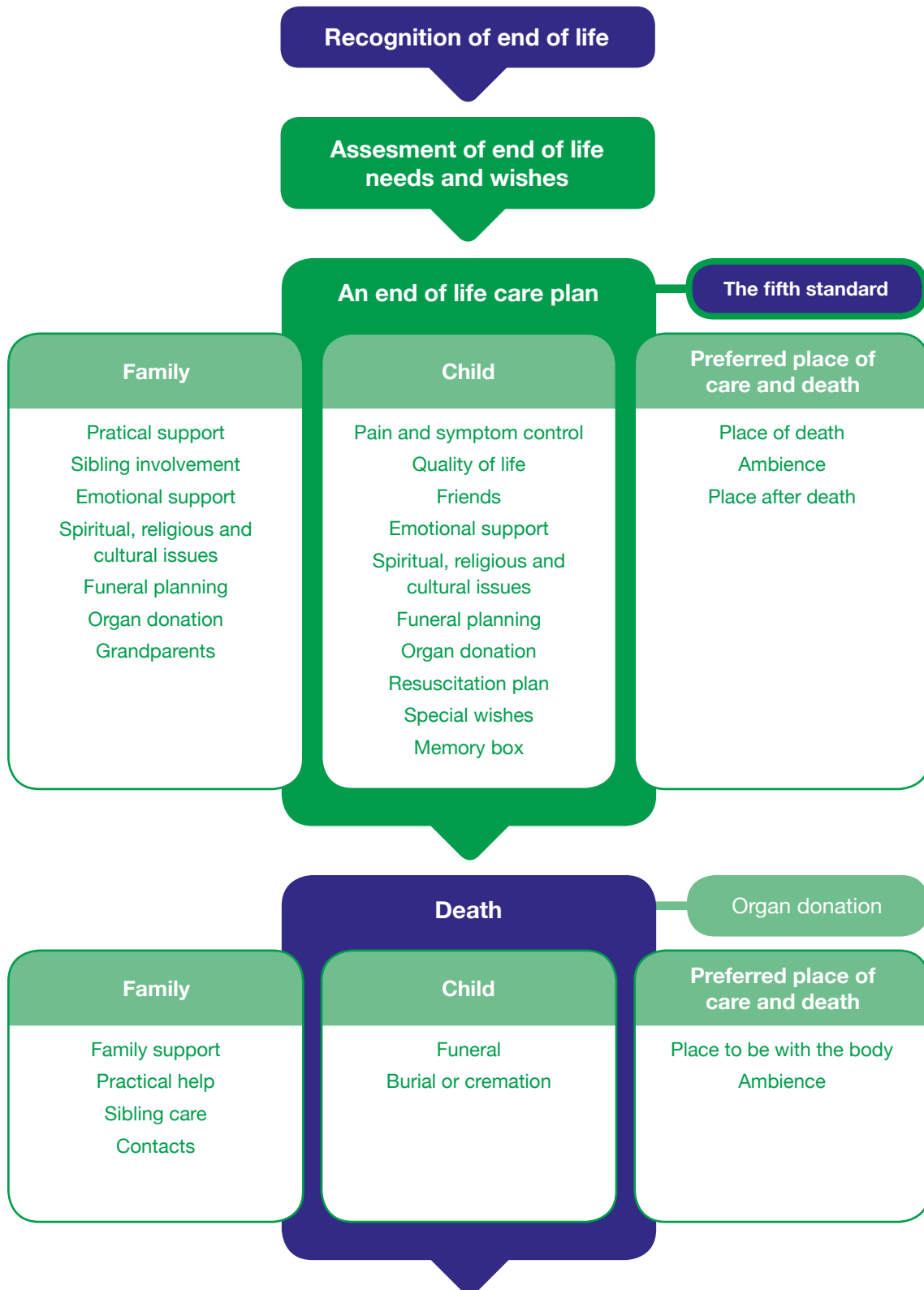
**Organ and tissue donation**

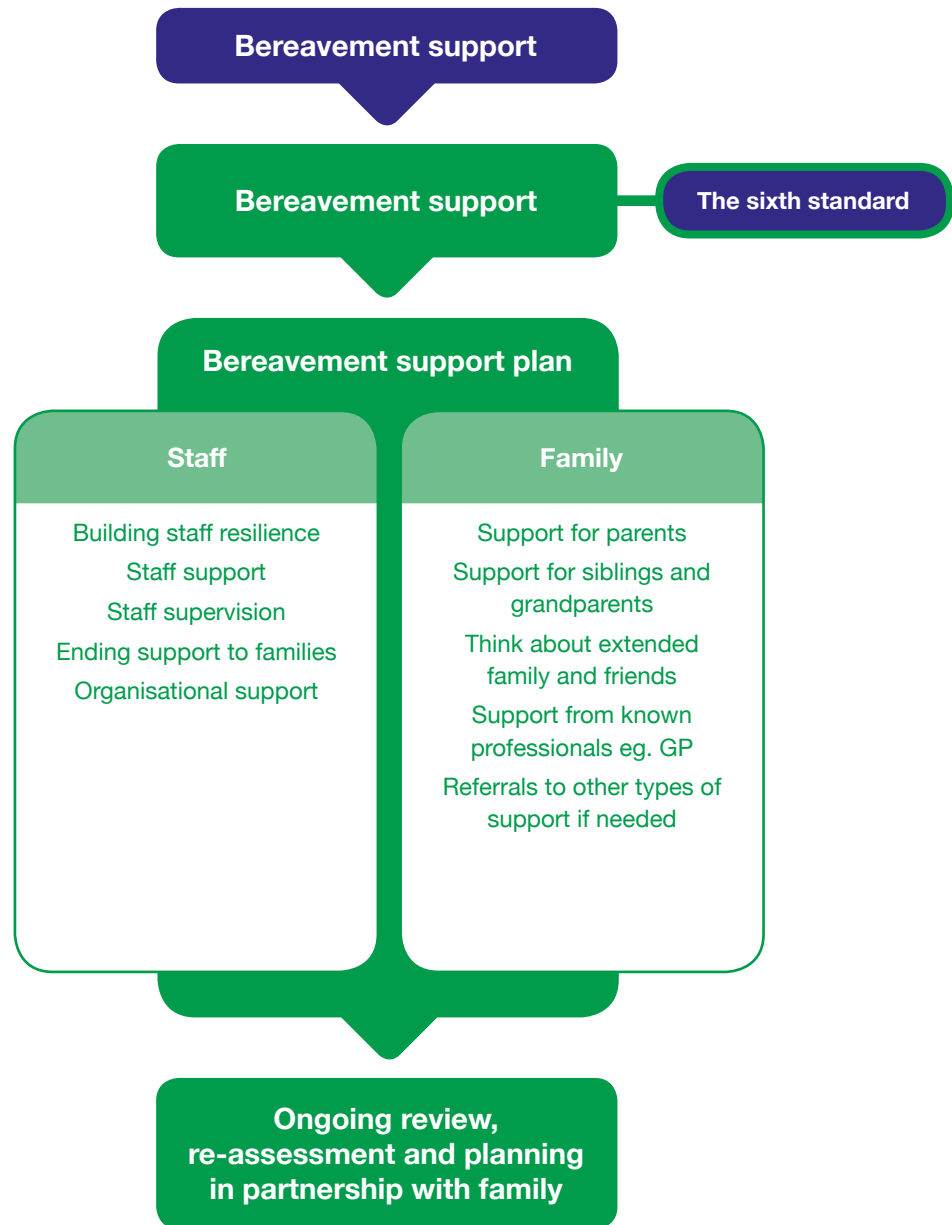
The family may wish to discuss the options with regard to organ or tissue donation. Parents should be fully informed about these issues and should feel that their decisions are understood and respected by all concerned. Young people with the capacity to decide independently should be involved in making decisions about this.

**Choices for place of care, death and after care of the child's body**

The ACP should address the question of preferred place of care at the time of death, and after death, and explore the family's preference for caring for their child's body after death. The environment in which the family feels most comfortable should also be a consideration. Many wish to be at home but others may choose a children's hospice or a hospital where they feel more confident to deal with emergencies. A combination of these places is also possible and this will require efficient collaborative working. Whatever the choice, the family will need 24 hour access to care in the end of life stage. Clarification will be needed about who will be prescribing medication, whether they

Figure 4: Core Care Pathway stage three: End of life and bereavement





have the appropriate skills and knowledge, and if not, who the supporting clinician will be. Planning will be required for supplies of medication and provision of out of hours pharmacy needs.

Professionals sometimes say that taking a child home or to a children's hospice can be problematic due to the shortness of time or because the child is technology dependent or may not survive the journey. In these instances it is important to explain these concerns to the family so that they can make an informed choice.

### **Post mortem**

Discussions surrounding post mortem may be required and families will need sensitive and clear information to assist them with any decisions. There are a number of reasons for a post mortem to be carried out, whether this is the choice of the family, a coroners request or a request from professionals. For further information see *A Guide to End of Life Care* (Together for Short Lives, 2012).

## **The fifth standard: An end of life care plan**

**Every child and family should be helped to decide on an end of life plan and should be provided with care and support to achieve this.**

### **What this means**

An end of life plan is a practical and more specific care plan relating to care at the time of death. An end of life plan should include:

- An assessment of the child's needs and a plan of care, discussed and developed with the child and their family. The child and family's choices and beliefs should be incorporated.
- A re-assessment of the child's current medication. If appropriate, 'non-essential' medication might be discontinued. Consideration should also be given about whether to discontinue inappropriate interventions at this stage such as blood tests, intravenous fluids and routine observation of vital signs.
- A symptom control plan which anticipates and prescribes for a range of possible symptoms such as pain, agitation, nausea and vomiting and respiratory tract secretion, and ensures that 'as required' subcutaneous and other medication is prescribed according to an agreed protocol to manage symptoms.

- A list of emergency contact details for the family of relevant staff and agencies. The GP practice, care team (for example, community children's nursing services, consultants) and others such as the ambulance, including out of hours service, should also be made aware that the child is now at their end of life stage.

### **Planning end of life care with the family**

As soon as it becomes apparent that the child is approaching the end of their life it is important that all professionals and agencies involved are brought together with the family to review and discuss their needs and wishes at this stage. This meeting should take place as soon as possible for the family, which could be a few weeks after the child is initially recognised as having a life-limiting condition. It may however need to be done urgently if the child is deteriorating rapidly. This is likely to be a very difficult time for the family and it may be the point at which they are facing the reality of their child's death for the first time. Some professionals who have been involved with the family may need to step back at this point and a new smaller core team identified to support the family. It will be important that within this team there are professionals with palliative care skills who are known to the family. It is important to recognise the family's need to have as much privacy as possible and that time with their child is very precious.

### **Support for staff**

It is important to recognise the need for peer support and supervision of staff so they are aware of their boundaries and at the same time acknowledging the emotional labour of caring for a child at the end of life. Clinical supervision and debriefs are also really valuable after death in supporting reflection and learning and improving care (Please see the Together for Short Lives *End of life planning series* for more information on staff support).

### **Effective symptom management**

This is important to ensure that the child's quality of life is maintained and the family have confidence in the professionals caring for their child in the face of unavoidable death. Children and young people can live for many years and enjoy their life to the full with effective symptom management. As end of life becomes evident, the way symptoms are managed can change. This may include difficult decisions surrounding the withdrawal of non-essential medications or other invasive interventions which should take place as part of end of life planning discussions.



It should be made very clear that sometimes when invasive treatment options such as ventilation are withdrawn after discussion with family and other professionals, that care is never withdrawn. The Royal College of Paediatrics and Child Health have published guidance on withdrawing treatment in children (RCPCH, 2004).

All discussions and planning should take place in the context of a multi-professional approach and involve those experienced in end of life planning, symptom management and who have knowledge of disease profiles. It is worth noting that not all symptoms will be solely physical or psychological.

All decisions should be child-centred and care should be delivered in partnership with the family. This involves skilled and sensitive communication, which empowers the child and family. Anticipatory prescribing, planning and preparing for the unexpected are key. A symptom management flowchart can sometimes be helpful to guide professionals and parents regarding likely symptoms and provide clear advice on the management of these symptoms.

#### **Difficult conversations**

Good communication is key to providing good care to children and families, especially at end of life. This involves careful listening, responding honestly and providing information, comfort and understanding at a difficult time. Getting these conversations right is the key to good end of life planning and it very helpful for professionals involved in these difficult conversations to have training in advanced communication skills.

#### **Care at the time of death**

This can be an extremely painful time for the family and also for those supporting them. The child will need to have loved ones close by, with necessary privacy and space. Professionals should be sensitive to the cultural and spiritual values and beliefs of families and should not obstruct the family's own preferences. It is always good practice to ask families directly about their beliefs, as these may be different from what is expected. Occasionally there may be conflict between the family and professionals regarding the best interests of the child (RCPCH, 2004).

It is helpful at this time for the family to consider what they want after the child's death. They will need to think about where they would prefer the child's body to go after their death. They will also need to consider who will need to be contacted, who will deal with the verification and death certification, whether there will be a post mortem, and whether they would like to discuss the

possibility of organ donation. If the family wishes to take the child home after death in hospital this should be recorded in the child's notes.

The child or young person must receive effective pain and symptom management. Anticipatory management may mean that medications are in the house just in case they are needed. The key will be ensuring that regular symptom reviews are undertaken and the right treatment administered. The appropriate analgesia should be administered at regular dosing intervals with adjunctive drug therapy for symptom and side-effect control.

It is possible that there will be a number of distressing symptoms and the child and family will need reassurance that these can be managed effectively and promptly. It is important that the family, the GP and the team have 24 hour access to a paediatric palliative care specialist, paediatrician or specially trained GP so that symptoms and pain can be controlled outside normal working hours and unnecessary emergency admissions to hospital can be avoided.

There are a range of pain assessment tools appropriate to the age and understanding of infants, children and adolescents, in particular the *Paediatric Pain Profile* (Institute of Child Health/ University College London/Royal College of Nursing Institute, 2003). It is important to maintain trust with the family and to seek external advice if symptoms are becoming difficult to control.

#### **Complementary therapies**

Music therapy, play therapy, story-telling, visualisation or relaxation techniques, and even hypnosis may have a role to play and should be considered as part of the care plan if the family wish.

#### **Communication at time of death**

The agreed end of life care plan will need to be documented, including a personalised resuscitation plan setting out what emergency treatment is to be used and what is not to be used by ambulance crews and local accident and emergency departments. It may be helpful to discuss this with the local emergency services and provide them with a copy of the document prior to death. The plan should allow for ongoing review of care and changing goals to comply with the wishes of the family. It is essential that the whole team is informed of changes and kept up to date with the child's care.

## Care after death

After death it is vital that parents retain control and have choice in the care of their child's body. Families need to have time and privacy with their child in the hours and days following the death. They need to know that almost anything they decide is possible, including moving the body to another place. Parents will appreciate advice from the care team or funeral director about care of the body at home (Dominica, 1997). In children's hospices a special 'cool room' may be available to the family in the days following death. It may also be possible to arrange for a mobile cooling device in the family home. For further details about a cool room and care after death see *A Guide to End of Life Care* (Together for Short Lives, 2012).

It is very important prior to death and after death that families are supported to build positive memories of their child. Taking a lock of hair, doing a hand and footprint and in some cases taking photographs, as this may be the first time for a long time they have seen their child's face without a tube in place, are all activities the family may wish to do.

Care should be taken to ensure that the family's religious or cultural beliefs and rituals are respected. Parents should be consulted about whether they want to be involved in laying out the child and choosing the clothes to be worn. They will need reassurance that their child will be treated with dignity and respect by any professional handling the body.

Play specialists can be particularly supportive for the child and family both before end of life and after. They can encourage the child and family to focus on building precious memories by working with all family members. Before end of life, play specialists can work with the child and siblings to build a memory box or create a portfolio of memorabilia for them to treasure after death.

Siblings should be given opportunities to express their emotions openly and ask questions. Their needs can often be overlooked by busy professionals, or parents overcome with grief. They should be asked if they wish to see their brother or sister's body and should not be excluded from decisions about funeral arrangements. They may decide they want to make a special contribution such as a prayer or a poem. They may also wish to place a gift or memento in their sibling's coffin. Play specialists have a definite role in supporting siblings through this time and early care planning should include the play specialist being introduced to siblings.

Grandparents and other close family members also need sensitive consideration as they are likely to be grieving not only for their grandchild but also for their own child's sake. Using a whole family approach empowers the family collectively and individually to select what support they need when they need it.

School communities may be dramatically affected by the death of a child, and education systems should include a process for supporting children, young people and staff through end of life, death and bereavement. It is important to remember the close relationship that may have been built between a child and their lunchtime supervisors and personal care staff, for example, and they should also be included in all supportive care. Schools can hold assemblies that celebrate the life of the child, organise fundraising events, plant a tree in memory or arrange for an achievement trophy to be awarded as an annual event.

There will be an immediate need to inform all those in contact with the family that the child has died. The family's key worker or another member of the team can assist in this if the family wishes. People to contact may include the GP, community or specialist nurses, health visitor, social worker, school, short breaks service, transport service, children's hospice and ambulance service. It is also important to ensure that any department or service expecting the child at an appointment is informed so that 'did not attend' letters are not sent out. Where appropriate, benefit agencies should be informed as soon as possible.

Written information should be provided for the family about procedures and entitlements following the death, including:

- Registering the death
- Procedure required for cremation
- Contact details of funeral director
- Advice on benefits or entitlements
- Information about the Child Death Review process

The same high standard should be expected in all settings. Environments where children die infrequently should have access to skilled advice from the staff who have already been supporting the child and family. This may include the children's hospice or community children's nursing teams. Staff members should be informed in advance as to how to care for the child and family at the time of death, and resources should be available to help them do this. The impact of the child's death on the staff must also be considered. For those who do not routinely care for dying children, this is likely to be a very distressing time.

Assisting them to care well for the child and family is the best action to help them to cope. In the event of a death on a general ward, staff may not always be clear about procedures. Training and simple written resources should be available to all staff, particularly where paediatric trained staff may not be available 24 hours a day.

When a death is expected it is usually not necessary to hold a post mortem. Some families may be asked if they will elect for post mortem examination to assist the furtherance of knowledge about rare childhood conditions. The family should not feel they are under any pressure or compulsion to agree to this and must be provided with full information about post mortem procedures. The consent of the family to their child's post mortem examination must be based on truth and understanding and they must be reassured that nothing will be happening that they have not agreed to. In very rare cases, such as sudden unexpected death or death after surgery, a post mortem may be required by the coroner and the family should receive the same full information about the procedures involved.

### Key goals for an end of life care plan

- Professionals should be open and honest with families when the approach to end of life is recognised.
- Joint planning with families and relevant professionals should take place as soon as possible.
- A written plan of care should be agreed and shared with emergency services, including decisions about methods of resuscitation.
- Care plans should be reviewed and altered to take account of changes.
- There should be 24 hours access to pain and symptom control including access to medication.
- Those managing the control of symptoms should be suitably qualified and experienced.
- Emotional and spiritual support should be available to the child and family.
- Children and families should be supported in their choices and goals for quality of life to the end.
- There needs to be clear understanding of the formal processes that are needed after death and the timing of these.

## The sixth standard: Bereavement support

**Bereavement support should be provided along the care pathway and continue throughout the child's death and beyond.**

### What this means

Bereavement is a fluid and dynamic process which is unique to every individual. People continue relationships, but their lives have also been totally shattered so they find themselves putting the pieces back together again. Bereavement support should be provided along the care pathway and continue through the child's death and beyond.

The death of the child is not the end of the care pathway for the family. They may experience grief for many years to come and may need support along the way. The family's bereavement support needs should be assessed, planned and delivered through their care team.

There is a considerable body of literature on bereavement. In the past some emphasis has been placed on concepts such as 'stages or tasks of grieving' (Wimpenny, Costello, 2011) but these may not always reflect the experiences or particular needs of bereaved families (Davies, 2004). More recent perspectives on parent grief such as 'continuing bonds' recognise that parents wish to continue 'holding on' to their relationship with their child rather than 'letting go'.

Those who have been involved with a family throughout their journey are probably best placed to offer support. Where this is not possible, bereavement support may be provided through referral to other services, for example the family GP or a local children's hospice. Grief is a normal reaction, but specialist counselling by a qualified practitioner should be available if the family need this. The family should know what help is available and feel able to ask for it if they need it. Those in the team who are working with the family should make follow-up contact based on assessed need and if appropriate, liaise with the lead bereavement professional to ensure that the family's needs are met.

Some families may find it helpful to set aside an identified time each day within the first few months when they know they can focus on the death of their child, rather than feeling that their grief consumes them every hour of the day. It is helpful if difficult times such as birthdays, religious festivals or the anniversary of the child's death are remembered.

Particular care is needed with siblings. Brothers and sisters have been referred to as the ‘forgotten mourners’ because they may not have expressed their needs directly (Hindmarsh, 2000). Siblings are affected not only by the loss of their brother or sister but by the impact it has on the family and the relationships within it. Children should be included and not shielded from the grief felt by others in the family, so that they do not feel that they also have to hide their feelings. Siblings may find it helpful to attend the funeral and take part in other family events and rituals with appropriate information and support.

Sibs is a UK charity representing the needs of siblings of disabled people. They produce a number of useful resources for families.

[www.sibs.org.uk](http://www.sibs.org.uk)

The family may also experience secondary losses such as the changed nature of their relationships with one another, with other family members or with the professionals who have cared for them and their child. The intensive involvement, the feeling of friendship and support of the members of the team will largely cease and many families feel suddenly cut off from what was previously a major part of their lives. The family GP and primary care team should be prepared to provide support for many years. In addition they may suffer financial hardship as allowances are likely to be withdrawn or reduced.

No one can anticipate quite how they will feel or react after the death of their child; most people describe a ‘rollercoaster’ of emotions, ranging from numbness to furious anger, profound sadness to sometimes a certain relief. Seemingly irrational behaviour and reactions are also very common, as well as overwhelming physical exhaustion or ‘manic’ energy and compulsive activity. Families, communities and cultures may grieve and mourn differently, and rituals can often help to bring healing and closure. It’s worth keeping in mind that while there are similarities, children do not grieve in the same way as adults.

### Staff supervision and support

It is very important that children’s palliative care professionals have good support and supervision. This is key to providing good care to a child and family, and the individual professional has a responsibility to build their own resilience, to care for themselves and other colleagues.

Professionals involved in caring for children and young people with life-limiting and life-threatening conditions should have robust supervision in place, be aware of their professional boundaries and at the same time recognise the emotional labour of caring for a child and family at the end of life. This needs to be acknowledged by their employer.

There can be many different professionals involved with a family with different professional backgrounds and it is important that after the death of a child there is a formal debrief or time of reflection offered even when it goes well. It is just as important to celebrate when it goes well as it is to reflect when things could have gone better. These times of reflection and learning are important for improving care in the future. This in turn will also build resilience and sustainability within services.

The key to this is regular clinical supervision, self-care and working within strong professional and team boundaries. This in turn helps build resilience to continue to be effective in the delivery of children’s palliative care.

Bereavement should be seen as a ‘normal process’ but different groups of parents may have different needs depending on the nature of their child’s death.

### Key goals for bereavement support

- The family should be allowed time and privacy with their child.
- Parents should feel in control of events before and after the death and should be able to follow their own choices and wishes.
- Families should all be offered bereavement support, and this offer should be repeated as it may well not be heard or taken up in the first instance.
- The bereavement needs of siblings should be recognised and supported.
- The needs of care staff should be considered including supporting staff in ending their involvement with the family as part of agreed bereavement plans.

### End of life: Resources to help

Jassal, S. (2011) *Basic Symptom Control in Paediatric Palliative Care* (8th Edition)  
[www.togetherforshortlives.org.uk/symptomcontrol](http://www.togetherforshortlives.org.uk/symptomcontrol)

Association of Paediatric Palliative Medicine (2012) *Master Formulary* [www.appm.org.uk](http://www.appm.org.uk)

General Medical Council (2010) *Treatment and care towards the end of life – good practice in decision making* [www.gmc-uk.org/guidance/ethical\\_guidance/end\\_of\\_life\\_care.asp](http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp)

Goldman, A. Hain, R. and Liben, S. (2012) *Oxford Textbook of Palliative Care for Children*, Section three.

West Midlands Paediatric Palliative Care Network (2011) *West Midlands Children and Young People's Palliative Care Toolkit: Algorithms on symptom management* (sections 3-16)  
[www.togetherforshortlives.org.uk/externalresources](http://www.togetherforshortlives.org.uk/externalresources)

Together for Short Lives (2011) *A Parent's Guide: Making critical care choices for your child*  
[www.togetherforshortlives.org.uk/criticalcare](http://www.togetherforshortlives.org.uk/criticalcare)

**Child Bereavement UK** produces various resources to help support families through bereavement: [www.childbereavementuk.org](http://www.childbereavementuk.org)

**Winston's Wish** have a special area of their website for bereaved children and young people: [www.winstonswish.org.uk/foryoungpeople](http://www.winstonswish.org.uk/foryoungpeople)

**Perinatal** support website: [www.perinatalhospice.org](http://www.perinatalhospice.org)

**Sibs** is the only UK charity representing the needs of siblings of disabled people. Sibs support siblings of all ages who are growing up with or who have grown up with a brother or sister with any disability, long term chronic illness, or life limiting condition: [www.sibs.org.uk](http://www.sibs.org.uk)

Together for Short Lives (2012) *A Guide to End of Life Care* [www.togetherforshortlives.org.uk/eol](http://www.togetherforshortlives.org.uk/eol)

“When our second child was born with a complex condition we had moved and had a local community children’s nursing team. Our nurse said to us “You will not be on your own. We will be with you every step of the way”, and true to their word that is how it has been. The team has taught us how to care for [our child]. Recognising symptoms and daily physiotherapy and medicines started to become part of everyday life. The team have the most amazing positive approach; they are our teacher, coach, listener and friend.”

**Family, Midlands**

# Appendices

## Appendix one: Glossary

### **Care pathway/journey**

ACT's description of a care pathway approach to working with children who have life-limiting and life-threatening or life-threatening conditions is a way of engaging with a child and their family's needs, which can be used to ensure that everything is in place so that families have access to the appropriate support at the appropriate time.

### **Children's palliative care**

Palliative care for children with life-limiting and life-threatening conditions is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement. (Together for Short Lives, 2013)

### **Care of the dying**

Care of the dying is the care of the patient and family in the last days and hours of life. It incorporates four main types of care: physical, psychological, social and spiritual, and supports the family at that time and into bereavement.

### **Children**

Throughout this document, the term 'children' is used to describe babies, children and young people up to their 19th birthday.

### **Children's hospice services**

Children's hospice services provide palliative care for children and young people with life-limiting conditions and their families. Delivered by a multi-disciplinary team and in partnership with other agencies, children's hospice services aim to meet the needs of both child and family – physical, emotional, social and spiritual – through a range of services.

These include:

- 24 hour access to emergency care.
- Specialist short break care.
- 24 hour telephone support.
- Practical help, advice and information.
- Provision of specialist therapies, including physiotherapy, play and music therapy.
- Support, education and training for carers.
- 24 hour end of life care.
- Support for the entire family (including siblings, grandparents and the extended family).
- Bereavement support.

Children's hospice services deliver this care in the home (commonly termed 'hospice at home service') and/or in a purpose built building.

### **Complex care/continuing care**

Complex care, sometimes known as continuing care, is an individualised package of care beyond what is available through standard health services. It is provided to children with highly complex health care needs or intense nursing care needs.

### **Community services**

Community services refer to a service that an individual or organisation performs within the local community. This might include community children's nurses (CCNs) who deliver nursing care and support within the local community including visiting a patient's home. Community services may also include some of the services delivered by the local council.

### **End of life**

The end of life stage begins when a judgement is made that death is imminent. It may be the judgement of the health or social care team, but it is often the child or young person or their family who first recognises its beginning.

**End of life care**

End of life care helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It focuses on preparing for an anticipated death and managing the end stage of a terminal medical condition. This includes care during and around the time of death, and immediately afterwards. It enables the supportive and palliative care needs of both child and their family to be identified and met throughout the last stage of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support and bereavement support for the family. This is not confined to specialist services but includes services provided by any health or social care professional in any setting.

**Family**

The term 'family' includes parents, other family members involved in the child's care, or other carers who are acting in the role of parents. Family includes informal carers and all those who matter to the child or young person.

**Hospice at home**

Hospice at home is a term commonly used to describe a service which brings skilled, practical children's palliative care into the home environment. Hospice at home works in partnership with parents, families and other carers.

**Key working**

Key working or care co-ordination is a service involving two or more co-ordinated agencies. It encompasses individual tailoring of services based on assessment of need, inter-agency collaboration at strategic and practice levels and a named key worker for the child and their family. (Care Co-ordination Network UK, 2006).

**Life-limiting/life-shortening conditions**

Life-limiting conditions, sometimes known as life-shortening conditions, are those for which there is no reasonable hope of cure and from which a child or young person will die. Some of these conditions cause progressive deterioration rendering the child increasingly dependent on parents and carers.

**Life-threatening conditions**

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

**Needs-led**

Need-led is the term used to describe services provided on the basis of the needs of the patient and family, rather than as a result of assessing the resources that are available.

**Parents**

The term 'parents' is used to mean any carer for a child whether that is a married or unmarried couple, a single parent, guardian or foster parent.

## Appendix two: Useful organisations

Listed below are some of the national organisations that provide support for babies, children and young people with life-limiting conditions and their families. There are many others and this is by no means an exhaustive list. Please call Together for Short Lives 0117 989 7820 for details of other sources of support.

**Bliss**

Bliss is the special care baby charity which provides vital support and care to premature and sick babies across the UK. Bliss offers guidance and information, funds research and campaigns for babies to receive the best possible level of care regardless of when and where they are born.

[www.bliss.org.uk](http://www.bliss.org.uk)

Tel: 0207 378 1122

Helpline: 0500 618140

Email: [hello@bliss.org.uk](mailto:hello@bliss.org.uk)

**Carers Trust**

Carers Trust works to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

[www.carers.org](http://www.carers.org)

Tel: 0844 800 4361

Email: [info@carers.org](mailto:info@carers.org)

**Carers UK**

Carers UK is a charity set up to help people who care for family or friends. They provide information and advice about caring alongside practical and emotional support for carers. Carers UK also campaigns to make life better for carers and influences policy makers, employers and service providers, to help them improve carers' lives.

[www.carersuk.org](http://www.carersuk.org)

Tel: 0207 378 4999

Advice line: 0808 808 7777

### **Cerebra**

Cerebra is a charity set up to help improve the lives of children with brain related conditions through research, education and directly supporting the children and their carers.

[www.cerebra.org.uk](http://www.cerebra.org.uk)

Tel: 01267 244229

Email: [info@cerebra.org.uk](mailto:info@cerebra.org.uk)

### **Child Bereavement UK**

Child Bereavement UK supports families and educates professionals both when a baby or child dies or is dying, or when a child is facing bereavement. Every year they deliver training to around 5000 professionals at the front line of bereavement support.

[www.childbereavementuk.org](http://www.childbereavementuk.org)

Tel: 01494 568900

Email: [enquiries@childbereavementuk.org](mailto:enquiries@childbereavementuk.org)

### **Childhood Bereavement Network**

The Childhood Bereavement Network (CBN) is the hub for those working with bereaved children, young people and their families across the UK. They underpin members' work with essential support and representation: bringing them together across localities, disciplines and sectors to improve bereavement care for children.

[www.childhoodbereavementnetwork.org.uk](http://www.childhoodbereavementnetwork.org.uk)

Tel: 0207 843 6309

Email: [cbn@ncb.org.uk](mailto:cbn@ncb.org.uk)

### **The Child Death Helpline**

The Child Death Helpline is a helpline for anyone affected by the death of a child of any age, from pre-birth to adult, under any circumstances, however recently or long ago.

[www.childdeathhelpline.org](http://www.childdeathhelpline.org)

Helpline: 0800 282 986

Email: [contact@childdeathhelpline.org](mailto:contact@childdeathhelpline.org)

### **CLIC Sargent**

CLIC Sargent is a cancer charity for children and young people, and their families. They provide clinical, practical, financial and emotional support to help families cope with cancer and get the most out of life. They are there from diagnosis onwards and aim to help the whole family deal with the impact of cancer and its treatment, life after treatment and, in some cases, bereavement.

[www.clicsargent.org.uk](http://www.clicsargent.org.uk)

Tel: 0300 330 0803

### **Climb (Children Living with Inherited Metabolic Diseases)**

Climb aims to provide Metabolic Disease specific information, advice and support to children, young people, adults, families and professionals in the United Kingdom and information and support to families worldwide, to fund educational and primary research programmes and to investigate treatments and medical services.

[www.climb.org.uk](http://www.climb.org.uk)

Helpline: 0800 652 3181

Email: [enquiries@climb.org.uk](mailto:enquiries@climb.org.uk)

### **The Compassionate Friends (TCF)**

TCF is a charitable organisation of bereaved parents, siblings and grandparents dedicated to the support and care of other bereaved parents, siblings and grandparents who have suffered the death of a child or children. They offer support both directly to bereaved families and indirectly by fostering understanding and good practice amongst professionals concerned with child death and by increasing public awareness.

[www.tcf.org.uk](http://www.tcf.org.uk)

Helpline: 0845 123 2304

Email: [info@tcf.org.uk](mailto:info@tcf.org.uk)

### **Contact a Family**

Contact a Family is a national charity that exists to support the families of disabled children whatever their condition or disability. Their vision is that families with disabled children are empowered to live the lives they want and achieve their full potential, for themselves, for the communities they live in, and for society. They offer support, information and advice to over 340,000 families each year and campaign for families to receive a better deal.

[www.cafamily.org.uk](http://www.cafamily.org.uk)

Helpline: 0808 808 3555

Email: [info@cafamily.org.uk](mailto:info@cafamily.org.uk)

### **Cystic Fibrosis Trust**

The Cystic Fibrosis Trust funds research to understand CF better and to develop new and better treatments, they set standards of CF care and review services to make sure they are meeting those standards, and provide information and advice to people with CF and their families.

[www.cftrust.org.uk](http://www.cftrust.org.uk)

Helpline: 0300 373 1000

Email: [enquiries@cftrust.org.uk](mailto:enquiries@cftrust.org.uk)



**GOV.UK**

Information about government services.

[www.gov.uk](http://www.gov.uk)

**Disabled Living Foundation**

DLF is a national charity that provides impartial advice, information and training on daily living aids.

[www.dlf.org.uk](http://www.dlf.org.uk)

Helpline: 0845 130 9177

Email: [info@dlf.org.uk](mailto:info@dlf.org.uk)

**Genetic Alliance UK**

Genetic Alliance UK is a national charity supporting all those affected by genetic conditions. They aim to improve the lives of people affected by genetic conditions by ensuring that high quality services and information are available to all who need them.

[www.geneticalliance.org.uk](http://www.geneticalliance.org.uk)

Tel: 0207 704 3141

Email: [contactus@geneticalliance.org.uk](mailto:contactus@geneticalliance.org.uk)

**Maypole Project**

The Maypole Project provides support for children with complex medical needs and their whole family. They support over 190 children with life-limiting and life-threatening illnesses and their families every year across South East London.

[www.themaypoleproject.co.uk](http://www.themaypoleproject.co.uk)

Tel: 01689 889889

Email: [helpline@themaypoleproject.co.uk](mailto:helpline@themaypoleproject.co.uk)

**Muscular Dystrophy Campaign**

The Muscular Dystrophy Campaign is a UK charity focusing on muscular dystrophy and other related conditions. They are dedicated to beating muscular dystrophy and other related conditions by finding treatments and cures and to improving the lives of everyone affected by them.

[www.muscular-dystrophy.org](http://www.muscular-dystrophy.org)

Information Line: 0800 652 6352

Email: [info@muscular-dystrophy.org](mailto:info@muscular-dystrophy.org)

**Newlife Foundation for Disabled Children**

Newlife Foundation helps disabled and terminally ill children in the UK. It provides equipment to help individual children, nurse led support services, pioneering medical research, awareness and campaigning.

[www.newlifecharity.co.uk](http://www.newlifecharity.co.uk)

Tel: 01543 462777

Nurse Helpline: 0800 902 0095

Email: [info@newlifecharity.co.uk](mailto:info@newlifecharity.co.uk)

**Organ Donation**

[www.organdonation.nhs.uk](http://www.organdonation.nhs.uk)

Tel: 0117 975 7575

Information line: 0300 123 2323

Email: [enquiries@nhsbt.nhs.uk](mailto:enquiries@nhsbt.nhs.uk)

**Rainbow Trust Children's Charity**

Rainbow Trust Children's Charity provides practical and emotional support to families who have a child with a life-threatening or terminal illness.

[www.rainbowtrust.org.uk](http://www.rainbowtrust.org.uk)

Tel: 01372 363438

Email: [enquiries@rainbowtrust.org.uk](mailto:enquiries@rainbowtrust.org.uk)

**REACT**

React (Rapid Effective Assistance for Children with Potentially Terminal illness) is a charity working to improve the quality of life for children with life-limiting illnesses living in financially disadvantaged households throughout the UK.

[www.reactcharity.org](http://www.reactcharity.org)

Tel: 0208 940 2575

Email: [react@reactcharity.org](mailto:react@reactcharity.org)

**Samaritans**

Samaritans' vision is that fewer people die by suicide. They work to achieve this vision by making it their mission to alleviate emotional distress and reduce the incidence of suicide feelings and suicidal behaviour.

[www.samaritans.org](http://www.samaritans.org)

Helpline: 08457 909090

Email: [jo@samaritans.org](mailto:jo@samaritans.org)

**Sands**

Sands is an organisation supporting anyone affected by the death of a baby and promotes research to reduce the loss of babies' lives.

[www.uk-sands.org](http://www.uk-sands.org)

Tel: 0207 436 7940

Helpline: 0207 436 5881

Email: [support@uk-sands.org](mailto:support@uk-sands.org)

**Sibs**

Sibs is a UK charity representing the needs of siblings of disabled people. Siblings have a lifelong need for information, they often experience social and emotional isolation, and have to cope with difficult situations. They also want to have positive relationships with their disabled brothers and sisters and to be able to choose the role they play in future care.

[www.sibs.org.uk](http://www.sibs.org.uk)

Tel: 01535 645453

Email: [info@sibs.org.uk](mailto:info@sibs.org.uk)

## SWAN UK

SWAN UK (Syndromes Without A Name) is a project run by Genetic Alliance UK offering support and information to families of children with undiagnosed genetic conditions.

[www.undiagnosed.org.uk](http://www.undiagnosed.org.uk)

Tel: 0207 704 3141

Email: [swan@geneticalliance.org.uk](mailto:swan@geneticalliance.org.uk)

## Tamba

The Twins and Multiple Births Association (Tamba) is a charity set up by parents of twins, triplets and higher multiples and interested professionals. It helps parents and professionals to meet the unique challenges that multiple birth families face.

[www.tamba.org.uk](http://www.tamba.org.uk)

Tel: 01483 304442

Email: [enquiries@tamba.org.uk](mailto:enquiries@tamba.org.uk)

## Winston's Wish

Winston's Wish is a childhood bereavement charity and provider of services to bereaved children, young people and their families in the UK.

[www.winstonswish.org.uk](http://www.winstonswish.org.uk)

Helpline: 0845 20 30 40 5

Email: [info@winstonswish.org.uk](mailto:info@winstonswish.org.uk)

## Appendix three: References

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## A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions

This *Core Care Pathway for Children with Life-limiting and Life-threatening Conditions* is the revised third edition of the world's first care pathway for children with palliative care needs, published in 2004.

The *Core Care Pathway* aims to ensure that families experience a co-ordinated approach to care, which places them at the centre of the planning process, throughout the every stage of their child's life, and beyond. It can be used in the care of any child with a life-limiting condition, no matter of age, condition or care setting.

This pathway is intended to be adapted for local use according to local protocols, resources and circumstances, and can be used alongside more specific pathways associated with a particular disease or condition.

This third edition builds on the success of the original care pathway, now widely adopted across many care settings, including children's hospices, hospitals, community care and intensive care units. It reflects the developments in children's palliative care, and the changes to healthcare provision that have taken place over the past eight years. It also includes a new 'standard' on bereavement, which will help make sure the family's needs are met beyond the death of their child.

The *Core Care Pathway* is relevant for all members of the team caring for a child who has either a life-limiting or life-threatening condition, including those who work regularly in children's palliative care, and those providing more generalist services. It will also be useful for those planning the delivery of services, such as directors of care and commissioners.

Together for Short Lives produces a suite of pathways which can be used alongside this *Core Care Pathway*. Find out more at [www.togetherforshortlives.org.uk/carepathways](http://www.togetherforshortlives.org.uk/carepathways)



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