



Valuing short lives

A Care Pathway to Support Extubation within a Children's Palliative Care Framework

First edition 2011



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A Care Pathway to Support Extubation within a Children's Palliative Care Framework

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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.

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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. ACT 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 provides a national helpline service.

ACT together

ACT represents a membership of over 1,000 families and children's palliative care professionals. We provide members with a range of benefits including publications, newsletters, information bulletins, training and conferences, as well as professional support and guidance.

ACT works with professionals to share best practice and develop 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 ACT to 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.

Train to Care

ACT's Train to Care service is designed to raise standards and deliver excellence in children's palliative care by improving practice and developing knowledge, skills and experience. ACT offers both standard learning modules and a bespoke children's palliative care consultancy service to help evaluate, develop or improve services. As part of this consultancy service ACT can help you to develop a care pathway approach to your work including the implementation of this pathway to support extubation within a palliative care framework. If this is something you would like to discuss, please contact ACT at the numbers below or email traintocare@act.org.uk

Contact ACT

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Foreword

Modern medical care has brought with it a huge improvement in the benefits which can be given to individual patients.

Some situations are so complex and uncertain that treatments are embarked upon which turn out to be futile. Drawing back from these interventions can be one of the most difficult and emotional areas of medical practice. Death with dignity in an inevitable situation can be thwarted by aggressive attempts to save life.

Artificial ventilation is one such life sustaining intervention which is hugely successful and life saving for many, but one that can be very difficult to draw back from when the primary problem becomes untreatable.

Difficult decisions have to be taken in the best interests of the patient and with full and open discussion with parents and carers.

The whole process of compassionate extubation is one where everyone needs help. Firstly parents need to understand all of the options and implications of each, and then professionals, so that they can explain all of this in a way that parents can understand. This is an area of medicine where decisions cannot easily be made by a single professional and discussion with colleagues is vital.

A 'good' death and well planned end of life care are central to ACT's philosophy of care. This *Care Pathway to Support Extubation within a Children's Palliative Care Framework* provides professionals with the tools that they need to support families to make informed choices at this difficult time.

The pathway has been developed by experienced professionals in partnership with parents and provides a clear framework with the child and his/her parents at the centre.

I recommend this to all who may support babies, children or young people who may find themselves in what seems an impossible situation. Even in these extreme circumstances a good death is possible.

Cicely Saunders, the pioneer of palliative care, said *"The way people die lives on in the memories of those left behind."* The use of this pathway should enable parents and professionals to live comfortably with their memories.



Professor Sir Alan Craft
March 2011



Making the decision to follow this pathway can enable some families to spend precious moments with their child outside of a highly clinical and technical environment.

Introduction

ACT's work with children's palliative care spans 22 years and our philosophy has always been to promote the best possible quality of life and care for every life-limited baby, child or young person and their family.

Giving families real choice has been key to this approach; a choice of place of care, a choice of place of death, a choice of emotional and bereavement support; and putting the child and family at the centre of decision making to produce a 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, and a neonatal care pathway in 2009. This care pathway approach, now widely adopted across the UK, has helped to improve the family's journey throughout their child's life and eventual death.

The need for a dedicated care pathway to support extubation

ACT has now developed this *Care Pathway to Support Extubation within a Children's Palliative Care Framework* to complement its three pathways for neonates, children and young people. It can be drawn on at any time during the child's journey, once it is recognised that continued invasive aggressive treatment is not in the child's best interests.

ACT's experience in neonatal, children's and young people's palliative care has shown us that more children with life-limiting or life-threatening conditions

are being enabled to live longer through ongoing advances in medical care, including the use of mechanical ventilation.¹

Some of these children have a very poor prognosis. This pathway focuses on children who are in the situation of being at the end of their life and who are dependent on respiratory support. Many of these children will be in an intensive care environment.

Some of these children are now being given the choice to die at home, in a hospice or a hospital closer to home, where the withdrawal of mechanical ventilation is part of their end of life care plan. This pathway recognises that extubation actually means taking out a tube and discontinuing mechanical ventilatory as well as all other critical care support. This is the process that has traditionally taken place in intensive care environments, although in recent years there has been an increasing trend to supporting and enabling the process to occur outside of the acute hospital; taking it into the family home or a children's hospice.

An increasing number of professionals have told us that they have been called upon both to support the withdrawal of life-sustaining ventilation more frequently, and also to manage this process outside of the more traditional intensive care setting. Making the decision to follow this pathway can enable some families to spend precious moments with their child outside of this highly clinical and technical environment.

1. Children's Hospices UK has recognised that the number of children and young people under the age of 17 years who receive long term ventilation rose from a total of 141 in 1998 to 933 in 2008 (Wallis, Paton et al, 2010) and has produced a useful resource which aims to assist staff to support children and young people (and their families) who require ventilation. Children's Hospices UK, 2011. *Supporting Ventilated Children in Children's Hospices Settings*. Bristol: Children's Hospices UK.

It is recognised that some children will not die around the time of the extubation and plans need to be in place to care for the child in this eventuality. Parents need to be informed that this may happen and proactive parallel planning should be commenced to ensure that if the child or young person does survive the withdrawal of ventilatory support, then ongoing care can be put in place to support both them and their family. Up to one third of children transferred to hospices for terminal care survive to go home, and some survive for prolonged periods of months or even years.²

These developments in clinical practice and an increase in extubating terminally ill children outside critical care units have stimulated much debate and consideration within children's palliative care, neonatal and intensive care sectors. ACT, as the lead UK charity representing the children's palliative care sector, seeks to ensure the highest quality of care is provided at the end of a child's life. This, and choice for families in their child's place of care and death are integral to the process of withdrawing life-sustaining treatment.

The pathway to support extubation was developed in response to a growing awareness of different practice and approaches to withdrawing life-sustaining ventilation and the need for clear guidance for all professionals who may be involved. The development of this pathway is the result of a wide collaboration with expert professionals. It is accompanied by a leaflet for parents and carers who are at the point of making critical care choices for their child.³

ACT's care pathway to support extubation: aims and structure

ACT's *Care Pathway to Support Extubation within a Children's Palliative Care Framework* draws together all the professionals and resources needed to support the child and family along their unique care journey before, during and after extubation, where this is their chosen end of life care option.

It has been developed to support the overall process of extubation for this group of children in a wide range of environments including: critical care settings, general hospitals, children's hospices and the child's home.

It has been designed to facilitate communication between professionals and the child and their family so that they can explore care options when it is clear that continuing life-sustaining treatment is not in the best interests of the child.

It encourages open and honest communication that will support a family to make individualised choices

that are right for them, and enable the professionals supporting them to develop and implement an agreed care plan.

The pathway provides a framework and tools to assist this and can be adapted to fit with local and regional services and practice. As such this pathway does not include detailed drug regimes nor rigorous time scales, as this is something more appropriately covered in local pathways and plans for the individual child, linking into local protocols and practice.

The pathway has been designed as a flexible tool that can accommodate the specific needs of the child and family, whatever their decision. The framework also accommodates the uncertainty around the outcome of extubating a child. Although children may be expected to die shortly following extubation, some may survive for weeks, months or years. ACT's *Care Pathway to Support Extubation within a Children's Palliative Care Framework* encourages professionals to plan for both possibilities and to prepare the family for this uncertain future.

Guided by six sentinel standards, this pathway recognises that children and their families will make varied and individual journeys according to their own needs and circumstances. It provides a template to facilitate everyone around the child in keeping with their journey and ensuring that the child and family are always at the centre of the care planning process. This document is divided into three parts:

Part One

This section provides an introduction to children's palliative care and ACT's care pathway approach. It discusses the need for a dedicated pathway approach and outlines the principles that ACT recommends in adopting and delivering the *Care Pathway to Support Extubation within a Children's Palliative Care Framework*.

Part Two

Part two takes the reader through the *ACT Care Pathway to Support Extubation within a Children's Palliative Care Framework*. There are three stages to the pathway: the journey towards a decision to withdraw life-sustaining ventilation; the practicalities of withdrawing life-sustaining ventilation; and care at the time of death.

Part Three

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

2. Lapwood, S., 2010. Personal Communication.

3. ACT, 2011. *A Parent's Guide: Making critical care choices for your child*. Bristol: ACT.

Pathway summary diagram: A Care Pathway to Support Extubation within a Children's Palliative Care Framework



ACT believes that families should be aware of the different care and support options available from the outset so that they can make informed choices.



Part One

ACT's approach to children's palliative care

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).⁴

Life-limiting or life-shortening conditions are those conditions 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.

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's and family's quality of life at the centre of care. This 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 for children does not focus as much on end of life, and is more family-centred. Over the past three decades much work has been accomplished to promote the need for services for babies, children and young people with life-limiting or life-threatening conditions.

4. ACT, 2009. *A Guide to the Development of Children's Palliative Care Services*, 3rd Edition. Bristol: ACT.

Palliative care for children is different from adult palliative care in a number of significant 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, although the child may survive into early adulthood.
- 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 this and responsive to each child’s changing levels of communication and 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/freeresources
 You can also read about ACT’s philosophy and approach to children’s palliative care in *The ACT Charter*, Appendix Three of this document.

The relationship between palliative care and treatments aimed at cure or prolonging life

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 comes.
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, also 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.



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

The ACT care pathway approach

ACT's first care pathway was developed in 2004 as a tool to help professionals plan appropriate care for children and young people with life-threatening or life-limiting conditions and their families, and co-ordinate the various services and individuals that are 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 to 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, and *A Neonatal Pathway for Babies with Palliative Care Needs* in 2009.

ACT's *Care Pathway to Support Extubation within a Children's Palliative Care Framework* aims to identify the explicit issues that need to be considered when caring for babies, children and young people where the withdrawal of life-sustaining medical intervention in general, and extubation in particular, is being considered. It is designed for all settings, including: critical care units, hospices or home. It cross references to the other three ACT care pathways, and can be used alongside them.

The pathway is guided by sentinel standards based, where possible, on evidence. The prime intention of this pathway is to provide a means for developing essential components that can underpin more detailed local pathways. It focuses on putting children 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 many of the children who are at the centre of this pathway are currently being cared for in hospital; some of these children will be known and others unknown to local services. As such, this pathway is designed to be started well before discharge from hospital, and to continue during and after the withdrawal of life-sustaining treatment, either in hospital, at home or in a children's hospice.

This pathway also acknowledges that increasing numbers of children with long term ventilation are being cared for in the community, and decisions between the family, the child's specialist and intensive care team along with their community team, may be taken whilst the child continues to be cared for at home.

Within this document, extubation is recognised explicitly as the cessation of *mechanical ventilatory support*; however we recognise that it is still possible to provide ventilatory support with non-invasive mask ventilators. This pathway focuses on those children where all support is withdrawn, although the principles described will be useful for all situations where life-sustaining treatment is being withdrawn.

Withdrawing life-sustaining treatment: the need for a pathway

ACT believes that families should be informed about the different care and support options available from the outset so that they can make informed choices. ACT's care pathway approach sets out how palliative care should support the child and parents throughout their individual journey.

Withdrawing life-sustaining treatment has a number of unique facets. Care is often initially provided in busy intensive care environments in which the child's condition and prognosis may change suddenly. Family members will find that their lives, which will have already been significantly affected by the child's serious decline in health, will be affected in an even more profound manner by the withdrawal of treatment.

The Royal College of Paediatrics and Child Health is keen to promote palliative care and ensure that the child's needs continue to be assessed and met as '*a re-direction of management from life-sustaining treatment to palliation represents a change in beneficial aims and objectives and does not constitute a withdrawal of care*'.⁵

Professionals working in intensive care services are used to providing sophisticated expert care utilising high levels of technical skills and knowledge. These professionals are now being increasingly challenged to provide palliative care as an integral part of the child's care. The environment of such units traditionally relies heavily on technology and equipment, whilst a child with palliative care needs may require highly intensive care but may not need such a high level of technical care.

The focus of this pathway is to support families living through their child's end of life care stages, where withdrawal of life-sustaining treatment is part of that care plan. The pathway aims to support this to happen in an environment that promotes a dignified, peaceful time where the family can be together without inappropriate or non-beneficial interventions.

ACT was inspired to develop this pathway by a number of different factors including an awareness that more children with life-limiting or life-threatening conditions are being enabled to live longer by the use of mechanical ventilation. Some children, for whom any continued invasive aggressive treatment is not in their best interests, are now being given the opportunity to die at home, in a children's hospice or in another place, where withdrawal of mechanical ventilation is part of their end of life care plan.

ACT is aware that many of its members and colleagues across the UK are being asked with more frequency to support this end of life choice. ACT recognises that death soon after extubation is not the only outcome, even when it is anticipated. This unpredictability confirms the need for parallel planning to ensure the ongoing care of the child or young person in cases where they survive. Following an informal survey via ACT's PaedPalCare online forum (Lapwood, personal communication), it is becoming clear that the outcome following extubation is both variable and unpredictable, with some long term survivors. This clearly has implications for communication, decision-making and planning at every stage.

In collaboration with a wide range of individuals and organisations already experienced in extubating these children at home or at a children's hospice, ACT wanted to develop a pathway to share evolving good practice and to provide a framework for others

5. Royal College of Paediatrics and Child Health (RCPCH), 2004. *Withholding or Withdrawing Life Saving Medical Treatment in Children: A framework for practice*, 2nd Edition. London: Royal College of Paediatrics and Child Health.

to replicate and develop locally. Development of this pathway was also inspired by a growing awareness of different practice and approaches to withdrawing life-sustaining ventilation and the need for a clear framework and guidance for all professionals who may be involved in supporting a child and their family through this difficult process.

The pathway to support the withdrawal of life-sustaining treatment is based on the principles of providing the best possible quality of life and care and real choice in the child's place of care and death. It shows that extubation can be a positive care option for some children and their families, in so far as it offers the option of allowing a natural death and can enable some families to spend precious moments with their child outside of a highly clinical and technical environment.

The pathway has been designed to:

- Support the clinical process of extubation for this group of children in a wide range of environments including: an intensive care setting, general hospitals, children's hospices and in the child's home.
- Facilitate communication between professionals, the child and their family to explore care options when it is clear that continuing life-sustaining treatment is not in the child's best interests.
- Encourage open and honest communication that will enable the family to make individualised choices that are right for the child and themselves, and enable the professionals supporting them to develop and implement an agreed care plan.

- Provide a flexible tool that can accommodate the specific needs of the family, whatever their decision.
- Provide the framework and tools that can be adapted to fit with local and regional services and practice.
- Encourage parallel planning to take into account the unknown outcome following the extubation of a child.

Ethical and legal considerations

ACT recognises that decisions about the withdrawal of life-sustaining medical treatment in children raise strong emotions in families, health professionals and the public. It is one of the most common reasons for cases to be brought to the courts or for ethics committees to be consulted.

The overriding legal and ethical principle is that all treatment decisions must be taken in the child's best interests. A healthcare professional cannot be forced to provide medical care which in their bona fide professional judgement is not in a child's best interests. There is no legal or ethical duty to initiate or continue life-sustaining treatment which is excessively burdensome relative to the likely benefits and is therefore considered not to be in the child's best interests. However under the law of homicide/assisted suicide it is illegal to act positively and intentionally to cause or hasten death. Although the legal principles on end of life issues are clear, the application of the law in actual cases may cause difficulty and controversy.



There is a legal distinction between an omission to act (which includes both withdrawing and withholding treatment) and action which is intended to bring about someone's death (for example, lethal injection). An omission to act, knowing that this will result in the person's death is permissible, where it is not in the person's best interests to continue life-sustaining medical treatment (Airedale NHS Trust v Bland, 1993).⁶ It is therefore allowable by law to withdraw or withhold life-sustaining medical treatment if the omission is in the patient's best interests. However, if a child's parents disagree with the decision you will need to go to court to seek a declaration as to the lawfulness of withdrawing or withholding treatment.

The duty to provide life-sustaining treatment is not absolute, for example when a treatment is unlikely to be successful, such as cardiopulmonary resuscitation or when it is considered not to be in the patient's best interests to be kept alive.

There is also a legal distinction between a positive act which is not intended to bring about a person's death but may have as a foreseeable consequence the hastening of death and an act which is intended to cause death. For example, it is lawful to give pain relieving drugs that may, as a side effect, shorten life in a terminally ill child provided the intention is to relieve pain, as in the doctrine of *double effect*.⁷

Additionally, the law in all four UK countries can vary. Appendix Two describes the current position in relation to English law, but professionals are advised to seek up to date local legal advice if they have concerns in individual cases. Professionals should also consider whether there is a need to involve mediation services in contentious discussions, rather than immediately seeking a legal judgment.

Ethics and extubation in a palliative care framework

Care of children with life-limiting illnesses may raise ethical dilemmas over what *ought* to be done, that cannot be resolved by appeal to purely clinical facts, especially where moral and ethical principles may conflict. This is particularly relevant when extubation is being considered.

Ethical and moral duties and responsibilities of healthcare clinicians

Clinicians owe special ethical obligations (duties) to their patients. They must have the best interests of their patients as their paramount concern.

The practice of palliative care is consistent with the ethical duties of medicine. Good palliative care confers more benefit than harm, respects and promotes such autonomy as the child is capable of, and provides support for parents and carers. Although life-sustaining treatment may be withdrawn, it is essential that palliative care continues to the point of death and beyond. Palliation is an essential practical component of any proposal to limit life-sustaining treatment.

Parental responsibilities, rights, duties and powers

Those with parental responsibility (see Appendix Two) have moral, ethical and legal responsibilities for their child's upbringing and authority for decision making. They would be expected to determine their child's best interests until he or she is able to do so for him/herself. Parents are empowered to rear their children in accordance with their own values provided they act in the child's best interests.

A family's concept of their child's best interests is likely to be determined by their own ethical framework, which in turn depends on a number of variables. Their values may differ from those of professionals and parents may have difficulty in acknowledging the child's increasing right to make decisions for themselves.

Arguments in favour of limiting life-sustaining treatment (LST)

Decisions to limit (withhold or withdraw) LST (including ventilation) are regularly made in clinical medicine. In all cases the ethical, moral and legal justification to limit LST is the judgement that it is no longer in the patient's best interests to provide it.

The situation for many children and young people with life-limiting conditions is that their lives are often perceived as lacking in quality and may be seen as unbearable. However this is a subjective judgement and surrogate decision-making on behalf of children is fraught with significant 'assessment errors', and may represent the surrogate's own projected feelings about the child's situation.

6. Airedale NHS Trust v Bland [1993] 1 All ER 821 HL.

7. The principle of double effect; also known as the rule of double effect is a set of ethical criteria for evaluating the permissibility of acting when one's otherwise legitimate act (for example, relieving a terminally ill patient's pain) will also cause an effect one would normally be obliged to avoid (for example, the patient's death).

Therefore a decision to formally change the goals of treatment or care, for example by discontinuing ventilation, poses intellectual and emotional challenges and requires an understanding of the ethical and legal issues involved. It can only be sustained if there is adequate and appropriate palliative care, which should include support for the family.

Introducing the topic of limiting LST may lead to conflict between those involved, especially when there are serious moral questions about sustaining life. Multi-disciplinary team members require qualities of empathy, sympathy and good communication skills so as to permit open, constructive and sensitive discussions with families.

If conflicts over a proposed course of action arise, such as discontinuation of ventilation, it is essential that they are resolved before practical action is taken. This process may involve communication, negotiation, consensus building, clarification of facts, education, obtaining second opinions, medico-legal advice, independent mediation and formal ethical review. If these fail to achieve resolution and agreement then it may be necessary to seek the opinion of the Court, as the final arbiter of best interests, as to what would be the lawful course of action.

Principles of the care pathway to support extubation within a children's palliative care framework

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

A unique journey for every child and family

The whole of family life is affected by the death of a child. Grief is an individual concept: some 'heal'; some never want to heal; some look at continuing relationships (in a myriad of ways); some see 'dead' as dead and gone. Choice is therefore vital. It is important to ask the family what they want, to ensure that the whole family focus is retained while ensuring a professional approach, underpinned by theory.

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 support groups suit some, but not all. Couple support can be helpful because of the strain the parents' relationship is under when caring for a dying child.

Parallel planning

Although survival following the withdrawal of life-sustaining treatment in this context may be thought unlikely, it is possible in some cases. Therefore this should be discussed, both within the professional team and with the family, and plans should be put in place in case this happens. Planning for further assessment or support from health, social care and education services may seem inconceivable and may be discontinued, or never started. It is important that proactive parallel planning is practised: planning for delivery of end of life care, whilst also continuing to plan and make available the full range of local children's services in case of the child's ongoing survival (whilst acknowledging realistically the relative likelihood of this).

Planning for life whilst also planning for death allows a child's full potential to be achieved. Families can often draw comfort from planning for the future at times of great uncertainty. A process should be in place to prepare parents if their child requires subsequent readmission to hospital. This is likely to be to a children's ward, or other unit or ward the family are familiar with (rather than the intensive care unit). This may be in the same or a different hospital, with a different consultant and care team involved in their care.

Uncertainty

Families often experience repeated uncertainty and losses; first the loss of the 'normal' child, followed by the anticipated loss of a child predicted to die. At times, this child may defy medical expectations and survive episodes of life-threatening deterioration, only for the family to face their death in the future. Often clinicians will be asked to give an estimation of how long the child will live. The best and most accurate answer is that "YOU DO NOT KNOW". Following extubation, children may die very quickly, or may confound predictions and continue to live for weeks, months or longer.

Ability to respond quickly and flexibly

It is crucial to remember the importance of talking to parents and the family, giving them choices and maintaining a flexible, 'can-do' attitude, to support the family's choices. If they choose to allow their child to die at home or at a local hospice, then this extubation pathway should be followed to support the child's rapid discharge from hospital. At such times, it is vital that one practitioner is identified to take the lead, so they can act as the family's first point of contact for communication, and to ensure that information flows to all services.

Communication

There should be an honest and open approach to all communication with parents. Parents should be treated as equal partners in any discussions with the care team. Parents have certain legal rights to make decisions about their child's treatment (see Appendix Two).

Spiritual support

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

Psychological support

Psychological support is needed throughout the family's journey, from diagnosis, through end of life care and following the death of the child. 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 this extubation care pathway.

Key worker

Every family should be entitled to a named key or lead worker who will enable the family to build up and maintain access to an appropriate network of support. A key worker⁸ 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 who can communicate their needs and wishes, and who will ensure that their care plan is being delivered effectively.

24 hour support

Every child should have access to a 24 hour multi-disciplinary children's palliative care team for flexible support in the home or other setting, and be in the care of a local paediatrician (depending on local protocols about the handover of care between consultants). This will help to develop contingency plans for care on a longer term basis in cases where the child survives for longer than expected following extubation.

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 hospice services and other health, social care and education organisations as they consider diversity and cultural issues in children's palliative care.

Care for the team around the child

Every professional who is called upon to support the child and their wider family throughout this care pathway will, no doubt, find this journey emotionally challenging. Every member of the team around the child and family should receive support, supervision and an opportunity to feedback and discuss what is happening. This should be a part of ongoing support and supervision.

Professionals may spend intensive periods of time with a child and family, but never know the outcome for the child. This may happen, for example because a child leaves the intensive care unit so that they can be extubated in another environment, such as a hospice or at home. It can be hard for the professional to have a sense of closure or to be able to 'deal' with this, if they do not know the outcome for the child and the family. Professionals who provide care in the later stages of the pathway and who are involved during and after extubation should be encouraged to feed back to the referring team.

In some circumstances, staff will have been caring for a child long term in a very intense manner, for example, daily in their home. The impact upon staff around the time of decision making and through to bereavement can be profound. Staff are likely to need access to more substantial emotional support than in many other situations where they have cared for a dying child.

8. A key worker is both 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).

Resources that can help

South Central Strategic Health Authority (England), 2010. *Advance Care Plan Policy* (For an excerpt of this policy please see Appendix Two on page 48). www.oxfordshirepct.nhs.uk/about-us/documents/255Childandyoungpersonadvancedcareplanpolicyoctober2010.pdf

The Ethox Centre, 2010. *Ethical and Legal Issues at End of Life*. www.ethox.org.uk/education/undergraduate-course/ethical-decision-making-at-the-end-of-life/End%20of%20Life%202010-11.doc/view

Royal College of Paediatrics and Child Health, 2004. *Withholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice*. London: RCPCH.

ACT, 2011. *A Parent's Guide: Making critical care choices for your child*. Bristol: ACT. (See www.act.org.uk)

The Children's Hospices UK, 2009. *Diversity Toolkit*. Bristol: Children's Hospices UK.

Children's Hospices UK, 2011. *Supporting Ventilated Children in Children's Hospices Settings*. Bristol: Children's Hospices UK.

This care pathway draws together all the professionals and resources needed to support the child and family along their unique care journey.



Part Two

The ACT Care Pathway to Support Extubation within a Children's Palliative Care Framework

1

Stage One:

The journey towards a decision to withdraw life-sustaining ventilation

The start of the journey for many children recognised as having a life-limiting or life-threatening condition may begin antenatally, at birth, during development, during a period of intensive care, following a critical event or a period of deterioration in the child's condition, or at end of life. For some families, entry to this pathway will begin with the devastating news that their child has been diagnosed with a life-threatening or life-limiting condition. Breaking this news to the family requires great skill and sensitivity.

For some families, their journey will begin when their child is recognised as having a condition which cannot be cured, or following an acute medical crisis such as infection or trauma which will move them straight to the end of life phase. In cases where a child's survival may be uncertain, early referral to palliative care services can help manage this uncertainty by developing a number of alternative care plans to manage the eventual outcome.

Families may wish to start to make choices about their child's care, including a preferred place of care for their child, for example taking into account which team and which environment will offer them the care that is most appropriate for their child's condition and their own circumstances.

Care professionals should consider whether routine interventions are really necessary. With palliative care beginning in the critical care setting, it is essential that the need for *any and all* procedures and interventions, both diagnostic and therapeutic, should be carefully reviewed.

The First Standard:

Sharing significant news

In cases of new diagnoses, or when revisiting a prognosis made earlier, every family should receive the disclosure of their child's prognosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity. Information should be provided to the family in language that they can understand.

Key goals in sharing significant news

- Parents should be treated with openness and honesty.
- Parents should be acknowledged as experts in the care of their child.
- Significant news should be shared in a place of privacy.
- Professionals should allow plenty of time for sharing news and discussing what this means with families.
- Parents should be given the opportunity to hear news together.
- Advocates and interpreters should be readily available to support families.

- News should be shared using clear, jargon-free and readily understandable language.
- There should be open communication between professionals and the family.
- Parents should be given time to explore care options and ask questions.
- Sharing significant news should be backed up by helpful written material.

What this means

Acknowledging that a child is unlikely to survive their current episode of care and is expected to die prematurely is undoubtedly one of the most difficult tasks that any professional has to undertake. 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, 1994). Families need honesty, respect and, above all, time from those professionals disclosing the diagnosis or likely prognosis. Professionals should acknowledge that the parents are experts in the care of their child. It is essential that families receive significant news in a place of privacy and at a time when the professionals involved are not likely to be disturbed. If disclosure is avoided or postponed, parents are likely to stumble on the truth at a later stage, and their trust and confidence in professionals will be damaged. Research shows that parents need information at this early stage and using language that they can understand (Sloper and Turner, 1993).

The child'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. Parents and legal guardians of young children have a right to be included in any decision-making process that will affect their child. However, the decision-making process is complex. For parents to make an informed choice they will need to understand all the different care options for their child. The care team should explain and explore all the options with the family, and the family should be given time to consider what they would like for their child. It is important that the family do not feel rushed into making decisions. Remember, everyone is different and will have their own personal beliefs about what is right for their child. ACT has produced a leaflet to support families during this time. (*A Parent's Guide: Making critical care choices for your child* – see www.act.org.uk)

Whilst written information is always valuable as a back-up to face-to-face discussion with parents, it should never be a substitute for personal jargon-free communication. Parents should have time to discuss the options available for the care of their child and be

given the opportunity to ask questions. Professionals should ensure that there is someone available to provide support for single parents. 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 their child's diagnosis or prognosis.

Parents may also want a supporter with them, either another family member or friend, or perhaps a religious or spiritual leader, or someone from their care team to help advocate for their wishes and needs. From the time of diagnosis parents and professionals should recognise that they will be working together to share the care of the child.

Professionals should also check whether family members have 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. Understanding and retention of information may be helped by the provision of relevant information leaflets, and/or a handwritten summary or recording of the conversation. Families should also be given the opportunity for further face-to-face discussion again to repeat and review all communications.

Where appropriate, interpreters should be readily available for the discussions and staff should not rely on family members to translate at this time. The training and preparation of staff who will have to handle the sharing of significant news and provide support and care to families at such a distressing time should be a high priority. Appropriate guidelines should be devised using established good practice.

Resources that can help

Buckman, R. A., 2005. *Breaking bad news: the S.P.I.K.E.S. Strategy*. Community Oncology. www.communityoncology.net/journal/articles/0202138.pdf

Scope, 1993. *Right From The Start – template document. A guide to good practice in diagnosis and disclosure*. London: Scope Publications.

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

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

Diagram 1: Stage One: The journey towards a decision to withdraw life-sustaining ventilation

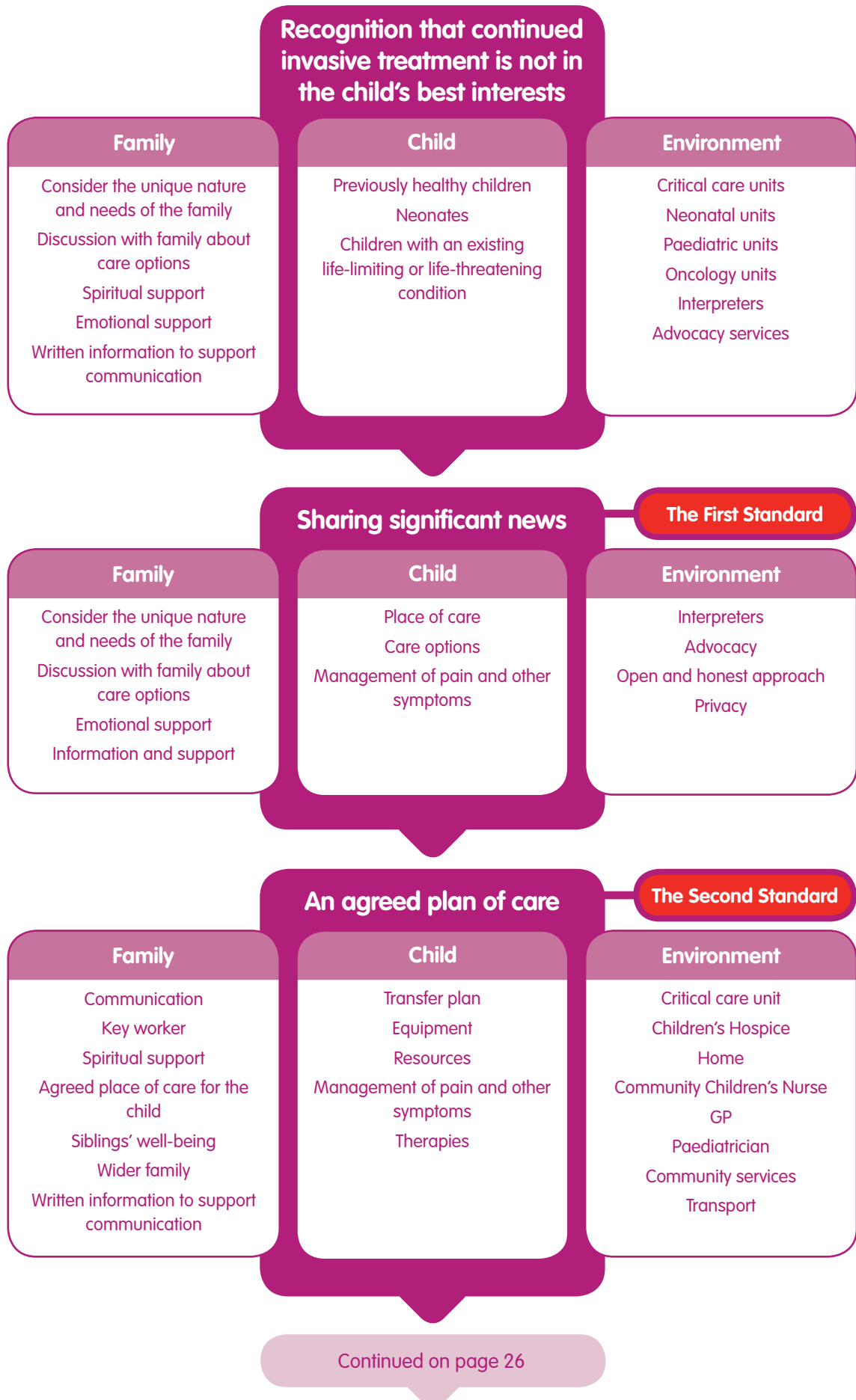
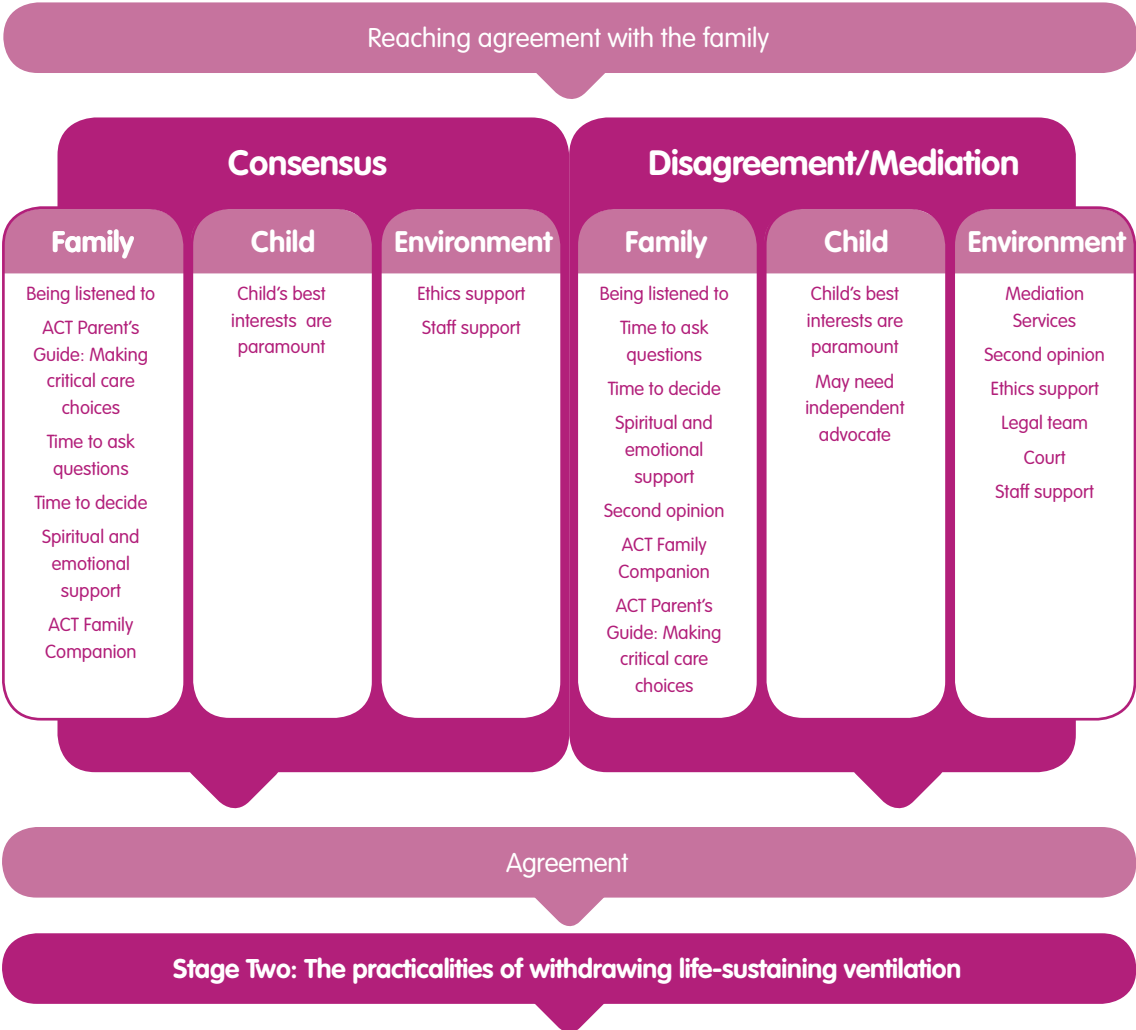


Diagram 1 (continued)



The Second Standard: An agreed plan of care

Every child and family should have an agreed plan of care, including, if appropriate, a transfer plan involving the family or carers, hospital, community services and hospice service. The resources and equipment that the child and family need should be planned and prepared before the child leaves hospital.

Key goals in developing an agreed plan of care

- A key worker should be identified. The role of key worker may change throughout the child's journey, but it is essential that the family know who this person is at each stage and how to contact them. The key worker will be the focal point for arrangements and communication with the family.
- Consensus between the care team and family should be achieved. The family should be supported in discussing their child's critical care plan and place of care.
- 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 prefer a children's hospice or a hospital. A combination of environments is also possible, but this will require efficient co-ordination by the key worker and collaborative working across the appropriate services.
- Planning should begin as soon as possible and where appropriate a clear plan for transfer should be agreed with the family, hospital and community services if the child is being transferred to a hospice or community setting. A clear plan is needed regardless of the setting.
- Families may find it helpful to have other family members or supporters such as religious, faith or spiritual leaders to support them. This should be facilitated at an early stage whenever possible.
- The need for parallel planning should be discussed with the family. Professionals should take steps to ensure that this planning commences and is a continuous strand throughout the child's journey.
- Community based services should be notified as soon as practicable, this should include children's hospice services.
- A lead community children's nurse (CCN) should be agreed before transfer. It may be appropriate for this nurse to be identified as the key worker.
- The child's GP and local palliative care team should be informed and invited to become involved as appropriate.
- Shared medical care plans between consultants and medical services should be in place.
- Equipment and supplies should be planned and provided before transfer.
- Clear lines of communication should be agreed, including on-call arrangements for contact with staff such as CCNs.
- If transfer to a children's hospice is planned, a member of the hospice team should meet the family at the hospital before discharge, if time allows. It may be helpful for members of the hospice team/ specialist palliative care team to accompany a patient transferring from an acute setting to home or to the hospice. This can assist with practical arrangements, continuity of care, and timely pain and symptom management.
- The family will need 24 hour access to care during their child's end of life phase. It is important to clarify who will be providing medical support and medication and whether they have the skills and knowledge to do so.



What this means

Clinicians, when they recognise that a child is nearing the end of their life, need to be able to communicate this clearly and effectively to the family. Although the child is receiving ventilatory support, it will be becoming clearer that this support does not provide the child with the opportunity for cure. Also, there will be increased recognition that there is no expected recovery from the underlying condition. This communication can be difficult and requires high level skills and experience. The Royal College of Paediatrics and Child Health's *Withholding or Withdrawing Life-Sustaining Treatment Guidelines*⁹ provide supporting information for professionals considering the withdrawal of treatment.

It is important that those involved in the care of the child travel through the resulting ethical decisions together. This includes discussions between staff teams and between the family and staff, allowing those involved to agree a way forward within ethical guidelines, and leading to the agreement of an end of life care plan. This should include identifying the planned place of care and place of death for the child.

The appointment of a key worker can assist with communication and make it easier for parents to have one identified worker to keep them up to date with plans and to introduce other professionals. It may be more appropriate to also have an identified named professional for the family liaison activity on each shift or on a daily basis.

The care team should work with the family to clarify the family's wishes for their child's care. Families will need to be informed about the choices they have, both in terms of the type of care and place of care. It can be helpful to bring other professionals who will be involved in the child's care into the hospital to enable the family to get to know the team. These could be community children's nursing services or hospice teams.

The key to ensuring that families receive the right support at the right time is for one agency to take a lead role and to work 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 pivotal in fulfilling this role.

It is essential that the right equipment, anticipatory medication and supplies are in place before the child is transferred out of hospital. It can be difficult to arrange for specialist equipment to be provided at short notice once the child leaves hospital.

Reaching agreement with the family

Ideally the family and the care team will reach decisions about the child's care that everyone is agreed on. Taking time to talk through all the realistic care options, and ensuring that the family fully understands these options can help you to reach agreement.

There may be situations where it is difficult to reach consensus between the care team and the family. At this stage you may have to try and resolve matters through mediation. You may also need to involve your clinical ethics team. The family may wish to seek a second opinion about the best options for their child's care. It is important that the family are fully supported at this stage. They may find it helpful to seek spiritual support or to talk to other family members, religious leaders or the hospital chaplain.

On the rare occasions where the family and the care team still fail to reach consensus on what care is in the best interests of the child, a Court ruling may need to be sought.

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).

Care Co-ordination Network UK (CCNUK) has developed a number of useful resources for key workers (www.ccnuuk.org.uk).

Royal College of Paediatrics and Child Health, 2004. *Withholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice (Second Edition)*. London: RCPCH.

ACT, 2011. *A Parent's Guide: Making critical care choices for your child*. Bristol: ACT.

Broach S., Clements L., Read. J., 2010. *Disabled Children: A Legal Handbook*. London: Council for Disabled Children.

9. Royal College of Paediatrics and Child Health, 2004. *Withholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice (Second Edition)*. London: RCPCH.

2

Stage Two: The practicalities of withdrawing life-sustaining ventilation

This stage covers developing an end of life plan, preparing the child, family and professionals for extubation, and the extubation process itself. It includes some suggestions about the practical aspects of extubation, however it is recognised that many units will have already developed their own procedures. You can use the key information, goals and standards to help you review and revisit your procedures and to explore developing these further.

The Third Standard: An end of life plan

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

Key goals in developing an end of life plan

- A core care team around the child should be established.
- Families should be given a choice of place of care for their child, where possible.
- Professionals should encourage discussion about the child's and family's choices for quality of life and provide the appropriate support to make these choices possible.
- An end of life plan should be agreed and shared with the family. This should be reviewed regularly.
- Personal resuscitation plans should be discussed and developed.
- Organ donation and post-mortem examinations should be discussed with the family.
- Actual and anticipatory symptom and pain management plans should be developed.
- Supplies of medication and out-of-hours pharmacy needs should be planned for.
- Future prescribing should also be anticipated.
- Families should be given contact details for key professionals.

- The family and team should have access to 24/7 care and this should include a children's palliative care specialist, paediatrician or specialist GP throughout the palliative stage of care.
- Emotional support should be provided for the family, including any siblings.
- Families should be supported to memory build and to carry out any special wishes with their child.
- Families should be supported to prepare and plan any special ceremonies before or after death.

What this means

As soon as it has been decided that the child will be extubated it is important that all the professionals and agencies involved are brought together with the family to discuss their needs and wishes. This is likely to be a very difficult time for the family and it may be the point at which they are facing up to the reality of their child's death for the first time.

Some people who have been involved with the family may no longer be needed and a small core team may need to be identified. Professionals sometimes find it difficult to 'let go' of the child or family and may themselves need support in recognising that the family needs to have as much privacy as possible and that this time with their child is very precious.

The suggestion may be made that the child should not be resuscitated and precise details about what the family want and do not want should be explored. It might be possible to develop a written Personal Resuscitation Plan (possibly as part of an Advance Care Plan) with the consultant and other people looking after the child, to assist in communication between different professionals. The family may also wish to discuss the options with regard to organ donation and the subject of post-mortem may need to be explained. Parents should be fully informed about these issues and should feel that their decisions are understood and respected by all concerned.

The environment in which the family feels most comfortable should be a consideration. Some may wish to be at home, but others may choose a children's hospice or a hospital. A combination of these places is also possible, but this will require efficient collaborative working.

There will also be the possibility that the child may develop other distressing symptoms and the child and family will need reassurance that these can be anticipated and managed effectively. It is important that the family and the team have 24 hour access to a paediatric palliative care specialist, paediatrician or specially trained GP so that symptoms and pain

Continued on page 33 >

Diagram 2: Stage Two: The practicalities of withdrawing life-sustaining ventilation

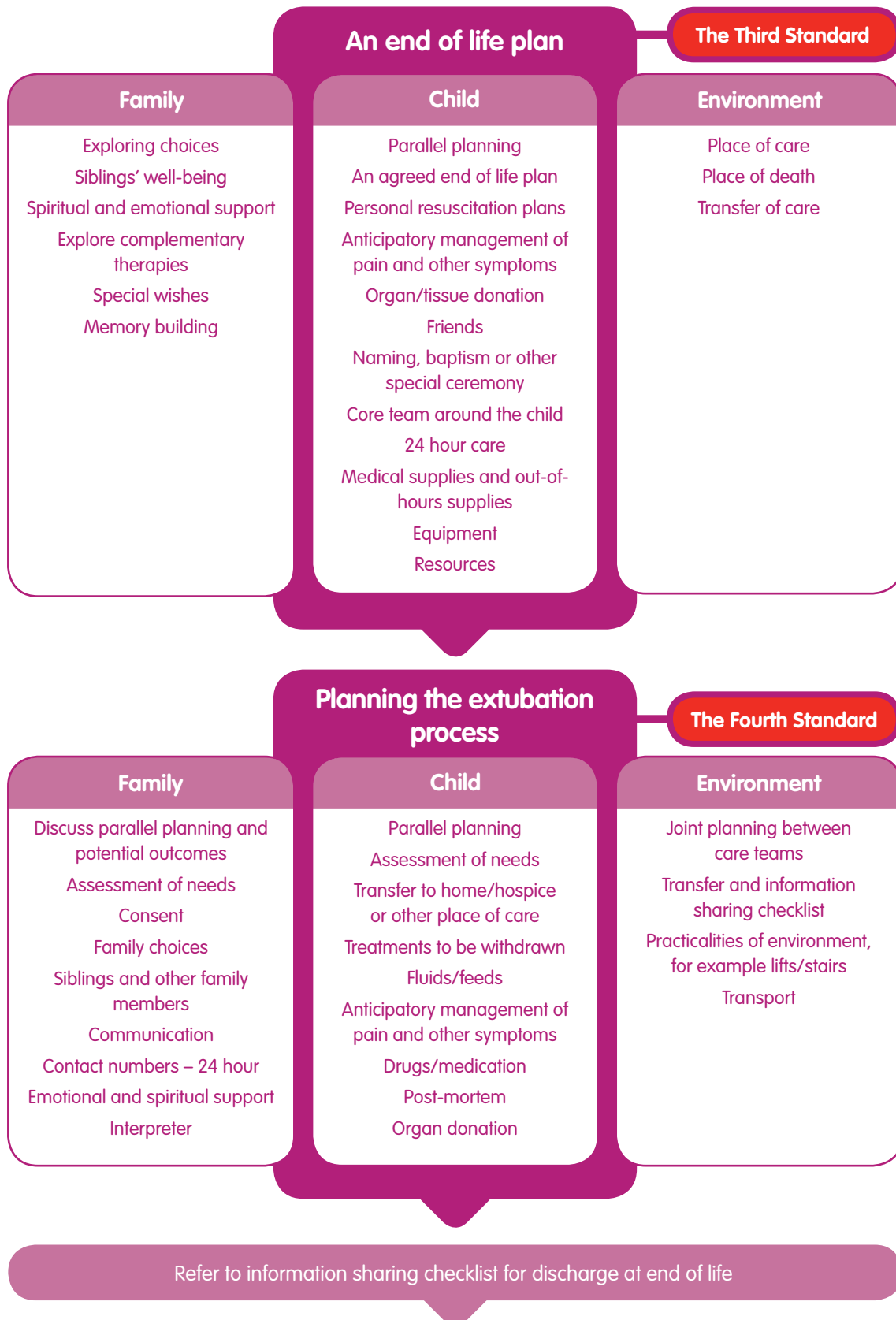


Diagram 2 (continued)

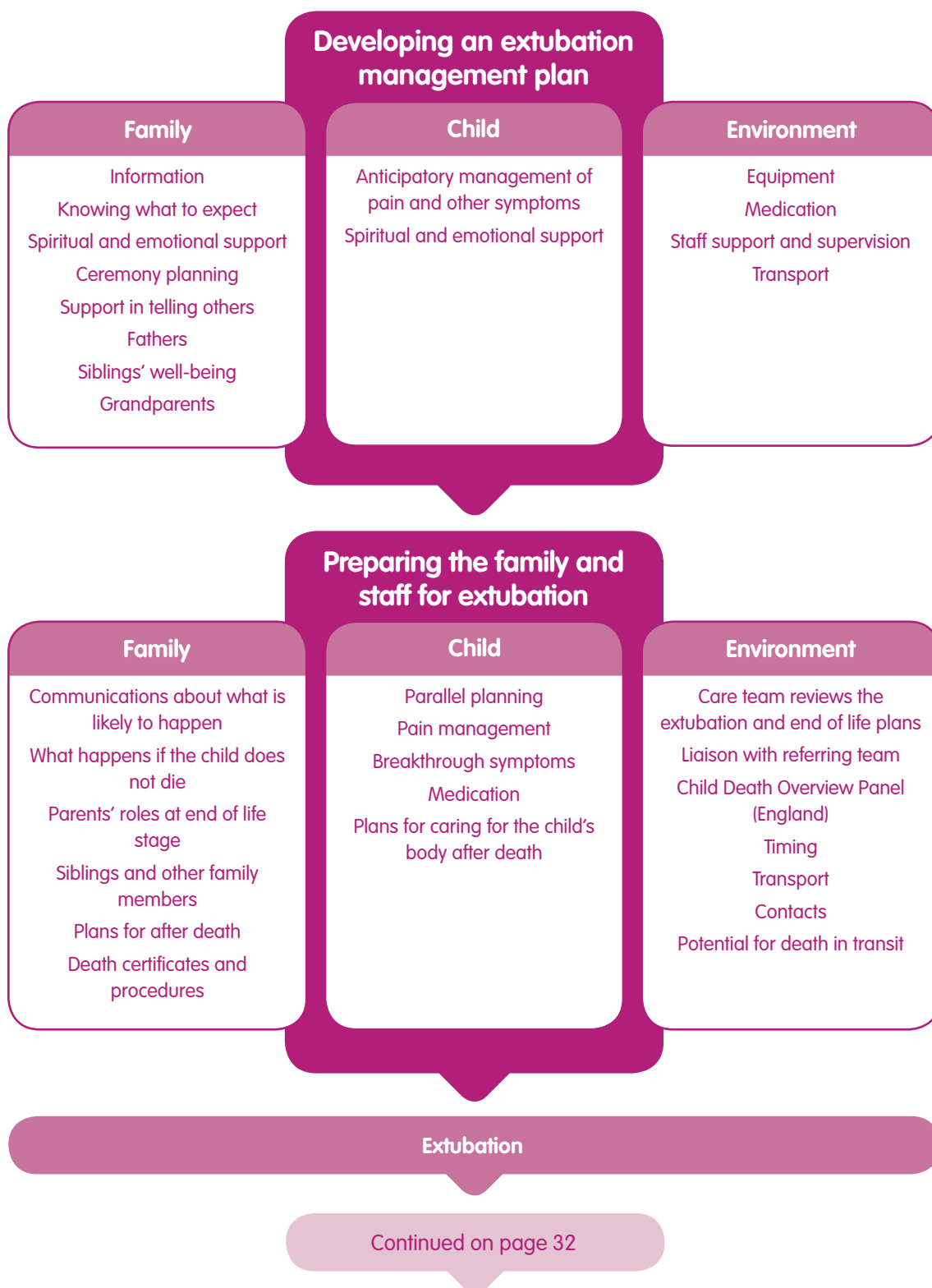
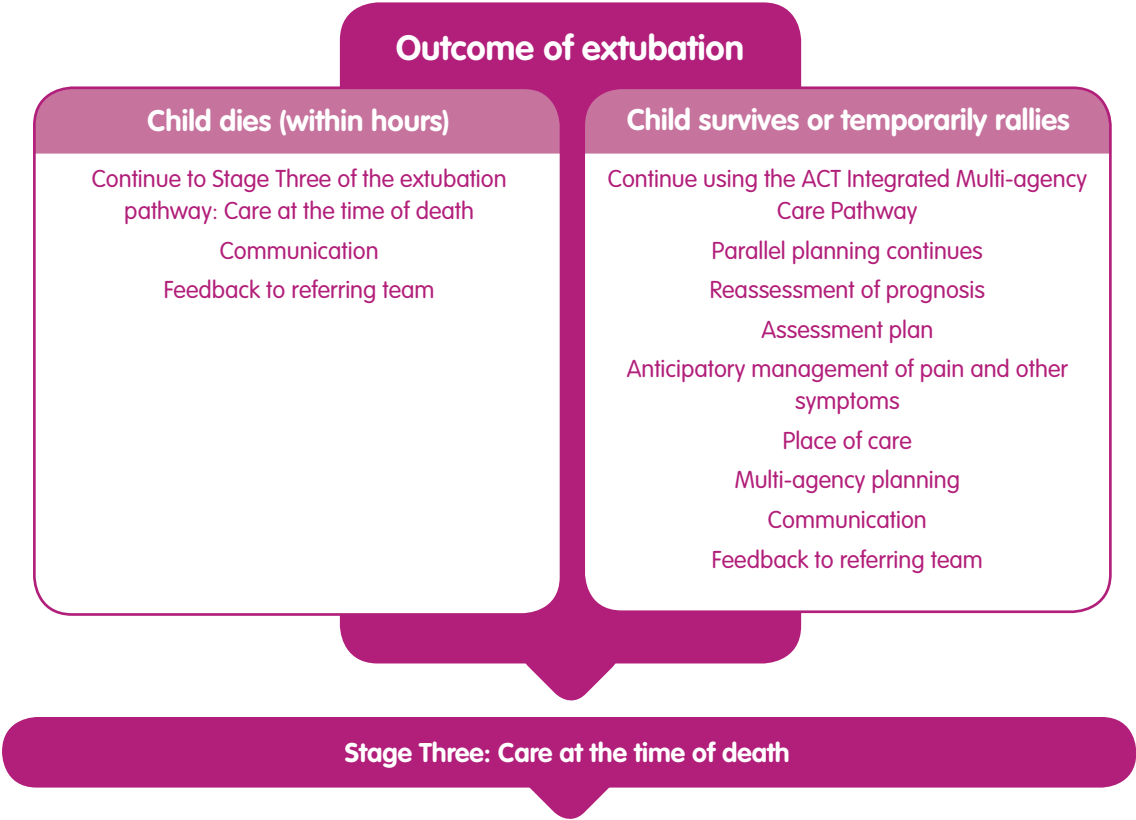


Diagram 2 (continued)



can be controlled outside normal working hours and unnecessary emergency admissions to hospital can be avoided.

If the child does not die as expected following extubation, the family will need continuing 24 hour access to care throughout the palliative/terminal stage. Clarification will be needed about who will be prescribing and whether they have the appropriate skills and knowledge. If not, they will need to be supported by a physician who has.

Planning for supplies of medication, out-of-hours pharmacy needs, and for providing end of life care should be in place. This is needed in order to ensure that the child or young person receives effective pain and symptom control beyond extubation. The key will be ensuring that regular symptom reviews are undertaken and the right treatment administered. The appropriate analgesia should be administered at regular dosing intervals with adjunctive drug therapy for symptom and side-effect control. There are a range of pain assessment tools appropriate to the age and understanding of individual infants, children and adolescents, in particular those produced by the Royal College of Nursing, which can act as useful reference guidelines.¹⁰ A comprehensive guide to children's palliative care symptom and pain management can also be found in Dr Satbir Jassal's *Basic Symptom Control in Paediatric Palliative Care: Rainbows Children's Hospice Guidelines*.¹¹ It may sometimes be necessary to request advice on pain and symptom management and this is far preferable to getting something wrong and jeopardising the family's trust. The family's decision to provide end of life care at home may be thwarted if there is a breakdown in symptom management resulting in admission to hospital.

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

The agreed end of life care plan will need to be documented, including the personalised resuscitation plan, setting out what emergency treatment is to be used and what is not to be used by ambulance crews and by 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. If the presence of such a

plan and 'not for resuscitation' decision is logged with the ambulance service (by home post code) this will make it easier for them to avoid offering inappropriate resuscitation attempts in the case of a medical emergency with the child. The plan should allow for an ongoing review of care and changing goals to comply with the child's best interests and the wishes of the family. It is essential that all the team are informed of changes and kept up to date with the child's care.

Supporting the child and 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 child or young person. Depending on the age of the child or young person, the school community may continue to be involved and should be informed about the child's progress. The child may want to continue seeing friends, and carry on with other social activities for as long as possible. Siblings and grandparents, where appropriate, should be included in discussions about choices for quality of life.

Emotional support is essential at this time. Some families find the thought of discussing death with the child or young person extremely distressing and may feel it is better to shield the child from such knowledge. In all but the very youngest it is actually most likely that the child already knows that death is possible, but feels responsible for the distress this will cause the family. The best approach is to encourage and enable the family to spend as much quality time with their child as possible, giving them time to talk, and enabling them to gain a sense of how they are feeling and what they want to happen. Planning together for death may provide a positive experience for both the child and the family at an otherwise totally bleak time.

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

10. See www.rcn.org.uk/development/practice/clinicalguidelines/pain

11. Jassal, S., 2011. *Basic Symptom Control in Paediatric Palliative Care: Rainbows Children's Hospice Guidelines (8th Edition)*. Bristol: ACT. (A copy can be downloaded at www.act.org.uk)

Resources that can help

ACT, 2011. *A Parent's Guide: Making critical care choices for your child*. Bristol: ACT.

Dr Jassal, S., 2011. *Basic Symptom Control in Paediatric Palliative Care: Rainbows Children's Hospice Guidelines (8th Edition)*. Bristol: ACT.

Dr R Hain and Dr S Jassal, 2010. *Oxford Specialist Handbook in Paediatric Palliative Medicine*. Oxford: OUP.

British Medical Association, the Royal Pharmaceutical Society of Great Britain, the Royal College of Paediatrics and Child Health, and the Neonatal and Paediatric Pharmacists Group, 2010. *British National Formulary for Children*. (See www.rcpch.ac.uk/Publications/bnfc)

General Medical Council (GMC), 2008. *Consent: Patients and Doctors Making Decisions Together*. London: GMC.

General Medical Council (GMC), 2010. *Treatment and care towards the end of life*, London: GMC.

ACT has a dedicated end of life webpage which includes links to various end of life resources and other useful documents: www.act.org.uk/endoflife

The Fourth Standard: Planning the extubation process

The child and family should be kept central to the process. The family should be made aware of the roles and responsibilities of members of the care team. The child and family should receive high quality care led by skilled and competent professionals. Care transitions should be seamless and should be supported by parallel planning.

Key goals in planning the extubation process

- The child and the family should be kept central to the planning process at all times.
- An assessment of the child's and family's needs should be made in partnership with the family.

- Family strengths and potential stress factors should be identified, and consideration given to how staff can help the family cope with the process, including the burden of uncertainty.
- Care should be taken to ensure that fathers and siblings and other key family members are involved and included in care planning and provision.
- Individuality and ethnicity should be respected.
- Confidentiality and consent should be addressed.
- Consistent and systematic documentation should be used.
- Contact details of those who should be informed of the death of the child should be identified with the family, for example the school, GP or hospital ward.
- Parallel planning should be in place.
- Communication should be open, honest and fluid throughout the process.
- Straightforward and jargon-free language should be used.

What this means

Usually the lead professionals at this stage of care will be a lead doctor from the specialty caring for the child and a senior doctor (usually consultant or specialist GP) skilled in children's palliative care.

Joint planning with families and relevant professionals should take place as soon as possible, and be ongoing, flexible and responsive to changing conditions and need. All possible scenarios, for example, immediate death, and the possibility of longer term survival, should be planned for.

The following sections have been written with the assumption that the child will be transferred from a critical care setting to the family home, a hospice or a community setting prior to extubation. However, the general principles for planning and practice are applicable in all care settings.

Before extubation

Once the child has been accepted onto the pathway the checklist below should be followed:

- ✓ Confirm that the child has a life-limiting diagnosis and is entering the final stages of life and meets the Royal College of Paediatrics and Child Health (RCPCH) criteria for withholding or withdrawing life-sustaining treatment.¹²
- ✓ Confirm that parallel planning has commenced and ensure contact details for support and for the on-going care team are documented and shared with the family.
- ✓ Ensure that there has been good verbal and written communication between the critical care team and the receiving team, including clear information about the medication regime and its effectiveness.
- ✓ Check that the staff and family are aware that if the child is being transferred to a hospice, there will be no facility available to re-intubate the child.
- ✓ Check and discuss whether there are other treatments that will be withdrawn, for example inotropic support or haemofiltration.
- ✓ Clarify and discuss any necessary changes to medication and any lead time needed to establish the child's stability before transfer.
- ✓ Confirm what discussion has occurred regarding reintroduction of feeds/fluids in the event of the child's ongoing survival following extubation.
- ✓ Discuss the child's case with the coroner to explore whether a post-mortem will be required.
- ✓ Check whether tissue and organ donation has been discussed with the family.
- ✓ Ensure that an information sharing checklist for discharge has been completed. This should include key contact numbers and names (see the checklist on page 36).
- ✓ Check that all practicalities at the place for transfer have been considered, such as availability of lifts, stairs, space etc.
- ✓ Arrange for an interpreter if needed.
- ✓ Arrange for pastoral or other spiritual support.
- ✓ Ensure that the referring team has organised timely transport (as agreed with the receiving team), and has details of directions for the ambulance and for the family, and is clear about how long the transporting team is able to remain with the child once the transfer has happened.
- ✓ Check that there is an appropriate sedation/pain relief regime in place. This should recognise that changes may need to happen before transfer with the details of any plan for conversion to oral/subcutaneous/buccal medications and appropriate symptom control on transfer.
- ✓ Ensure that there is an understanding that accidental extubation is possible and under most circumstances there will be no plan to re-intubate the child. In transport situations, this means that the child may well die in transit. Agree what should happen if the child dies en-route to the destination.
- ✓ Confirm between the critical care team and hospice/GP that any drugs and pumps can stay with the child. Drugs, doses and formulations not stocked by the hospice, such as intravenous fentanyl must be transferred with the child. The length of supply should be agreed between hospital and hospice/GP.
- ✓ If the child is to be transferred to a hospice, it is recommended that at least a 48 hour supply of anticipated medication should be transferred with the child. If the child is to be extubated at home, a larger supply of medication will need to be prescribed by the hospital and accompany the child.
- ✓ Detailed discussions will need to take place regarding parallel planning in the event that the child survives extubation.
- ✓ The family needs to be made aware that if fluids are to continue following transfer, the main route will usually be oral, but may be continuing via nasogastric tube or gastrostomy if that is the child's norm.
- ✓ It is also important to discuss the symptom control priorities in the event of the child's ongoing survival and where reintroduction of withdrawn medications may require consideration.
- ✓ If a family would like to consider organ or tissue donation, the clinician should contact the relevant service. See Appendix Five for regional contact details.

12. Royal College of Paediatrics and Child Health, 2004. *Withholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice* (Second Edition). London: RCPCH.

Information sharing checklist for discharge at end of life

This checklist has been designed to help professionals co-ordinate and plan for the child's discharge. It includes key prompts for information sharing and can help to clarify the different roles and responsibilities of the care team around the child.

Information for families

- ✓ The family should be fully aware of any medication/intervention to be discontinued and the timescale for withdrawal.
- ✓ Written symptom management plan.
- ✓ Parents/carers need to understand how to administer drugs required (e.g. buccal).
- ✓ Contact number for the palliative care team/local hospice.
- ✓ Contact number for the Children's Community Nursing Team and details of on-call cover.
- ✓ Contact number for the GP, including out-of-hours contacts.
- ✓ Information should be provided about who to call and relevant procedures at the point of death.
- ✓ It is important that the information is adapted and accurate for those children who are 'out of the area.'

Sharing of discharge information with professionals

- ✓ Written symptom management plan.
- ✓ Emergency Care Plan/Advance Care Plan/Resuscitation Plan (including the ambulance directive).
- ✓ Hospital discharge letter.
- ✓ Contact details for the family.

Information to be shared with the GP, children's community nursing team, palliative care consultant, hospice team, local hospital and ambulance service

Local services need to share:

- ✓ Their on-call arrangements.
- ✓ Ability to admit the child if required.
- ✓ Availability to visit at home.

Clarity is needed about:

- ✓ Who will prescribe and provide medication when needed, and how?
- ✓ Who will be available to verify/certify death?
- ✓ Availability of a bereavement suite.
- ✓ Availability of family support.

Records should be made of:

- ✓ Religious, cultural or spiritual practices to be observed prior to or after death.
- ✓ Any plans that the family has made for a post-mortem or cremation/funeral (including the timescale).
- ✓ Where the family want the child's body to be after death.

Supply of the following needs to be considered:

- ✓ Regular medication to be continued.
- ✓ Medication required for symptom management.
- ✓ Oxygen/suction/saturation monitor if needed.
- ✓ Nasogastric tube/feeding pump if needed.
- ✓ Catheters/pads/nappies.
- ✓ Syringes/syringe driver.

Practical issues:

- ✓ Issues relating to access in and out of buildings/rooms with the equipment required need to be considered (including moving a portable ventilator where appropriate).
- ✓ Consideration of when to arrange the discharge home, for example it is often more difficult to arrange discharge late on Friday afternoons/over Bank Holiday weekends, so special attention to detail should be paid to ensure smooth transfers and ongoing care.

Developing the extubation management plan: Issues to consider

Details about the respiratory status (ventilator settings, recent blood gas, risk of upper airway obstruction); cardiovascular status (inotropic support, shock); and neurological status (level of consciousness, seizure disorder, muscle strength, cranial nerve function, presence of neuromuscular agents) will help formulate a treatment plan.

For example, children with severe heart and lung disease will survive a much shorter time without mechanical ventilatory support and inotropic support than children with severe neurological conditions but a stable cardiopulmonary status. Children with severe cardiopulmonary disease are likely to need minimal to moderate increases in the medicines that they have been receiving for analgesia and sedation.

Children who have been intubated may develop respiratory distress due to upper airway obstruction once the tube is removed. To reduce airway oedema and inflammation, these children may benefit from the administration of anticipatory corticosteroids before extubation.

Children with altered consciousness or coma are likely to have a poor respiratory drive and cough reflex. The child can normally be kept comfortable during extubation with low doses of opiates and benzodiazepines. In contrast, children who are alert, but have weak respiratory muscles may require higher doses of opiates and benzodiazepines to achieve comfort.

Access routes for medicines and nutrition after transfer should be clarified with the receiving team before transfer. Most children undergoing extubation have parenteral access for analgesics and sedatives. Many children have a central line for infusions. Occasionally the child will have a peripheral intravenous (IV) line.

Sometimes, it may not be possible to maintain an IV line in the hospice or home environment so children may require conversion from IV to subcutaneous infusions, ahead of transfer, or to transfer with appropriate medication for later conversion to subcutaneous infusions or, rarely, oral medicines.

Children who are being transferred should already have a symptom management plan. The receiving doctor will need to adjust the medicines as required. The transfer plans should include drugs that have been used for pain, anxiety, seizures, and any other treatments for comfort on a regular and 'as needed' basis. All drugs must be available through an appropriate route at the time of the child's arrival.

Special consideration needs to be given to children who are unable to express emotions, for example those with neuromuscular conditions. This will help to ensure the proactive management of potentially distressing symptoms.

The family should be asked if they wish for any special ceremonies to be carried out before extubation and their wishes should be recorded in the extubation management plan.

The receiving care team should ensure that any special equipment needed before extubation is readily available.

Review with the family: on admission to hospice or on arrival at home

During the receiving doctor's first encounter with the family, it is important to confirm the extubation management plan and their wishes and expectations.

- Clinical findings should be reviewed.
- The receiving doctor should ensure that all paperwork and documentation is available and reviewed.
- The family's agreement for extubation, (and the agreement that the child is not for active resuscitation or reintubation) should be confirmed.
- The desired level of sedation for the child at the time of extubation should also be confirmed with the family.
- The family should be supported in deciding who they wish to be present during the extubation, and should be asked if they want to have any special ritual, music or memory making activities at that time.
- The family should be asked about their religious or spiritual needs and whether they have made or discussed funeral arrangements.
- Professionals should document discussions in the child's records and consider the most appropriate time to remove monitoring.
- Staff should also be prepared to manage the rare, but possible withdrawal of parental consent for extubation. A 'change of heart' is possible, especially on arrival at the new place of care.

Preparing the family and staff for extubation

The care team should review the specific management and end of life care plans and goals for the child. Plans for the management of breakthrough symptoms should be developed. The care team should discuss, with the help of the family, how they will determine if the child is in pain or anxious (for example unique body movements, facial expressions or vocalisations). The care team should ensure that medication is available to manage any discomfort.

The lead doctor and members of the care team should discuss plans with the family, and ascertain what they understand about the situation and what they expect to happen. For example explaining that breathlessness may occur, but that it can be managed.

Family members should be reassured that their child will be properly sedated or in a coma, and that although some involuntary movements or gasping may happen, this does not reflect suffering. They should be informed about how the doctors will confirm death. The family should be asked who they wish to be present during the extubation, and ensure that there is appropriate space for them at the bedside. Parents should be asked if they would like to hold their child during the extubation process and as the child dies. Arrangements should be made for the care and, if wished, the involvement of the child's siblings.

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

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

What this means

Preparing for extubation will be a busy and demanding time. It is essential that the care team approach this care in partnership with the family, with the child being kept central to the process.

A model extubation plan is included in Appendix One. ACT recommends that local areas develop a shared protocol for services involved in that area.

It is essential that there is clarity in respect of the lead role and the care team should identify who will take responsibility for informing organisations.

Staff may not always be clear about the procedures they should follow after the death of a child. Training and simple written resources should be available to all staff, particularly where paediatric trained staff are not available on a 24 hour basis.

When the child dies, relevant organisations should be notified, including the local Child Death Overview Panel, which reviews the deaths of children in England. The death may still be considered as 'unexpected' if the antecedent cause of the deterioration was unexpected or unexplained, even if the death is predictable by the time of extubation. Informing the Child Death Overview Panel and/or the coroner ahead of the death may enable the rapid response to be stood down appropriately, potentially avoiding additional distress for the family. The Care Quality Commission should also be notified in the case of a child who dies in a children's hospice in England.

Services need to have contingencies for continuing support if a child's end of life phase is prolonged. Care at end of life should ensure that the family's spiritual and cultural needs are taken into account.

Dealing with the outcome of extubation

Clearly the extubation of a child is likely to result in immediate death, and this extubation pathway is geared towards that outcome. If the child dies shortly after extubation, then the professionals and family can move to Stage Three of this pathway (*Care at the time of death*).

In some cases the child continues to breathe unassisted, and this is why parallel planning for both eventualities of the child dying or not dying imminently is so key throughout the child's and family's journey.

Predicting the time when a child is likely to die post extubation is never going to be easy. For some, it may be very quick and for others it may extend to hours, days, weeks or sometimes years. It is not uncommon for some children to return to greater

stability following a period of serious decline and ventilation. If the child survives beyond a few days following extubation, the child's and family's needs and the child's prognosis should be continually reassessed, the care should be reviewed and updated, and parallel planning should continue. At this stage it may be appropriate for the family and child to move to another ACT care pathway; the ACT *Integrated Multi-agency Care Pathway for Children with Life-Limiting Conditions*,¹³ the ACT *Neonatal Pathway*¹⁴ or the ACT *Transition Pathway*.¹⁵ At such an uncertain time, continued careful compassionate communication, decision-making and support for the family will be vital in order to keep in step with the child's journey.

Resources that can help

British Medical Association, 2007. *Withholding and withdrawing life prolonging medical treatment: guidance for decision-making*. London: BMA.

The British Association for Perinatal Medicine, 2009. *Guidance on the management of babies born extremely preterm*. London: BAPM.

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

Care Co-ordination Network UK, 2000. *A Resource Pack: Developing a key worker service for families with a disabled child*. Suzanne Mukherjee, Patricia Sloper, Bryony Beresford, Peter Lund and Veronica Greco. London: CCNUK.

General Medical Council, 2011. *Treatment and care towards the end of life*. London: GMC.

General Medical Council, 2008. *Consent: patients and doctors making decisions together*. London: GMC.

Dr Jassal, S., 2011. *Basic Symptom Control in Paediatric Palliative Care: Rainbows Children's Hospice Guidelines* (8th Edition). Bristol: ACT.

The Royal College of Paediatrics and Child Health, 2004. *Withholding or withdrawing life sustaining treatment in children*. London: RCPCH.

13. ACT, 2004. *A Framework for the Development of Integrated Multi-agency Care Pathways for Children with Life-threatening and Life-limiting Conditions*. Bristol: ACT.

14. ACT, 2009. *A Neonatal Care Pathway for Babies with Palliative Care Needs*, Bristol: ACT.

15. ACT, 2007. *The Transition Care Pathway*. Bristol: ACT.

Stage Three: Care at the time of death

3

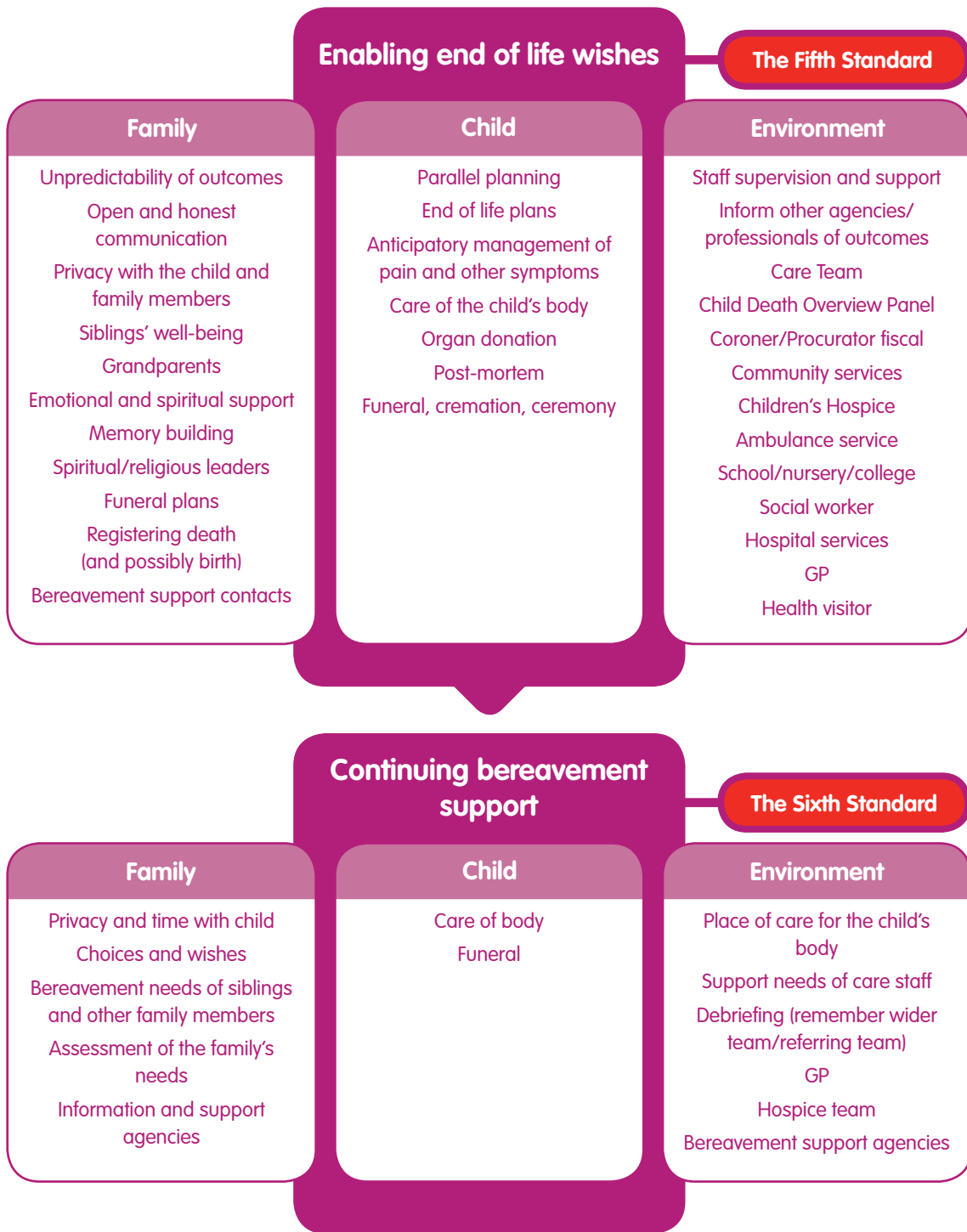
The Fifth Standard: Enabling end of life wishes

The child's end of life plan should be carried out in a timely way in accordance with the parents' wishes.

Key goals in enabling end of life wishes

- Families should be supported in their choices and goals for quality of life to the end.
- The agreed plan for the child and family should be followed.
- The family should be allowed time and privacy with their child.
- Parents should feel in control of events before and after death and should be able to follow their own choices and wishes.
- The family members and others whom the family wish to have with them should be present.
- Emotional and spiritual support should be available to the family or parent carers.
- The needs of siblings and grandparents should be considered and included around the time of death, and immediately afterwards, as part of the end of life plan.
- Staff involved should have access to their own sources of support and supervision.
- Fully informed consent should be sought for a post-mortem, where relevant.
- When a post-mortem is performed, families should be informed of its findings by a professional they know, and who has a full understanding of the implications of the pathology report. This meeting should take place face-to-face, in an environment that will not generate undue anxiety. Parents must be informed, and support should be provided when considering the implications for the return of, or management of tissue samples taken during the post-mortem.
- Earlier discussions regarding possible tissue and organ donation should be reviewed and consent confirmed.

Diagram 3: Stage Three: Care at the time of death



- Professional contacts should be informed of the child's death immediately.
- Practical advice and written information should be given to the family about the care of the child's body, official procedures and entitlements or benefits.

Movement into the end of life phase is clearer when there has been a decision to stop all life-prolonging treatment. The family will be aware that the child's death is inevitable and will have had some time to plan. They are likely to be anxious for reassurance that pain and symptoms will be adequately controlled and that their child will not suffer. A clear end of life plan will help with this.

Professionals working with these children and families should be honest and open and explain that their child's death is expected, although it may not occur. Families should not be given false hope and should be allowed to plan for death. The term 'a good death' is difficult to define, as it is personal to each individual. But the key is that the child and family should be able to exercise choice and receive full care and support in that choice. It is therefore advisable for an end of life plan to have been agreed in advance, based on the family's needs and wishes around what they want to happen at the time of death. Making a plan can help to mitigate some of the anxieties for the family and professionals and ensure that events happen as they wish.

What this means

This will be an extremely painful time for the family and also for those who are supporting them. However, sometimes there may also be a sense of relief. The child will usually want to have loved ones close by. Professionals should be sensitive to the family's need for privacy, space and support and should not obstruct the family's own coping and grieving processes.

After the child's death it is vital that parents retain control and choice in the care of their child's body. Families need to have time and privacy with their child in the hours and days following the death. They need to know that almost anything they decide is possible, including moving the body to another place. Advice may need to be taken from the coroner if death falls into the 'unexpected' category, for example due to the antecedent condition causing deterioration, such as traumatic brain injury. Ideally, in most such cases, the coroner and Child Death Overview Panel (in England) should have been alerted and procedures agreed prior to the death.

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 child's body to be cared for in a cooled room. It may be 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 and keep some special memories of their child. They may wish to take photographs, keep a lock of hair, or make hand or footprints. Keepsake activities incorporating the child and their siblings should be considered, such as integrating all their hand or foot prints into one picture for the siblings as they grow older.

Care should be taken to ensure that the family's religious and/or cultural beliefs and rituals are respected. They may well want their religious leaders present and should be offered this support.

Parents should be consulted about whether they want to be involved in 'laying out' their child and choosing which clothes to dress them in. They will need reassurance that any professional caring for their child's body will treat their child with dignity and respect.

Siblings should be given opportunities to express their emotions openly and ask questions. Their needs can often be overlooked by professionals, or by 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, as well as discussing whether they wish to attend themselves. Siblings may decide they wish to make a special contribution such as a prayer or a poem. They may also wish to place a gift or memento into the 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 loss.

There will be an immediate need to inform those professionals in contact with the family of the child's death. The family's key worker or another member of the team can assist in this if the family wishes. People and organisations to contact may include:

- The local Child Death Overview Panel (England).
- Coroner or procurator fiscal.
- Referring medical team.
- Other consultants and hospital services (including medical records department).
- The family GP.
- The midwife.
- Community or specialist nurses.
- Health visitor.
- Social worker.
- Children's hospice.
- Local religious leaders.
- Ambulance service.
- School/nursery/college.

It is also important to ensure that any department or service expecting the child at an appointment is informed to ensure that 'did not attend' or further appointment letters are not sent out.

Where appropriate, benefit agencies should be informed as soon as possible.

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

- Certifying and registering the death (and in some cases the child's birth).
- Procedures required for cremation and funeral.
- Contact details of local religious leaders.
- Advice on benefits or other entitlements.
- Contact details for care staff and bereavement support.

Post-mortem arrangements

When a death is expected, and a death certificate can be issued, it is usually not necessary to hold a post-mortem. A post-mortem may be helpful in some cases, for example to help parents consider the implications for future pregnancies, and to answer questions. ACT is aware that some families have experienced difficulties later on when they have reflected upon their decision not to choose a post-mortem at the time of death, and later wished that they had asked for one in order to help answer some of their unanswered questions. Some families may also be asked if they will elect for post-mortem examination to assist the furtherance of knowledge about rare childhood conditions. This may affect their wish to have their child's body at home after death.

If a post-mortem is not required by the coroner, the family should not feel that they are under any pressure or compulsion to agree to one. They 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 to happen, many parents have great anxiety over their child being transferred and left alone in the mortuary. Discussions with mortuary staff may reduce the time that parents will be separated from their child. 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 child 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 child's post-mortem examination must be based on truth and understanding and they must be reassured that nothing that they have not agreed to will happen.

Funeral planning

Families should be made aware that they can choose to have one ceremony, more than one, or none. They may want to reflect upon what they hope a ceremony will achieve. A ceremony may provide:

- A chance to bring together everyone whose life was touched by their child, to say goodbye and to draw comfort from each other.
- An occasion that will create memories that the family can look back on.
- An opportunity to share the joy that their child 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 child at the funeral, but feel they may be unable to do this in person. They may want to consider making a video or 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 child.

Resources and organisations that can help

Tissue Donor Selection Guidelines:
www.transfusionsguidelines.org.uk/docs/pdfs/dsg_ctd_203_04.pdf

UK Blood Transfusion and Tissue Transplantation Services: www.transfusionsguidelines.org.uk/Index.aspx?Publication=CTD&Section=17&pageid=1539

The Child Death Helpline

The Child Death Helpline is 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
 Helpline: 0800 282 986
 Email: contact@childdeathhelpline.org

ACT, 2011. *A Parent's Guide: Making critical care choices for your child*. Bristol: ACT.

Dr R Hain and Dr S Jassal, 2010. *Oxford Specialist Handbook in Paediatric Palliative Medicine*. Oxford: OUP.

ACT has a dedicated end of life webpage which includes links to various ACT end of life resources and other useful documents: www.act.org.uk/endoflife

- Bereavement support should be offered based on assessed need.
- The bereavement needs of siblings should be recognised and support provided.
- The parents may want details of who they can contact to discuss any plans for future pregnancies. This may include contact with a clinical genetics service.
- The needs of care staff should be considered. Some may need support in ending their involvement with the family as part of an agreed bereavement plan.
- Staff support is essential. Debriefing, ongoing support and supervision should be readily available.

What this means

Grief and loss issues face the family throughout the whole of this pathway and constitute an integral aspect of all children's palliative care.

The death of the child is not the end of the 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 for by the family's key worker. The key worker may not necessarily deliver this care themselves, but should ensure that appropriate support is made available. It is important to take the 'long view' and parents need to know where they can seek support after they have moved on from the support offered by the hospital. Good end of life care that is appropriate and sensitive to the family's own needs can provide comfort in bereavement in the long term.

The body of literature on dying and bereavement is extremely large and 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, 1970; Worden, 1992) but these may not always reflect the experiences 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 child rather than 'letting go' (Silverman and Klass, 1996). It should be acknowledged that grief for a beloved child may never end or resolve, as Talbot (2002), 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."*¹⁶

The Sixth Standard: Continuing bereavement support

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

Key goals in continuing bereavement support

- The family should be allowed time and privacy with their child.
- Parents should feel in control of events before and after death and should be able to follow their own choices and wishes.

16. Talbot, K., 2002. *What forever means after the death of a child: transcending the trauma, living with the loss*. New York: Brunner-Routledge.

Those who have been involved with the family throughout their child's care are probably best placed to offer support for a limited time. Where this is not possible, bereavement support may be provided through referral to other services, for example the family GP, a local children's hospice or a specialist bereavement organisation. Grief is a normal reaction, but specialist counselling by a qualified practitioner should be available if a member of the family needs it. The family should know what help is available and feel able to ask for help.

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.

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 loss 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. They may find they get the support they need at school, and the family may find it helpful to work with the school to support their children, and to keep the school updated.

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 loss of their child, rather than feeling that their grief consumes them every hour of the day. It can be helpful if potentially difficult times such as birthdays, religious festivals, or the anniversary of the child's death are especially remembered.

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. The intensive involvement and 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 that the need for this may continue in the longer term.

Every professional who is called upon to support the child and their wider family throughout this care pathway journey will, no doubt, find this emotionally challenging. Each member of the team around the child and family should receive support, supervision and an opportunity to feedback and discuss what is happening. This should be a part of ongoing support and supervision.

Resources and organisations that can help

The Child Bereavement Charity

The Child Bereavement Charity is a charity that supports families and educates professionals both when a child is dying or has died, and when a child is bereaved of someone important in their life.

www.childbereavement.org.uk

Tel: 01494 568900

Email: 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.childhoodbereavementnetwork.org.uk

Tel: 020 7843 6309

Email: 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.uk

Helpline: 0800 282 986

Email: contact@childdeathhelpline.org.uk

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.

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Helpline: 0845 123 2304

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Sibs

Sibs supports siblings who are growing up with or who have grown up with a brother or sister with any disability, long term chronic illness, or life limiting condition. Sibs can provide parents with phone support on talking to siblings about diagnosis, as well as activities for explaining disability or illness to siblings.

www.sibs.org.uk

Tel: 01535 645453

Email: info@sibs.org.uk

TCF Sibling Support

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

www.tcsiblingsupport.org.uk

Tel: 0845 123 2304

Email: info@tcsiblingsupport.org.uk

SupportLine

SupportLine provides confidential emotional support for children and adults. Staff help callers to develop healthy and positive coping strategies and provide details of counsellors, agencies and support groups across the UK.

www.supportline.org.uk

Tel: 020 8554 9004

Email: info@supportline.org.uk

Winston's Wish

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

www.winstonswish.org.uk

Helpline: 0845 20 30 40 5

Email: info@winstonswish.org.uk



ACT's pathway provides a framework that can be adapted to fit with your local services and practice.

Part Three

Appendices

Appendix One: The practical management of extubation

(Adapted from George Mark Children's House Hospice Chicago by Serena Cottrell and Fiona Reynolds.)

Organisations are encouraged to make checklists for the process of extubation relevant to their local situation and to develop local policies. This is an example of factors to consider.

- Confirm that enteral feeds have been withheld for several hours prior to extubation to reduce the risk of aspiration.
- Children who have been intubated for weeks or who have evidence of intubation with an endotracheal tube that is too small, may develop respiratory distress due to upper airway obstruction once the tube is removed. To reduce airway oedema and inflammation, these children may benefit from the administration of anticipatory corticosteroids before extubation.
- The care team should establish that the child has adequate symptom control prior to extubation. The drugs and doses required will depend on the individual child, their diagnosis, their previous requirement of analgesics and sedatives, and the optimal degree of consciousness agreed. Symptoms of withdrawal should be anticipated.
- Medicines for symptom control should be available at the bedside. The care team should remove any unnecessary medical paraphernalia.
- Appropriate equipment such as suction, catheters, fans and oxygen equipment should be ready at the bedside. It should be agreed who will remove the endotracheal tube and who will suction.
- Confirm the role of the family; would they like to hold their child, is there any special music they would like to play?
- Establish who the family would like present in terms of extended family. Ensure that there is adequate space for this.
- Consider whether the family would like to dress their child in any special clothes, or to have any special toys available.

Children to undergo immediate extubation

The doctor or nurse (or designee) should suction the mouth and endotracheal tube (ET). If the ET is cuffed, deflate the cuff, remove the ET and place it under a clean towel. Silence the ventilator alarm, turn off the ventilator, and move it out of the way. Suction excessive oropharyngeal secretions. Occasionally terminal weaning is performed prior to extubation. The family should be encouraged to take part in their child's care and in activities to relieve discomfort. They should also be encouraged to hold and talk to their child, and provide assurances. The care team should remain available to spend as much time as needed with the family, discussing questions and concerns.

When the child has died, the family should be encouraged and supported to spend as much time with their child as they want. Care services should ensure that acute grief support and follow-up bereavement support is available to families.

Appendix Two: South Central Strategic Health Authority (England) – Advance Care Plan Policy 2010

(Extract from the guide for clinical staff with an update from the main author of this section, Mr Robert Wheeler, December 2010.)

18 year olds and older (terminology for this age group is adult)

- The legal definition of an adult is anyone of 18 years or over.
- Anyone of 18 years of age or above can make his or her own decisions about consenting to, or refusing treatment. She can make a legally binding Advance Decision, or appoint a Lasting Power of Attorney (LPA) to represent her wishes in the event of losing her capacity.
- The principles expressed in the Mental Capacity Act 2005 (MCA) apply only to the particular decision being considered. So a person may lack capacity for a decision concerning withdrawal of life-sustaining treatment but have capacity for another, for example the preferred place of care.
- The MCA 2005 provides tests for capacity. A person lacks capacity if they have an impairment or disturbance that affects the way their mind or brain works and the impairment or disturbance means that they are unable to make a specific decision at the time it needs to be made. This two-stage test should therefore be used if a clinician has cause to believe that the person lacks capacity.

A person is deemed to be 'unable to make a decision' if they cannot:

- understand information relating to the decision that has to be made;
 - retain that information in their mind;
 - use or weigh that information as part of the decision-making process, or;
 - communicate their decision.
- The time span for retention of information should be until the end of the conversation about DNACPR.
 - This test is simply a summary of the tests of capacity that have been used for the last 20 years, and does not represent new information. The advent of the MCA 2005 does not change the identity of the decision maker. If an adult is found to lack capacity then the decision is made on best interests. The only person who determines best interests (i.e. decides what the best interests of the person are) is the

decision maker. The decision maker is usually the clinician in charge, otherwise the Court of Protection, its deputy, or someone with Lasting Power of Attorney. Others, including parents or Independent Mental Capacity Advocates, are not empowered to determine best interests; they merely support the decision maker by, amongst other means, providing the information to allow the decision to be made.

16 and 17 year olds (terminology for this age group is young person)

- Although applicable to young people in many respects, the MCA 2005 does not permit 16 and 17 year olds to make arrangements to enable them, once incapacitated, to refuse life saving treatment. Thus there is no provision for them to appoint Lasting Powers of Attorney, or to make an Advance Decision to refuse treatment.
- There is a presumption that 16 and 17 year old young people have the capacity to make decisions for themselves. Young people of this age can consent to treatment and may be able to refuse treatment in some circumstances. But this does not generally apply to decisions about withdrawal of life-sustaining treatment: legal advice may be required in this situation.
- The key consideration is to make decisions consistent with the best interests of the young person.
- If a 16/17 year old is thought to lack capacity for a decision and is accompanied by a person with parental responsibility, this person is generally able to provide consent. The parents have a right to provide consent under the normal arrangements under the common law, and the Children Act 1989 (CA).
- For 16/17 year olds the main effect of the MCA 2005 is to consolidate into Parliamentary law (statute) the common law that has for many years accumulated, with respect to how 16/17 year olds who lack capacity have decisions made about them.
- In the context of medical decision-making, the MCA 2005 might be applicable in situations where there is disagreement between the parents and the clinicians, as to the young person's best interests, or capacity. Additionally, in the rare event that there is a concern that parents are not acting in the young person's best interests, the MCA 2005 Code of Practice should be followed.
- The MCA 2005 runs in 'parallel' with the CA, and the Mental Health Act 1983 (MHA). These statutes are drawn up in such a way as to co-exist, rather than provide contradictory advice. There will be

times when it is not clear whether a clinical problem should be approached via the CA 1989, or MHA 1983 (and thus through the Family Courts), or the MCA 2005, (and thus the Court of Protection). Sometimes the distinction may be rather fine.

For persons under 16 years of age (terminology for this age group is child)

- For these children the MCA can only provide decisions through the Court of Protection (a body that the MCA creates) about property and finance relating to children in certain circumstances. However it has no role in resuscitation/withdrawal or withholding of life-sustaining treatment decisions.
- Those with 'parental responsibility' for the child make decisions on the child's behalf (Children Act 1989). This 'parental responsibility' bestows on parents the responsibility of making decisions for, and acting in the best interests of the child, until he or she is old enough to make their own decisions. Since the CA came into force there have been some amendments to the automatic bestowing of parental responsibility, and this differs in different parts of the United Kingdom.

The current position in England is that:

- In relation to children born before 1 December 2003, if the parents have never been married, only the mother automatically has parental responsibility. The father may acquire it in various ways, including by entering into a parental responsibility agreement with the mother, or through a parental responsibility order made by a court.
- For children born after 1 December 2003, both parents have parental responsibility if they are registered on the child's birth certificate. This applies irrespective of whether the parents are married or not.
- If special guardianship is held then birth parents retain parental responsibility and must be contacted in 'exceptional circumstances'.
- If both parents have parental responsibility, neither lose it if they divorce, and responsibility endures if the child is in care or custody. It can, however, be restricted by court order and it is lost if the child is adopted.
- The child's step-parent can share parental responsibility with the child's divorced parents, if all are in agreement.
- Where the child has been formally adopted, the adoptive parents are the child's legal parents and automatically acquire parental responsibility.
- Where the child has been born as a result of assisted reproduction, there are rules under the Human Fertilisation and Embryology Act 1990 that determine the child's legal parentage.
- A person other than a child's biological parents can acquire parental responsibility by being appointed as the child's guardian or by having a residence order made in his or her favour, in which case parental responsibility lasts for the duration of the order.
- A local authority acquires parental responsibility (shared with the parents) while the child is the subject of a care or supervision order.
- When do parents hand over the responsibility for making decisions to their child? In practical terms, when is a child old enough to make his or her own decisions affecting their care, and ultimately their life? As a child develops and matures so will his or her understanding of their illness or disability. They will come to understand their condition, the reasons for their treatment, and the consequences of not having that treatment. This maturity, or competence has been referred to as 'Gillick' competence.
- The child who understands the nature of their illness and the likely outcomes of treatment options should be involved where possible in the decision-making process.
- The child's family and health care team must decide whether the child is competent to make his or her own decisions relating to resuscitation, and to what degree they will be involved in the discussions.
- Over the last decade the Courts have been consulted several times regarding children who have made 'competent' decisions that were at odds with the wishes of their health care professionals and/or those with parental responsibility for them. The current position in the Common law is that a 'child' under 18 can consent to treatment, but if they refuse treatment then those with parental responsibility for them can override that decision, but it would be wise to seek legal advice case by case in such circumstances.
- The consultant in charge of the child's care has final responsibility for resuscitation/withdrawal or withholding of life-sustaining treatment decisions. There is no legal obligation on the doctor to provide any medical treatment if it is not in the best interests of the child.

Appendix Three: The ACT Charter

For babies, children and young people with life-limiting and life-threatening conditions and their families

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

1. Every child should be treated with dignity and respect whatever their physical or intellectual ability.
2. Parents should be acknowledged as the primary carers and involved as partners in all care and decisions involving their child.
3. Every child should be given the opportunity to participate in decisions affecting his or her care, according to age and understanding.
4. An honest and open approach should be the basis of all communication.
5. Information should be provided for the parent, the child, the siblings and other relatives, appropriate to age and understanding.
6. The family home should remain the centre of caring wherever possible with appropriate support provided to all the family. Care away from the home should be provided in a child-centred environment by staff trained in the care of children, young people and families.
7. Every family 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.
8. Every child and family should receive emotional, psychological and spiritual support to meet their needs. This should begin at diagnosis and continue throughout the child's lifetime, death and in bereavement.
9. 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.
10. Every family should be given the opportunity of regular consultations with a paediatric specialist who has particular knowledge of the child's condition.

11. Every family should 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 should have access to education, extended school opportunities and other appropriate childhood activities.
13. The needs of adolescents and young people should be addressed and planned for well in advance using a young person-centred approach.
14. Every family should have timely access to practical support, including clinical equipment, financial grants, suitable housing and domestic help.

Appendix Four: 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/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, 2009).

Care of the dying

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

Children'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/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, this includes care during and around the time of death, and immediately afterwards. It enables the supportive and palliative care needs of both child/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.

Futility of treatment

This term reflects a recognition that continued invasive aggressive treatment is not in the child's 'best interests' or that continued invasive aggressive treatment confers more burden than benefit.

Hospice at home

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

Key working

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

Life-limiting/life-shortening conditions

Life-limiting conditions, sometimes known as life-shortening conditions, are those for which there is no reasonable hope of cure and from which 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.

Needs-led

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

Parents

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

Appendix Five: Directory of useful organisations

Listed below are some of the national organisations that provide support for babies, children, young people 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 or visit www.act.org.uk for details of other sources of support.

Bliss

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

www.bliss.org.uk

Tel: 0207 378 1122

Helpline: 0500 618140

Email: information@bliss.org.uk

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.

www.cerebra.org.uk

Tel: 01267 244229

Email: info@cerebra.org.uk

Children's Hospices UK

A national charity that can provide information on local children's hospice services.

www.childhospice.org.uk

Tel: 0117 989 7820

Email: info@childhospice.org.uk

The Child Bereavement Charity

The Child Bereavement Charity supports families and educates professionals both when a child is dying or has died, and when a child is bereaved of someone important in their life.

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www.childdeathhelpline.org.uk

Helpline: 0800 282986

Email: contact@childdeathhelpline.org.uk

CLIC Sargent

CLIC Sargent cares for children and young people with cancer and their families – in hospital and in the community. It provides specialist nurses and doctors, play specialists and home from home services, family support in the community, holidays, information and grants. It also helps survivors and supports the bereaved after treatment.

www.clicsargent.org.uk

Child Cancer Helpline: 0800 197 0068

Email: helpline@clicsargent.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

Helpline: 0800 652 3181

Email: info.svcs@climb.org.uk

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

Helpline: 0845 123 2304

Email: info@tcf.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

Free helpline: 0808 808 3555

Email: info@cafamily.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

Helpline: 0845 859 1000

Email: 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

Tel: 0207 704 3141

Email: mail@gig.org.uk

Muscular Dystrophy Campaign

The Muscular Dystrophy Campaign is a UK charity dedicated to improving the lives of children and adults affected by muscle disease. It provides free care and support, funds research to find treatments and cures, campaigns to bring about change and awards grants towards the cost of equipment such as wheelchairs.

www.muscular-dystrophy.org

Information Line: 0800 652 6352 (freephone)

Email: info@muscular-dystrophy.org

Organ Donation

England and Wales: National Tissue Donor Referral Centre

Tel: 0800 432 0559

Scotland: Scottish National Blood Transfusion and Tissue Services

Tel: 0131 536 5751

Northern Ireland: Local organ donation team

Tel: 0300 123 1208

Northern Ireland: Regional Transplant Coordinator

Tel: 028 90 329 241

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

Helpline South: 01372 453309 North: 01434 602961

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

Helpline: 08457 909090

Email: jo@samaritans.org

Sands

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

www.uk-sands.org

Tel: 0207 436 7940

Helpline: 0207 436 5881

Email: support@uk-sands.org

Sibs

Sibs supports siblings who are growing up with or who have grown up with a brother or sister with any disability, long term chronic illness, or life-limiting condition. Sibs can provide parents with phone support on talking to siblings about diagnosis, as well as activities for explaining disability or illness to siblings.

www.sibs.org.uk

Tel: 01535 645453

Email: info@sibs.org.uk

TCF Sibling Support

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

www.tcfsiblingsupport.org.uk

Tel: 0845 123 2304

Email: info@tcfsiblingsupport.org.uk

Winston's Wish

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

www.winstonswish.org.uk

Helpline: 0845 20 30 40 5

Email: info@winstonswish.org.uk

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A Care Pathway to Support Extubation within a Children's Palliative Care Framework

Withdrawing any life-sustaining treatment is one of the most difficult areas of clinical practice that professionals will face, and finding the right way to open up this dialogue with parents and children can feel insurmountable. Yet for those children in circumstances where treatment can merely sustain life, but cannot restore health or confer other benefits, then withdrawing treatment and the provision of good palliative care can be an active and positive experience for the child, the family and all the professionals that support them.

ACT's *Care Pathway to Support Extubation within a Children's Palliative Care Framework* provides professionals with the tools that they need to support families to make informed choices at this difficult time and focuses on children who are in the situation of being at the end of their life and dependent on respiratory support. This pathway provides a template to draw together all the professionals and resources needed to support the child and family along their unique care journey before, during and after extubation, where this is their chosen end of life care option, wherever that process takes place.

ACT's *Care Pathway to Support Extubation within a Children's Palliative Care Framework* is essential reading for all professionals who may support children with palliative care needs throughout their journey and end of life stage; including professionals who work in the children's palliative care sector, in general hospitals, children's hospices or in the community, or in specialist hospital services such as critical care settings in neonatology, intensive care, neurology, oncology and cardiology.



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