



Valuing short lives

# A Neonatal Pathway for Babies with Palliative Care Needs

First edition 2009



**ACT** for children **ACT** for families **ACT** together **ACT** now!

# About ACT

## ACT for children

Hearing the news that your child has a health condition that is life-threatening or will shorten their life is devastating. It's a time when families need care, support and information. ACT aims to help families and children along this journey, every step of the way.

There are approximately 23,500 children and young people in the UK who have been diagnosed with health conditions for which there is no reasonable hope of cure.

ACT works with policy makers and practitioners to improve practice and provision and to raise awareness of what children, young people and families need. It also campaigns for the development of integrated, equitable and sustainable children's palliative care services.

## ACT for families

ACT helps family members, friends and carers, and provides them with the information and support they need in order to access the best possible care. We lobby on their behalf, and empower families to have a voice in the development of services.

ACT provides families with publications, resources, information and a free regular newsletter called *ACT for families*. ACT has a UK-wide online *Find Help* service that directs families and professionals to the services and support they need, and also runs a national helpline.

## ACT together

ACT represents a membership of almost 800 families and children's palliative care professionals. We provide our members with a range of benefits including publications, newsletters and information bulletins and offer professional support and guidance.

ACT works with professionals to develop and share best practice and the evidence base of what works best.

By working together we are better placed to raise awareness of what children and families need. The bigger our voice, the more we can achieve.

## ACT now!

Help us continue the important work we do to raise awareness and ensure children and young people who are not expected to reach adulthood have the best possible quality of life and care.

If you would like to become a member of ACT and help strengthen the voice of those caring for life-limited children and young people, please get in touch.

If you would like to discuss how you can develop a neonatal care pathway for your service, please contact ACT.

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Follow ACT on Twitter and be the first to hear about developments in children's palliative care across the UK. [www.twitter.com/ACTforfamilies](http://www.twitter.com/ACTforfamilies)

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*A Neonatal Pathway for Babies with Palliative Care Needs* is endorsed by Bliss and the Child Bereavement Charity.



Valuing short lives

**ACT** is the only organisation working across the UK to achieve the best possible quality of life and care for every life-limited child and their family.

ACT is a registered charity and a company limited by guarantee. Registered Charity No. 1075541 Company Registration No. 3734710 England

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# Contents

<b>Acknowledgements</b>	6
<b>Foreword</b>	7
<b>Introduction</b>	9
A Neonatal Pathway for Babies with Palliative Care Needs: Pathway summary diagram	11
<b>Part One: The ACT approach to children's palliative care</b>	13
Introduction to children's palliative care	13
Neonatal palliative care	15
The ACT care pathway approach	16
The need for a neonatal care pathway	16
Principles of the neonatal care pathway	18
<b>Part Two: The Neonatal Pathway for Babies with Palliative Care Needs</b>	21
<b>Stage One: Entry to the pathway</b>	21
The First Standard – Breaking news	22
The Second Standard – Planning for going home	24
<b>Stage Two: Living with a life-limiting or life-threatening condition</b>	26
The Third Standard – A multi-agency assessment of the family's needs	26
The Fourth Standard – A multi-agency care plan	28
<b>Stage Three: End of life and bereavement</b>	30
The Fifth Standard – An end of life plan	30
The Sixth Standard – Continuing bereavement support	34
<b>Part Three: Appendices</b>	37
<b>Appendix One:</b> The ACT Charter	37
<b>Appendix Two:</b> Glossary of terms	38
<b>Appendix Three:</b> Directory of useful organisations	40
<b>Appendix Four:</b> References	43

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# Foreword

Every year around 80,000 babies are admitted to special care baby units across the UK. This is one every six minutes. About a quarter of these babies will be admitted to intensive care, fighting for their lives.

The outcomes for very small or very sick babies continue to improve every year, but are often difficult to predict. They are the convergence of many inter-related issues, right at the edge of medical science. Sadly for many hundreds of families every year, including my own, even the best clinical care can not save their baby and uniquely challenging decisions need to be faced by families and professionals.

Having a baby in a neonatal unit is a hugely stressful and emotional experience at the best of times; a daily rollercoaster of emotions as the condition of your baby changes. The impact of a baby passing away in the first few days, weeks or months is almost beyond comprehension. Almost all babies who die, still die on a neonatal unit. For many the opportunity of consistent support through this time, to take their baby home or to consider the use of hospice services, is not available as it is for older children. This needs to change.

There is more focus on neonatal care today than at almost any time in the past decade. The publication of the NHS Neonatal Taskforce documents in England, the Maternity Services Action Group report in Scotland and the All Wales Neonatal Standards have put neonatal issues towards the top of the health agenda. In parallel to the emphasis on high quality clinical care in these policy documents is the equal objective of ensuring that babies and their families are treated with respect and dignity and have their individual care requirements identified. This includes social and psychological support, and also a welcome emphasis on the importance of palliative care and bereavement support. All of this makes the publication of this new pathway extremely timely.

I hope that you will be able to use this excellent and comprehensive document to review your current practice and to identify any improvements in the care that you and your team offer.

More importantly I hope that this document will stimulate some positive debate among neonatal and palliative care professionals about the importance of providing palliative care support to sick and premature babies, especially outside of the hospital environment. This is often challenging, especially in the economic conditions that the NHS currently faces. However it is usually very small changes on a unit or in a network, those that require some time and thought rather than significant sums of money, that can make the biggest difference in providing high quality care. The benefits to these babies and their families are almost without measure.



**Andy Cole**  
Chief Executive  
Bliss

Ninety-eight per cent of neonatal deaths occur in a hospital setting, with few babies being supported to die at home or at a children's hospice.

## Introduction

ACT's work with children's palliative care spans 21 years, and our philosophy has always been to promote the best possible quality of life and care for every life-limited child 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 a care plan that is right for them.

ACT 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. ACT published its first care pathway for life-limited and life-threatened children in 2004, followed by a transition care pathway in 2007 to encourage better planning and support for those young people who receive palliative care and need to make the transition to adult palliative care services. This care pathway approach, now widely adopted across the UK, has helped to improve the family's journey throughout their child's life.

Although we have seen great progress in how palliative care services are delivered to children, we have a long way to go in ensuring that all families have real choices, and this is especially challenging in the case of babies with palliative care needs.

Every year over 80,000 babies are admitted to a specialist neonatal<sup>1</sup> unit for care in the UK and on average there are 2,109 neonatal deaths each year from causes likely to require palliative care (Health and Care Partnership Analysis, 2007). Ninety eight per

cent of neonatal deaths occur in a hospital setting, with few being supported to die at home or at a children's hospice. Palliative care is only routinely provided for babies and children over 28 days old, with neonates generally being cared for within the clinical environment of the neonatal unit.

Some of these babies, particularly those for whom there is no hope of cure, and those who are close to their end of life phase, could be transferred either to their family's home or a local children's hospice, with appropriate support. By doing this the family would be able to maximise their short and precious time with their baby, in a place where they may feel they have more control over the care of their baby. ACT believes that families should, where possible, be given more choice in the place of care and death for their baby.

1. A neonate is a baby in the first 28 days of life.

ACT has recognised the need for a dedicated care pathway for those very young babies who need palliative care, and many of ACT's members – including children's hospices and community nursing teams – have already adapted their services to support families whose babies are approaching their end of life, to give families greater choice, support and care.

Anecdotal evidence from ACT's members, families and professionals alike, has shown that quality of life for families is greatly improved when babies can be transferred to the family home, a children's hospice or even the local hospital, where more family members are able to be involved in the final days of the baby's life.

This *Neonatal Pathway for Babies with Palliative Care Needs*<sup>2</sup> aims to draw together the professionals and resources needed to accompany the baby and family along their unique care journey. It has been written for professionals and commissioners of services to ensure that the appropriate care and resources are available in the right place, at the right time for each of these babies. This is an integrated care pathway to support professionals working in maternity and obstetric services, neonatal and children's services as they care for young babies who have life-threatening or life-limiting conditions. The pathway is intended to be used in the care of babies up to four weeks old.

The pathway will be of relevance and interest to the children's and young people's palliative care sector but is more specifically aimed at the neonatal service providers and practitioners and maternity services, as well as professionals such as midwives and obstetricians.

Guided by six sentinel standards, the ACT *Neonatal Pathway* recognises that babies and their families will make varied and individual journeys according to their own needs and circumstances, and provides a template to ensure the baby and family are always at the centre of the care planning process.

The pathway is designed to be started either antenatally or prior to discharge from hospital and follow the baby through to the community, as soon as the baby's condition is recognised as life-limiting or life-threatening.

*A Neonatal Pathway for Babies with Palliative Care Needs* is divided into three parts:

**Part One**

This provides an introduction to children's palliative care and ACT's care pathway approach. It discusses the need for a dedicated neonatal care pathway approach and outlines the principles that ACT recommends in adopting and delivering the *Neonatal Care Pathway*. This part of the resource will be particularly useful for those professionals who do not routinely work within a palliative care setting.

**Part Two**

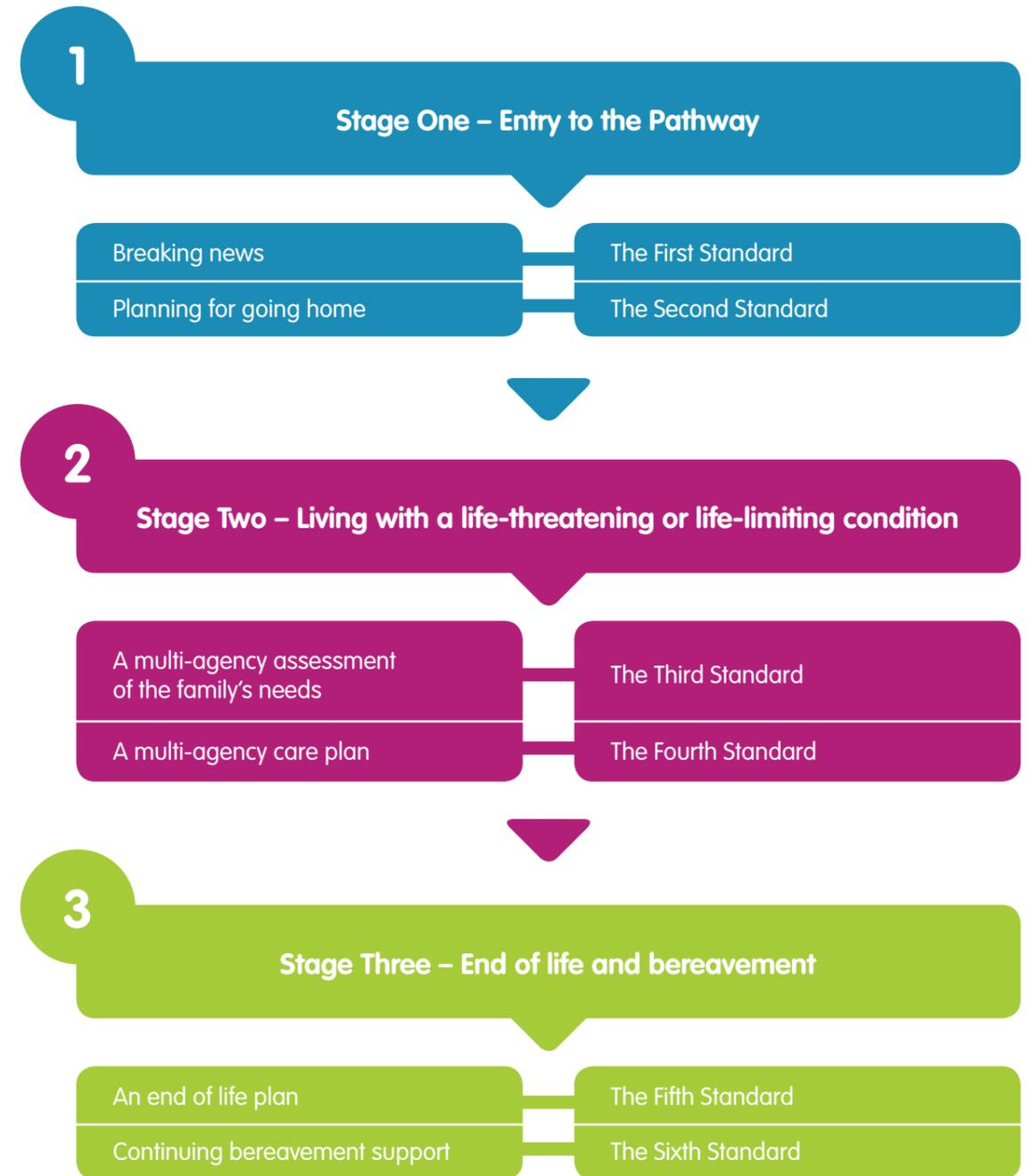
This section takes the reader through the ACT *Neonatal Pathway for Babies with Palliative Care Needs*. There are three stages to the pathway: entry to the pathway; living with a life-limiting condition; and end of life and bereavement care. Each stage of the pathway includes sentinel standards: breaking news; planning for going home; a multi-agency assessment of family's needs; a multi-agency care plan; an end of life plan and finally, continuing bereavement support. For each of the standards, key goals are identified and useful resources to support care are provided.

**Part Three**

This provides useful reference information, including a glossary of terms and definitions and a directory of useful organisations which will be of use to professionals working with neonates and the families that they support.

ACT hopes that this new care pathway will be a tool to encourage professionals working within neonatal services to offer families greater choice; and to enable families to have the best possible experience and memory of their baby, no matter how short their life may be. We hope that our new pathway will go some way to improving the involvement of families, and accommodate their wishes and choices, especially when time is precious.

**A Neonatal Pathway for Babies with Palliative Care Needs: Pathway summary diagram**



2. Throughout this publication we refer to the *A Neonatal Pathway for Babies with Palliative Care Needs* as "The ACT Neonatal Care Pathway" for ease of reference.

# Part One

## The ACT approach to children's palliative care

Over the past two decades much work has been accomplished to promote the need for services for children and young people with life-limiting or life-threatening conditions.

### Introduction to children's palliative care

Palliative care for children and young people with life-limiting 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 (ACT, 2009).

Life-limiting or life-shortening conditions are those for which there is no reasonable hope of cure and from which children or young people will die. Life-threatening conditions are those for which curative treatment may be feasible but can fail.<sup>3</sup>

Until the 1980s the term palliative care was largely associated with the care of adults in the final terminal stages of cancer. The adult hospice movement, led by Dame Cicely Saunders, developed an ethos of care that put the patient and family's quality of life at the centre of care. They took into account not only physical needs but also the emotional, practical and spiritual needs of the individual. It is important to recognise that there are significant differences between palliative care for adults and children in

relation to the conditions involved and the approach to care, which does not just focus on end of life, and which is more family-centred. Over the past two decades much work has been accomplished to promote the need for services for children and young people with life-limiting or life-threatening conditions.

<sup>3</sup> The definitions of the terms *life-limiting* and *life-threatening* referred to in this document are current at the time of publishing (November 2009). However there is ongoing debate and a Delphi consultation in progress relating to them.



Palliative care for children is different from adult palliative care in several ways:

- The number of children who die is small, compared with the number of adults.
- Many of the individual conditions are extremely rare with diagnoses specific to childhood.
- The time scale of children's illness is generally different from adults; palliative care may last only a few days, weeks or months, or it may extend over several years.
- Many of the illnesses are familial; there may be more than one affected child in the family.
- Care embraces the whole family. All family members may be vulnerable as they face the changes in life that the child's diagnosis creates. Parents and siblings are especially vulnerable and parents often have a great responsibility for personal and nursing care.

- A characteristic of childhood is continuing physical, emotional and cognitive development. Children's palliative care providers need to be aware of and responsive to each child's changing levels of communication and their ability to understand their illness, treatments and prognosis. Children with life-limiting or life-threatening conditions face many periods of transition throughout their life.
- Provision of education and play when a child is sick is essential, and education is a legal entitlement. This introduces an additional dimension which adds to the complexity of care provision.

ACT has published a paper setting out the similarities and differences between adult and children's palliative care, which can be downloaded from the ACT website: [www.act.org.uk](http://www.act.org.uk)

Palliative care is an approach to care which can be used exclusively or in conjunction with curative treatments. The diagram below explores the different relationships between palliative care and those treatments aimed at cure or 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 dawns.
Key:  curative  palliative	

## ACT categories of life-limiting and life-threatening conditions



ACT 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 need for palliative care should always be assessed on an individual basis.

<b>Category 1</b>	<b>Life-threatening conditions for which curative treatment may be feasible but can fail.</b> 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. Examples: cancer, irreversible organ failures of heart, liver, kidney.
<b>Category 2</b>	<b>Conditions where premature death is inevitable.</b> There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. Examples: cystic fibrosis, Duchenne muscular dystrophy.
<b>Category 3</b>	<b>Progressive conditions without curative treatment options.</b> Treatment is exclusively palliative and may commonly extend over many years. Examples: Batten disease, mucopolysaccharidoses.
<b>Category 4</b>	<b>Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death.</b> 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.

## Neonatal palliative care

Families should be informed about what palliative care support is available from the outset. This will enable them to make choices about which elements of a service they wish to access at different points throughout their care journey. For parents of young babies, this discussion may take place before their baby is born, very soon after birth, or as it becomes clear that curative treatments are unlikely to succeed.

Neonatal palliative care has a number of unique facets distinguishing it from children's palliative care. One of the main differences is that care is often provided in a busy and intensive care environment where the baby's condition and prognosis may change suddenly.

This pathway aims to set out how palliative care should support the baby and parents throughout their individual care journey.

Professionals working in neonatal services are used to providing babies and families with sophisticated expert care using high levels of technical skills and knowledge. They are increasingly challenged to provide neonatal, and sometimes, antenatal palliative care as technology allows more accurate prenatal diagnosis. The environment within neonatal units can foster a dependency on technology and equipment: a baby with palliative care needs may need highly intensive care but will not require the same level of technical care, and the focus of this pathway is on enabling families to spend time with their baby, bonding and building memories, in a more home-like environment, and with less technologically dependent care wherever possible.

## The ACT care pathway approach

ACT's first care pathway was developed in 2004 as a tool to help professionals in planning appropriate care for children and young people with life-threatening or life-limiting conditions and their families, and co-ordinating the various services and individuals that will be involved in a child's care. It presents a pathway which professionals can use to engage with the child's and family's needs and make sure everything is in place for families to access the appropriate support at the right time. This first care pathway was followed by the publication of ACT's *Transition Care Pathway* in 2007 for teenagers and young people with palliative care needs.

This *Neonatal Care Pathway* proposes a broad and generic template for developing a specific care pathway for neonates diagnosed with or recognised as having life-threatening or life-limiting conditions. Some services have already adapted ACT's original care pathway for use with babies, recognising their local resources and service arrangements. This *Neonatal Care Pathway* builds on these experiences and aims to identify the particular issues which need to be considered when caring for life-limited babies in all settings.

This document will be of use to those working to improve the provision and consistency of care and support to babies and families, and will help in providing a clear pathway from diagnosis or recognition, through ongoing care to the baby's end of life, death and into bereavement. Babies and their families will make varied, individual journeys according to their own needs and circumstances. The prime intention of this pathway is to provide a means for developing essential, universal components that could underpin more detailed local pathways. The document focuses on putting babies and families at the centre of a planning process, with the aim of delivering integrated services in response to individual needs.

It is recognised that currently many babies who require palliative care are often cared for in hospital. As such, this pathway is designed to be started either antenatally or prior to discharge from hospital, and follow the baby through to the community, either at the family home or in a children's hospice.

## The need for a neonatal care pathway

Every year over 80,000 babies are admitted to a specialist neonatal unit for care in the UK. Of these, the babies that would benefit from the ACT *Neonatal Care Pathway* are those with life-limiting and life-threatening conditions. Such conditions will have begun in utero or early in the neonatal period and are anticipated to lead to a baby's premature death.

At the end of 2008 Children's Hospices UK carried out a survey of their members to explore current experience of children's hospice services in caring for babies born prematurely and their families. The survey focused on the provision for neonates, referral criteria, rates of referral, counselling and bereavement services, as well as ways to inform potential future service and strategic development. Just over a third of hospices responded.

The survey noted the following key points:

### Bereavement

All of the responding children's hospices offered the same bereavement services to the families of neonates who died that they offer to all other bereaved families supported by their service.

### Capacity to provide a service for neonates

Most children's hospices were already providing a service for neonates.

### Staff skills

All those who replied felt that staff working in their care teams had the capabilities (in terms of skills and knowledge, behaviours and attitudes) to care for neonates with palliative and end of life care needs.

### Conclusion

Most notably, all respondents stated that a neonatal care pathway is essential. Good working partnerships and collaborative working is vital for all palliative care services. Training for staff and consideration for extra skills development is important. Extra resources and time may be required.

(Children's Hospices UK, 2008)

The ACT *Neonatal Care Pathway* aims to ensure that there is a co-ordinated approach to family-centred care throughout a baby's short life, 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 in hospital, in their home, or in a children's hospice.

The *Neonatal Care Pathway* should also be used when the care team has agreed in partnership with the family that a baby is at the end of life phase (this would include babies that are unlikely to survive post-extubation), when it is recognised that the baby has a life-threatening condition, or when a decision to withdraw treatment has been reached. Services may wish to consider using this care pathway for babies who are still-born, particularly with those families who have familiarised themselves with the pathway during the antenatal period. Alternatively, Sands, the stillbirth and neonatal death charity, has produced comprehensive guidance on good practice in the care of stillborn babies ([www.uk-sands.org](http://www.uk-sands.org)).

Individual, sensitive, and quality care is also supported by the *Bliss Baby Charter – for special care babies* (Bliss, 2005) which states:

Every baby in the United Kingdom regardless of race, religion or culture has the right to benefit from:

- The same respect and dignity as adults.
- The decisions affecting their care being made in their best interest.
- The same level of specialist care as children and adults.

- The same chances of survival as babies born in similar countries and circumstances.
- The information and support needed by parents to help them care for their baby and achieve the best quality of life possible.
- The opportunity to have their mother's breast milk when appropriate.
- The necessary support and care after going home.

In addition, the ACT approach to neonatal palliative care states that:

- Parents shall be acknowledged as the primary carers and involved as partners in all care and decisions involving their baby.
- The family home shall remain the centre of caring whenever possible. Care away from home should be provided in a child-centred environment by staff trained in the care of young babies.
- Every family shall be given the opportunity to have consultations with a paediatric specialist who has particular knowledge of their baby's condition.
- Every family shall have timely access to practical support, including clinical equipment, financial grants, suitable housing and domestic help.



## Principles of the neonatal care pathway

There are a number of overarching themes which should be considered at every stage of the care pathway:

### Communication

There should be an honest and open approach to all communication with parents, who should be treated as equal partners in any discussions with the care team.

### Spiritual support

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

### Multiple losses

Families often experience repeated losses; first the lost of the 'normal' expected baby, followed by the anticipated loss of a baby predicted to die. At times, this baby may defy medical expectations and survive, only for the family to face their death in future years. Some families may also face multiple losses with more than one child having the same medical condition.

### A unique journey for every baby and family

The whole of family life is affected by the death of a baby. Grief is an individual concept: some 'heal'; some never want to heal; some look at continuing relationships with their child after death; some see 'dead' as dead and gone. Choice is therefore vital, and it is important to ask the family what they want, to ensure the whole family focus is retained while maintaining a professional approach. All forms of support should be available throughout the family's journey. Sometimes a professional approach, over-reliant on theories and ideas, can lead to over-focused, over-theorised and sometimes inappropriate support for families. Mutual help such as 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 dying baby.

### Multiple admissions

Babies 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 baby to be admitted to different environments, and possibly different hospitals under different care teams.

### Psychological support

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

### Key worker

Every family should be entitled to a named key worker who will enable the family to build up and maintain access to an appropriate network of support. A key worker<sup>4</sup> should be identified as soon as possible after the care pathway commences. This would be a person that the family would get to know well and who would have local knowledge and expertise. Ideally, each family should have a key worker to be their main contact; someone that can communicate their needs and wishes, and who will ensure that their care plan is being delivered effectively.

### 24 hour support

Every baby should have access to a 24 hour multi-disciplinary children's palliative care team for flexible support in the home, and be in the care of a local paediatrician or neonatologist (depending on local protocols about the handover of care between consultants).

### Ability to respond quickly

Some babies will have a very short time to live and the normal planning meetings and appointment of key workers may not happen. It is crucial therefore to remember the importance of talking to parents and the family, giving them choices. If they choose to allow their baby to die at home or at a local hospice, then this pathway should be followed to support the baby's discharge from hospital. At such times, it is vital that one practitioner is identified to take the lead, to act as the family's first point of contact for communication, and to ensure information flows to all services.

### Post-natal care of the mother

It is important to remember that the baby's mother has recently given birth, either naturally or by Caesarean section, and she will need care and support. Services taking the lead on care of the baby should also ensure that the mother is seen by midwifery and health visiting services to ensure appropriate care.

### Diversity and cultural issues

Culturally appropriate care which respects diversity helps to 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 Children's Hospices UK *Diversity Toolkit* (Children's Hospices UK, 2009) is a useful resource to support both hospice services and other health, social care and education organisations as they consider diversity and cultural issues in children's palliative care.

4. A key worker is a source of support for disabled children and young people and their families and a link by which other services are accessed and used effectively. Key workers have responsibility for working together with the family and with professionals from services and for ensuring delivery of an inter-agency care plan for the child and family (Care Co-ordination Network UK, 2009).

Some neonates, especially those for whom there is no hope of cure, and those who are close to their end of life, could be transferred to their family home or a local children's hospice, with appropriate support.



## Part Two

### The Neonatal Pathway for Babies with Palliative Care Needs

Before and during pregnancy, parents need to have relevant information and knowledge to help them give their baby the best start in life. This should include: the mother's diet, the importance of good antenatal care, and recognising symptoms which warrant medical attention. If there is a risk identified about a genetic condition which may be passed on to the baby, then families should be given appropriate information, genetic counselling and support.

#### 1

#### Stage One: Entry to the pathway

The start of the journey for many babies recognised as having a life-limiting or life-threatening condition (see Diagram 1) may begin during the antenatal period (from the confirmation of pregnancy); during or following the birth of the baby; or triggered by a professional or parental concern or a critical event after birth. For some families, entry to the ACT *Neonatal Care Pathway* will begin with the devastating news that their baby has been diagnosed with a life-threatening or life-limiting condition. In some cases, the diagnosis will be given a name; for others this may not happen. Breaking this news to the family requires great skill and sensitivity.

Parents may find it helpful to have another family member or professional who is not involved in the baby's direct care with them to act as their advocate and who can remind the team of their care plan.

Staff delivering antenatal care need to be sufficiently skilled in giving information to parents and carrying out routine monitoring and screening during

pregnancy. They need to be alert to complications that may arise and be able to refer quickly when needed. Maternity services need to provide high quality care to mothers and babies, including intensive care facilities which minimise the risk of long term disability in babies born prematurely or with complications. It is important to consider the impact of the following which might lead to entry to the *Neonatal Care Pathway*:

- **Premature birth.**
- **Birth trauma.**
- **Maternal health and environment.**  
Problems associated with the mother's health whilst the foetus is developing in the womb. For example, infection, alcohol, drugs, or malnutrition.
- **Genetic abnormality in the baby.**  
This may occur by chance or be inherited through one or both parents' genes. The abnormality could be diagnosed before or shortly after birth, or become apparent at a later stage.
- **Acute medical condition in the baby.**  
For example, following infection, or cerebral haemorrhage.

For some families, palliative care will begin in the antenatal period when the baby is recognised as having a condition which cannot be cured. In this case, when a baby is stillborn or lives for only a short time after delivery, end of life care will begin at birth. In cases where babies are diagnosed with a life-threatening condition antenatally, their survival may be uncertain, but early referral to palliative care services can help manage this uncertainty by developing a number of alternative care plans to manage the eventual outcome.

It is important that all babies 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. Families may wish to choose where their baby is going to be cared for by determining which care team will offer them the care that is most appropriate for the baby's condition and for the family's circumstances.

Care professionals should consider whether routine interventions are really necessary, for example, whether routine blood tests are beneficial or essential to the baby's care, or whether the distress caused is greater than the potential benefit.

### The First Standard: Breaking news

**Every family should receive the disclosure of their baby'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 family using language they can understand.**

#### What this means

Breaking the news to parents that their baby is expected to die prematurely is undoubtedly one of the most difficult tasks that any professional has to face. In spite of efforts to improve this area of care, many parents are still treated clumsily or insensitively and the experience lives with them for a very long time (Scope, 1993). Families need honesty, respect and above all, time, from professionals disclosing the diagnosis or prognosis. If disclosure is avoided or postponed, parents are likely to discover the truth at a later stage, damaging their trust and confidence in professionals. Research confirms that parents need information at this stage, and that this information needs to be in a language they can understand (Sloper and Turner, 1993). Staff should be mindful that breaking bad news can be complicated by the situation changing quickly; perhaps the baby will be taken to a neonatal unit while the mother receives ongoing care.

Whilst written information is always valuable as a backup to face-to-face discussion with parents, it should never be a substitute. Parents should have time to discuss the options available for the care of their baby and be given opportunities to ask questions. Providing details of sources of support at the earliest possible stage is also beneficial to families who often feel a sense of isolation following the starkness of a diagnosis. Often neonatal and maternity units will have information about local support groups for parents. Professionals should ensure that there is someone available to provide support for single parents. Contact a Family is an organisation that provides information on parent support groups. You will find details of other support groups and organisations that can help families in Appendix 3: Directory of useful organisations (see page 40).

Parents may also want a supporter with them; this could be another friend or family member, or perhaps someone from their care team, to act as an advocate for their wishes and needs. From the time of diagnosis, parents and professionals should recognise that they will be working together to care for the baby.

The training and preparation of staff that will have to handle breaking significant news and provide support and care to families at such a distressing time should be a high priority. Appropriate guidelines for effective communication when breaking bad news should be devised using established good practice.

Professionals should also check whether all family members have fully understood what has been said. It can be difficult for families to take all the information on board when they are in a state of shock. Misunderstandings at this point may cause problems at a later stage.

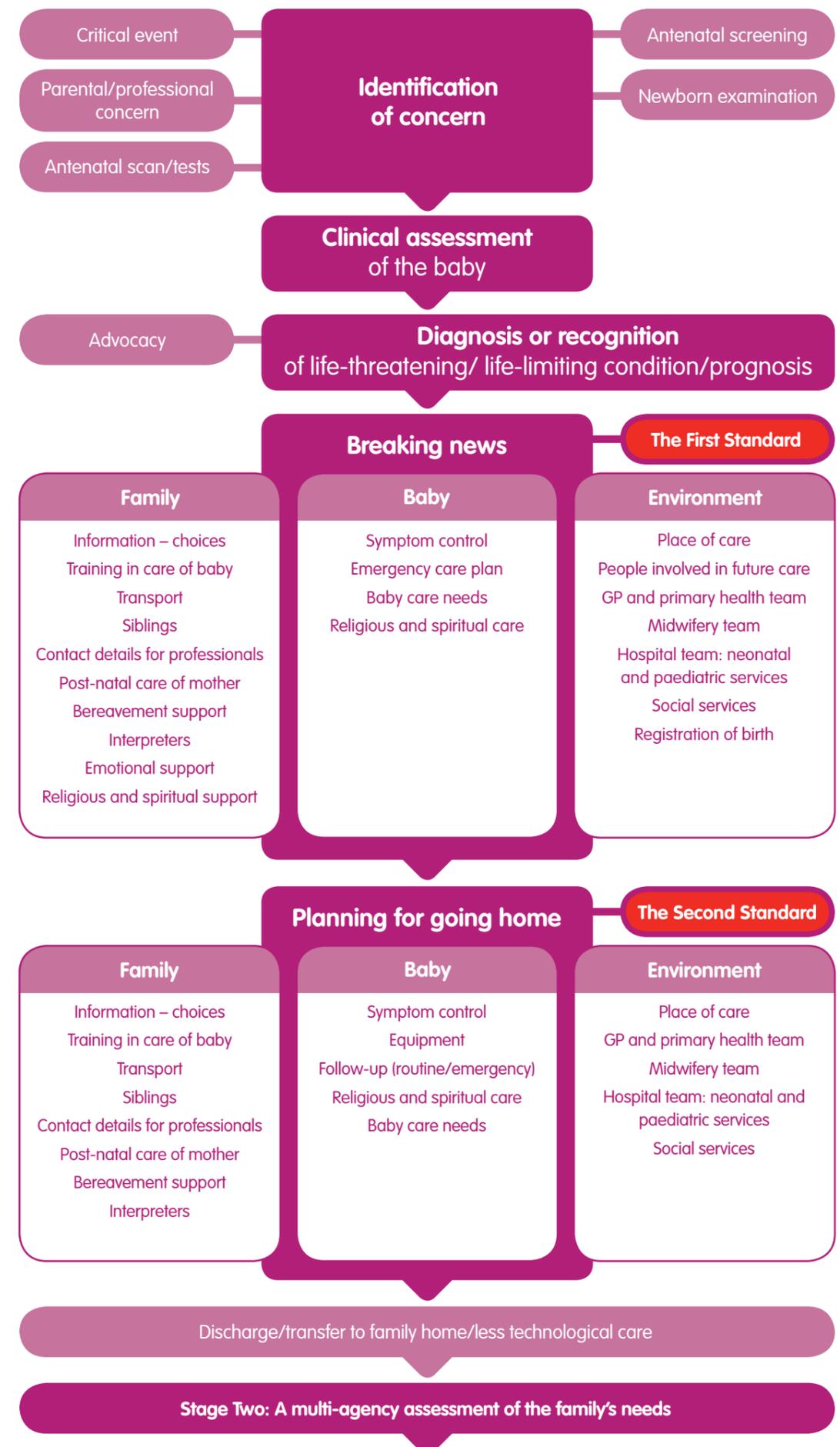
#### Key goals in breaking news

Good practice in breaking bad news has been described by the charity Scope as providing the family with:

- Plenty of time.
- A place for privacy.
- The opportunity for parents to be together to hear news.
- Helpful written material.
- Information conveyed in readily understandable language.

(Scope, 1993)

Diagram 1: Stage One: Entry to the pathway



In addition to the Scope guidelines, ACT recommends that:

- Parents should be treated with openness and honesty.
- Parents should be acknowledged as experts in the care of their baby.

## The Second Standard: Planning for going home

**Every baby and family should have an agreed transfer plan involving the family or carers, hospital, community services and hospice services. The family should be provided with the resources they require before leaving hospital.**

### What this means

Following recognition that a baby has a life-limiting or life-threatening condition, the primary aim should be for the family to be supported to spend time together, outside hospital wherever possible. The timing of discharge from hospital will depend on whether hospital treatment for the baby's condition is needed and on the parents' wishes. For many parents, the knowledge that their baby has special care needs, combined with their status as 'new parents' may lead to them making a choice to be discharged somewhere other than their own home, for example a children's hospice, a relative's home or even their local hospital. Even if the baby is going to stay in hospital, this palliative care approach is still appropriate.

After diagnosis professionals should aim to reunite the mother and baby as soon as possible. This may be challenging, as the parents and baby might be in separate locations, occasionally in different hospitals or even different towns.



### How children's hospice services can help

Children's hospice services have been developed to provide specialist care and support for children with life-limiting conditions and their families, from the moment of diagnosis onwards. This support is provided either within the hospice or in the comfort of the family's own home. Children's hospice services provide specialist short breaks (respite care) and regular short stays for the child or for the whole family together. They also provide emergency and end of life care; specialist advice and expertise; practical help and information; and 24 hour telephone support. An increasing number of services are working together to develop good practice and care in the emerging area of hospice care for babies.

The importance of discharge planning cannot be over-emphasised. Taking home a baby with a life-limiting diagnosis, sometimes needing complex medical procedures and medical equipment, is a truly daunting task. Families may also need additional support to help them prepare other children for the discharge home. Careful planning for this critical transition is vitally important. It is essential that care for the mother in the post-partum period is not forgotten.

Going home from hospital will require an initial needs assessment meeting at the hospital involving the family, key hospital staff, maternity staff, the GP and community nursing staff such as health visitors and community children's nurses, and social services.

The hospital team will provide vital input to discharge planning. Ongoing liaison between hospital and community teams will be important for the future care of the baby. In some cases the hospital may provide an outreach service. A number of needs should be discussed and agreed to enable a smooth transfer home, such as training in complex procedures, availability of equipment, pharmacy supplies, transport, and normal baby care. Clear lines of communication should be agreed and the family should know how to access 24 hour help.

### Key goals in planning for going home

- Community based services and children's hospice services should be notified as soon as possible.
- There should be a community service in-reach facility available in hospital for the family, either in person or via the telephone. This will enable the community staff to meet the baby's family before discharge home and become familiar with the baby's care and the family's expectations.
- Planning should begin as soon as possible and a clear plan for transfer should be agreed with the family, hospital and community services.
- A lead community children's nurse should be agreed before transfer, and the baby's GP should be invited to become involved. Shared medical care plans should be in place.
- Equipment and supplies should be provided before transfer.
- Training should be provided for carers before transfer.
- Clear lines of communication should be agreed.
- A home visit should be arranged on the same day as the transfer.
- A 24 hour contact number should be provided to the family.
- A key worker should be identified.
- If transfer to a children's hospice is planned, a member of the hospice team should meet the family at the hospital before discharge.

### Resources that can help

Bliss, the special care baby charity, produces leaflets, booklets and fact sheets, explaining a wide range of issues that affect premature and sick babies ([www.bliss.org.uk](http://www.bliss.org.uk)).

Care Co-ordination Network UK (CCNUK) have developed a number of useful resources for key workers ([www.ccnuke.org.uk](http://www.ccnuke.org.uk)).

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

*Breaking Bad News ...Regional Guidelines Developed from Partnerships in Caring.* Department of Health, Social Services & Public Safety (DHSSPS), 2003. Belfast: DHSSPS.

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

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

# 2

## Stage Two: Living with a life-limiting or life-threatening condition

Whether a baby's condition involves active treatment or not, care and support will sometimes move from the immediate and intense activity surrounding diagnosis or recognition to what is often called 'the maintenance phase' (see Diagram 2). This is the time when parents may be particularly vulnerable. They may become isolated, and may suffer from exhaustion, stress or depression. Many feel that once they are at home they are simply expected to get on and cope. In order to help families access the care and support best suited to their individual situation, it is essential that a full assessment of the baby's and family's needs takes place quickly. This process should begin as soon as possible after diagnosis and should be multi-disciplinary and multi-agency, involving assessments of health, psychosocial and practical needs.

### The Third Standard: A multi-agency assessment of the family's needs

Every family should receive a multi-agency assessment of their needs as soon as possible after their baby's diagnosis or recognition that their baby's condition is life-threatening or life-limiting. They should have their needs reviewed at appropriate intervals.

#### What this means

The key to ensuring that families receive the right support at the right time is making sure one agency takes a lead role and works in partnership with the family, enabling them to take control of their situation and helping them access the various services, equipment and support they need. In recent years the development of specialist multi-disciplinary community teams has been key to fulfilling this role. For many babies, the community neonatal service, the child development team or the community children's nursing (CCN) team have the central role. Where there is a transition from the neonatal outreach team to a local CCN team, joint working from the outset is essential to establish trust. These local CCN teams will help to co-ordinate care for the baby and family. Where appropriate, the hospital or hospice will also play an important part in the co-ordination of care, providing a vital link with the baby's consultant and other key staff.

**The multi-disciplinary palliative care team**  
Local multi-disciplinary palliative care teams are increasingly being established. These teams often include community children's nurses (CCNs), paediatricians, children's hospice staff, social workers, psychologists and therapists who deliver community-based care to children with life-limiting conditions. Community children's nursing services are the bedrock for children's palliative care services.

A number of different models of CCN services that support the delivery of children's palliative care are described in the *Textbook of Community Children's Nursing, 2nd Edition (Sidey and Widdas, 2005)*.

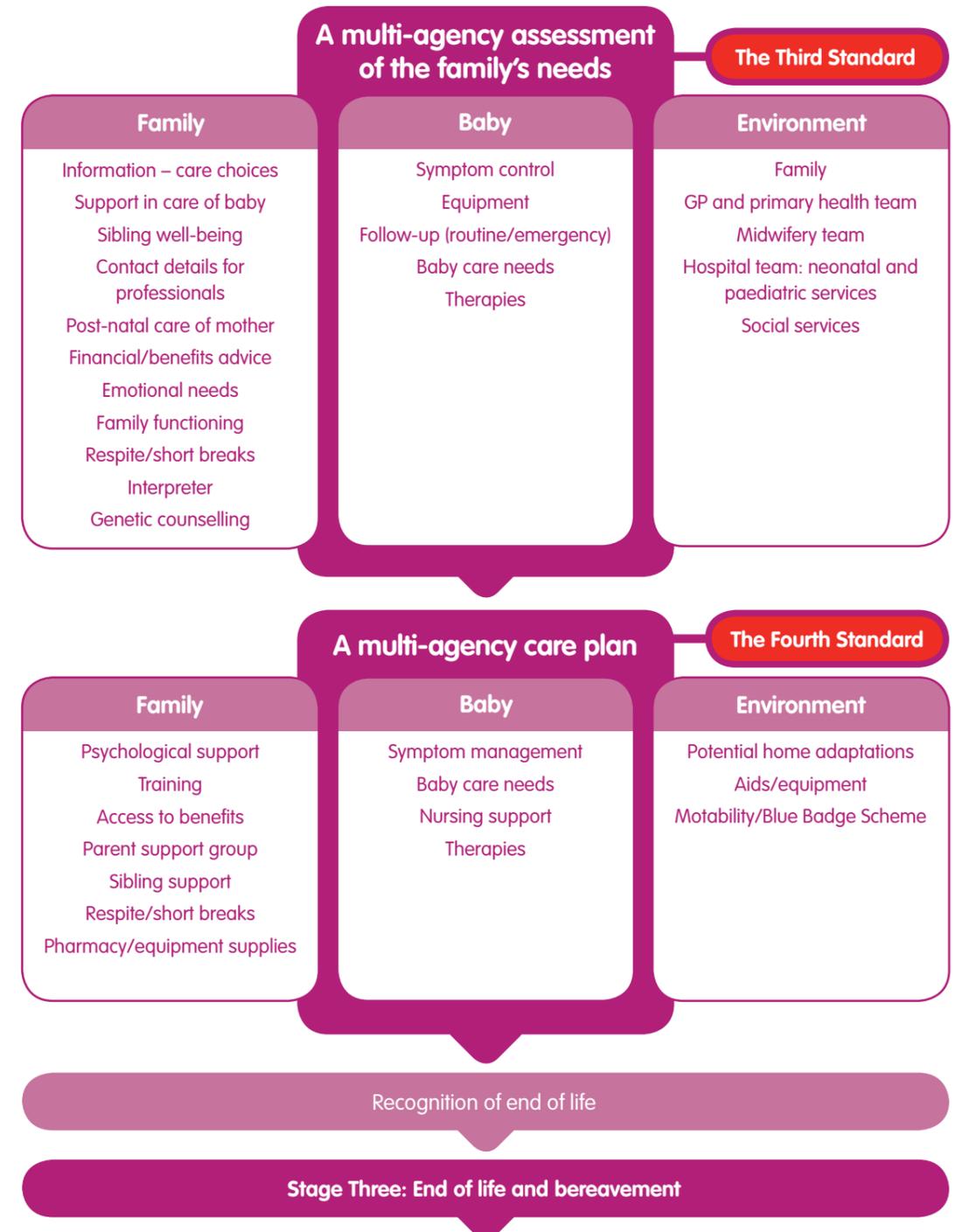
The importance of the family needs assessment stage cannot be understated. It forms an introduction to the care team that will play a central co-ordinating role, and is an important foundation for building trust, partnership and support for future care. For most, the care of the baby is likely to take place in the home, although for some babies the hospital is likely to continue to play a major part. A comprehensive whole family needs assessment process should begin as soon as possible after diagnosis or recognition of a life-limiting condition.

The needs assessment will provide the opportunity for the family's 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. Its ultimate goal should be that the baby and family receive the help and support they need, when they need it, in the place that they are most comfortable. It should draw together multi-disciplinary expertise to ensure that families are spared repeated individual assessments by different professionals. Information gathered at the assessment stage should therefore be shared as appropriate between professionals and agencies.

A multi-agency needs assessment should be carried out by staff with appropriate competency and local knowledge, and there should be clear objectives to:

- Gather factual information about the baby and individual family members.
- Explore the concerns and feelings of family members, including extended family members where possible.
- Assess the full range of medical, nursing, practical, social, psychological and spiritual needs.

Diagram 2: Stage Two: Living with a life-threatening or life-limiting condition



- Reach an understanding of the individual situation and the impact on the family.
- Explore all the options within local provision.
- Culminate in an agreed plan for action and/or intervention.

The assessment should cover the needs of the whole family. Information gathered should include factual details about the baby and family; details of the professionals and services involved; medical information; nursing and personal care needs of the baby; and the emotional needs of the family. The assessment should be seen as an ongoing process rather than a single event and, according to the individual 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 all the individual factors that impact on the baby's and family's quality of life and guide the delivery of specific services to meet their needs.

For many families the management of the baby's symptoms will be the prime consideration. They need to feel assured that their baby will be as pain and symptom free as possible and they may require ongoing support and assistance in achieving this. Knowledge of how to access informed practitioners, both in and out of working hours, is essential to allay fears and treat symptoms quickly. The needs of all family members should be given careful consideration, particularly their emotional needs and the need for practical help and short breaks. Siblings are often marginalised and may suffer problems at school, with their peers, or in their emotional well-being. Some services provide dedicated sibling groups that provide support. Equipment needs should be assessed and provided in a timely manner and the practical and financial needs of the family will also require assessment.

### Key goals in a multi-agency assessment of the family's needs

- Babies and families should have their needs assessed as soon as possible after diagnosis or recognition.
- A holistic and multi-agency approach should be used to avoid the need for multiple assessments.
- An assessment of needs should be made in partnership with the family.
- The baby should be kept central to the process.
- Care should be taken to include the needs of the whole family.

- The family's religious, cultural and personal beliefs should be respected.
- Information should be gathered and recorded systematically to ensure consistency.
- Straightforward and jargon-free language should be used.
- Confidentiality and consent should be addressed.
- Assessment information that is gathered should be made available to the family.
- It should be clear who is taking the lead role.
- Those undertaking needs assessments should have appropriate skills and local knowledge.

## The Fourth Standard: A multi-agency care plan

**Every family should have a multi-agency care plan agreed with them for the delivery of co-ordinated care and support to meet their individual needs. A key worker to assist with this should be identified and agreed with the family.**

### What this means

Following the needs assessment process it should be possible to agree the level of support the family requires and the services that should be involved. Some families' service needs may be minimal in the early stage; others may need a variety of different services and professionals, and needs will change, with variation in the number of professionals involved. The care plan should be a working document that is shared, providing details of all the professionals and services required for the specific needs identified in the assessment process.

The highest priority is to ensure the family has access to the various co-ordinated services and professionals. They will also need full information about services and the reassurance that everyone they come into contact with understands their needs.

### Information support

Information is a vital part of the family's needs. 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 through and prioritise it. Each team should also have access to interpreters. The baby's siblings should have information that is suitable for their age and level of understanding.

### A holistic approach to the care plan

The care plan should be comprehensive, including all aspects of the family's needs. There should be a focus on the baby's quality of life, including symptom control and personal care as well as their emotional and psychological care. The plan should include information about accessing benefits, equipment, aids and adaptations.

### Out-of-hours support

Every family needs to have an individual out-of-hours plan. This may vary from standard local support to an on-call community children's nurse or other care professional.

### Key goals for a multi-agency care plan

- Every family should have a key worker to co-ordinate their plan.
- Information should be available to the family.
- The plan should include the whole family and take account of the baby's symptoms and personal care.
- The plan should include psychological care for the baby's siblings and parents.
- A tailored out-of-hours plan should be provided.
- Information should be provided about:
  - How to access benefits and financial assistance.
  - How to access flexible short breaks.
  - How to support parents' and carers' needs, including the protection of their health.
  - How to access aids and equipment.

### Key goals in reviewing needs

- The baby's and family's needs should be reviewed regularly.
- The family should be able to request a review at any time.
- Services and professionals should regularly review their effectiveness in co-ordinating and delivering care plans.
- Families should be given extra support at key times, particularly following hospital admission, a change in the baby's condition, or in times of family crisis.
- A change in prognosis should be communicated to the family.
- A new care plan should be agreed to take account of any changes.

### Parallel planning

For some babies, survival into early childhood is unlikely, but possible, and there may be periods where the team feel end of life is imminent, but the baby pulls through. Planning for nursery, further assessment or developmental support from birth to five years services may seem inconceivable and may be discontinued, or never started. It is important that proactive parallel planning is practiced, delivering end of life care as required but continuing to plan and make available the full range of local birth to five years services where possible. Planning for life and planning for death allows a baby's full potential to be achieved, and planning for the future at times of great uncertainty can also be comforting. There should also be a process to prepare parents should their baby require admission to hospital; this is likely to be to a children's ward and not the neonatal unit. This may be in a different hospital, with a different consultant and care team.

### Resources that can help

Care Co-ordination Network UK (CCNUK) website: [www.ccnuke.org.uk](http://www.ccnuke.org.uk).

*Care co-ordination and key working, the stories and experiences of two families.* This DVD aims to promote the concepts and show the benefits of care co-ordination and key working. It is a tool which shows the stories and experiences of two families and their respective key workers. Although produced in Scotland, the messages in the DVD are relevant across the UK. [www.ccnuke.org.uk](http://www.ccnuke.org.uk)

*Getting it Right for Every Child: Guidance on the Child's or Young Person's Plan.* This document supports the implementation of *Getting it Right for Every Child* providing a framework for planning and action to help improve outcomes for children in Scotland. It contains useful messages and resources which could be adapted for use across the UK: [www.scotland.gov.uk/Publications/2007/01/22142141/0](http://www.scotland.gov.uk/Publications/2007/01/22142141/0)

Common Assessment Framework resources focus on services in England, but can be adapted for use more widely: [www.dcsf.gov.uk/everychildmatters/strategy/delivering-services1/caf/cafframework/](http://www.dcsf.gov.uk/everychildmatters/strategy/delivering-services1/caf/cafframework/)

*A resource pack: developing a key worker service for families.* Mukherjee, .S, Sloper, P., Bereford, B., Lund, P., & Greco, V., 2006. York: Care Co-ordination UK.

## Stage Three: End of life and bereavement

### Recognition of end of life

Predicting the time when a baby is likely to move into the final phase of its life is not always easy. For some, there may have been a series of fluctuations in their condition and some babies will appear to return to greater stability following a period of serious decline.

The realisation that death is imminent may be quite sudden, possibly only hours or days before death. The family may have had little time to acknowledge this or plan for death. For others, movement into the end of life phase is clearer, especially in cases where there has been a decision to stop all life-prolonging treatment. The baby's quality of life up to the point of death will be a major consideration, and there may be difficult decisions surrounding the withdrawal of non-essential drugs or other invasive interventions. The Royal College of Paediatrics and Child Health has published guidance on withdrawing treatment in children (RCPCH, 2004), and the British Medical Association has also published guidance and extensive discussion on the ethics of end of life care (See [www.bma.org.uk/ethics/end\\_life\\_issues/index.jsp](http://www.bma.org.uk/ethics/end_life_issues/index.jsp).) The British Association for Perinatal Medicine has published guidance on the management of extremely premature birth (BAPM, 2008) which also provides supportive information about difficult decision making.

At this point, personal resuscitation plans should be reviewed and updated, and end of life care planning commenced. Relevant agencies such as the ambulance service should be notified of these plans. The family will usually be aware that their baby's death is inevitable and will have some time to plan. They are likely to be anxious to know that pain and symptoms will be adequately controlled and that their baby will not suffer.

Relevant organisations should be notified of the baby's death, such as the local Child Death Overview Panel (in England), which reviews the deaths of all local babies and children, and the Care Quality Commission should also be notified in the case of babies who die in a children's hospice.

Professionals working with these families should be honest and open about the probability that the baby's life is nearing an end. Families should not be given false hope and should be allowed to plan for death. The family should be able to exercise choice and receive full care and support in that choice. It is therefore advisable for a plan to be agreed in advance if possible, based on the family's needs and wishes. Making a plan can help to eliminate some of the family's anxieties and ensure that events happen as they wish (See Diagram 3).

## The Fifth Standard: An end of life plan

**Every family should be helped to prepare an end of life plan for their baby and should be provided with care and support to achieve this.**

### What this means

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

As soon as it becomes apparent that the baby is approaching end of life, it is important that all professionals and agencies involved are brought together with the family to discuss their needs and wishes, and to explore where they wish their baby to be cared for. The environment in which the family feels most comfortable is an important consideration. Many wish to be at home or at a relative's home, but others may choose a children's hospice or hospital. With efficient co-ordination from the key worker and collaborative working across the appropriate services, a combination of these places is also possible. Whatever the choice, the family will need 24 hour access to care at end of life. It is important to clarify who will be providing medical support and medication and to ensure they have the skills and knowledge to do so.

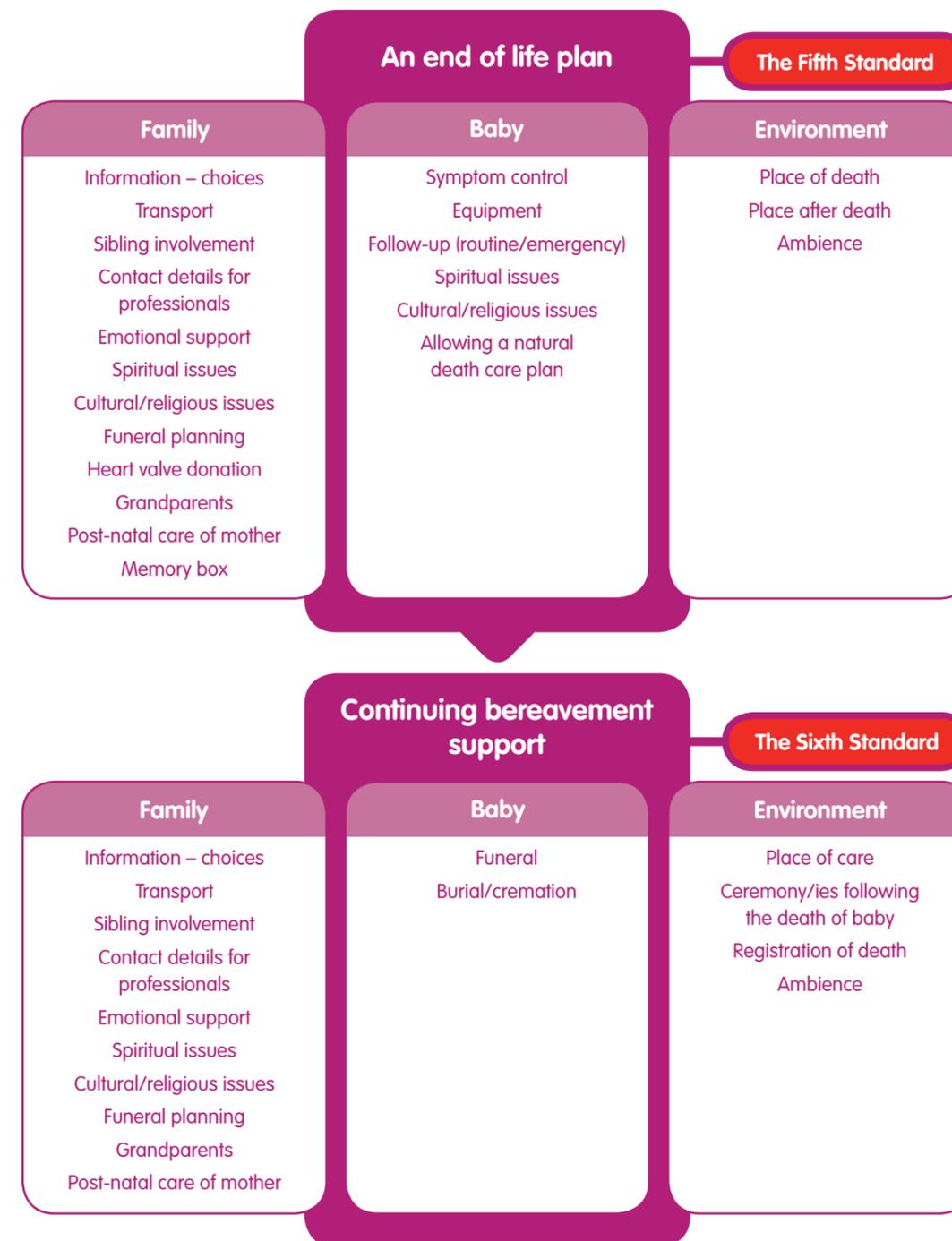
Supplies of medication and equipment, and out-of-hours pharmacy and equipment needs should be discussed and planned. This may need to happen urgently if the baby's health is deteriorating rapidly. This is likely to be a very difficult time for the family and it may be the point when they face up to the reality of their baby's death for the first time. A small core team needs to be identified to support this.

Professionals sometimes find it difficult to 'let go' of the baby or family and may themselves need support to recognise that families need privacy and that time with their baby is very precious.

#### Resuscitation plans

The suggestion may be made that the baby should not be resuscitated; however the precise details about what the family want and do not want should be fully explored. A written personal resuscitation plan should be developed with the consultant and other care team members. These plans allow families, in partnership with the health team, to tailor what interventions are appropriate for their baby and will assist communication between different professionals. The family may also wish to discuss the option of heart valve donation and the subject of post-mortem may need to be discussed. Parents should be fully informed about these issues and should feel that their decisions are understood and respected by all concerned.

Diagram 3: Stage Three: End of life and bereavement



**Plans for providing care at end of life**

The baby should receive effective pain and symptom control and regular symptom reviews should take place. Appropriate pain relief should be administered at regular intervals with other associated drug therapy for symptom and side-effect control. The family's decision to provide end of life care at home may not be possible if there is a breakdown in symptom control resulting in admission to hospital.

There may be a possibility of other distressing symptoms such as agonal respiration (gasping respiration) and the family will need reassurance that although frightening to watch, this can be managed effectively so that the baby is not distressed. It is important that the family and the team have 24 hour access to a children's palliative care specialist, paediatrician, nurse or specially trained GP so that symptoms and pain can be controlled around the clock and unnecessary emergency admissions to hospital can be avoided.

The agreed end of life plan will need to be documented, including the personalised resuscitation plan, which sets out what emergency treatment is to be used/not 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. This is also helpful if the family is receiving home-based care, as staff will need to be updated on each visit about the current resuscitation plan. Most local ambulance services offer a facility providing key information when an ambulance is called to a 'flagged address'. The plan should allow for an ongoing review of care and changing goals to comply with the wishes of the family. It is essential that all the team are informed of changes and kept up to date with the baby's care.

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

Parents and other significant family members should be encouraged and supported to continue their caring role with the baby. Siblings, grandparents and other relatives/carers, where appropriate, should be included in discussions about choices regarding quality of life. The local children's hospice may be able to help with this. Emotional support is essential at this time, and the family's cultural and spiritual needs and preferences must be taken into account.

For many families, memory building is important when life is short and the future uncertain. If the family have not already done so, they may want to arrange a ceremony to name their baby.

**Sustainable support**

End of life is difficult to predict in all babies with complex needs: teams need to be available to

sustain many weeks of care at end of life, and have contingencies for support if a baby's end of life phase is prolonged. Plans of care need to be devised that are sustainable and not dependent on the goodwill of one or two practitioners. Robust, appropriately staffed and trained teams are essential to provide the quality of care required.

**At the time of death**

This will be an extremely painful time for the family and also for those supporting them. The baby will need to have loved ones close by, and professionals should be sensitive to the family's need for privacy, space and support and should not obstruct the family's coping and grieving processes. In some cases, withdrawal of life prolonging treatment such as mechanical ventilation may be suggested, and the family will need time to come to terms with this.

Occasionally there may be conflict between the family and professionals about the best interests of the baby (RCPCH, 2004). With patience and sensitivity, allowing the family as much time as possible, agreement to withdraw treatment can be reached if appropriate. A useful guide, *Consent: patients and doctors making decisions together* published by the General Medical Council, (GMC, 2008) sets out a framework for good practice covering the various situations that doctors may face in the course of their work, including decisions at the end of life. It reinforces the importance of openness, trust and good communication.

There may be a need at this time for the family to review what they want to happen after the baby's death. This might include:

- Where would they like their baby's body to be cared for?
- Who will need to be contacted?
- Who will deal with the death certificate?
- Will there be a post-mortem?
- Has heart valve donation been discussed?

**After death**

After the baby's death it is vital that parents retain control and choice in the care of their baby's body. Families need to have time and privacy with their baby 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.

In some cases the family may decide they wish to transfer to another setting, such as a children's hospice, and this should be supported wherever possible. If the family wishes to take the baby to a hospice, or to their home after death, this transfer should be recorded in the baby's notes.

Parents may appreciate advice from the care team or funeral director about care of the body at home (Dominica, 1997). In many children's hospices there are facilities to allow the baby's body to be cared for in a cooled room, for as long as the family wish. It is also possible to arrange a mobile cooling device in the family home, usually from the funeral director, but sometimes via the local children's hospice service.

The family may wish to create some special memories of their baby. They may wish to take photographs, keep a lock of hair, or make hand or footprints. Parents should be consulted about whether they want to be involved in 'laying out' their baby and choosing which clothes to dress them in. They will need reassurance that their baby will be treated with dignity and respect by any professional handling him or her.

Keepsake activities incorporating the baby and their siblings should be considered, such as integrating all their hand or foot prints into a picture for the siblings as they grow older. Siblings should be given opportunities to express their emotions openly and ask questions, as their needs can often be overlooked by professionals, or parents overcome with grief. Parents should be encouraged to ask their children if they wish to see their brother's or sister's body and to include them in decisions about funeral arrangements. They may decide they wish to make a special contribution such as a prayer or a poem, or they may wish to place a gift or memento into their sibling's coffin. Grandparents also need sensitive consideration as they are likely to be grieving not only for their grandchild but also for their own child's sake.

Immediately after the baby's death, it is important to inform all professionals in contact with the family of the news. The family's key worker or another member of the team can assist in this if the family wishes.

People to contact may include:

- Neonatal services
- Midwife
- GP
- Community or specialist nurses
- Health visitor
- Social worker
- Children's hospice
- Religious leaders
- Ambulance service

It is also important to ensure that any department or service expecting the baby at an appointment is informed to ensure that 'did not attend' letters are not sent out. Where appropriate, benefit agencies should also be informed as soon as possible.

Written information should be provided for the family about procedures and entitlements following the death. This should include:

- Registering the death (and, at times, the birth).
- Procedures required for cremation.
- Contact details for funeral directors.
- Contact details for local religious leaders.
- Advice on benefits or other entitlements.
- Contact details for care staff.

When a death is expected it is usually not necessary for a post-mortem to take place. A post-mortem may be helpful in some cases, to answer questions and to help parents consider the implications for future pregnancies. Some families may also be asked if they will elect for a 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 sensitive and full information about post-mortem procedures and be given time to reach their decision.

If a post-mortem is required, many parents have great anxiety over their baby being transferred and left alone in the mortuary. Discussions with mortuary staff may reduce the time parents will be separated from their baby. An understanding of the mortuary environment and practices may reassure them that their child will continue to be cared for with dignity and respect. The core staff caring for the baby and family should fully understand the post-mortem process or be able to access staff to answer questions, provide information and allay fears. The consent of the family to their baby'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.

**Organ donation**

Heart valves can be transplanted to save the lives of patients, including very young children, suffering from diseased or damaged valves. There are no other neonatal organs or tissues suitable for donation. Families take great comfort from the knowledge that their child's death could save the life of another child. Heart valves can be retrieved from neonates above 32 weeks gestation, and some heart valve banks stipulate a weight of 2.5kg and above. Heart valve donation must take place within 48 hours of death.

### Funeral planning

Families should be made aware that they can choose whether or not to have a ceremony, and that they can have more than one if they wish. It may help to think about what they hope the ceremony will achieve. It may provide:

- A chance to bring together everyone whose life was touched by their baby, to say goodbye and draw comfort from each other.
- An occasion to hold as a memory that they can look back on.
- An opportunity to share the joy that their baby brought to their lives and to the lives of others.
- A religious ritual.
- A quiet 'parent only' time.

Sometimes families may want to talk about their baby at the funeral, but feel they are unable to do so. If this is the case, they may want to consider making a recording that could be played at the funeral. They may also find it useful to talk to someone who has previously arranged such a service for a baby.

### Key goals in planning for end of life care

- Professionals should be open and honest with families when it is recognised that the baby is approaching its end of life.
- Joint planning with families and relevant professionals should take place as soon as possible.
- A written plan of care for the baby and family should be agreed, including decisions about methods of resuscitation.
- Care plans should be reviewed and altered to take account of changes.
- End of life plans should be reviewed with the GP or doctor at least every two weeks, in order to avoid complications with the death certificate at a later stage.
- There should be 24 hour 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 family and carers.
- Families should be supported in their choices and goals for quality of life to the end.

- Staff involved should have access to their own lines of support and supervision.
- The needs of siblings and grandparents should be considered and included at the time of death and immediately afterwards as part of the end of life plan.
- Fully informed consent should be sought for post-mortem.
- When a post-mortem is performed, families should be informed of its findings by an informed professional that they know in a face-to-face setting.
- Professional contacts should be informed of the baby's death immediately.
- Practical advice and written information should be given about care of the baby's body, official procedures and entitlements.
- Possible heart valve donation and consent issues should be discussed.

## The Sixth Standard: Continuing bereavement support

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

### What this means

The death of the baby is not the end of the care pathway for the family. They will be grieving for many months and years to come and may need support along the way. The family's bereavement support needs should be assessed and planned by their key worker. The key worker may not necessarily deliver this care themselves, but they should ensure that it takes place.

The body of literature on bereavement is extremely large and within it much has been written about the grieving process. In the past some emphasis has been placed on concepts such as 'stages or tasks of grieving' (Kubler-Ross, 1969) but these may not always reflect the experiences or particular needs of bereaved families (Davies, 2004). More recent perspectives on parental grief such as 'continuing bonds' recognise that parents wish to continue 'holding on' to their relationship with their baby rather than 'letting go' (Klass, Silverman and Nickman, 1996). There are also resources for adults looking for ways to help their child/children through grief and bereavement (Brown, 1999). It should be acknowledged that grief for a beloved child may never end or resolve, as Talbot, a bereaved mother and grief counsellor, notes:

"Healing after the death of a child does not mean becoming totally pain-free. Healing means integrating and learning how to live with loss. It means being able to love others and reinvest in life again. Healing comes when parents decide that they will not permit pain to be the only expression of their continuing love for their child." (Talbot, 2002).

Those who have been involved with a family throughout 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 help 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 baby, rather than feeling that their grief consumes them every hour of the day. It can be helpful if difficult times such as birthdays, religious festivals, or the anniversary of the baby'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 this 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.

Where parents lose a twin, it is essential to recognise that the pain parents experience at the death of their baby is not reduced because they have another baby of the same age. Sometimes parents will be facing the loss of both twins (and more in cases of multiple births). The Twins and Multiple Births Association (Tamba) have a number of resources to support parents and professionals in this situation ([www.tamba.org.uk](http://www.tamba.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 baby. The intensive involvement, the feeling of friendship and support of members of the team will largely cease and many families feel suddenly cut off from what was previously a major part of their

lives. In addition they may suffer financial hardship as allowances are likely to be withdrawn or reduced. The family GP and primary care team should provide as much support as possible and should be prepared to provide support for many years.

### Key goals in continuing bereavement support

- The family should be allowed time and privacy with their baby.
- Parents should feel in control of events before and after death and should be able to follow their own choices and wishes.
- Bereavement support should be offered based on assessed needs.
- 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.
- The parents may want details of who they can contact to discuss any plans for a future pregnancy or need to make contact with a genetic service.
- Midwives should be sensitive to the mother's needs in future pregnancies, and there may be a need for support and counselling.

### Resources that can help

Information about how to buy individually designed coffins: [www.colourfulcoffins.com](http://www.colourfulcoffins.com)

Information about funeral cribs for stillborn and premature babies and younger children: [www.lawsonparry.biz](http://www.lawsonparry.biz)

The Child Bereavement Charity produces various resources to help professionals support families through bereavement: [www.childbereavement.org.uk/for\\_professionals/articles\\_and\\_leaflets](http://www.childbereavement.org.uk/for_professionals/articles_and_leaflets)

Bereaved children and young people can dedicate stars to their deceased family and friends at the Winston's Wish website: [www.winstonswish.org.uk/foryoungpeople/skyscape](http://www.winstonswish.org.uk/foryoungpeople/skyscape)

Perinatal hospice/palliative care programs and support website: [www.perinatalhospice.org/Perinatal\\_hospices.html](http://www.perinatalhospice.org/Perinatal_hospices.html)

# Part Three

## Appendices

ACT's Charter sets out what children with life-limiting and life-threatening conditions and their families should expect from services.

### Appendix One: The ACT Charter

ACT's Charter sets out what children with life-limiting and life-threatening conditions and their families should expect from services.

1. Every child shall be treated with dignity and respect whatever their physical or intellectual ability.
2. Parents shall be acknowledged as the primary carers and involved as partners in all care and decisions involving their child.
3. Every child shall be given the opportunity to participate in decisions affecting his or her care, according to age and understanding.
4. An honest and open approach shall be the basis of all communication.
5. Information shall be provided for the parent, the child, the siblings and other relatives, appropriate to age and understanding.
6. The family home shall remain the centre of caring wherever possible with appropriate support provided to all the family. Care away from the home shall be provided in a child-centred environment by staff trained in the care of children, young people and families.
7. Every family shall have access to a 24 hour multi-disciplinary children's palliative care team for flexible support in the home, and be in the care of a local paediatrician.
8. Every child and family shall receive emotional, psychological and spiritual support to meet their needs. This shall begin at diagnosis and continue throughout the child's lifetime, death and in bereavement.
9. Every family shall be entitled to a named key worker who will enable the family to build up and maintain access to an appropriate network of support.
10. Every family shall be given the opportunity of regular consultations with a paediatric specialist who has particular knowledge of the child's condition.
11. Every family shall have access to suitable flexible short term breaks (respite care) both in their own home and away from home, with appropriate children's nursing and medical support.
12. Every child shall have access to education, extended school opportunities and other appropriate childhood activities.
13. The needs of adolescents and young people shall be addressed and planned for well in advance using a young person-centred approach.
14. Every family shall have timely access to practical support, including clinical equipment, financial grants, suitable housing and domestic help.



## Appendix Two: Glossary of terms

### Care pathway/journey

ACT's description of a care pathway approach to working with children who have life-limiting 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 and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of quality of life for the child or young person and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement (ACT, 2008).

### 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.

### Child

A child is defined as a young person up until 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 end of life care.
- Support for the entire family (including siblings, grandparents and the extended family).
- Bereavement support.
- 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 as well as play and music therapy.
- Provision of information, support, education and training where needed to carers.

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 phase 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 is care that 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, which includes care during and around the time of death, and immediately afterwards. It enables the supportive and palliative care needs of both the child or young person and their family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support and support for the family into bereavement. This is not confined to specialist services but includes those 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/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, 2009).

### 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 children or young people 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 children with cancer. Children in long-term remission or following successful curative treatment are not included.

### Needs-led

Needs-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.

### Neonate

A baby in the first 28 days of life.

### 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.

### Short breaks

Short break care has three main functions:

- To provide the child or young person with an opportunity to enjoy social interaction and leisure facilities.
- To support the family in the care of their child in the home or an alternative community environment such as a children's hospice.
- To provide opportunities for siblings to have fun and receive support in their own right.

Short breaks may offer the whole family an opportunity to be together and to be supported in the care of their child or it may offer care solely for the child or young person.

### Specialist short break care

Specialist short break care refers to a setting of care, a programme of care or a service that provides additional care for highly complex or technology dependent children who may otherwise be excluded from short breaks provided by social care. It may take place in the child's home or in a setting outside of the home such as a hospital, long-term care facility or hospice. Specialist short breaks will often address some aspects of symptom management. Specialist short breaks should also meet the functions described under general short breaks.

### Supportive care

Supportive care is an 'umbrella' term for all services, both general and specialist, that may be required to improve the quality of life for people with life-threatening conditions. It recognises that people need some forms of care that are not directed towards cure from the time that the possibility of a life-threatening condition is raised.

## Appendix Three: Directory of useful organisations

Listed below are some of the national organisations that provide support for babies with life-limiting conditions and their families. There are many others and this is by no means an exhaustive list. Please call ACT's helpline on 0845 108 2201 for details of other sources of support.

### Neonatal and birth specialists

#### 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: [information@bliss.org.uk](mailto:information@bliss.org.uk)

#### Sands

Sands is an organisation which can offer parents support when their baby dies during pregnancy or after birth.

[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)

#### The Twins and Multiple Births Association (Tamba)

Tamba is a UK wide organisation helping parents of twins, triplets and more and professionals to meet the unique challenges that multiple birth families face. Their Bereavement Support Group ([www.tamba-bsg.org.uk](http://www.tamba-bsg.org.uk)) provides support for families who have lost one or more children from a multiple birth, during pregnancy or at any stage afterwards.

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

Tel: 01483 304442

Helpline: 0800 138 0509

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

### Information and support – General

#### Carers UK

Carers UK campaign to urge people to recognise the true value of carers' contribution to society and to ensure carers get the practical, financial and emotional support they need.

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

Tel: 0808 808 7777

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

#### Children's Hospices UK

Children's Hospices UK is the national charity that gives voice and support to all children's hospice services.

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

Tel: 0117 989 7820

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

#### Citizens Advice Bureau (CAB)

The Citizens Advice Bureau service helps people resolve their legal, money and other problems by providing free, independent and confidential advice, and by influencing policymakers. Your local branch can be found on the website or in your telephone directory.

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

#### Contact a Family

Contact a Family is a national charity providing advice, information and support for any family with a disabled child, whatever the child's condition. Their helpline staff can answer queries on all aspects of raising a disabled child, from providing medical information about a diagnosis, giving advice about benefits and services, through to schooling and assessments and statements of special educational needs.

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

Helpline: 0808 808 3555

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

#### Crossroads Caring for Carers

Crossroads service is about giving time and improving the lives of carers by giving them a break from their caring responsibilities.

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

Tel: 0845 450 0350

Email: [information@crossroads.org.uk](mailto:information@crossroads.org.uk)

#### Directgov

A government website providing information about benefits and entitlements.

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

#### Disabled Living Foundation

A national charity that provides free, impartial advice about all types of equipment for disabled people. It can help you find products and suppliers and also has an equipment demonstration centre. They also produce factsheets and other information resources.

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

Helpline: 0845 130 9177

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

#### Family Fund

The Family Fund helps families with severely disabled children to have choices and the opportunity to enjoy everyday life. They give grants for things such as washing machines, driving lessons, hospital visiting costs, computers and holidays.

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

Tel: 0845 130 4542

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

#### 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

In England & Wales:

National Tissue Donor Referral Centre

Tel: 0800 432 0559

In Scotland:

Scottish National Blood Transfusion Service

Tel: 01315 365751

#### 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)

Helpline South: 01372 453309

Helpline North: 01434 602961

#### REACT

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

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

Tel: 0208 940 2575

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

### Information and support – Condition specific

#### Cerebra

Cerebra is a charity set up to help improve the lives of children with brain related conditions through researching, educating and directly supporting children and their carers. Parent Support is the Cerebra information and support service for parents, carers and others involved with any child with a brain related condition (brain injuries, neurological disorders, mental disabilities and developmental problems).

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

Tel: 01267 244229

Helpline: 0800 328 1159

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

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

Climb is committed to fighting metabolic diseases through research, awareness and support. For diagnosed and undiagnosed families with metabolic disease, they can supply long term support for all issues to do with diagnosis, treatment, benefit advice, small grants, family issues, bereavement and more.

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

Helpline: 0800 652 3181

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

#### Cystic Fibrosis Trust

The Cystic Fibrosis Trust is the UK's only national charity dealing with all aspects of Cystic Fibrosis (CF). It funds research to treat and cure CF and aims to ensure appropriate clinical care and support for people with Cystic Fibrosis.

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

Helpline: 0845 859 1000

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

#### GIG (Genetic Interest Group)

The Genetic Interest Group (GIG) is a national alliance of patient organisations which support children, families and individuals affected by genetic disorders.

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

Tel: 0207 704 3141

Email: [mail@gig.org.uk](mailto:mail@gig.org.uk)

## Bereavement

### Child Bereavement Charity

The Child Bereavement Charity offers specialised training and support for professionals whose work brings them into contact with bereaved families. They also produce resources including memory boxes, workbooks and DVDs. Families can also contact them to request information or a telephone support session.

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

Tel: 01494 446648

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

### Childhood Bereavement Network

The Childhood Bereavement Network seeks to ensure that all children and young people in the UK, together with their families and other care givers, including professional carers, can easily access a choice of high-quality local and national information, guidance and support to enable them to manage the impact of death on their lives.

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

### The Compassionate Friends UK

The Compassionate Friends is an organisation of bereaved parents and their families offering understanding, support and encouragement to others after the death of a child or children. They also offer support, advice and information to other relatives, friends and professionals who are helping the family.

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

Helpline: 0845 123 2304

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

### Samaritans

Samaritans provides confidential non-judgmental emotional support, 24 hours a day for people who are experiencing feelings of distress or despair, including those which could lead to suicide.

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

Helpline: 0845 790 9090

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

### TCF Sibling Support

Sibling Support is a project run by The Compassionate Friends and provides nationwide self-help support for people who have suffered the loss of a brother or sister.

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

Tel: 0845 123 2304

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

### Winston's Wish

Winston's Wish is a childhood bereavement charity providing services to bereaved children, young people and their families.

[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 Four: References

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## A Neonatal Pathway for Babies with Palliative Care Needs

Ninety eight per cent of neonatal deaths occur in the clinical, and often impersonal, environment of a hospital setting, with very few parents currently being supported to allow their baby to die at home or at a children's hospice.

Some of these babies, especially those for whom there is no hope of cure, and those who are close to their end of life, could be transferred to their family's home or a local children's hospice, with appropriate support. Palliative care is generally only provided for babies over 28 days old, and this new pathway aims to change this norm.

*A Neonatal Pathway for Babies with Palliative Care Needs* has been developed primarily to help support those professionals working in maternity, obstetric and neonatal units who care for babies with life-threatening or life-limiting conditions. It aims to encourage practitioners and commissioners to ensure that the appropriate care is available in the right place, at the right time for each of these babies.

This essential resource draws together the professionals and resources needed to accompany the baby and family along their unique care journey. It will help to ensure that appropriate palliative care is administered to babies, no matter how young they are, or how short their lives may be, making sure the parent's wishes are taken into account at every stage throughout their baby's life, and afterwards.



Valuing short lives

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**ACT** is the only organisation working across the UK to achieve the best possible quality of life and care for every life-limited child and their family.

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