



A Guide to End of Life Care

Care of children and young people before
death, at the time of death and after death

**A Guide to End of Life Care
Care of children and young people before death,
at the time of death and after death**

**First edition © Together for Short Lives, August 2012.
Due for review 2014.**

Author

Helen Bennett: Care Development Manager, Together for Short Lives

Editor

Susannah Woodhead: Communications Officer, Together for Short Lives

Design

Qube Design Associates

Consultation group

Catherine Pickering: Head of care service development, Rainbow Trust Children's Charity

Francis Edwards: Paediatric palliative care liaison nurse, The Bristol Royal Hospital for Children.

Gill Wilson: CNS Advancing practice and development, Demelza Hospice Care for Children

Julia Hodgson: Projects manager, Together for Short Lives

Katrina McNamara: Director of practice and service development, Together for Short Lives

Rachel Black: Head of clinical education and development, Demelza Hospice Care for Children

Sally Le Masurier: Community palliative care nurse, The Children's Trust

Acknowledgements

This guide would not have been possible without support and feedback from a number of people. We are grateful to all those who commented on various drafts for their contribution and direction, and to all those who shared their practice experience of caring for a child at the end of life and after death.

The *End of life planning series* including *A Guide to End of Life Care* has been made possible by funding from The Samuel Sebba Charitable Trust, The St James's Place Foundation and Michael Cornish Charitable Trust.

A Guide to End of Life Care has been adapted from Care of the Child after Death (Children's Hospices UK 2011).

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

Registered charity in England and Wales (1144022) and a company limited by guarantee (7783702).



Together for Short Lives

4th Floor, 48-52 Bridge House,
Baldwin Street, Bristol BS1 1QB
T: 0117 989 7820
info@togetherforshortlives.org.uk
www.togetherforshortlives.org.uk

Disclaimer

While great care has been taken care to ensure that the contents of this document are correct and up to date at the time of publishing, neither its authors nor its publishers can guarantee its correctness and completeness. The information contained in the document is intended for general use only and users should take appropriate steps to verify such information and as necessary obtain legal and/or professional advice. None of the authors or the publishers accept responsibility for any loss, damage or expense resulting from the use of this information and no actions should be taken in reliance on it without relevant professional advice.



Contents

Foreword	5	Section 3: Care at the time of death	22
Section 1: Background and context	6	3.1 Introduction	
1.1 Introduction		3.2 Care of the family	
1.2 Background		3.3 Care of the child at time of death in different settings	
1.3 How to use this guide		3.4 Legal issues	
• Aims of the guide		• Expected and unexpected death	
• Sections of the guide		• Verification of death	
1.4 End of life planning prompt sheets		• Notification	
		• Child Death Overview Panel (CDOP)	
Section 2: Care before death	10	• The role of the coroner or procurator fiscal	
2.1 Introduction		• Post mortems	
2.2 Care of the family		• Certification of death	
2.3 Spirituality, faith and cultural care		• Registration	
• Spirituality			
• Ethnicity, culture and religion			
• Death and dying in world religions			
2.4 Communication			
• Talking with children			
• Difficult conversations			
• Sharing significant news			
2.5 Advance Care Planning (ACP)			
2.6 Organ and tissue donation			
2.7 Symptom management planning			

Note: Throughout this document the term 'child' is used to mean child, neonates, babies and young people. The term 'family' acknowledges the diverse relationships within a family including the role of the carer whoever that may be.

Contents

Section 4: Care after death 32

- 4.1 Introduction
- 4.2 Care of the family
- 4.3 Transferring the child to a funeral directors or a cool room
- 4.4 Funeral directors
- 4.5 Personal care of the child after death
 - Ongoing care of the body
- 4.6 Cool rooms in children's hospices
 - Accessibility of the cool room
 - Setting up a cool room
 - Length of time in the cool room
- 4.7 Placing the child in the coffin
- 4.8 Further support
- 4.9 Moving the body and repatriation
- 4.10 Cremation
- 4.11 Burial

Section 5: Bereavement support 46

- 5.1 Introduction
 - 5.2 Immediate support
 - 5.3 Collecting memories
 - 5.4 Preparation for the funeral or service
 - 5.5 Ongoing support
 - 5.5 Further resources
-

Section 6: Staff support and supervision 50

- 6.1 Introduction
- 6.2 Training and professional development

Section 7: Resources and Appendices 54

- 7.1 Further resources
 - 7.2 Glossary of terms
 - 7.3 References
 - 7.4 Related legislation
 - 7.5 Appendix 1: Checklist of practical tasks to complete at the time of death and following death
 - 7.6 Appendix 2: Outline of learning and competence for staff
-

Foreword

There can be few greater tragedies for a family than the death of their child. The circumstances surrounding their child's death can have huge impact on family members and can imprint memories which may last a lifetime.

We live in a culture and at a time in which common practise has often caused families to lose control over the way things are done at this crucial time. They may already have felt helpless in the face of illness or accident, powerless to stop the relentless course of events resulting in death and now they desperately need to be given back some degree of control.

A Guide to End of Life Care gives those of us who are privileged to be alongside families around the time of the death of their children an invaluable resource. It enables us to comply with necessary legislation while always acting with compassion and sensitivity, recognising the unique needs and attributes of each family member. If we listen, if we gently encourage them to take control around the time of death and in the days that follow, if we are around to support them and to encourage them to do things their way, we may well lay the first stepping stones through the flood of grief which follows the death of a beloved child.



Sister Frances Dominica, OBE DL FRCN FRCPCH
Vice President, Together for Short Lives

Section 1 Background and context



1.1 Introduction

Over the past few years a number of resources have been developed to support professionals working in children's palliative care. These documents aimed to identify, promote and extend best practice, enhancing the quality of care for children and young people with life-threatening and life-limiting conditions, and their families.

A Guide to End of Life Care builds on previous work of ACT and Children's Hospices UK (the two charities that merged to form Together for Short Lives in October 2011) and draws together many resources around end of life care, including *Care of the Child after Death* (Children's Hospices UK 2011). This new resource is part of an *End of life planning series* and provides information and recommendations for end of life care of the child across the sector regardless of setting. It focuses on principles of best practice in the care of the child and family before death, at the time of death, and after death. It includes sections on the use and practice of the cool room, communication, Advance Care Planning and symptom management at the end of life.

There remains little evidence or guidance surrounding care of the child at the end of life and after death. Much of our evidence base is drawn from a consensus of professional practice and from the wider field of literature on death and

bereavement. This guidance should be read alongside recent publications from the Department of Health, *Quality Standards for End of Life Care*¹, *Guidance for Staff Responsible for Care after Death*² and *When a Person Dies*³, all of which offer comprehensive guidance to support best practice.

In addition the material contained in this document supports practice in line with the principles and standards set out by national guidance and by Together for Short Lives. It encompasses the legal requirements and standards of care set out by external regulators including Healthcare Improvement Scotland, the Regulation and Quality Improvement Authority (Northern Ireland) the Care Quality Commission (England), Healthcare Inspectorate Wales and Local Safeguarding Boards (England and Wales).

Integral to this guidance are key principles of practice that underpin a learning framework to help develop the knowledge and skills of staff who work with families at such an intensely emotional time.

1. NICE (2011)
2. National End of Life Care Programme (2011)a
3. National End of Life Care Programme (2011)b

This guide is written for all practitioners working with children at end of life and this information aims to support professionals in making sense of the complexities surrounding end of life care. The ultimate aim is to establish safe and effective practice for children at end of life to improve the experience for children and families.

Key resources

- NICE 2011 *End of life care for adults quality standard (QS13)*
<http://guidance.nice.org.uk/QS13>
- National End of Life Care Programme 2011 *Guidance for staff responsible for care after death (last offices)*
<http://www.endoflifecareforadults.nhs.uk/publications/guidance-for-staff-responsible-for-care-after-death>
- National End of Life Care Programme 2011 *When a person dies: Guidance for professionals on developing bereavement services*
<http://www.endoflifecareforadults.nhs.uk/publications/when-a-person-dies>

1.2 Background

Together for Short Lives encourages a care pathway approach for children with life-threatening and life-limiting conditions and their families from diagnosis, throughout their care journey, at the time of death and beyond death⁴. This includes end of life care, care of the child after death, and extends to the care of the body and the cultural and spiritual care of the family. For staff working in a children's palliative care setting, caring for a child after death and supporting the needs of the family is integral to their professional role.

4. ACT (2004)
5. Ibid

1.3 How to use this guide

Aims of the guide

This guidance has been developed to support the care of the child at end of life, at the time of death and beyond. It offers comprehensive information aligned to the third phase of the care pathway, recognition of end of life and bereavement⁵. It is designed to enhance current practice and provide a consistent approach in care. It therefore aims to:

- Provide knowledge and skills for the care of the child at end of life, before death, at time of death and after death, and care of the family.
- Develop a greater awareness of the regulatory and legal requirements after death.
- Promote excellent communication between professionals and families and the wider sector.
- Recognise and value the importance of the wider cultural and spiritual dimensions of care.
- Enable the sharing of good local practice across the sector.
- Support effective bereavement care, informed by a greater understanding of grief and loss.
- Support the care of all staff by advocating the importance of reflection and supervision.
- Enable individual organisations to improve and add detail to current policy and procedures.
- Identify competencies related to end of life care and care after death.

Sections of the guide

This guidance is presented in sections that cover the practical, legal and spiritual issues of caring for a child at end of life. It is divided into care before death, care at the time of death, and care after death. In addition there is a useful section on bereavement which signposts to resources available elsewhere. There is also a section focusing on staff supervision and learning and development. The guide has been designed in a flexible format so that you can easily locate separate sections that apply to specific points in the care pathway.

The main sections of the A Guide to End of Life Care are:

Care before death highlights the essential components of care in relation to planning, alongside the importance of the wider dimensions of cultural and spiritual care. It addresses the need for effective Advance Care Planning recognising the need for discussions around organ donation, preferred place of care and anticipatory symptom management planning.

Care at the time of death acknowledges the sometimes difficult and challenging aspects of care at the time of death. It provides a comprehensive overview of *expected* and *unexpected* death – particularly in relation to children's palliative care. It explains the processes to follow in reporting a death to the coroner (or procurator fiscal) and to the local Child Death Overview Panel (CDOP) in England and Wales. It also guides professionals through the legal processes of registration of death including, verification, certification and notification of death.

Care after death encompasses the care and support of the child and family after death. It addresses the practical issues of transferring the child following death to a different location and setting up the cool room (see section 4.5). It also covers practical arrangements for the family following death, including burial and cremation, and describes the role of the funeral director.

Bereavement support offers general support and guidance in relation to grief, loss and bereavement. It highlights the importance of collecting meaningful memories at the same time as supporting and guiding the family through their preparations for the funeral and returning home. It also directs staff to consider the types of follow-up care and continuing contact that families might find useful, provided by the community, hospital, hospice organisation or others. It recognises the need for appropriate bereavement support that can respond to the needs of the individual regardless of their faith, culture, personal beliefs and ethnic origin.

Staff support addresses the support of staff through reflection, supervision and debriefs. It recognises the emotional weight for staff of working in this field, as well as the duty of care that employers hold in supporting those staff. It also addresses some key components of induction training and professional development in relation to end of life care and care after death.

Each of the sections highlights a number of good practice points, as well as reflective questions to enhance learning and to encourage reflective practice. Each section also highlights some key resources to signpost staff to current and robust information to support practice.

When using the guidance it is important to consider the following points:

- Identify a senior member of staff who will lead the process of developing practice within the team.
- Make sure that you involve everyone who needs to be involved (i.e. all staff who play a part in end of life care and care after death).
- If using the guidance for professional development, identify a senior/experienced member of staff who is able to provide support and mentorship.

1.4 End of life planning prompt sheets

A Guide to End of Life Planning has been written to promote best practice in the care of children and families and can be used as a theoretical resource to develop services and enhance individual professional development. We recognise that in practice, at the coalface of care, finding key points and priorities from a detailed document can be cumbersome and time consuming. There are occasions when practitioners benefit from quick reminders or prompts, in order to deliver comprehensive care. We have therefore developed a number of prompts that sit alongside this guide that will be more accessible in practice. Each prompt sheet relates to a section of the guide and summarises the key messages and principles to deliver safe and effective care.

The prompt sheets can be found in the resources section of the Together for Short Lives website www.togetherforshortlives.org.uk.

You can also order hard copies by emailing: info@togetherforshortlives.org.uk or calling 0117 989 7820.

Section 2

Care before death



2.1 Introduction

Caring for a child before death can be challenging, involving participation in complex decision making⁶ and symptom management⁷.

It is important to ensure that an Advance Care Plan (ACP) or end of life plan has addressed issues of resuscitation and organ or tissue donation, and that a symptom management plan for end of life is in place. Links with a symptom management team can be helpful in providing additional advice and support, although not all services have access to this. The ACP should also address the question of any preferred place of care at the time of death and after death.

Professionals involved in the care pathway potentially include hospital and hospice staff, community nurses, doctors, family support, the police, the coroner, the funeral director, faith leaders and midwives. It is vital to have good communication and co-ordination between all relevant professionals and local services, in order to ensure that both staff and families are aware of what is available and are able to make informed choices.

2.2 Care of the family

It is estimated that there are at least 49 000 children and young people in the UK with a life-threatening or life-limiting condition that may require palliative care services⁸. Children are living with increasingly complex conditions requiring skilled, intense and continuous care. For families this has a significant impact on their physical, social, emotional and financial circumstances and places an increasing demand on parents and carers in the care of their child. The need for meaningful, non-judgemental support at end of life is critical⁹. The importance of appropriate, timely and co-ordinated systems of care to provide such support for the whole family cannot be underestimated.

Families should be empowered through appropriate information to make decisions and their children, as appropriate, should be integral to the decision making process. For some families the capacity to make these sorts of decisions may be fraught with difficulty, and they may not be able to decide entirely about some things until the death is a reality.

2.3 Spirituality, faith and cultural care

Part of what makes people human is the need to make sense of life and death and find meaning and purpose in them. For many this is understood through spirituality, faith, religion and cultural values. Attention to people's needs, wishes and beliefs in this area should be the approach of all healthcare professionals.

There is a wealth of resources to guide staff in providing spiritual and cultural care, and it is not the intention of this guidance to cover these in depth. Our purpose is to raise key points and provide prompts for discussion.

This section therefore focuses on defining spirituality and outlining what is believed in the leading world religions and faith groups, although we acknowledge that there is a myriad of other faiths and cultures not mentioned here. The definition of spirituality recently agreed by the European Association for Palliative Care (EAPC) is adopted within this guidance to support a greater recognition and understanding of spirituality. The brief introduction to various faith groups is presented in such a way as to encourage dialogue with families and other professionals and promote greater understanding of faith and culture. Each family will be different, and it is important to remember there are numerous variations within each of the faiths addressed.

6. GMC (2010)
7. ACT (2011)
8. Fraser et al (2011)
9. Kirk S, Glendinning C. (2002)

Spirituality

‘Spirituality is the dynamic dimension of human life that relates to the way persons (individual or community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, self, to others, to nature, to the significant and/or sacred.’ EAPC task force on spiritual care in palliative care, 2011¹⁰

Ethnicity, culture and religion

The Commission for Racial Equality uses the term ‘ethnic minorities’, believing that cultural and religious differences are important. Thus there is a tendency to use the notion of ‘ethnicity’ rather than race in relation to common features such as language, religion and origin. Many religious groups will have their own philosophical and social systems. It is important to recognise the distinct differences in culture between people from different communities. Each situation is unique and will require creative and flexible responses.

Some people find a focus for their lives through a commitment to religion; others may not adhere to external signs of religious practice but still have strong spirituality and faith; some may have no faith but keep the values of religious traditions and rituals in which they were brought up. For many people religious observance is expressed through every day practices, and there are many examples that illustrate how faith can offer people solace and hope, particularly in relation to death.

Death and dying in world religions

Death and dying arouses great curiosity. There are a multitude of questions about the meaning and purpose of life and death for which faith and religion seek to offer answers. Many world religions teach that there is some kind of continuity or survival after death. They also give reassurance by helping individuals and communities to make sense of life and death, offering shape and meaning to the experience of grieving.

Staff must be prepared to acknowledge and respect an individual’s beliefs and values, even though they may not understand or share them. It is helpful for staff to have some knowledge of the beliefs and rituals associated with death and dying, particularly in relation to issues immediately following death and in care of the body. This is particularly important when supporting families at home or when using a cool room in a children’s hospice.

In many faiths life is a preparation for death and the life to come. It is extremely difficult to summarise the rituals and ceremonies that are most commonly observed at the time of death or immediately afterwards. The following summary of various faith communities attempts to raise awareness of their main customs and beliefs, and how these may affect the care provided at the time of death and after death.

The Buddhist community

There are three main schools of Buddhism – Theravada, Mahāyāna and Vajrayāna – each school demonstrating diversity of practice. Followers strive to walk in the path of the Buddha, following his example. Through Buddhism people attempt to achieve liberation from the cycle of rebirth in which all living things are caught.

The wishes of a Buddhist family would depend upon their individual beliefs and preferences. Families will usually wish to be with their dying child at the end of life. Buddhists strive to face death with an attitude of quiet and calm acceptance. Therefore anything that encourages this is likely to be

appreciated. The family may request that the body be left undisturbed for a while where practically possible, as it is commonly believed that it takes time for the mind to leave the body completely. Burial or cremation is a personal choice and no specific advice is given in relation to this.

Organ donation is very much a matter of personal choice too, determined by whatever the child or family consider most beneficial in accordance with their beliefs. Donation may be regarded as an act of generosity by Buddhists, and families should be approached sensitively to determine their wishes.

The Christian community

Three main movements are embraced by the Christian tradition, namely the Orthodox Church, the Catholic Church, and Protestantism. There is enormous diversity of practice within these churches but at the heart of Christianity is the figure of Jesus Christ as the Son of God within the trinity of Father, Son and Holy Spirit.

Faced with adversity, Christians often find support in the hope of salvation and in belief in an afterlife. In many Christian communities ministers strive to support families in the context of the fellowship of the church, drawing on the support of the community, family and friends to provide comfort and solace. Prayers may be integral to all parts of life and death. An older child or young person may receive Holy Communion and/or the sacrament of the sick (or sacrament of reconciliation).

Decisions after death relating to care of the body or organ donation will depend on the wishes and preferences of individual families. In some traditions Mass or Holy Communion may be included in the funeral service, and families may choose either cremation or burial.

The Hindu community

Hinduism demonstrates diversity in devotion, sacred writing and practice. In the Indian tradition the life of a person is held to be a pilgrimage from the cradle to the grave. In life the Hindu is said to pass through 16 stages, or take 16 steps, each of which is dedicated to God. The first of these steps takes place before birth and the last takes place after death in the ceremony of cremation.

Hindus’ belief in rebirth is based upon the conviction that the soul is immortal and indestructible. In the days following a child’s death the whole family may mourn for a period of between 11 and 13 days. In this time they may rely on support from their religious community. There are likely to be mourning rituals that may stretch through the first year after the child’s death.

A child may be given a small amount of Ganges water before death. Generally parents will invite members of the community to help wash their child’s body, and the body may be wrapped in a white shroud or white clothes.

A gold coin or leaf from the sacred tulasi plant may be put in the child’s mouth after death. It is likely that the family will choose to place the child on the floor rather than in a raised bed. Often the body will remain with the family until the funeral, and the first part of the ceremony can take place at home.

The eldest male in the family will play a key role in the funeral service. Very young children will usually be buried, whereas older children can be cremated. Families may wish for their child’s funeral to take place as soon as possible after death, and in many cases this will be within 24 hours or as soon as the death has been registered.

There are many references within Hindu scripture to acts of selfless giving. Organ donation is considered a virtuous act, but families should still be approached sensitively to determine their wishes.

The Jewish community

Judaism in the UK is mainly divided into Orthodox, Reform, Liberal and Progressive forms.

It is usual for parents to be with their child at the time of death, and some would wish for a Rabbi to be present. The body of a Jewish child may be cleansed and made pure through a religious ritual called *Taharah* (purification). The *Taharah* is performed by the local society, the *Chevra Kadisha*, which offers comfort and practical support to the bereaved in partnership with the wider Jewish community. Traditionally the *Taharah* is an absolute requirement of Jewish law, and non-Jews are unable to perform the sacred tasks of preparing the child’s body for burial.

10. European Association for Palliative Care (EAPC)



Burial may take place within 24 hours of death unless it is a Saturday (*Sabbath*) or another holy day. Family members may mourn for 30 days after the death, a period in which men do not shave. They are also likely to refrain from attending celebrations for a year after the death. A tombstone will be consecrated with a ceremony at the cemetery.

Judaism teaches that life is precious and should be preserved whenever possible. Families should be approached sensitively to determine their wishes concerning organ donation.

The Muslim community

Muslims believe that the Qur'an was repeatedly revealed by *Allah* (God) to the prophet Muhammad verbally through the angel *Jibril* (Gabriel) over a period of approximately 23 years, beginning in 610 CE and concluding in 632 CE. But there are many cultural variations within Islam. In general terms Islam is seen as *deen*, a complete way of life in which one submits himself to Allah to achieve peace in body and mind. Islam teaches that Allah created life and that humankind is the highest form of creation.

Islam teaches that people have free will but that when they die, their earthly deeds will be accountable before Allah on the day of judgement. Faced with adversity many Muslims express solidarity within the community, and friends and relations play an important part in supporting families. If possible the declaration of faith (*Shahada*) will be recited before death. The child's eyes and mouth will be closed and their head will be turned towards their right shoulder. Then the body will be positioned facing Mecca (south east in the UK). Family members will try to be together where possible. The child's body is washed three times and dressed in clean clothes. It is then covered with a plain, clean cloth. Those who have helped with washing the child will wish to cleanse themselves afterwards. The body may be returned to the place of birth. In some cases the body may be embalmed, although this is not recommended.

A child is considered to be a gift from Allah, and should not be knowingly harmed in any way. Because of this it would generally be insensitive to talk to families about organ donation.

Families will often wish to make the funeral arrangements themselves and the burial will take place as soon as possible. Relatives may visit the grave on Fridays after the

child's death. It is likely that mourners may avoid bodily contact with persons of the opposite sex (other than blood relatives). Mourning ends with Qur'anic reading and charity.

The Sikh community

In Sikhism references to death are often associated with birth, and the words *janum* (birth) and *moran* (death) generally occur together. According to Sikh belief humankind is not born sinful but in the grace of God, which gives the soul the opportunity to become 'God in flesh'. A person is not born free; rather they become free through breaking the cycle of life in order for their soul to rise to communion with God. This means that for Sikhs life is mortal but the spirit is immortal.

Sikhism teaches that the day of judgement will come to everyone immediately after death. It also teaches that heaven and hell are not locations but are symbolically represented by joy and sorrow, bliss and agony, light and darkness. Hell is seen as a corrective experience in which people suffer in continuous cycles of birth and death.

In Sikhism there are two distinct doctrines about rebirth. Firstly, the soul passes from one life to another in spiritual progress towards *nirvana* (perfection). This is eventually achieved through reincarnation. There are many references in Sikh scripture to acts of selfless giving. Organ donation is considered a virtuous act, and families should be approached sensitively to determine their wishes.

Secondly, rebirth can be in the form of animal life as a punishment. In striving for *nirvana* it is believed that the soul of the Sikh passes through a number of stages and moral conditions. Children are considered to be without sin.

It is usual for parents to be with their child at the time of death. The child's body will be washed and dressed by the family or by members of the religious community. It will be covered with a clean white sheet, and money or other gifts may be placed in the coffin. A very young child or baby may be buried, with older children being cremated. Families may find comfort in hearing passages read from the *Guru Granth Sahib* (holy book). Sikhs may wish a young person to wear the five Ks wherever possible, including a white turban for a male. Females will be dressed in a red sari or a red shroud.

Relatives will gather for about ten days after a funeral, either at home or at the *Gurdwara* or temple, for reading of the holy book.

Secular practices

Different cultures have their own communal ways of expressing grief, and there is a diversity of perceptions about what happens when earthly life is over. The way in which people respond to death depends on their community, culture and family values, which play a large part in shaping both the way people live their lives and how they respond to death.

For many people, a secular point of view is one that does not accept the existence of a god or gods, or the notion of an afterlife. This stance can include views about ethical and moral issues and is driven by a view that human life is time-limited, with no 'other world' to go to and no notion of rebirth. Earthly life is the only existence – it is not a prelude to another existence or the consequence of a previous one. The British Association of Humanists is a well established organisation that holds and promotes this view. There are also other groups of humanists and individuals who might describe their beliefs in this way.

Most families will want to celebrate their child's life. Carefully chosen words, songs, readings and (in some cases) hymns may add to the sense of occasion. Flowers are often part of the funeral, and candles may be used to represent the flame of the child's life (and the extinguishing of it). There are many different and diverse ways in which families choose to respond to death and remember their child.

Good practice points

- Always remember to be guided by the family and to ask if you are not sure. Never assume because a family have declared they are of a certain faith that you know the practices they will follow.
- If a family are outside of their home or country they may wish to be guided by their local community or embassy as to cultural and religious practices at the time of death.

Reflective question

Think about the number of families you have cared for from the same faith community, and consider the differences you experienced in their individual beliefs and practices.

Key resources

- *Multi-faith index*: www.mfghc.com
This website houses guidelines from the 'Multi-faith group for healthcare chaplaincy'. It has brought together guidelines that have been produced by a number of different NHS Trusts that cover many different faiths with regard to different issues of relevance in healthcare, inclusive of death and dying.

2.4 Communication

Effective, skilled and sensitive communication is essential in all aspects of children's palliative care and important throughout the care pathway¹¹. It is described as pivotal within a team approach to care whereby good communication and information can empower families with the knowledge to make informed decisions about care¹².

The aim of communication is therefore to reach an understanding between professionals and family, giving a message that is not received or understood is not communication. Essential skills and the process for effective communication are well highlighted throughout health and social care literature and are included here as a means to emphasise the importance of communication in children's palliative care. In addition it is crucial to recognise the importance of both information giving and emotional support, for communication to be perceived as being effective¹³.

11. National End of Life Programme (2012)a

12. Price J, Cairns C (2009)

13. Duke S, Baily C (2008)

Essential skills for communication

- Importance of body language
- Non-verbal skills
- Listening skills
- Open, focused questions
- Build trust - always be respectful and polite
- The importance of process:
 - Greeting and introduction
 - The story so far
 - How this might change
 - Plan for next steps
 - Conclude

There remain a number of barriers to effective communication including:

- Fear of making things worse or not being able to answer difficult questions.
- Lack of confidence in starting conversations, exploring concerns or closing conversations.
- Workplace issues such as environment, workload priorities, lack of support or training.

With comprehensive training, reflection and supervision these barriers can be overcome. Providing the opportunity for junior staff to observe and learn from skilled practitioners is essential in developing effective communication skills.

Talking with children

Working with children in palliative care means being able to communicate not only with the affected child, but also siblings, friends and peers. Talking with children involves a number of complex challenges including truth telling and confidentiality. A number of myths and misconceptions remain including, children do not want to know, that they do not and will not understand or that we could cause harm by telling the truth. Research with children in oncology clearly emphasises why we need to talk to children¹⁴.

14. Gibson F, Aldiss S, Horstman M, Kumpunen S, Richardson A, (2010).

By talking with children:

- We may discover what they know and do not know.
- We may discover their preferences and their family's preferences for involvement in decision making.
- We are better able to understand their preferences for care.
- We may uncover useful information and preferences in relation to a child's symptoms and symptom management.
- We may uncover their fears and misconceptions.
- We are better able to share information openly and honestly.

Thus the essential skills of communication highlighted above are equally important when engaging with children.

There are additional issues and skills to consider when talking to children:

- Age and development.
- Awareness and understanding of illness and death.
- Family connections – the values and beliefs of the family and how they make and process decisions.
- Truth telling and confidentiality.

Further skills for talking with children

- Talk with them, not about them.
- Speak in the child's language (recognising body language and play language).
- Show them respect – don't rush them and don't interrupt.
- Listen attentively.

Good practice points

- Open and honest communication with children and families will help us to better understand their preferences for care.
- Essential skills of communication are as important for engaging with children as with adults.
- Additional issues to consider include, age and development, connections with families, truth telling and confidentiality.

Reflective question

Consider a time where you are talking with a group of children about care. What additional skills did you draw on to ensure that what you were saying was received and understood?

Difficult conversations

Skilled and effective communication is central to quality care for children and their families at end of life. By carefully listening and responding in a meaningful way professionals can support families by providing information, comfort and understanding at such a challenging time. Difficult conversations can be the most testing for healthcare professionals and is an area of care and support that we do not always get right. Inadequate communication can leave a lasting impact on families throughout their care journey and beyond¹⁵. Conversely, effective communication can have a positive impact¹⁶ and families can feel empowered in the care of their child. Understanding and responding to children and parents when engaged in difficult conversations requires advanced communication skills. The need for staff to be supported through training courses will increase their ability and skill in communicating with families.

Key principles in managing difficult conversations

- Be able to work through your own reaction to the news before preparing yourself to share this with someone else.
- Good, clear, sensitive communication can and does make all the difference to how a family receives and responds to the information.
- You need to make the time and space to share the information by allowing enough uninterrupted time.
- Know your facts and anticipate what the issues might be.
- Be adequately prepared in relation to the clinical situation and the family situation, for example think about what roles different people play in the family and how they process information.
- Always be prepared to ask for help if you need further support.

- Have a framework for the conversation (see traffic light framework on p.18), and consider rehearsing with a colleague beforehand.
- Ask open questions to help you assess what the family already know and understand and what their concerns are.
- Repeat and clarify to make sure the family members understand everything you are telling them.
- Always be open and honest.
- Think about how and where you are getting your support from after these conversations.
- Give feedback to all that need to know and document information as appropriate and in line with current guidance.
- Summarise what has been said. Set up a further appointment. Offer to speak with other members of the family and share written materials with them.

Key resources

- The National End of Life Care Programme: Communication skills tools www.endoflifecareforadults.nhs.uk/education-and-training/communication-skills
- Connected: National Communication Skills Training www.connected.nhs.uk

The framework on the next page (adapted from University of Southampton 2012) also offers a supportive process for managing difficult conversations.

15. Cancer Services Collaborative Improvement Partnership (2004)

16. Coad J (2008)

Essential skills for managing difficult conversations

Stop Look Think

Resist the temptation to run!

Make eye contact & pay attention = you are important

Negotiate: "are you able to say what's worrying you?" = I'm willing to listen, but I can see it's hard and I don't want to distress you

Listen Respond

Silence: don't be afraid to be quiet and let the person gather their thoughts

Open questions: "how are you feeling / what do you think about that" = I'm interested/concerned

Educated guesses: "I imagine that came as quite a shock" = I have an idea about how you might be feeling, do you want to talk to me about it?

Prompt: "yes, go on" = I'm still listening

Acknowledge & Reflect: "you've had a rotten time by the sound of it" or "you look/sound upset" = how you feel matters, I can see you're upset, it's OK to tell me about it, I want to help

Clarifying: "what are the things about it that upset you?" = I'd like to understand exactly what the problem is

Make a plan, end the conversation

Paraphrasing to sum up: "being ill has been really distressing/you really want to get some answers about this" = I want you to know I've heard and I'm checking I've got it right

Open directive questions: "what's most important to you right now?" = I think you might have concerns/needs and I want to help

Summarising: "so what's most important is ...[list of things said]" = I've heard you, have I got it right, have I missed anything out?

Permission: "can I talk to someone about this?" = I think you need more help than me, but I'd like your permission first

Remember to close: I'm glad you talked to me, would you like me to come back/let you know when I've done... = it was alright to talk to me, you've given me things to do on your behalf and I know that you need to know when I do them

17. Adapted from University of Southampton (2012)



Sharing significant news

For many professionals the most challenging area of communication surrounds breaking bad news or sharing significant news. There are a number of frameworks to help support this process - the *Six stepped protocol*, designed as a systematic guide to the communication of bad news may be viewed more generally as a model for communicating any important information.

Six stepped protocol

Adapted from *How to Break Bad News: A Guide for Health Care Professionals* by Robert Buckman.¹⁸

1. Getting started

- Planning what to say
- Creating a conducive environment
- Allotting adequate time
- Determining who else needs to be part of the conversation

2. What does the patient know?

- Establish what the patient knows
- Child's parents
- Assess ability to comprehend new bad news
- Reschedule if unprepared (discuss)

3. How much does the patient want to know?

- Recognising and supporting patient preferences
- Advance preparation
- Handling difficult cases

4. Share information

- General guidelines for breaking bad news - The **WPC** chunk method
 - **W**arn
 - **P**ause
 - **C**heck back

5. Respond to emotions

- Be prepared for strong emotions
- Listen
- Validate the response
- Take time
- Encourage descriptions of the feelings
- Use appropriate non-verbal communication

6. Plan, follow-up

- Identify options
- Suggest sources of support
- Start a plan
- Follow up appointment/conversation
- Ensure the family have a contact name and number
- Before leaving assess support at home and safety of the patient and family

Useful reminders for effective communication

- Use clear language.
- Be honest.
- Avoid monologue, promote dialogue.
- Avoid jargon and euphemisms.
- Pause frequently.
- Check for understanding.
- Use silence and body language.
- Be prepared to say you don't know.

18. Buckman R (1992)



2.5 Advance Care Planning (ACP)

Advance Care Planning (ACP) is a process of discussion between an individual and their care provider¹⁹ and often those close to them. The *End of Life Care Strategy*²⁰ clearly states that ACP and clarity around resuscitation decisions is essential to quality care. This is as important for children and families as it is for adults receiving end of life care. ACP may lead to actions such as advance statements about wishes and preferences, preferred place of care, withdrawal of treatment and resuscitation status. For children and families this will include decisions relating to care in the case of acute deterioration and may also address preferences for organ and tissue donation.

All conversations surrounding ACP require sensitive and meaningful discussions that take account of multiple dimensions of care including the condition and illness trajectory, the relationships within the family, hopes and wishes and expectations of care. Careful consideration must take place to ensure that appropriate conversations are held at the most appropriate time and those decisions are reviewed on a regular basis. Good communication and co-ordination between all relevant professionals and local services is essential to ensure that staff and families are aware of what care is available and that they are able to make informed choices.

Key resources

- NHS South of England (2012) End of life care documents www.southofengland.nhs.uk/what-we-do/end-of-life-care/central-area-documents
- National End of Life Care Programme (2011) *Capacity, care planning and advance care planning in life limiting illness: A Guide for Health and Social Care Staff*. www.endoflifecareforadults.nhs.uk/publications/pubacpguide

19. National End of Life Care Programme (2012)b
20. Department of Health (2008)

2.6 Organ and tissue donation

There may be an opportunity for children with a life-threatening or life-limiting condition and their families to consider organ or tissue donation. In all cases where organ or tissue donation is chosen, there must be a defined cause of death and all processes must adhere to the Human Tissue Act (2004), Scotland (2006).

To be effective, conversations should take place prior to death, and families should be informed of what is possible given their child's condition. Many children are able to donate tissue and corneas despite having a genetic condition.

When talking to parents about organ or tissue donation, staff should be aware of the family's values and beliefs. Studies have shown that parents appreciate being informed about organ donation²¹, and that most parents are pleased to hear about the opportunity to donate organs and/or tissue. If professionals and families feel that it would be helpful and appropriate to have a more in-depth discussion about organ donation, then further information and support are available through a specialist nurse for organ donation within the local trust or nationally at www.uktransplant.org.uk. The specialist nurse for organ donation will be able to provide information for families as well as training and support for staff in how to broach the subject with parents.

If families choose organ or tissue donation, it is worth noting that this may influence place of death. Some organs or tissues need to be retrieved within four hours of death to be viable. Discussions to support this choice for families will therefore need to be managed sensitively.

Good practice points

- All families should be able to discuss options of organ and tissue donation if they wish.
- All professionals working in palliative care should know who their local transplant co-ordinator or specialist nurse is, and where to go for further advice.

21. Paediatric Intensive Care Society (2002)

2.7 Symptom management planning

Effective symptom management for children is essential to ensure comfort but also to enhance their quality of life. This is as important at the end of life as it is throughout the journey, and anticipatory planning for end of life is vital in managing what is likely to happen. Children and parents should be given appropriate and timely information and wherever possible should take the lead on decisions surrounding their child's care. A symptom management flowchart can sometimes be helpful to guide professionals and parents regarding likely symptoms and the management of such symptoms²².

It is not the intention of this guidance to describe symptoms in detail. This information can be found in *Basic Symptom Control in Paediatric Palliative Care* (ACT 2011)²³ and the *Oxford Textbook of Paediatric Palliative Care* (2nd Edition)²⁴.

In addition the pharmacological management of children's palliative care whilst acknowledging the challenges around unlicensed drugs, dosages for children, preparations and research with children, is comprehensively covered in the *APPM Master Formulary* now in its 2nd edition²⁵.

Key points surrounding symptom management planning:

- Multi-professional approach involving those experienced in end of life symptom planning.
- Child centred care delivered in partnership with the child and family.
- Skilled and sensitive communication.
- Empowering children and families.
- Understanding, knowledge and information of disease profiles.
- Anticipatory planning – be prepared for the unexpected.
- Combining pharmacological and non-pharmacological methods.
- A holistic approach – Total Pain²⁶.

22. Willis E (2007)
23. ACT (2011)
24. Goldman A, Hain R, Liben S (2012)
25. APPM (2012)
26. Saunders C (1978)

These include:

- Deciding who is going to prescribe and dispense medication at end of life.
- Making sure the ambulance control are fully aware of advance care plans.
- Determining who is going to verify and certify death in and out of hours.
- Supplying the family with contact details of professionals who are available in and out of hours.
- Ensuring the wishes of the family are known, including which professionals they would like around at the time of death.

Essential information and decisions should be recorded and the family should be fully aware of what is going to happen at end of life and at the time of death.

Key resources

- ACT (2011) *Basic Symptom Control in Paediatric Palliative Care*
- Goldman et al (2012) *Oxford Textbook of Paediatric Palliative Care* (2nd Edition)

Section 3 Care at the time of death



3.1 Introduction

Caring for a child at the time of death is a significant moment and it is essential to provide sensitive and meaningful care and support that meets the individual needs of each family.

Multi-professional care planning and joint working are pivotal to the care of the child, recognising the cultural and spiritual dimensions of care. There will be a number of practical tasks to carry out including the verification and certification of death and it will be critical to ensure co-ordinated and seamless care delivery.

3.2 Care of the family

For many parents, caring for a child with a life-threatening or life-limiting condition has meant a significant journey from the point of diagnosis with multiple experiences of grief and loss along the way. Supporting families at the time of death and beyond requires sensitivity and compassion recognising this unique journey and all that has gone before.

Predicting death in children is not easy, and it can be an intensely emotionally time waiting for a child to reach the point of death. Parents are likely to experience an overwhelming sense of grief as their child dies, even when death is anticipated.

When you think a child has died, do not feel that you have to immediately verify the death. You do not have to rush to do anything if the death was expected.

It is important to be aware of the processes and legal issues surrounding death, and at the appropriate time the family will need to be informed about these. But before this happens they may simply want some time on their own, and you should facilitate this where possible. Throughout this very difficult time it is always best to ask the parents what they want at each stage – do not be afraid to ask.

Some parents may need guidance on what they are able to do, for example holding their child or lying on the bed with them. They may wish to sleep for a while before doing anything.

Despite all the practical tasks to be completed it is important to work alongside the family, to go at their pace and continue to learn about their desires and wishes. These may change at any time. Staff will need to be competent in all aspects of care after death to ensure best practice and to support high standards of care. All tasks need to be carried out in the context of a sensitive and caring approach to support the family. Staff will need to ensure that they are able to communicate effectively with families to get an understanding of their expectations and wishes around faith, spiritual and cultural care (see section 2.3). Clear documentation for all decisions and arrangements at end of life and after death must be recorded.

3.3 Care of the child at time of death in different settings

Supporting children and their families in their preferred place of care and preferred place of death means that end of life care and care after death can take place across many settings. A child can be moved from one setting to another during this period of time. Effective and skilled joint working is essential to support families and advance planning should be integral to care. Effective communication and explaining to families what will happen and what may happen will avoid sudden changes to care, which can be distressing for families. Families should be able to choose the place of death and where possible this should be facilitated. Depending on where a child dies there will be local and organisational policies and procedures that professionals need to be aware of in order to meet the regulatory requirements at time of death.

3.4 Legal issues

When a child dies, there are a number of steps that need to be taken to support the legal requirements for registration of death. These include the process of verification, certification and notification of death. There are also requirements as to when to report a death to the coroner (or the procurator fiscal in Scotland) and to the Child Death Overview Panel (CDOP) in England and Wales. You need to be mindful of the need to advise parents about post-mortems where applicable and to request cremation certificates. All staff working with families at the time of a child's death must be competent in advising and informing parents appropriately and sensitively of the necessary requirements.

This guidance addresses many of the legal and regulatory requirements across the four countries of the UK. But practice does vary considerably between nations, and if in doubt it is always best to seek additional local advice.

Expected and unexpected death

One of the challenges of working with children and young people with life-threatening or life-limiting conditions is defining an expected or unexpected death. It is vital to be able to assess and identify an unexpected death and initiate a prompt investigation. Doing so enables everyone to learn from the experience and improve care in the future^{27, 28}.

Expected death is the natural and inevitable end to an irreversible terminal illness. Death is recognised as an expected outcome. The decision that death is expected should be clearly documented in the clinical records. Supportive and sensitive communication should have taken place between all those involved, and an end of life plan should be in place.

Unexpected death is the sudden and unforeseen death of a child. National and local policies will outline procedures for the Sudden Unexpected Death of Infants and Children (SUDI) and it is essential these policies are discussed in relation to children with life-limiting and life-threatening conditions.

For children and young people with a life-limiting or life-threatening condition, unexpected death can be described where death:

- Was not anticipated as a significant possibility for example, 24 hours before the death; or
- Where there was a similarly unexpected collapse or incident leading to or precipitating the events which led to the death (DSCF 2010).

It is important to recognise the distinction between expected and unexpected death. If death is *unexpected* (based on the definition above) or suspicious in any way, it must be reported to the doctor. The doctor must inform the coroner or procurator fiscal. In England and Wales there is an additional requirement to inform the rapid-response team, including the on-call designated paediatrician. In Northern Ireland the Police Service of Northern Ireland (PSNI) will need to be informed.

Where there is any uncertainty, those responsible for managing unexpected death must be consulted. If in doubt the processes for unexpected death should be followed until there is evidence to inform a different decision to be made^{29, 30}.

27. The Fatal Accidents and Sudden Deaths Inquiry (Scotland) Act (1976)

28. Department for Children Schools and Families (DCSF) (2010)

29. Crown Office and Procurator Fiscal Service (2008)

30. Department for Children Schools and Families (DCSF) (2010) section 7.29

31. Ibid section 7.6

Deaths that need reporting to the coroner or procurator fiscal

- Identity of deceased unknown.
- Cause of death unknown.
- If the deceased wasn't seen by the certifying doctor either after death or within 14 days before death.
- Sudden, unexpected, suspicious, violent (homicide, suicide, accidental) or unnatural deaths.
- Deaths due to alcohol or drugs.
- Deaths due to self neglect or neglect by others.
- Deaths due to industrial disease related to the deceased's employment.
- Death may be due to abortion (i.e. doubtful stillbirth).
- Deaths during surgery or before recovery from effects of anaesthetic.
- Deaths within 24 hours of admission to hospital.
- Deaths during or shortly after detention in police or prison custody.

It is expected that children with a life-limiting or life-threatening condition will die prematurely however, it is not easy to anticipate when, or in what manner they will die. There are likely to be a number of factors contributing to a sudden unexpected death and it is important to identify these factors by a detailed investigation. Therefore the unexpected death of a child with a life-limiting or life-threatening condition should be managed in the same way as any other unexpected death so as to determine the exact cause of death and any contributory factors³¹.

If there has been no explicit advance decision for a 'do not resuscitate' order prior to collapse and the wishes of the child and family are unknown there is a presumption that every reasonable effort will be made to resuscitate unless the fact of death is unmistakable.

Where nurses are involved with or called to an unmistakable unexpected death they should always follow principles that support best practice. Knowing whether the child has an ACP and/or 'do not resuscitate order' is essential for informing the process. Nurses must ensure that they are acting in line with their knowledge and scope of practice. For all unexpected deaths the nurse must contact the relevant medical practitioner for further direction.

There has been significant debate among families who have experienced difficult and inappropriate referrals that have caused unnecessary anguish and distress. It is of the utmost importance to anticipate and plan as far as possible how to manage the unexpected death of a child with a life-threatening or life-limiting condition, in order to avoid any unnecessary distress to the family and to ensure that correct processes are followed. This planning needs to include discussions at a senior level with all professionals and agencies involved locally, and each children's service must have a policy and protocol that are adhered to in the case of unexpected death.

For all unexpected deaths it is vital to promote effective communication and establish good relationships with professionals locally. It is also essential for children's services to develop a local policy to ensure that agreed procedures are followed and that families are treated with sensitivity.

The management of an unexpected death

In any setting, when a child with a known life-threatening or life-limiting condition dies in a manner that was unexpected or was not anticipated:

- Access to the room should be restricted – staff must not contaminate the scene if a death is suspicious.
- Nothing must be removed or touched, only switched off until the medical practitioner arrives.
- Intravenous lines, nasogastric tubes and tracheostomy tubes etc must remain in place.
- The medical practitioner will inform the coroner (or the procurator fiscal in Scotland) and in England and Wales the designated paediatrician on call as part of the rapid-response team should also be informed.
- The police will be informed and attend (it is likely that the coroner or procurator fiscal will not attend out of hours, but this will depend on local resources and procedures).
- The child should not be washed.
- The child should not be transferred to the mortuary or cool room unless the coroner has given specific permission.
- There will need to be a senior member of staff to support the process, together with those professionals who already know the family.
- All medication should be kept for a period of time in accordance with local policy and procedures.
- If the child dies unexpectedly at home, the general practitioner should lead this process if possible.
- At all times sensitive and skilled communication with the family and other professionals is vital.

Good practice points

- All staff should receive training to enable them to understand the distinction between expected and unexpected deaths, particularly relating to children with life-threatening or life-limiting conditions.
- Each children's service must have a policy and protocol to guide the management of unexpected death.

Reflective question

Consider a child known to the service experiencing an expected deterioration in their condition and dying unexpectedly. What questions would you ask to help you understand the principles of expected and unexpected death as they would apply in this situation?

Verification of death

Verification of death is the procedure for determining when a patient has actually died and is the physiological assessment to confirm the fact of death. All deaths should be subject to professional verification that life has ended³². This is separate from the certification process, and can be performed either by a medical practitioner or by another qualified professional. A nurse can verify death, as there is no legal requirement for a medical practitioner to do so.

Verification of death is a significant point in the pathway for families and although it is a practical task, is undertaken at a profound and spiritual moment. It should be completed sensitively and honestly, supporting the family throughout.

For further information on verification of death please see *The verification of expected death in childhood: Guidance for children's palliative care services* (Together for Short Lives, 2012).

32. Secretary of State for the Home Department (2003)



Good practice points

- Nurses have the authority to verify death if they are trained and assessed as competent to do so.
- There must be an agreed policy in place to support nurse verification.

Reflective question

Reflect on a past experience, or talk with an experienced colleague, about how you would manage undertaking the very practical tasks involved with supporting a family immediately following a child's death.

Notification

Notification of death is required within 24 hours to the appropriate regulatory inspectorate. In England, Wales, Scotland and Northern Ireland the relevant authorities are:

Care Quality Commission

(England)
www.cqc.org.uk

Healthcare Inspectorate

(Wales)
www.hiw.org.uk

Regulation and Quality Improvement Authority

(Northern Ireland)
www.rqia.org.uk

Healthcare Improvement Scotland

(Scotland)
www.healthcareimprovementscotland.org

Local Safeguarding Children Board (LSCB) and Child Death Overview Panel (CDOP) in England and Wales

The safeguarding of children around death has resulted in a number of scrutinised procedures to ensure processes are in place so that children are protected. These procedures should also help healthcare professionals understand more about why children die and to take action on any lessons learned³³. Local Safeguarding Children's Boards (LSCB) across England and Wales are required to review all child deaths through a sub-committee known as the Child Death Overview Panel (CDOP).

Initial notification

In England and Wales it is compulsory to notify a child death to the LSCB for review by the local CDOP. This has been a statutory responsibility since 1 April 2008. All children's services will need to complete the appropriate documentation as soon as possible following the death of a child. For deaths that occur after 5pm, at weekends or on bank holidays, the written notification proforma should be sent the next working day. All deaths of under-18s must be notified, irrespective of their cause, including all baby deaths. The proforma should be completed as fully as possible and sent immediately to the local CDOP contact.

Rapid-response processes

The rapid-response team are a group of key professionals who come together for the purpose of enquiring into and evaluating each unexpected death of a child. This process enables professionals to capture immediate information about unexpected child deaths. In addition to managing support for the bereaved family, this ensures that there are opportunities for information gathering and timely investigation.

There will be varied local arrangements regarding how these actions are co-ordinated. Check with your local CDOP to find out how the rapid response is managed in your area. If a child with a known life-threatening or life-limiting condition dies in a manner not anticipated, the rapid response team should liaise closely with a member of the palliative or end of life medical team to jointly determine how best to respond.

33. Department for Children Schools and Families (DCSF) (2010)

Child Death Overview Panel (CDOP)

The Child Death Overview Panel (CDOP) is set up and co-ordinated by the Local Safeguarding Children Board (LSCB) in England. It does not normally involve frontline staff. The overview panel reviews all child deaths by first requiring all services involved to complete as much information as they can via the agency report form. Having gathered all available information, the panel identifies patterns and trends, and makes recommendations for improving care and outcomes in the future. A useful guide is published for parents and carers explaining the child death review process, and is helpful for parents regardless of the manner in which their child has died, whether the death was expected or unexpected³⁴.

For children with life-limiting conditions, there is a special supplementary form that should be completed by the person or organisation providing care towards the end of life (e.g. children's hospice, community children's nursing service, GP). This is to help gather information nationally about the deaths of children with known life-limiting illness. It is also designed to be useful for paediatric palliative care services, who may keep a copy to support their own reflection, audit and local service development.

Good practice points

Child Death Overview Panels have three levels of regulatory requirements:

- Initial notification
- Rapid-response
- Child review

The role of the coroner or procurator fiscal

Understanding the role of the coroner or procurator fiscal is central to good practice. Building a good relationship locally can be really valuable, particularly as there may be regional variations in the role of coroner or procurator fiscal that you need to come to recognise. Effective communication and joint working are essential to formulate agreements around

the reporting process. Some deaths require notification to the coroner (or procurator fiscal in Scotland) before the death can be registered.

The coroner or procurator fiscal has a duty to investigate all sudden, unexpected, accidental, suspicious or unexplained deaths. An investigation is also carried out where a medical practitioner is unable to issue a medical certificate, for whatever reason, to detail the cause of death. Until this investigation is completed, the death cannot be registered. Although there are some differences between the role of coroner in England and Wales, the coronial system in Northern Ireland and the role of procurator fiscal in Scotland, there are also many similarities:

- All unexpected deaths must be reported as soon as possible, before any death certificate can be issued.
- The coroner or procurator fiscal will decide if further investigations are necessary. They may decide that the death can be dealt with by a medical certificate of cause of death (MCCD) once the cause of death has been agreed. Alternatively, there may be a need for further investigation in the form of a post mortem by a pathologist (preferably with a paediatric focus) and/or a full inquest.

If the death is confirmed by post mortem with no inquest then the death can be registered by using a form from the coroner (England, Wales and Northern Ireland) or by the pathologist completing the post mortem in Scotland. If the case proceeds to inquest, then the coroner issues the death certificate and any certificates necessary for burial or cremation. In the vast majority of cases there is no objection to the release of the body. It may be, however, that cremation is not allowed as this will lead to destruction of evidence and so the body will need to be buried instead.

Post mortems

Post mortems (PMs) are a legal requirement for any sudden death when the cause is not apparent. Specific cases where referral to the coroner or procurator fiscal is required, and where a PM would normally be necessary, include death post-operatively and death within 24 hours of a hospital admission. A PM examination may also be carried out if requested by the parents and/or medical professionals to

establish cause of death, particularly if the condition of the child is undiagnosed. If the coroner or procurator fiscal requests a PM, families have no legal right to decline and the PM will go ahead with or without their consent³⁵.

Post mortems are undertaken by a pathologist who is also a medical practitioner. A PM involves examining body organs and tissue to establish possible conditions or illnesses that may have brought about death. It is likely that the examination may involve two incisions; one along the length of the breastbone and the other at the back of the head. On completion, the incisions are generally sutured and covered with an adhesive dressing to prevent leakage.

In some cases it is advisable for the child to go to the funeral director following a PM, in order for the condition of the body and its presentation to be managed in a professional and sensitive way. In the event of a PM it is best that staff and families seek advice from a funeral director as to how the body might be cared for appropriately. This will largely depend on the type and extent of the PM and the condition of the body.

In Northern Ireland there are two types of PM examination³⁶; consented hospital PMs and non-consented coroner's PMs. In either case consent (where required) must be sought from those with parental responsibility. Both parents should be consulted where possible, and both should sign the form. If either parent is known to object then a PM should not be carried out. The coroner's liaison officer will communicate with the next of kin regarding consent for further use of tissue and organs. This can only proceed when the investigation is complete and the coroner has agreed to their release. Further information is available at www.coronersni.gov.uk

Sensitive communication and good information and advice for the family are essential at this time. A number of hospital trusts have information leaflets for families and professionals that offer helpful advice.

Certification of death

Certification of death is an essential preliminary to registration and the law requires a medical practitioner to certify the cause of death^{37, 38}. This process requires the medical practitioner to complete a 'Medical certification of

cause of death' (MCCD) which includes a statement of the cause of death, the date the child died, the date the child was last seen alive and whether they have seen the body after death. If the medical practitioner is unable to establish cause of death then the case must be referred to the coroner or procurator fiscal.

The MCCD acts as a safeguard in establishing the cause of death, and MCCD findings are the main source of national data on mortality. Following the Shipman Inquiry³⁹ a number of changes to the process of death certification have been introduced. Further changes will follow as part of an improvement programme across the UK, with separate amendments due to be made in England and Wales,⁴⁰ Scotland⁴¹ and Northern Ireland.⁴² For current requirements and recent changes, see each country's website. Further changes to processes surrounding death certification will take place in 2014.

Currently the MCCD is completed by a medical practitioner – either the one who has been treating the child or the one who saw them last. Communication can continue after the death has been verified and before the certificate is issued, particularly if there are concerns surrounding the death. It is advisable to discuss with the family the wording used in relation to cause of death before they are given the certificate, so that there is no confusion and no unnecessary distress to the family.

The MCCD is not the same as the death certificate issued following registration of death. The MCCD is required to register the death.

An infant born after 24 weeks' gestation that survives even for the briefest period of time must be issued with a MCCD, and the child's parents will need to register the birth and death.

35. Hallam et al (1999) (pp87-103)

36. DHSSPSNI (2006)

37. The Coroners Act (2009)

38. Births and Deaths Registration Act (1953)

39. Shipman Inquiry (2004)

40. Department of Health (2010)

41. Certification of Death (Scotland) Bill (2010)

42. DHSSPSNI (2011)

34. FSID (2010)

Registration

Any death needs to be registered within five days in order for the certificate of registration of death (death certificate) to be issued. Registration of death can only take place if the coroner has released the body and all enquiries are complete. Registration of death is also required before a funeral can take place. Timely and sensitive planning is required to ensure the process of registration is completed to avoid any unnecessary delays to the funeral.

A child's death may be registered by appointment in the district where they have died or in the district in which they lived. Parents and close family members can register the child's death. The registrar will also allow others to register the death if there are no relatives available. These may include someone who was present at the death, the person taking care of the funeral arrangements or the person finding the body. Further information can be found on local government websites.

Sometimes there is a need to register the birth at the same time, such as when a neonate has come straight from the Neonatal Intensive Care Unit (NICU) without going home, and the birth has never been registered. Registrars, if telephoned in advance, can make special arrangements to manage and support families in this situation. Occasionally members of staff may be required to support families registering a death (and occasionally a birth too) if there is no one able to help them do this.

The following are needed to register a death

- The child's full name.
- The child's date and place of birth and home address.
- The names of the parents, their home addresses and occupations.
- The date and place of death.
- The completed medical certificate of cause of death (death certificates are needed for administrative purposes; if there has been a post mortem, no medical certificate will be required).
- An NHS medical card (if possible).
- The child's birth certificate.
- If the death has been reported to the coroner or procurator fiscal, additional information will be required. Advice can be sought from your local coroner.
- Information about any benefits the family receives.

The person registering the death might be asked:

- Their relationship to the deceased child.
- Whether they were present at the time of death.
- Whether the child is to be cremated or buried.

Once the death has been registered the registrar will issue a Certificate for Burial or Cremation, known as the 'green form' (England and Wales), form 14 (Scotland) or form GRO 21 (Northern Ireland). This must be passed onto the funeral director in order for the funeral to take place. In addition a Certificate of Registration of Death, commonly called a death certificate (form BD8 in England and Wales or form 36 in Northern Ireland) is issued for social security purposes. Additional death certificates can also be bought at this time for a nominal sum. These will be needed by the executor or administrator when sorting out the deceased person's affairs (this is relevant for all those over 18).

In England and Wales the registrar may offer families *What to Do after Death*⁴³, which offers helpful advice and support.

Key resources

- *What to do after Death*
www.direct.gov.uk/en/Governmentcitizensandrights/Death/WhatToDoAfterADeath/Guide/index.htm
- Together for Short Lives (2012) *Verification of expected death in childhood: Guidance for children's palliative care services*.



43. www.direct.gov.uk/en/Governmentcitizensandrights/Death/WhatToDoAfterADeath/Guide/index.htm

Section 4

Care after death

4.1 Introduction

The death of a child can be a challenging and intensely emotional time both for families and for professionals.

Alongside the emotional and spiritual care of the family there are a number of practical and regulatory requirements that need to be considered. This section supports these practical, emotional and spiritual aspects of care, and offers guidance to support standardised local policy and practice.

Good practice points

- The choice of where to provide care after death may include a combination of options.
- There is no need to rush: go at the parents' pace, gently guiding them through the things that need to be done following the death of their child.

4.2 Care of the family

The most important priority when caring for a child and family is to provide skilled and sensitive communication, incorporating the cultural and spiritual dimensions of care and giving appropriate information at the right time. Honest and open communication is needed to balance the needs and wishes of the child and family with the practical tasks that need to be undertaken after death.

When a child dies it is hoped that support after death will already have been discussed through the development of an Advance Care Plan (ACP) and that staff will know where the child should be cared for. It may be that prior to death the child will have participated in the development of their own ACP and contributed to this decision. The child may be cared for on the ward, in the hospital mortuary, at the funeral director, or in a cool room at a children's hospice or in their own home. Care can also be provided by a combination of these options.

Parents should be informed that (within reason) whatever choice they make is an acceptable choice and that there are no right or wrong ways to care for their child. It is also acceptable for them to change their minds. In all cases professionals should endeavour where reasonably possible, within available resources, to support the wishes of the family in whatever they choose.

Reflective question

Consider how you would engage families in a conversation about the care they wish for their child after death. What are the important things you need to know and what does the family need to know?

4.3 Transferring a child to a funeral director or cool room

When a child has died, whether in hospital, at home or in a hospice you need to be aware of the family's wishes about where they would like their child cared for after death. It is important to remember that the child does not need to be moved or transferred immediately, however professionals will need to be aware of the condition of the body and the need to reduce body temperature while also attending to and meeting the needs of the family. It is best practice to aim to transfer the child within four to six hours of death to the mortuary, funeral directors or cool room.

Before a child is moved, verification of death must have taken place and it is good practice for certification of death to be completed by the attending medical practitioner who has been caring for the child at the end of life. The family do not need the completed forms to transfer their child. If moving a child before certification of death you will need permission from the coroner or procurator fiscal.

It is helpful to know how the family are travelling, and whether they need support. There are no laws to say a family cannot transport their child themselves if they wish, but it is advised that they nominate a driver. It is advisable to inform the local police when transferring a body.

From hospital

If the child is in hospital and the family are not intending to use the hospital mortuary it is important to be aware of regulations for passing through the mortuary. If they are transferring their child from the hospital mortuary it is likely that funeral directors will be best placed to facilitate this. In any circumstance, involving mortuary technicians and being aware of hospital policy is essential.

To home

If the child has died in a hospice or in hospital, the family may wish to take the child home for a period of time. A funeral director can organise this and will be able to facilitate travel. Sometimes families wish to go home with their child on the way to the funeral.

At home

Increasingly children at the end of life are being supported to die at home, with their family around them. Within the first few hours after death, an air-conditioning unit or cooling blanket at home is not necessary. However, if the family wish to keep the child at home for longer it is advisable to use one. Good practice is to aim for cooling of the body within four to six hours of death if the child is remaining at home. Radiators need to be turned off immediately. When using a portable air conditioning unit it is important to position the unit appropriately in the room and keep all windows closed. It is advisable to anticipate in advance the practical arrangements that will need to be made, such as accessibility for funeral directors in bringing a coffin or moving the body. All these practical considerations need to be discussed while maintaining safe practice and the principle of ensuring privacy and dignity for bereaved families and friends.

Hospice cool rooms

Most children's hospices today provide a cool room where children can be placed after they die, until their funeral⁴⁴ or before being transferred to a funeral director. Some hospices have more than one cool room, the second room being an adapted child's bedroom either with an air-conditioning system installed or with access to a portable conditioning unit. Where appropriate the air conditioning unit can also be used to support a child who has died to remain in their own home. (See section 4.5 for further information regarding children's hospice cool rooms).

4.4 Funeral directors

A good relationship with a funeral director can ensure the best support for families and staff. Working in partnership with a local funeral director is essential to support safe and effective care. The National Association of Funeral Directors provides good advice and lists funeral directors locally. Funeral directors should be licensed with the British Institute of Funeral Directors.

Some families think about funeral planning well in advance and may already have chosen a funeral director. If not, information about funeral directors should be provided when the family are ready. Booklets such as *Information about what to do after death* can be provided, along with information about bereavement support services.

Choices about burial, cremation and the funeral are a central part of grieving over the death of a child⁴⁵. There is no requirement to rush to have a funeral within days of death (unless for cultural, religious and/or personal reasons). It is important to remember this if the parents are uncertain about interment options.

Many funeral directors offer their basic services free of charge to families when a child dies under the age of 16. This generally includes costs of organising the funeral and the coffin, but there is likely to be a charge for cars, flowers and extra services. Funeral directors are able to discuss the various options available.

Funeral directors are highly skilled at what they do and can be contacted for any advice about the death of a child. They are able to offer support in many areas following the death of a child. The list below gives some idea of how they can help but is by no means exhaustive.

Funeral directors are able to:

- Collect the body and ensure that all necessary documents are completed.
- Liaise with the crematorium or cemetery to arrange the burial or cremation.
- Arrange the attendance of a minister or other qualified person.
- Transport the coffin and any floral tributes to the cemetery or crematorium.
- Make the necessary payment on the family's behalf.
- Remove the cremated remains from the crematorium until the final resting place is resolved.
- Advise on the care and condition of the body.
- Prepare the child for viewing (on request).
- Provide help in procuring headstones.

It should be noted that families may choose not to use a funeral director. Increasingly some families seek to make their own arrangements.

44. Children's Hospices UK (2010)

45. Dent A, Stewart A (2004)

4.5 Personal care of the child after death

Once an expected death has been verified, the family can be supported with decisions about personal care. Parents may wish to be involved in the personal care of their child, and this presents an opportunity to recognise cultural, spiritual and religious beliefs. Families also need to be sensitively informed of any changes to the child's body over the hours and days following death, particularly if they choose to use the cool room. Staff caring for the child and family should do so with dignity and respect, affording the family time and privacy.

Many parents choose to wash their child but may need guidance about how and what is appropriate. It is acceptable at this point, if parents have been asked and agree, to remove tubes or other medical equipment such as cannulas, nasogastric tubes, tracheostomies and gastrostomy buttons. Careful attention is needed when removing tubes. If the child has had them for some time, they may have become part of their features. If this is the case, then removing a tube may feel to the family like taking away part of their character. Some children and families have names for their tubes. Staff also need to be sensitive to whether the parents want to be present or not.

Care needs to be taken in relation to any residual fluid or leakage. It is good practice to aspirate first and be prepared with tissues and wipes. If leakage is excessive staff should take advice from the funeral director. It is not the responsibility of staff to undertake packing procedures to prevent leakage. If there is obvious leakage, lines can be left in.

After removing a gastrostomy, cannula or lines, the site should be covered with a waterproof dressing. It is common practice to remove gastrostomies and nasogastric tubes however staff need to be aware of local regulations and practice concerning the removal of tubes and lines. As medical technology becomes increasingly complex, staff may need to seek more specialist advice about the appropriate removal of lines and new devices in the future.

Care needs to be taken with the eyes and mouth – again support from the funeral director may be necessary. It is helpful to slightly incline the child (head and shoulders upwards) to avoid pooling in the upper body.

Often families will choose a favourite outfit and have a favourite toy to place with their child before the child is transferred to the cool room or collected by the funeral director.

Ongoing care of the body

Once death has occurred it is still essential for parents to retain control and choice in the care of their child. There are changes to the body that occur following death, and these can be frightening. It is vital to keep the family fully informed of all that is happening. Appropriate information needs to be shared gently at every stage.

Communication with the funeral director is important to help with monitoring the condition of the child's body. If at any stage the body deteriorates significantly, parents should be told that the child may need to be placed in a coffin or go to the funeral directors. Parents should be informed about such matters early on so that they are fully aware of what may happen.

Following the cessation of life known as somatic death, the process known as molecular death begins. This involves the progressive disintegration of the body. As the heart stops beating circulation ceases, and without the supply of oxygen the cells begin to die.

Algor mortis

After the heart stops beating the body immediately starts to become cold. This phase is known as algor mortis or the death chill. The outer body can chill within two hours but this may take up to eight hours. The centre of the body will take much longer.

The greater the surface area exposed, the more quickly the body will cool. Clothing and covers will insulate the body from cooling. The cooling process is important to slow down the disintegration process – something that may require sensitive explanation to families if they wish to wrap their child up in blankets. The family should be able to cuddle their child but it is important to balance this against the need to cool the body as soon as possible.

Changes to the eyes

The eyes may become sunken in appearance, which may be alarming for family and carers. If the child's eyes remain open after death, they cannot naturally be closed. After discussion with the family, the undertaker can be asked to put in 'stays' to keep the eyes closed.

Pallor and loss of skin elasticity

The skin will become pale due to the cessation of blood circulation and the denial of oxygen. It may also become dry. Moisturiser can be applied to the face and body, and *Vaseline*® or lip balm is helpful for keeping the lips moist. Some parents like to take on this responsibility, as it is something they are able to do for their child during this time. Skin can become fragile and there is a possibility of it breaking down, particularly if parents are stroking their child. It should be gently explained that stroking may damage the skin.

Lividity

Lividity or livor mortis is the dark purple discolouration of the skin that results from gravitational pooling of blood in the veins and capillary beds after circulation stops. Lividity is apparent within half an hour of death, as dull red patches or blotches start to appear. These patches may deepen in intensity and coalesce (join together) over the following hours to form large areas of reddish-purple discolouration. After about 10-12 hours the lividity becomes 'fixed'. Lividity is more noticeable in some bodies than others. In many instances you will find that the blood pools at the part of the

body that is in touch with the underlying surface. If the child is on their back, for example, it will pool along the back, the buttocks and at the back of the legs and head. However, it is generally more noticeable in the earlobes and fingernail beds.

Rigor mortis

Death usually leads to a short period in which the muscles are flaccid, followed by muscle stiffening known as rigor mortis. Rigor mortis can be apparent within three to four hours of death but will disappear 36-48 hours after death. This is important in regards to timing when parents' request their child is dressed in particular clothes.

Bleeding

With the cessation of blood flow, agents normally used to arrest bleeding will not work. The only way to arrest bleeding is to block it, by suction or packing the nose, for example. If the child or young person is bleeding any proposal to block the blood flow should be discussed with the family. The funeral director should be consulted for advice if bleeding persists and becomes a problem. Using dark towels and bedding will help to make the bleeding less obvious. Remember to use universal precautions related to the handling of blood. If bleeding persists and this becomes a safety risk, it may be appropriate for the child to be transferred to the funeral directors.

Seepage or leakage of bodily fluids

This can occur at any time after a child has died. Urinary and faecal leakage are common, and to deal with this a pad can be placed under the child and checked regularly. If there is leakage from any other orifice especially on movement of the body (the mouth or nose, for example) then suction should be available. The equipment associated with this can be placed unobtrusively under the bed. Remember to use universal precautions when dealing with any body fluids. It is helpful to ensure you have a supply of pads, wet wipes, flannels and clean linen as appropriate. If there is seepage the child will need to be checked more frequently.

Prosthesis

Some children may be fitted with some kind of prosthesis at the time of death, e.g. nasogastric tube, central lines, tracheostomy tubes. If these are to be removed, it is vital to discuss this with parents and seek their permission.

Embalming

This is the process of temporarily preserving the body to avoid deterioration. It must be carried out at the funeral director's premises and there is normally a basic cost. Embalming cannot take place until the coroner has completed enquiries and the death is registered. All organisations need to adhere to embalming rules, and the law requires facilities to be fully equipped to perform the procedure. Funeral directors should be members of the Society of Allied Independent Funeral Directors (SAIF) or Members of the British Institute of Embalmers (MBIE).

There are different types of embalming for which the funeral director can provide information. Arterial embalming, the injection of embalming chemicals into an artery and draining through a vein, is the most common. It is not necessary or required to embalm children unless advised by the funeral director or requested by the family. However, many cultures use the embalming process and for some it may have religious meaning. If embalming is seen to be appropriate or requested, the child can be transferred to the funeral director then returned to the cool room. It is sometimes advisable to embalm following a post mortem.

Embalming is likely to be appropriate where there may be additional or accelerated changes to the body because of chemotherapy and/or other treatments, or where disease has adversely affected the condition of the body at the time of death. It is wise to anticipate when a body may break down more quickly and important to note that the more a body is moved the more quickly it will deteriorate.

If a family request a Green Burial this will not be permitted if the child has been embalmed. For further information see the Natural Death Centre.

Good practice point

- It is important to be aware of the changes that are likely to occur to the body following death, so that you are able to inform the family sensitively about these.

Reflective question

Reflect on your experience of caring for a child following death and how you supported the family in discussing any changes to the body. If this is not something you have yet experienced, it might be helpful to consider shadowing and learning from a colleague.

4.6 Cool rooms in children's hospices

Definitions

A 'children's hospice cool room' is a designated, quiet room where children and young people may be placed after they die for a few days or until their funeral, and where the family can spend time with their child.

A 'cool room facility' refers to the use of a portable air conditioning unit that can be installed in a room either in the hospice or within the family's own home, where the child may stay for a few days following death.

The development and practice of children's hospice cool rooms

The practice of cool rooms was first introduced by the founders of Helen House in the 1980s⁴⁶. Initial thinking was based around a single-purpose room, designed to look as much like an ordinary room as possible, with ordinary windows but also the capacity to cool the room as required. An additional room would be furnished as a simple sitting room⁴⁷, with the idea that *"between times the room can be used by anyone seeking a comfortable, intimate place for reflection or quiet conversation"*⁴⁸.

In practice, children's hospice cool rooms are also referred to by an appropriately compassionate name (the star room, for example, or the angel, butterfly or rainbow room). They are usually complemented by an adjoining family suite, where the family can stay and spend time with their child after death.

Emerging evidence in caring for the child after death⁴⁹ suggests that families who use cool rooms can find it immensely valuable. However research is limited and the full impact on families of using cool room facilities to support care after death is under researched. Moreover, there is little material available to support best practice in care and service provision.

Because of this lack of official guidance there have been significant variations in the use of cool rooms by children's hospices, including different lengths of stay, varying room temperatures and differences in the type of activities that may take place in a cool room. Although a number of practices are guided by local protocols and advice from professionals working in the locality, such differences continue to raise much debate.

This guidance aims to provide guidance by collating experiences of practice from across the sector in order to support principles of care after death and when using a cool room.

Accessibility of the cool room

Access to a cool room is a key consideration for children's hospices and local services. Currently there is evidence of a wide variety of practice.⁵⁰ Addressing the issue of access to support the use of the cool room, and developing policy at local level in collaboration with other services is highly recommended.

When drawing up local policy, children's hospice professionals are advised to talk to a wide range of professionals, including local coroners, the children's community team and CLIC nurses, the neonatal unit, the local accident and emergency department and the wider children's palliative care network in the region. A joint strategy and policy involving all services and agencies should be developed to support equality of access for all children and families that may benefit from the service.

Ideally a cool room should be accessible to all children with life-limiting or life-threatening conditions in a hospice catchment area. All hospices need to consider how they manage this, and whether use of the cool room may be extended to support children in other areas of practice, including those children who initially may have not met hospice service criteria prior to death.

Considerations for extending use of the cool room

- Children and young people with a life-threatening or life-limiting condition not already known to the service.
- Stillbirths and neonatal deaths.
- Transfer of children from other hospital units, i.e. paediatric intensive care, cardiac or high dependency units.
- Sudden infant death.
- Death of children from accidents.
- Care of children following organ donation.

Extending the use of the cool room offers support to a wider group of families through the initial days of bereavement. It is essential to widen access where possible, supporting equal opportunities for children and families. In developing the use of the cool room there are a number of practical issues to consider.

46. Worswick J (2002)

47. Ibid p101

48. Ibid p102

49. Forrester L (2008)

50. Children's Hospices UK (2010)



The issues that will need to be considered include:

- The resources available on a practical level within the children's hospice service.
- The training and competence of staff.
- The differing needs of families when a child has died from an acute illness, or as a result of a road accident or suicide, for example.
- The wider multi-professional team and the qualifications, skills and experience of the family support or bereavement support team.
- The training and education of staff to ensure they have the ongoing skills to meet the needs of families.
- The support from and relationship with the funeral director.
- The involvement of the coroner (or procurator fiscal in Scotland) and the local Child Death Overview Panel (CDOP) in England and Wales. It may be that if a post mortem is required (in particular a forensic post mortem) the child will not be released for a number of days. The service would need to consider the appropriateness of transfer to a cool room if the child had been dead for some time.
- If the child has been in a road accident or other serious accident, the degree to which the body has been mutilated will have some bearing on whether the cool room is appropriate for all concerned – both family and staff.

Once a local policy and procedures have been agreed, the details of these need to be shared widely among all professionals and partner agencies e.g. acute hospital settings. This will help to raise awareness about the local cool room facility, and to build understanding of the choices available to families.

Setting up the cool room

The cool room should be carefully prepared, whether in the family home or the hospice. This can be undertaken prior to death if appropriate. The room will need to be monitored throughout the length of stay to ensure adherence to instructions and regulations and keep the body safe. All staff are encouraged to follow advice from national guidelines, local policy and manufacturer's instructions for equipment such as air-conditioning units.

When setting up the cool room you will need to consider:

The temperature of the room

Most in-built units have a thermostat and will be pre-set to the required temperature. Once the unit has been switched on, the room must be constantly monitored. The new guidance from the Department of Health suggests that the room temperature should be kept below 12°C, and preferably within the 4-8°C range⁵¹. It is advised that this may be too cold for families to tolerate but the key principle is to reduce the temperature of the child's body as quickly as possible, within reason.

A balanced view needs to be taken between preserving the body and the needs of families spending time in the cool room. Some hospices have cold slabs, cold blankets or gel packs in order to support the cooling of the body. Care is required with all cooling procedures to ensure equipment is used correctly to avoid any unnecessary damage to the body (e.g. Gel packs placed directly on the child's body will burn the skin and towels and blankets need to be used as a shield).

There are no strict guidelines for the number of hours that a child's body can be kept in a room at home before a portable air-conditioning unit needs to be introduced. But if the family want the child to stay longer than 24 hours an air conditioning unit will certainly be needed. Again it requires sensitive professional judgement to respect the family's dignity and their role in caring for the body while recognising the need to reduce body temperature to preserve the condition of the body.

51. National End of Life Care Programme (2011)

Whichever system is in place there are a number of other considerations that you should be aware of to maintain the temperature of the body:

- Surface area of the body.
- Condition of the body at death.
- The size of the room (and therefore the size of the area in which temperature needs to be maintained).
- Windows (which should be shut) and curtains drawn in direct sunlight and/or for privacy.
- Whether there is an adjoining room (which should be kept closed as much as possible, although you should be aware of how often it is likely to be opened by family and friends). You may need to explain carefully and sensitively to the family that it is important to close the door to maintain room temperature.
- The room needs to be free of insects, particularly flies, in summer months.
- To be aware of and know how to manage any condensation.
- It is advisable to wear warm clothes when entering or carrying out any procedures in the cool room. By anticipating and preparing well for the task to be completed, staff will spend as little time in the room as possible.

If the family are in the cool room, care will need to be taken over the length of time they spend there, balancing professional judgement with the needs of the family. A good marker is recognising how quickly a member of staff becomes cold when working in the room. It is important to explain sensitively to the family that spending long periods of time in the cold room is not appropriate or safe.

Bed

The choice of bed is important, not only because of the need to take the family's preference into account but also in relation to optimising care of the body after death, before being placed in the coffin. The main bed will need to have the facility to go up and down to support care of the body and comply with moving and handling regulations for staff. If you are caring for a baby, a Moses basket can be placed on the bed.

Seating

Families may still wish to cuddle their child for periods of time following death, so a comfortable, well supported chair is advisable.

Bedding

The choice of bedclothes and decoration of the room are both important for families.

Washing and clothing

It is advisable to think about washing facilities in the cool room and the placement of all the equipment that may be needed to help manage care of the body and maintain hygiene. It may be that families require washing facilities associated with ritual hand washing.

Toys and pictures

Many families wish to take favourite toys, pictures and other objects into the room. The room can be decorated with such objects to meet the individual needs and wishes of each family. Notice boards can be placed on the wall so that pictures drawn in memory can be presented along with cards, photographs and other favourite pieces.

Lighting

The lighting can be as the family choose, although it is advisable not to have glaring, bright lights that can generate a lot of heat. Dim lighting via table lamps is best. If candles are used, everyone should be aware of the risks associated with naked flames. Candles should be used sparingly and with caution to minimise risk. Many rooms have the capacity to light one small candle, which for many families can provide a sense of spiritual meaning or simply help to create a calming, peaceful atmosphere.

Aromatherapy

The use of essential oils can be beneficial both from a therapeutic perspective and in masking any unpleasant odours.



Music

Music is often played in the cool room, either the child's favourite music or something calming to help provide comfort in the silence. Occasionally families may request favourite stories or DVDs.

Staff should endeavour to respond as best they can to family requests around music, lighting and decoration of the room. Enabling the whole family to choose and make simple decisions at this stage means siblings can also be involved in decisions.

Moving and handling

The importance of moving and handling policy and procedures is well recognised. It is equally central to care after death in a cool room environment⁵². Key areas to consider include the moving of the child into the room; the type of bed and its ability to go up and down; how the number of times a child is moved can be reduced, minimising how much time staff spend in the room, and ensuring physical safety for staff.

Infection prevention and control issues

It is essential that all care adheres to infection prevention policy and standards and guidance and advice are sought from the funeral director. Precautions must be taken during all procedures. Care in relation to flies and other insects needs to be given careful attention. In some cases a mosquito net may be used, with careful explanation to the family. Staff will need to seek advice on caring for a child who has recently had radioactive treatments.

Length of time in the cool room

The length of time a child's body may lie in a cool room has been and continues to be the subject of significant debate, and there is so much variation in practice, it is difficult to reach consensus. Among the issues up for debate are the widely differing needs and wishes of families, the increasing time needed for planning cremations and funerals, the care of staff and concern surrounding the deterioration of the body. Underpinning all of this discussion is an acknowledged need for research to develop the evidence base that is currently lacking to support practice in this area. Until such research is carried out, this guidance offers principles of good practice and practical guidance that needs to be balanced at all times with the needs and wishes of the family:

- Good, effective communication and a collaborative approach are essential. There needs to be dialogue between staff, the family and the funeral director.
- Supporting families with decision making should embrace sensitive but open communication at every stage. This includes taking a 'preventative approach' to avoid any surprises – not waiting until the body has deteriorated, for example, before telling the family what needs to happen when deterioration occurs. In this way families can be prepared for their child needing to be placed in a coffin or moved to the funeral director's premises as appropriate.
- Gently but firmly encourage families to recognise the need to plan for the funeral. Most families want to know what comes next after the death of their child, and this is an important opportunity to explain all that needs to happen so that they are not left for days without engaging in necessary discussion.
- Actively engage with the community to understand what support networks are available to the family. This is essential for encouraging and supporting the family in returning home.
- Care of staff should be paramount at all times, ensuring that they have the training, supervision and support they need. All aspects of care for the child and family need to be defined and supported through local policy and procedures.
- Staff need to know when and how to seek further advice and additional support if they feel that families are not coping. Careful assessment of a family's coping strategies is important when planning ongoing care.

52. Pike A (2004)

4.7 Placing the child in the coffin

Placing the child in a coffin can be a poignant moment in the grieving process. It needs careful planning and support from the funeral director. The condition of the child's body will determine when to place a child in a coffin, and continued sensitive communication with the family will enable them to make informed decisions in relation to care of their child. All moving and handling practices should be adhered to while maintaining the utmost respect and dignity for the child and family. It should be up to the family whether or not they want to be involved in this.

Placing the lid on the coffin can represent another significant moment, and the family should be asked when they are ready for the lid to be sealed, at the same time recognising the professional advice from the funeral directors.

4.8 Further support

Once the immediate preparation of the child's body has been completed either at the funeral directors, at home or in the cool room, staff need to turn their attention to supporting the family and helping them navigate their way through the next few days. For parents it is important to remember that the basic need to care for and comfort their child may not immediately go away. In the days following death, parents, siblings and the wider family will experience a variety of emotions. All families respond and cope differently, drawing on their values and beliefs. Families often need to spend time with the child to draw comfort and try to come to terms with all that has happened. Staff need to be prepared to answer any questions and to direct families to further support where appropriate.

The family will need to focus on funeral planning and arrangements for returning home if the child has been cared for in another setting. The family may need guidance and support in managing this. It is important to go at the family's pace, with sensitive communication and gentle encouragement to consider the planning that needs to be undertaken.

Initial discussions about bereavement support can take place at this time. You can make an early assessment of the family's support and coping strategies, whether they have family and friends around them and what support is available in the community.

Siblings

It may be that siblings were not with the child at the time of death, and families may need support in informing brothers and sisters with what has happened and supporting them appropriately. It is important to go at the family's pace and to read their behaviour and responses to decide what feels right. As with adults, siblings will show a diverse range of reactions and grief will affect children in multiple ways depending on their age, experience and relationships within the family. Honest and meaningful communication is important. Letting siblings know what is going on and actively involving them in what is happening can be very supportive and can help them to cope better. All conversations should take account of their individual needs, recognising their developmental stage and capacity to understand. Parents should know about any communication, and this should be in keeping with their wishes for sharing information. School, friends and the wider family continue to play an important role for siblings. For many they will be able to make their own decisions about how much they want to be involved. There are a variety of resources and information available for supporting siblings – see section 7.

Grandparents

It is increasingly the case that grandparents play a significant role in the care of the child who has died, occasionally being the main carer if a parent is at work. Grandparents are likely to feel grief that will equally impact on their life. In addition they carry the added dimension of supporting their own son or daughter through their own grief.⁵³ describes the complex questions and challenges faced by grandparents in trying to make sense of all that has happened. Support for grandparents is therefore important, and staff will need to be guided by them as to any support they may need.

53. Young C & Dowling T (2012)

4.9 Moving the body and repatriation

If a body is to be moved out of the country, the coroner must be notified. Only a coroner or procurator fiscal can give permission to move the child's body out of the country. When the child's death is registered, parents/carers will need to buy at least two certified copies of the death certificate in order to move the body out of the country (some consulates and embassies require more). Repatriation is increasingly common and funeral directors can give detailed advice on this. There is no restriction on moving bodies within England and Wales, although there are practical issues to consider if moving a body from one district to another.

When moving a body out of the country the family will need to obtain an 'out of country' form from the registrar or coroner. This is a form of notice to a coroner of intention to remove a body. The form must be handed to the coroner with the certificate for burial or cremation already issued. The coroner will acknowledge receipt of the notice and let the family know when the body can be moved. This is usually four clear days from when the notice was received, although in urgent situations it may be possible to speed things up.

Reflective question

Consider how you would support a family with the planning and preparation of registering the death of their child, and all that this would involve.

4.10 Cremations

Cremation is the act of disposing of a body by burning the remains. It is one of the oldest traditions surrounding death, used by many faiths and cultures. Ashes can be scattered in a sacred or significant place for the individual and/or their family. Cremations in England and Wales are governed by the Cremation Regulations (2008). The law governing cremation in Northern Ireland is the Cremation (Belfast) Regulations (Northern Ireland) (1961), and Scotland, the Cremation (Scotland) Regulations (2003).

Regulations around cremation remain complex and will change alongside the new guidance around death certification processes in 2014.

The procedures required for cremation of children are the same as for adults, and the process involved is similar across the UK.

Completion of cremation forms

When a child dies staff are likely to encounter a number of forms, the most common of which are:

- An application for cremation form signed by the next of kin or executor.
- Two cremation forms: A medical certificate completed by the medical practitioner who was treating the child during their last illness, and a confirmatory medical certificate completed by a second medical practitioner registered for at least five years who cannot be a partner or work colleague of the medical practitioner completing the first form.
- A certificate signed by the medical referee at the crematorium to authorise cremation. The medical referee has power to refuse cremation, require a postmortem examination or refer the matter to the coroner or procurator fiscal.

Disposal of ashes

Ashes may be scattered or buried at the crematorium, either by crematorium staff or by relatives and friends. Ashes can also be buried in a churchyard or cemetery, often with a short service.

Ashes can generally be scattered anywhere including rivers, with permission, but if you wish to scatter ashes on private land you should get consent from the landowner. Although UK law allows ashes to be taken abroad, many countries have strict rules on the importation of ashes and it is important to check before travelling.

When a neonate or baby is cremated there may be very little or no ashes remaining due to the size of the baby or the crematorium equipment – it is best to take advice from a funeral director and crematorium.

4.11 Burial

A burial can take place in a churchyard, a local authority cemetery or a private cemetery. Burials can also take place on private land, or at a woodland site, although in most cases this will have to be approved by the authority responsible for the site. Whether to bury the child or not (also known as interment) may be determined by faith and cultural tradition. Cost may also be a significant factor, as burials can be very expensive. For children some of these costs may be waived but it is always best to check with the funeral director and other organisations involved.

In theory anyone living in a parish has the right to be buried in the parish churchyard or to be buried next to relatives. But in practice many churchyards are full and may only be open to the interment of ashes. Cemeteries are run by local authorities or private companies, and most welcome direct enquiries from individuals. In the case of grave plots some families may choose a plot that can be used again in the future. Every cemetery will have its own regulations and directions for support.

Families are increasingly arranging funerals that take account of environmental concerns related to factors such as choice of coffin, flowers and the method and location of burial. There is good advice on eco, woodland and green burial grounds from the Natural Death Centre. It will also provide direction as to the regulatory requirements for burials. Further advice around death and burials can be found on local authority websites or by referring to the Which guide to *What to do when someone dies* (2010).⁵⁴

Key resources

- National Association of Funeral Directors www.nafd.org.uk
- Ministry of Justice: Cremations and Burials www.justice.gov.uk/coroners-burial-cremation/cremation
- The Natural Death Centre www.naturaldeath.org.uk

Good practice points

- It is really useful to have a separate form listing all the practical and regulatory requirements that need to be completed at the time of death. (see *Appendix 3*).
- Check that all staff are aware of and competent in dealing with the regulatory requirements in relation to the death of a child.

54. Wadey A (2010)

Section 5 Bereavement support

5.1 Introduction

Guiding families through bereavement does not necessarily require a specialist practitioner but all staff should be trained to support bereaved families and should have excellent communication skills.

Assessment of the family needs may determine that support from family, friends and other community networks is sufficient.

As well as caring for the family in the days leading up to the funeral, whether at home or within the hospice setting, it is important to ensure that support networks are in place for the first few weeks and months following the death of a child. Each organisation will offer a different model of bereavement support, depending on its location and resources. Those organisations with an extended family support or bereavement team may be able to offer regular post-bereavement sessions. Others may be constrained by having to cover an extensive geographical area, and may lean towards promoting ongoing support for families within their own community. Whichever model each organisation supports, there are a number of key principles and basic guidance to follow, based on good practice in bereavement care.

There is a wealth of literature on dying and bereavement, and it is not the intention of this guidance to cover this area in detail. Our aim is to provide an overview of current thinking, covering the basics of what is needed to support families through bereavement assessment and to signpost staff to more comprehensive resources and further support.

Current debate in relation to bereavement suggests a shift in thinking from solely recognising the influence and impact of risk factors, to incorporating the emerging evidence on individual coping and resilience. There is a strong debate that counselling support is not effective for everyone, and that many people can and should draw on their own

inner resources combined with those of family, friends and community to help them manage their grief. Bereavement support is not a 'one size fits all' and should be offered in response to individually assessed need.

New thinking recognises that an individual's response to loss will determine their capacity to cope with grief. This new understanding is helping to guide and inform an integrated approach to supporting bereaved families in which careful attention is paid to assessing their risk factors and individual coping styles. The *Help the Hospices Guidance for Bereavement Needs Assessment in Palliative Care*⁵⁵ is a useful and comprehensive resource.

The effect on different family members following the death of a child is likely to be varied. Where needed, it is an important part of good follow-up care to ensure that grandparents, siblings, estranged partners and other significant people are offered or directed towards relevant support.

55. Relf M, Machin L and Archer N (2010)



5.2 Immediate support

The initial hours following death can reveal an array of emotions, creating a sense of confusion that can make it difficult to make any decisions. In contrast, some individuals can immerse themselves in the practicalities that need to be completed. It is important just to be with families at this time, to be prepared to answer their questions and provide immediate support.

5.3 Collecting memories

Collecting memories that are meaningful can help to provide a 'life story' of the child. This can be undertaken before or after death, as appropriate. It can be very supportive to talk to the child and ask them what they would like in a memory box.

For the families of neonates, collecting memories can be particularly important because life has been short and relationships may have been mainly with professionals.

There are a growing number of suggestions to support families in creating memories:

- A small lock of hair from the back of the head.
- Handprints and footprints.
- Hand and foot sculptures.
- Decorating plates or other objects.
- Keepsake jewellery.
- Memory boxes.
- Ribbons.
- A book of remembrance – a formal record that is often held at the hospice to record the name of each child that has died.
- A more informal book of memories in which family, friends and hospice staff can capture precious moments with an individual child.
- A garden of remembrance – a place where a number of different objects and symbols can be used as an image of remembrance (e.g. pathways, stones, trees and water features).

5.4 Preparation for the funeral or service

Planning the funeral is a task that many families immerse themselves in, to ensure that the service captures the very essence of their child and the memories they hold. In funeral planning it is very important to involve the family support team, chaplain, funeral director and other agencies as early as possible – and preferably prior to death. It is likely that if children have the capacity and understanding, they will want to be involved in planning their own funeral. Siblings may gain a considerable amount by participating in funeral planning.

There are many different and special ways to remember a child within a service, whether religious or non-religious. There will be a number of people that can help with funeral planning, and the family should be encouraged to draw on the resources of their local community.

The options available for coffins, cars, readings and music are many, and the variety of choices can make it difficult to decide how to proceed. The family should be able to agree upon either cremation or burial, however, and other areas of planning are listed below. This is by no means an exhaustive list, and there are many other resources that may be helpful in guiding staff and families.

Things to consider in planning a service

- Type and decoration of the coffin or urn.
- Are the family going to decorate the coffin or urn?
- When to place the child in the coffin.
- Service sheet – with details of poems, readings, music.
- Care of siblings.
- Who will read?
- Flowers, gifts and donations.
- Clothing for the child.
- Releasing of balloons or lanterns.
- Lighting of candles.
- Gathering after the service.

5.5 Ongoing support

Following the funeral the family can be asked if they would like further contact. It is good practice to offer a follow up visit, and this may be a joint visit from the organisations who were involved in the child's care. Discussing openly what type of support can be offered and by whom can enable the family to feel an element of control in decision making. It may also be helpful to offer other sources of support in the community.

Siblings, grandparents and friends will experience similar pathways of grief and will also require ongoing support. Grief will change over time and different events, anniversaries and other significant moments will have an impact on the experience of grieving.

Many children's hospice services and children's hospitals offer programmes for ongoing support including sibling days, grandparents' days and annual remembrance days. All of these events continue to provide recognition of the bereaved family and an opportunity for them to remember and celebrate their child.

Reflective question

Where would you look for sources of community support for a bereaved family?

Key resources

- *Guidance for Bereavement Needs Assessment in Palliative Care* (Relf et al 2010)⁵⁶
- *Parents and Bereavement* (Young & Dowling 2012)⁵⁷
- *A Guide to developing good practice in childhood bereavement services* (The Childhood Bereavement Network, 2006)⁵⁸

56. Relf M, Machin L and Archer N (2010)

57. Young C & Dowling T (2012)

58. The Childhood Bereavement Network (2006)

5.6 Further resources

The following websites provide useful basic information plus lists of books and other more detailed resources for families, carers and professionals.

Bliss gives vital support and care to premature babies in the UK. They are devoted to improving the lives of babies born too soon, too small or too sick.

www.bliss.org.uk

The Childhood Bereavement Network (CBN) is the hub for those working with bereaved children, young people and their families across the UK.

www.childhoodbereavementnetwork.org.uk

The Child Bereavement Charity a leading national organisation that supports families and provides training to professionals across the entire spectrum of child bereavement.

www.childbereavement.org.uk

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

The Compassionate Friends support bereaved parents and their families.

www.tcf.org.uk

CRUSE is a national charity set up to offer free, confidential help to bereaved people. It produces booklets on coping with grief that you can buy online.

www.crusebereavementcare.org.uk

The Foundation for the Study of Infant Deaths is a leading baby charity aiming to prevent unexpected deaths in infancy and promote infant health.

www.fsid.org.uk

Grandparents' Association Works to improve the lives of children by working with and for all grandparents.

www.grandparents-association.org.uk

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

www.winstonswish.org.uk

Section 6 Staff support and supervision



6.1 Introduction

It is well documented that working with dying people is very demanding.

The loss and sense of helplessness when a patient dies can also be experienced by those caring for them. Senior managers have a duty of care that carries with it a strong sense of responsibility to ensure that staff are well supported. Informal support within the team as well as more formal supervision can help individual practitioners to reflect on their work and deal with their own feelings of grief and loss. Staff need to be given time to recognise their own ways of responding to the death of a child, to their own experiences of grief and loss, and what coping strategies they might use.

Staff also need support to recognise and reflect on their values and beliefs and those of others, so that they are equipped to respond openly to a family's faith and cultural needs. With this kind of support they will be less likely to find their own beliefs and responses intruding into the grief experience of a family they are caring for.

Supervision should be available to help with personal reflection, either individually or as a group. Group reflection can be difficult with very personal feelings, but it can also enhance team working and reduce any sense of isolation. It should be conducted in such a way as to maximise learning and identify any changes in practice that will benefit families.

Organisations need to look out for signs of stress in staff and take responsibility for providing teams with adequate training, supervision and general support. Training that addresses professional therapeutic relationships alongside the importance of professional boundaries is essential.

Mentoring new staff, especially those new to working in children's palliative care, should be a priority. Staff should be given the opportunity to shadow an experienced colleague as he or she supports a child and family through end of life and death.

It is good practice to offer a de-brief session following the death of a child. This gives dedicated time for reflection and learning. You need to be aware that there may be occasions when taking a particularly difficult decision near the end of a child's life can create divisions within a family, or in the staff group. When this occurs it can be very beneficial to offer staff the opportunity to hold a multi-disciplinary meeting. Helping staff to reflect in this way will help to ensure that families always receive the best care. It will also ensure that staff are heard and supported when struggling with difficult and emotive issues.

Good practice point

- All organisations should carry out a thorough clinical and psychosocial debrief to help ensure that lessons are learnt in order to develop and improve practice.

Reflective question

How can you effectively promote and use supervision individually and within your organisation?

6.2 Training and professional development

A central element of good practice is supporting staff through training to develop their knowledge, competence and confidence. It is hoped that this guidance provides a framework of learning that will be used to support professionals in developing the knowledge and skills needed to care for a child following death.

All staff should receive regular training and have frequent opportunities to develop their skills in practice. Training is particularly important in relation to communication with families, end of life care and supporting bereaved families. It is important to cover these areas at induction and to provide opportunities for junior and inexperienced staff to shadow and learn from experienced colleagues. In addition training courses should be provided and opportunities for role development offered, in the verification of death, for example.

Staff need to be well trained and professionally competent to be able to achieve high standards in the delivery of care, and this is equally important in care after death. Competence is not only about achieving a standard of care or achieving a particular task. It is also about working consistently within a model of learning that recognises a holistic experience of care. Three elements are key to this: the behaviour, attributes or tasks required to achieve competence; the operational means to achieve competence; and the means to make an assessment of staff performance that is measurable, in order to ensure a standard of competence. Staff need to be able not only to deliver high quality care from a strong professional knowledge base but also to reflect on the care given in such a way as to develop a thorough, holistic approach to practice.

Key resources

- End of Life Care for All (e ELCA): E-learning to enhance education and training for end of life care. www.e-lfh.org.uk/projects/e-elca/launch
- Help the Hospices education and training www.helpthehospices.org.uk/our-services/education-training
- Train to Care: Flexible training and consultancy from Together for Short Lives www.togetherforshortlives.org.uk



Section 7 Resources and Appendices

7.1 Further resources

Care Quality Commission
www.cqc.org.uk

Department of Health (England)
www.dh.gov.uk

Department of Health, Social Services
and Public Safety (Northern Ireland)
www.dhsspsni.gov.uk

Dying Matters Coalition
www.dyingmatters.org

European Association for Palliative Care (EAPC)
www.eapcnet.eu

Good Life, Good Death, Good Grief
www.goodlifedeathgrief.org.uk

Healthcare Improvement Scotland
www.healthcareimprovementscotland.org

Living and Dying Well (Scotland)
www.scotland.gov.uk

National Assembly of Wales
www.assemblywales.org

National Council for Palliative Care
www.ncpc.org.uk

National End of Life Care Programme (NEoLCP)
www.endoflifecareforadults.nhs.uk

Regulation and Quality Improvement Authority
(Northern Ireland)
www.rqia.org.uk

Scottish Grief and Bereavement Hub
www.griefhub.org.uk

Healthcare Inspectorate Wales
www.hiw.org.uk

The Maypole Project
www.themaypoleproject.co.uk

The National Association of Funeral Directors
www.nafd.org.uk

The Natural Death Centre
www.naturaldeath.org.uk



7.2 Glossary of terms

Certificate for Cremation or Burial

The certificate issued by the registrar once the death has been registered, to allow the body to be cremated or buried.

Child Death Overview Panel (CDOP)

Responsible for reviewing information on all child deaths and are accountable to Local Safeguarding Children's Boards (LSCBs).

Coroner

A coroner is responsible for investigating and determining the cause of death, particularly unexpected or suspicious deaths.

Death certificate

The actual death certificate is the entry in the death register; what the registrar issues is certified copies of this entry, signed by the registrar (commonly called the death certificate).

Designated paediatrician

The doctor assigned to respond to an unexpected death.

Local Safeguarding Children's Boards (LSCBs)

Developed following *Every Child Matters*, each Board is responsible for improving local safeguarding and ensuring that there is a strategic quality assurance framework to safeguard children.

Notification

Official reporting of death to regulatory organisations.

MCCD

Medical Certificate of Cause of Death, completed by a Medical Practitioner.

Procurator Fiscal

Responsible for investigating and determining the cause of death in Scotland (equivalent to the coroner).

The Scottish Commission for the Regulation of Care

The regulator of quality of care in Scotland.

The Regulation and Quality Improvement Authority

The regulator of quality of care in Northern Ireland.

The Care Quality Commission

The regulator of quality of care in England

Healthcare Inspectorate Wales

The regulator of quality of care in Wales.

Rapid response team

A group of key professionals who come together to respond to the unexpected death of a child.

Registration of death

The official entry of death on the death register.

Verification of death

The initial confirmation of death.

7.3 References

1. ACT (2004) *Integrated Multi-agency Care Pathways for Children with Life-threatening and Life-limiting Conditions*. ACT, Bristol
2. ACT (2011) *Basic Symptom Control in Paediatric Palliative Care (Eighth edition)*. ACT, Bristol
3. APPM (2012) *The Association of Paediatric Palliative Medicine Master Formulary*. www.appm.org.uk
4. Buckman R (1992) *How to Break Bad News: A Guide for Health Care Professionals*. The Johns Hopkins University Press. Maryland
5. Cancer Services Collaborative Improvement Partnership (2004) *Improving communication in cancer care*
6. Children's Hospices UK (2010) *Children's Hospice Care from March 2009 to September 2010: A report based on visits to all children's hospice services in the UK*. Children's Hospices UK, Bristol
7. Coad J (2008) 'Bringing together child health and social care provision: challenges and opportunities for multi-agency working' In Morris K, ed. *Social work and multi-agency working. Making a difference*. (pp. 29-46)
8. Crown Office and Procurator Fiscal Service (2008) *Death and the Procurator Fiscal*. Crown Office, Scotland
9. Department for Children Schools and Families (DCSF) (2010) *Working Together to Safeguard Children*
10. Dent A, Stewart A (2004) *Sudden Death in Childhood: Support for the Bereaved Family*. Butterworth-Heinemann, London
11. Department of Health (2008) *End of Life Care Strategy*. DH London
12. Department of Health (2010) *Improving the Process of Death Certification in England and Wales: Overview of programme*. DH, London
13. DHSSPSNI (2006) *Post Mortem Examinations – A code of good practice*. DHSSPSNI, Belfast
14. DHSSPSNI (2011) *Consultation paper on the review of death certification in Northern Ireland*, DHSSPSNI, Belfast
15. Duke S, Baily C (2008) 'Communication: patient and family'. In, Payne, Sheila, Seymour, Jane and Ingleton, Christine (eds.) *Palliative Care Nursing: Principles and Evidence for Practice*. OUP, Berkshire, (pp121-144)
16. Forrester L (2008) 'Bereaved parents' experiences of the use of 'cold bedrooms' following the death of their child'. *International Journal of Palliative Nursing* 14:12 pp578-585
17. Fraser et al (2011) *Life-Limiting Conditions in Children in the UK*, Division of Epidemiology, University of Leeds
18. FSID (2010) *The child death review. A guide for parents and carers*. FSID
19. Gibson F, Aldiss S, Horstman M, Kumpunen S, Richardson A, (2010). 'Children and young people's experiences of cancer care: a qualitative research study using participatory methods'. *International Journal of Nursing Studies*, 47(11):1397-1407
20. General Medical Council (GMC) (2010) *Treatment and Care Towards the End of Life: Good practice in decision making*. GMC, London
21. Goldman A, Hain R, Liben S (2012) *Oxford Textbook of Palliative Care for Children (2nd Edition)* OUP, Oxford
22. Hallam et al (1999) *Beyond the Body: Death and social identity*. Routledge, London (pp87-103)

23. Kirk S, Glendinning C. (2002) 'Supporting 'expert' parents: professional support and families caring for a child with complex health care needs in the community'. *International Journal of Nursing Studies*, 39(6):625-35
24. National End of Life Care Programme (2011) *Guidance for staff responsible for care after death (last offices)* <http://www.endoflifecareforadults.nhs.uk/publications/guidance-for-staff-responsible-for-care-after-death>
25. National End of Life Care Programme (2011) *When a person dies: Guidance for professionals on developing bereavement services* <http://www.endoflifecareforadults.nhs.uk/publications/when-a-person-dies>
26. National End of Life Care Programme (2012) *Advance Care planning: Support Sheet 3*. <http://www.endoflifecareforadults.nhs.uk/publications/rtssupportsheet3>
27. National End of Life Programme (2012) *Principles of good communication: Support Sheet 2*. <http://www.endoflifecareforadults.nhs.uk/publications/rtssupportsheet2>
28. NICE (2011) *End of life care for adults quality standard (QS13)* <http://guidance.nice.org.uk/QS13>
29. Paediatric Intensive Care Society (2002) *Standards of Bereavement Care*. PICS, London
30. Pike A (2004) 'Manual handling the deceased child in a children's hospice'. *Journal of Child Health Care* 8 (p198)
31. Price J, Cairns C (2009) 'Communicating effectively'. Chapter 3. In *Palliative care for children and their families. An interdisciplinary approach*. Palgrave Macmillan, Basingstoke
32. Relf M, Machin L and Archer N (2010) *Guidance for Bereavement Needs Assessment in Palliative Care* (Second edition). Help the Hospices, London
33. Saunders C (1978) *The Management of Terminal Disease*. Arnold, London
34. Secretary of State for the Home Department (2003) *Death Certificate and Investigation in England, Wales and Northern Ireland: The report of a fundamental review*. The Stationary Office, London
35. Shipman Enquiry (2004)
36. The Childhood Bereavement Network (2006) *A guide to developing good practice in childhood bereavement services*. NCB, London
37. Wadey A (2010) *What to Do when Someone Dies: From funeral planning to probate and finance*. Which, London
38. Willis E (2007) 'Symptom care flowcharts: A case study'. *Paediatric Nursing*. 19 (1) (pp 14-17)
39. Worswick (2002) *A House Called Helen: The Development of Hospice Care for Children*, 2nd edition. Blackwell's, Oxford
40. www.direct.gov.uk/en/Governmentcitizensandrights/Death/WhatToDoAfterADeath/Guide/index.htm
41. Young C & Dowling T (2012) *Parents and Bereavement*. OUP, Oxford

7.4 Related legislation

Births and Deaths Registration Act (1953)

Certification of Death (Scotland) Bill (2010)

The Coroners Act (2009)

The Cremation (Belfast) Regulations (Northern Ireland) (1961)

The Cremation Regulations (2008)

The Fatal Accidents and Sudden Deaths Inquiry (Scotland) Act (1976)

The Human Tissue (Scotland) Act (2006)

The Human Tissue Act (2004)

7.5 Appendix 1

Checklist of practical tasks to complete at the time of death and following death

Name of Child: DoB:

Date and time of death:

Task to complete	Signed	Dated
Advance care plan		
Symptom management plan		
Verification of expected death (by a qualified nurse if agreed prior to death) <ul style="list-style-type: none"> • Details of the time, date and place of death and the people present are all recorded • Notification of death to medical practitioner • Preparation of cool room as appropriate 		
Notification of infections to appropriate personnel		
Notification of death <ul style="list-style-type: none"> • External regulator • Child Death Overview Panel (England and Wales) 		
Ensure notification of the coroner or procurator fiscal, as appropriate <ul style="list-style-type: none"> • Post mortem requested/ necessary 		
Certification (medical practitioner) - to consider burial or cremation at this point <ul style="list-style-type: none"> • Medical certificate of cause of death • Signed by second doctor for cremation • Cremation form/copy of form to crematorium 		
Professionals to inform <ul style="list-style-type: none"> • GP • Consultant/paediatrician • Community nurse • School • Other/family members as requested by the family 		

Task to complete	Signed	Dated
Organisation members to inform <ul style="list-style-type: none"> • Team • Managers • Administrators 		
Registration of death <ul style="list-style-type: none"> • Appointment made for family • Documents to take – death certificate/birth certificate 		
Funeral arrangements – Burial or Cremation <ul style="list-style-type: none"> • Funeral director or celebrant • Arrangements for coffin • Date and venue • Service sheet • Flowers/gifts • Clothing • Representatives 		
Collecting memories		
Staff debrief, reflection and learning <ul style="list-style-type: none"> • Date set and staff informed 		

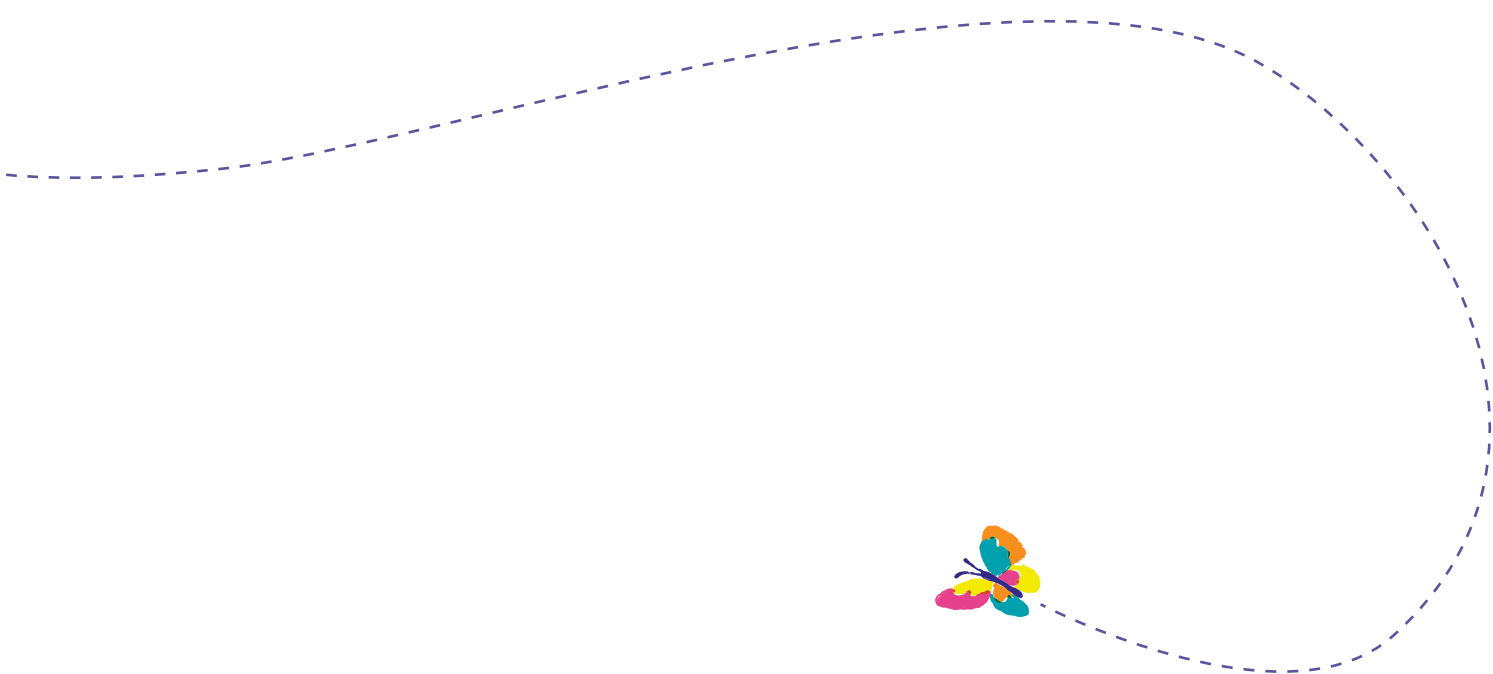
7.6 Appendix 2

Outline of learning and competence for staff

All staff should be able to use this guidance to develop their learning and competence in caring for a child at the end of life and after death. The following framework provides an outline of the key areas of learning that the guidance covers.

Outline for learning and competence of staff in:	Completion of section, signed and dated
Section One – Care before death <ul style="list-style-type: none"> • Care of the family • Cultural and spiritual dimensions of care • Advance care planning • Organ donation • Symptom management planning 	Signed: Date:
Section Two – Care at the time of death <ul style="list-style-type: none"> • Care of the family • Understanding expected and unexpected death • Verification • Certification • Notification • Child Death Overview Panel • The role of the coroner or procurator fiscal • Post mortem • Registration 	Signed: Date:
Section Three – Care after death <ul style="list-style-type: none"> • Care of the family • Funeral directors • Transferring a child after death to a different setting • The principles of care when using a cool room • Personal care of the child after death 	Signed: Date:

Outline for learning and competence of staff in:	Completion of section, signed and dated
Section Four – Bereavement support <ul style="list-style-type: none"> • How to support the family • The importance of collecting memories • How to support the family in preparing for the funeral • Ongoing support 	Signed: Date:
Section Five – Staff support <ul style="list-style-type: none"> • Supervision • Debriefs 	Signed: Date:



Together for Short Lives

4th Floor, Bridge House, 48-52 Baldwin Street,
Bristol, BS1 1QB

T: 0117 989 7820

F: 0117 929 1999

E: info@togetherforshortlives.org.uk

www.togetherforshortlives.org.uk

Together for Short Lives is a registered charity and a company limited by guarantee.
Registered Charity No: 1144022 Company Registration No. 7783702 England

