

# Caring for a child at end of life

A guide for professionals on the care of  
children and young people before death,  
at the time of death and after death

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When a child’s life is expected to be short, there’s no time to waste. Together for Short Lives is here to make sure the 49,000 seriously ill children and their families across the UK can make the most of every moment they have together, whether that’s for years, months or only hours. We stand alongside families, supporting them to make sure they get the vital care and help that they need.

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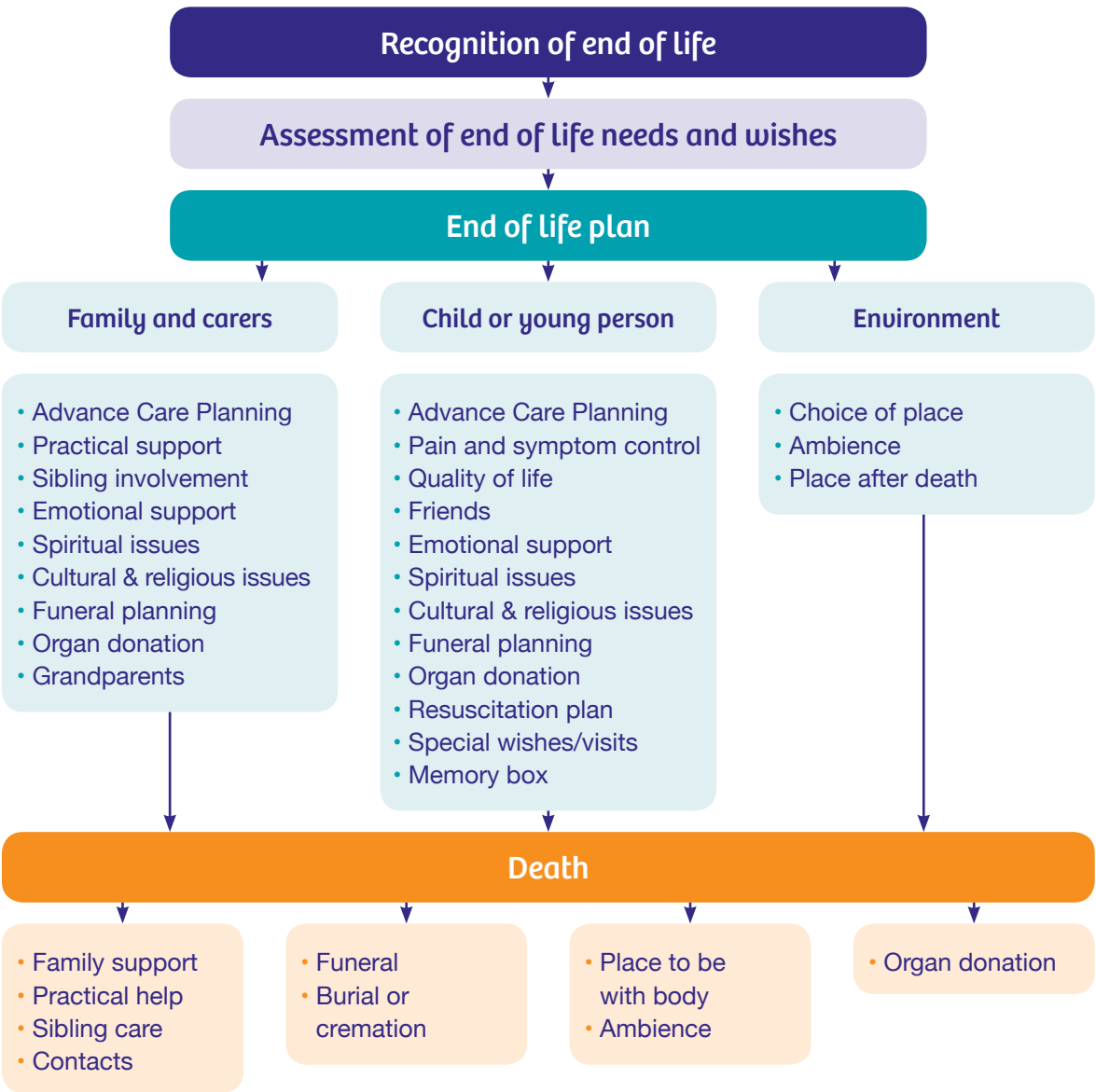
Note

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.

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# Together for Short Lives Core Care Pathway Diagram – End of Life and Bereavement



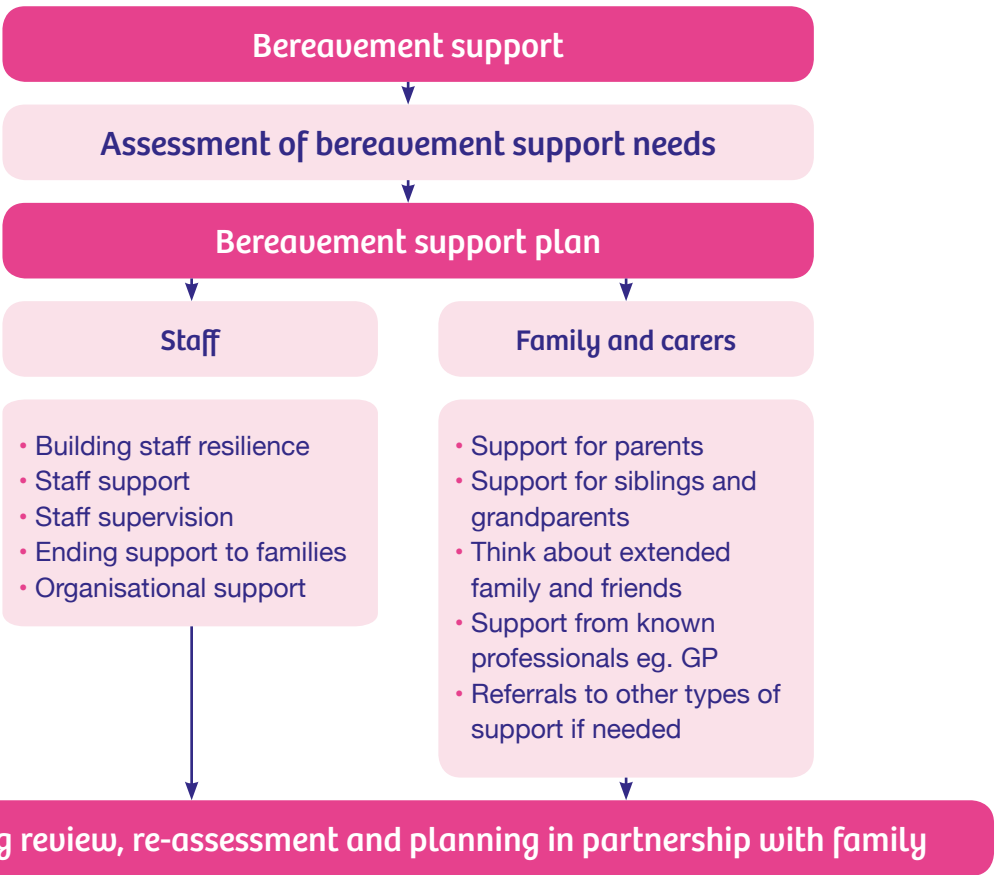
## Standard

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

### Goals

1. Professionals should be open and honest with families when the approach to end of life is recognised.
2. Joint planning with families and relevant professionals should take place as soon as possible.
3. A written plan of care (Advance Care Plan) should be agreed and shared with emergency services, including decisions about methods of resuscitation.

4. Care plans should be reviewed and altered to take account of changes.
5. A 24-hour symptom management plan should be developed which includes plans for accessing medication.
6. Those managing symptoms should be suitably qualified and experienced.
7. Emotional and spiritual support should be available to the child and family.
8. Children and families should be supported to achieve their end of life choices.
9. There needs to be clear understanding of the formal processes and timings that are needed in care after death.
10. Families should have time and privacy with their child after death.



## Standard

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

### Goals

1. Parents should feel in control of events before and after the death and should be able to follow their own choices and wishes.
2. Families should all be offered bereavement support and this offer should be revisited.
3. The bereavement needs of siblings should be recognised and supported.
4. The needs of care staff should be considered, including ending of bereavement support.

## NICE Quality Statements

- Statement 1:** Infants, children and young people with a life-limiting condition and their parents or carers are involved in developing an advance care plan.
- Statement 2:** Infants, children and young people with a life-limiting condition have a named medical specialist who leads and coordinates their care.
- Statement 3:** Infants, children and young people with a life-limiting condition and their parents or carers are given information about emotional and psychological support, including how to access it.
- Statement 4:** Infants, children and young people with a life-limiting condition are cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team.
- Statement 5:** Parents or carers of infants, children and young people approaching the end of life are offered support for grief and loss when their child is nearing the end of their life and after their death.
- Statement 6:** Infants, children and young people approaching the end of life and being cared for at home have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care.



# Introduction

Together for Short Lives encourages a care pathway approach for children with life-threatening and life-limiting conditions, and their families, that puts children and their families at the centre of care. The care pathway provides a framework for providing care to children and families from diagnosis and throughout their illness, from diagnosis through to bereavement care (Together for Short Lives, 2013)<sup>1</sup>.

This guide aims to provide a practical toolkit for all practitioners providing end of life care to babies, children and young people. It sets out key standards and goals for good practice alongside links to useful sources of information, legislation and regulations.

This guide supports practice in line with the standards set out by national guidance such as NICE, 2016<sup>2</sup>; NICE, 2017<sup>3</sup> and HM Government, 2018<sup>4</sup> and the requirements set out by external regulators including Healthcare Improvement Scotland<sup>5</sup>, the Regulation and Quality Improvement Authority (Northern Ireland)<sup>6</sup> the Care Quality Commission (England)<sup>7</sup>, the Healthcare Inspectorate (Wales)<sup>8</sup> and Local Safeguarding Boards (England and Wales).

Integral to this guidance are key principles that underpin a learning framework to help develop the knowledge and skills of staff who work with families at such an intensely emotional time. The guide aims to support professionals to establish safe and effective practice in order to improve the experience for children and families.

There is an accompanying booklet for parent carers which you may find a helpful resource to talk through with families when they have a child approaching end of life.

Key resources

- Together for Short Lives 2013. *Core Care Pathway*  
[www.togetherforshortlives.org.uk/resource/core-care-pathway/](http://www.togetherforshortlives.org.uk/resource/core-care-pathway/)
- NICE 2016. *End of Life Care for Infants, Children and Young People*  
[www.nice.org.uk/guidance/ng61](http://www.nice.org.uk/guidance/ng61)
- NICE 2017. *End of Life Care for Infants, Children and Young People Quality Statements*  
[www.nice.org.uk/guidance/qs160/chapter/Quality-statements](http://www.nice.org.uk/guidance/qs160/chapter/Quality-statements)
- HM Government 2018. *Child Death Review: Statutory and Operational Guidance (England)*  
[www.gov.uk/government/publications/child-death-review-statutory-and-operational-guidance-england](http://www.gov.uk/government/publications/child-death-review-statutory-and-operational-guidance-england)

1. Together for Short Lives (2013).  
2. NICE (2016).  
3. NICE (2017).  
4. HM Government (England) (2018).  
5. Healthcare Improvement Scotland.  
6. The Regulation and Quality Improvement Authority.  
7. Care Quality Commission.  
8. The Health Care Inspectorate Wales.



## Section 1 Care before death

## 1.1 Overview

**Caring for a child before death can be challenging, involving complex decision-making<sup>9</sup> and symptom management. Recognising that end of life is approaching enables families and professionals to focus on and plan together for the death of the child. Multi-agency care planning is fundamental to the care of the child at this stage and it is vital to have good communication and partnership between services. It is important to ensure that an Advance Care Plan (ACP) or end of life plan has addressed the family's priorities of care, preferred location of care, decisions about resuscitation and organ or tissue donation, and that a symptom management plan for end of life is in place.**

## 1.2 Communication

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 provide information, comfort and understanding to families at such a challenging time (Duke and Bailey, 2008)<sup>10</sup>. Effective, skilled and sensitive communication is essential in all aspects of children's palliative care and important throughout the care pathway (NHSE, 2012)<sup>11</sup>. Good communication and information can empower families with the knowledge to make informed decisions about care (Price and Cairns 2009)<sup>12</sup>. The aim of communication is therefore to reach an understanding between professionals and families, not merely giving a message that is neither received nor understood.

### Essential skills for communication

- Importance of body language and non-verbal skills
- Listening skills and the skill of being able to remain silent
- 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
  - checking they have understood
  - conclude and let them know where to go with any follow up questions.

Some practitioners may fear making things worse or lack confidence in starting conversations, exploring concerns or closing conversations, but 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, for example that 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 children (Gibson et al 2010)<sup>13</sup>. The essential skills of communication highlighted above are equally important when engaging with children. It is also important to be aware of the child's age and stage of development, their awareness and understanding of illness and death, any learning difficulty and the values and beliefs of their family and how they make and process decisions.

### Further skills for talking with children

- Talk with them, not about them.
- Use language they will understand, not euphemisms.
- 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.
- Find an environment that they are comfortable in.

#### Reflective question

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

### Managing difficult conversations

For many professionals the most challenging area of communication surrounds breaking bad news or sharing significant news (Amery, 2016)<sup>14</sup>. There are a number of frameworks to help support this process. Some useful tips are set out below for managing difficult conversations.

### Key principles in managing difficult conversations

- Create opportunities to be able to listen to families.
- 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.
- Ideally, you need to share the information in a dedicated space, 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 below) 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 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 as appropriate 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.



9. GMC (2010).

10. Duke S, Baily C (2008).

11. NHS England National End of Life Programme (2012).

12. Price J, Cairns C (2009).

13. Gibson F et al (2010).

14. Amery J (2016).



## Framework for managing difficult conversations<sup>15</sup>

### Stop Look Think

**Resist the temptation to run!**

**Make eye contact and 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

## 1.3 Care of the family

Children are living with increasingly complex conditions. This places an increasing demand on families in caring for their child and has a significant impact on their physical, social, emotional and financial circumstances. This means that care teams must provide skilled, intense and continuous care to families, with a particular need for meaningful, non-judgemental support at end of life (Kirk and Glendinning 2002)<sup>16</sup>. It also puts pressure on relationships within the family, in particular between parents, so sensitive communication is an essential part of children’s palliative care. 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 for their children and, where appropriate, children should be integral to the decision-making process. Each family reacts differently and needs information at different times. It should be remembered that decision-making is fluid – families often change their minds.

## 1.4 Spirituality, faith and cultural care

*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.*<sup>17</sup>

Part of what makes people human is the need to make sense of life and find meaning in death. For many this is understood through spirituality, faith and cultural values. There is a wealth of resources to guide staff in providing spiritual and cultural care and it is important to engage with local faith communities in order to learn more about these. All health and social care professionals should work to support the individual needs, wishes and beliefs of all families, recognising that there are numerous variations within faiths and different traditions.

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 religion; some have no 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 everyday practices, and there are many examples that illustrate how faith can offer people solace and hope, particularly in relation to death.

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. In some cultures funerals happen very quickly, in others it is inappropriate for a person of a different sex to handle the body of a child of the opposite sex, in some the washing of the body is part of the ritual. It is important to know ahead of time what is required.

### 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 time of death.

### Reflective question

Think about the families you have cared for from the same faith community, and consider the differences you experienced in their individual beliefs and practices. What local faith groups could you link with?

15. University of Southampton (2012).

16. Kirk S & Glendinning C (2002).

17. Nolan S et al (2011).

## Key resources

- Nash P et al (2015). *Multifaith Care for Sick and Dying Children and their Families: A Multi-disciplinary Guide*. Jessica Kingsley ISBN: 978-1-84905-606-9<sup>18</sup>

## 1.5 Ethics and decision-making

The choices associated with children's palliative care may involve complex decision-making (Larcher et al, 2015)<sup>19</sup> and raise ethical concerns about children's interests, parental decision-making and health care costs. Understanding all views and perspectives is important as part of the decision-making process. Finding opportunities for shared decision-making involving the child, parents and health care professionals is essential (Ray et al, 2018)<sup>20</sup>. It is important to have access to your local ethics group for support in this complex area.

## 1.6 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. 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 donation (PICS, 2002)<sup>21</sup>, and that most parents are pleased to hear about the opportunity to donate organs and/or tissue as early as possible in the Advance Care Planning process. If professionals and families feel that it would be helpful to have a more in-depth discussion about organ donation, then further information is available through a specialist nurse for organ donation within the local trust or nationally at [www.organdonation.nhs.uk](http://www.organdonation.nhs.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. Supporting families with this choice needs to be managed sensitively. 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 (England, 2004<sup>22</sup> and Scotland 2019<sup>23</sup>).

There is now an 'opt out' organ donation law [www.organdonation.nhs.uk/uk-laws/organ-donation-law-in-england/](http://www.organdonation.nhs.uk/uk-laws/organ-donation-law-in-england/) and after 2020 over 18s will be presumed to have consented to organ donation unless they are in a protected group. All children under the age of 18 and young people without mental capacity are one of these automatically opted out groups.

### Good practice points

- All families should be able to discuss options of organ and tissue donation as early as possible.
- 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.
- All staff who are going to discuss organ donation should clearly understand what the options are.

## 1.7 Advance Care Planning

Advance Care Planning (usually called anticipatory care planning in Scotland) is a process of discussion between an individual and their care provider and often those close to them. Advance Care Planning may lead to actions such as advance statements about wishes and preferences, preferred place of care, withdrawal of treatment and resuscitation status. For families this will include decisions relating to treatment options and choices of care in the case of acute deterioration and gradual deterioration of their child's condition. It may also address preferences for organ and tissue donation. All conversations surrounding advance care planning 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

- CYPACP network <http://cypacp.uk>

## 1.8 Symptom management planning

Effective symptom management planning for children is essential to ensure their comfort and enhance their quality of life. Anticipatory planning for symptoms that might occur at any point from diagnosis to end of life is important. The family's priorities for care, such as their preferred place of care may influence symptom management planning. A number of different plans for symptoms occurring at different times and in different locations may be required. A symptom management flowchart can sometimes be helpful to guide professionals and parents regarding likely symptoms and their management<sup>24</sup>.

It is not the intention of this guidance to describe the management of symptoms in detail. This information can be found in *Basic Symptom Control in Paediatric Palliative Care* (Together for Short Lives, 2016)<sup>25</sup>. Advice could also be sought from those experienced in providing symptom management for children with palliative care needs. When prescribing, information about drug preparations, dosages and licensing should be sought from the current version of the *APPM Master Formulary* now in its 4th edition<sup>26</sup>.

It is important to acknowledge that management of symptoms should not be limited to pharmacological approaches. There should be a multi-professional approach, involving those experienced in end of life symptom planning who have knowledge of the child's disease to address all domains of a child and family's suffering (physical, psychological, social and spiritual). Anticipatory planning is essential – it is better to be prepared and have a plan in place, even if it is not needed. Care should be child centred and delivered in partnership with the child and family, with careful and sensitive communication.

### Good practice points

- Identify who will take responsibility for prescribing and dispensing medication at the different time points of the child's life, in different care settings.
- Ensure a 'Just in Case' box is available when discharging the child home for end of life or when the condition deteriorates in a home setting.
- Ensure the symptom management plan is up to date and available to those who might need to access it, giving careful consideration to out of hours and/or emergency care providers, e.g. ambulance services.
- Supply the family with contact details of professionals who are available to support them, in and out of hours.

## Key resources

- APPM (2017). *Master Formulary 4th Edition* [www.appm.org.uk/guidelines-resources/appm-master-formulary/](http://www.appm.org.uk/guidelines-resources/appm-master-formulary/)
- Together for Short Lives (2016). *Basic Symptom Control in Paediatric Palliative Care* [www.togetherforshortlives.org.uk/resource/basic-symptom-control-paediatric-palliative-care/](http://www.togetherforshortlives.org.uk/resource/basic-symptom-control-paediatric-palliative-care/)

18. Nash P et al (2015).

19. Larcher V et al (2015).

20. Ray et al (2018).

21. Paediatric Intensive Care Society (2002).

22. The Human Tissue Act (2004).

23. The Human Tissue (Authorisation) (Scotland) Act (2019).

24. Willis E (2007).

25. Together for Short Lives (2016).

26. APPM (2017).



## 1.9 Managing Digital Legacy

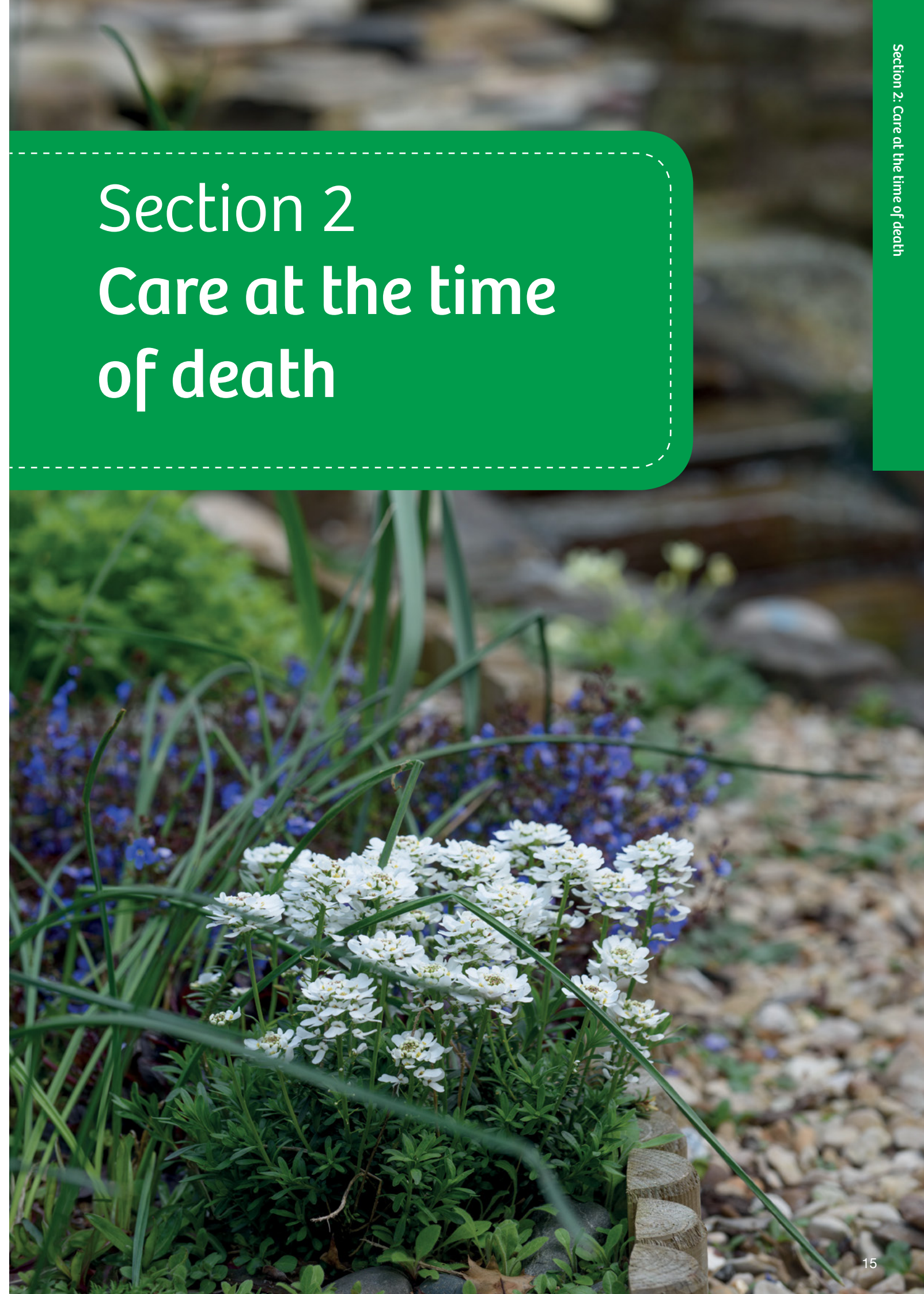
Alongside the health-related aspects of planning for a child's end of life care, it's also important to think about broader issues, such as the child or young person's online life. Children and young people spend a huge amount of time online, using social media, gaming, sharing photos, or if they are older using online facilities such as banking. It is important to prompt them and their families to think about how this will be managed after they die, enabling these accounts to be closed down or to be used to celebrate their life. It can be helpful to ask the young person and/or their family to start thinking about this early in case the death is unexpectedly sudden.

### Useful resource

- The Digital Legacy Association has a wealth of information about how to manage digital legacies and digital assets  
<https://digitallegacyassociation.org>



# Section 2 Care at the time of death





## 2.1 Overview

It is essential to provide sensitive and meaningful care and support when a child is dying 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. It is important to be familiar with the processes for dealing with expected and unexpected deaths, and the process for carrying out verification of death, to ensure that care is co-ordinated and seamless at the time of a child's death.

## 2.2 Care of the family

Many parents experience multiple feelings of grief and loss over the years of caring for a child with a life-threatening or life-limiting condition. Supporting families at the time of their child's death and afterwards 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 emotional 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, but you may need to be prepared to sensitively answer questions from anxious parents about whether or not their child has died.

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. You will need to be sensitive to the individual needs of the family, some will want information like this in advance, others will prefer to wait and discuss at the time. Families 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 wishes. These may change at any time. Staff 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 need to be able to communicate effectively with families to get an understanding of their expectations and wishes around faith, spiritual and cultural care (see section 1.4). Clear documentation for all decisions and arrangements at end of life and after death must be recorded.

A child can be moved after death if best practice for transporting a body is followed. This means that care can be provided across different settings to enable children and their families to be cared for and to die in their preferred place, where this is possible. Families should be able to choose their child's place of death and this should be facilitated, although it's important to recognise that this is not always possible if services are not available or treatment options require a different setting, for example if the child is in PICU and highly dependent on invasive support. It's also important to remember that many families will change their mind at any point. Effective communication and explaining what may happen can avoid sudden changes to care, which can be distressing.

## 2.3 Anticipated and unanticipated (expected and unexpected) death

One of the challenges of working with children and young people with life-threatening or life-limiting conditions is being able to identify those unexpected deaths that require further investigation to enable a prompt investigation so that there is learning from the experience (Scottish Government, 2016<sup>27</sup>; HM Government, 2018<sup>28</sup>; Child Death Review<sup>29</sup>).

**Anticipated 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.

**Unanticipated 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 (0-18 years) with a life-limiting or life-threatening condition, unexpected death can be described as:

- 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 (Working Together, 2018).

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 Coroner or Procurator Fiscal. This is usually done by the doctor. 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 (Crown Office and Procurator Fiscal Service<sup>30</sup>).

### Deaths that need reporting to the coroner or Procurator Fiscal

- Identity of deceased unknown
- If the cause of the death is 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
- 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 factors.

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.

It is essential 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. Each children's service must have a policy and protocol that are adhered to in the case of an unexpected death and establish good communication and relationships with professionals locally.

27. Scottish Government (2016).

28. HM Government (2018a).

29. HM Government (2018b).

30. Crown Office and Procurator Fiscal Service.

## 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, or 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.
- All staff should be aware of their local process.

## Reflective question

Consider a child known to the service who is deteriorating 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?

## 2.4 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.**

Experienced designated Registered Nurses have the authority to verify (confirm), notify and arrange for last offices and removal/transport of the body, providing they are trained and competent to work within local policies. Verification (or confirmation) 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.

All deaths should be subject to professional verification that life has ended<sup>31</sup>. This is separate from the certification process and can be performed either by a medical practitioner or by another qualified professional. There is no legal requirement for a medical practitioner to verify death. Registered Nurses who are trained and competent may confirm that death has occurred. This guidance pertains to the verification of expected death in childhood and the nurse will

need to understand the difference between expected and unexpected deaths and the process to follow for each situation.

All Registered Nurses must be aware of their accountability in practice regarding their knowledge, skill and competence when performing verification of expected death procedures.

## RCN: Confirmation or Verification of Death by Registered Nurses

[www.rcn.org.uk/get-help/rcn-advice/confirmation-of-death](http://www.rcn.org.uk/get-help/rcn-advice/confirmation-of-death)

A Registered Nurse may verify the fact that death has occurred if:

- the death is expected
- the DNR is signed in line with current guidance
- the death does not need reporting to the coroner
- the death is expected and verification of death agreed

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

## Principles of verification of expected death

Understanding the principles of verification is essential in order to support safe quality practice. Equally important is that healthcare professionals understand the nature of verification, and where it fits within the care pathway, as a precursor to medical certification of the cause of death, to ensure sensitive and timely support for the family. Organisations should ensure that there is a well thought out policy and clear protocols for verifying death which ensures support to families, sets clear boundaries for staff and reduces potential delays.

Verification of death requires a team approach and the agreement for nurses to verify should be taken by all those closely involved with the child including their family. The RCN guidance suggests that where practical verification of death should ideally take place within a timeframe of 4 hours, but this is sometimes difficult to achieve depending on where the child has died, the time of death and availability of staff.

Verification of expected death by Registered Nurses can take place across hospital, community and hospice care. In addition, the care of children is increasingly embracing a community approach and the need for nurses to verify expected death is becoming an urgent priority. It is therefore important that policies and comprehensive training are in place to enable registered nurses to verify death in all these settings. Key principles underpinning verification of expected death are:

- Policy and processes should be in place to support Registered Nurses in the verification of expected death.
- Verification of expected death should be understood in relation to the law.
- Verification of death is recognised within the context of expected and unexpected death and there are clear safeguards in place within the context of life-limiting and life-threatening conditions in children. The process of verification is underpinned by quality standards and outcome measures.
- Verification of expected death is an integral part of the end of life pathway.
- There is clear, sensitive, and effective communication for the agreement for nurses to verify death which has been discussed and approved with the multi-professional team including the medical practitioner and family at an appropriate time before the death of the child.
- Training is available for those nurses who take on the extended role of verifying death.
- Nurses have the knowledge, skills and competence to verify expected death.
- Nurse verification of death should avoid delays and prevent unnecessary call out of doctors, ambulance staff or coroners.
- The death of a child can be managed in a sensitive, timely and caring manner respecting the dignity of the child and the family.
- In England all deaths must be reported to the Child Death Overview Panel (CDOP). In cases of expected death there is a detailed process to follow and forms to complete.
- If a death is unexpected or there is any doubt surrounding the death, nurses must be aware of local procedures and know how and when to refer to the medical practitioner, coroner or Procurator Fiscal (and CDOP in England).

31. 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 undertake the very practical tasks involved with supporting a family immediately following a child's death.



## Section 3 Care after death



### 3.1 Overview

**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.**

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 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.

### 3.2 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 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 Advance Care Plan and contributed to this decision. However, we recognise that some families will be unwilling or unable to discuss this in advance. It is therefore important for professionals who are present at the time of death to be knowledgeable and confident to present options to the family and explain the differences between them, so that the family can reach informed decisions.

The child may be cared for on the ward, the hospital mortuary, the funeral directors, at a children's hospice or in their own home. Care can also be provided by a combination of these options. It's important to be aware of the policies of each service in your area and the support available, for example about the length of time that a child's body can be in the cool room, how a family can arrange viewings in the hospital mortuary or if the family decide to take their child home after death, what support will be available to them? Most families will not be aware of the difference in available care across settings and it is important that this is fully explained so they can make an informed choice.

Parents should be reassured 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.

#### 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.
- You will need to let families know what will be happening next, and in what timeframe, in accordance with local policy.

#### 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 do the family need to know?

### 3.3 Care of the body

Once an expected death has been verified, the family can be supported with decisions about personal care and advice and information can be sought from the funeral director about this. 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 changes to the child's body over the hours and days following death, particularly if they choose to use a cooling facility. Staff caring for the child and family should do so with dignity and respect, affording all 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 request or 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 before removing tubes and catheters and be prepared with tissues and wipes. If leakage is excessive staff should take advice from the funeral director or mortuary staff. It is not the responsibility of nursing 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.

If a child has been long-term ventilated, it can be a very significant moment for the family when the machine is switched off after their child has died.

Often families will choose a favourite outfit and have a favourite toy to place with their child before the child is transferred to a cooling facility or collected by the funeral director. If parents want the child to wear a specific outfit for their funeral, it can be helpful to suggest they save this for the day, due to the likelihood of leakage in the hours and days immediately after death.

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. This is also an indication of when to move the child into a coffin (see section 3.13).

Outside of the hospital setting, 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.





**Deterioration of the body – what to expect**

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:** Immediately after the death, you can close the eyes by gently pressing down on the eyelids. 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 secure the eyelids to keep the eyes closed. Over time, the eyes may become sunken in appearance, which may be alarming for the family and carers.

**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 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, eg nasogastric tube, central lines, tracheostomy tubes. If these are to be removed, it is vital to discuss this with parents and seek their permission. Some families request that recently amputated limbs are buried or cremated with their child.

**Embalming**

Embalming is not routine for children especially and is not usually necessary if they are to be buried within 10 days or so of death. However it may be appropriate if it is the family's choice for cultural or other reasons, for example if the family are moving the body abroad. It can be an appropriate choice if there are additional factors which will accelerate the deterioration of the body such as chemotherapy 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 to be aware that the more a body is moved the sooner it will deteriorate.

Embalming is the process of temporarily preserving the body to avoid deterioration. It must be carried out at the funeral directors' 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).

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<sup>32</sup>.

**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 something you have not yet experienced, it might be helpful to consider shadowing and learning from a colleague.

**Key resource**

SCYPPCN Collaborative Guidance for Staff to support families to take their child home after death [www.cen.scot.nhs.uk/wp-content/uploads/2018/01/2017-10-01Collaborative-guidance-for-staff-to-support-families-who-wish-to-take-their-child-home-after-death-FINAL-3.docx](http://www.cen.scot.nhs.uk/wp-content/uploads/2018/01/2017-10-01Collaborative-guidance-for-staff-to-support-families-who-wish-to-take-their-child-home-after-death-FINAL-3.docx)

**3.4 Cooling the body in different settings**

The cooling of the body, whether at home, in hospital or in a children's hospice needs to start as soon as possible.

**At home**

Increasingly children at the end of life and their families are being supported to die at home. It is not necessary to have special cooling equipment, but it is advisable to ensure good communication with the family's undertaker. If it is possible, the family may be able to borrow an air-conditioning unit or cooling blanket from a local children's hospice or hospital (or local building firm). Good practice in using this equipment 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 unit or cooling mattress it is important to position the unit appropriately in the room and keep all windows closed. It is advisable to anticipate in advance the equipment needed and the practical arrangements that will need to be made, such as the room being accessible for funeral directors to bring in a coffin and move 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.

32. The Natural Death Centre

### Hospice

Most children's hospices today provide a cool room where children can be placed after they die, until their funeral or before being transferred to a funeral director. Currently there is evidence of a wide variety of practice. Addressing the issue of access to 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, community children's nursing teams, 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.

## 3.5 Transporting the child's body

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 to be 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 cool the body within 4-6 hours and then the child can be transferred the next day to the mortuary, funeral directors or hospice 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 strongly advised that they nominate a driver. A Scottish Government consultation is currently underway which may regulate the transfer of a body by a registered person or organisation only. In some areas there is a policy to inform the local police in advance when transferring a body – this will depend on local policy and practice. If a family is transporting a child's body they should be provided with a letter with appropriate contact numbers, in case they are stopped. Special consideration should be given if the body is being transported to a different UK country (see section 3.14). It can also be helpful to provide template letters on a website as a downloadable resource.

### 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. Cooling facilities at home may be necessary.

## 3.6 The role of the coroner or Procurator Fiscal

Understanding the role of the coroner or Procurator Fiscal (in Scotland) 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 be aware of. Effective communication and joint working are essential to formulate agreements around the reporting process. Some deaths require notification to the coroner/Procurator Fiscal before the death can be registered.

The coroner or Procurator Fiscal has a duty to investigate certain types of deaths including:

- deaths when the cause of death is unknown
- deaths due to an accident
- deaths where the circumstances are suspicious
- deaths not considered 'natural' – where the deaths are sudden, unexpected or unexplained

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.

When a child is referred the coroner or Procurator Fiscal will decide if further investigations are necessary. They may decide that a medical certificate of cause of death (MCCD) can be issued once the cause of death has been agreed. Alternatively, they may decide there is 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 cause of death is explained by post-mortem then the death may 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.

## 3.7 Post-mortems

There are two kinds of post-mortems (PMs) – a Coroner's PM or a Hospital PM.

A Coroner's PM is requested by the Coroner (Procurator Fiscal in Scotland) as a legal requirement for any sudden death when the cause is not apparent. In these cases, consent from the family is not required. Specific cases where a PM would normally be necessary include death during an operation or before recovery from the effects of anaesthesia. If the coroner or Procurator Fiscal requests a PM, families have no legal right to decline. 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.justice-ni.gov.uk/articles/coroners-service-northern-ireland](http://www.justice-ni.gov.uk/articles/coroners-service-northern-ireland). Be aware that families may need additional support to understand why this is happening and why they can't refuse a coroner's PM.

A Hospital 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 and more information may be helpful to the family for a future baby. This can be a full PM or a limited PM which just looks at one system (eg brain or lungs). In the case of a Hospital PM there are clear consenting processes to be followed which include a cooling off period. Consent must be sought from those with parental responsibility and both parents should be consulted where possible. Sensitive communication and good information and advice for the family are essential at this time. Some hospital Trusts have information leaflets for families and professionals that offer helpful advice.

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.

Having had a post-mortem is not a contraindication to using a cold bedroom or taking the child home.

## 3.8 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. 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 Inquiry<sup>33</sup> a number of changes to the process of death certification have been introduced. For current requirements and recent changes, see each country's website.

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.

### Key resources

- What to do when someone dies  
[www.gov.uk/after-a-death](http://www.gov.uk/after-a-death)

### 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)

## 3.9 Notification of death

Notification of death is required within 24 hours or first working day after a weekend or Bank Holiday to the appropriate regulatory inspectorate.

The Care Quality Commission (England)  
[www.cqc.org.uk](http://www.cqc.org.uk)

The Health Care Inspectorate (Wales)  
[www.hiww.org.uk](http://www.hiww.org.uk)

The Regulation and Quality Improvement Authority (Northern Ireland)  
[www.rqia.org.uk](http://www.rqia.org.uk)

The Scottish Commission (Scotland)  
[www.healthcareimprovementscotland.org](http://www.healthcareimprovementscotland.org)

## 3.10 Child Death Overview Panel (CDOP) Process in England

The CDOP is a multi-agency panel set up by the local authority and Clinical Commissioning Group (CDR partners) to review the deaths of all children normally resident in their area in England. [www.gov.uk/government/publications/child-death-review-statutory-and-operational-guidance-england](http://www.gov.uk/government/publications/child-death-review-statutory-and-operational-guidance-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 unexpected: [www.england.nhs.uk/publication/learning-from-deaths-information-for-families/](http://www.england.nhs.uk/publication/learning-from-deaths-information-for-families/)

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. 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.

## 3 Forms for notification, reporting, analysis

Three standard forms should be used in the child death review process:

**Notification Form** (previously Form A) for initial notification of a death to CDR partners – this form needs to be completed only once by the team reporting the death in the place that the child died.

**Reporting Form** (previously Form B) for gathering information from all agencies involved in the child's care or who have information relevant to the case.

**Analysis Form** (previously Form C) initially drafted by the child death review meeting and completed at CDOP. The Analysis Form is the final output of the child death review process.

### Child Death Review meeting (CDRM)

The CDRM is held by the professionals caring for the child before death. Its purpose is to review all the circumstances surrounding the death of the child and to complete an analysis form that summarises all learning from the meeting. This is forwarded to the local CDOP office.

The aims of the CDRM are:

- to review the background history, treatment, and outcomes of investigations, to determine, as far as is possible, the likely cause of death;
- to ascertain contributory and modifiable factors across domains specific to the child, the social and physical environment, and service delivery;
- to describe any learning arising from the death and, where appropriate, to identify any actions that should be taken by any of the organisations involved to improve the safety or welfare of children or the child death review process;
- to review the support provided to the family and to ensure that the family are provided with the outcomes of any investigation into their child's death and a plain English explanation of why their child died (accepting that sometimes this is not possible even after investigations have been undertaken) and any learning from the review meeting;
- to ensure that CDOP and, where appropriate, the coroner is informed of the outcomes of any investigation into the child's death; and
- to review the support provided to staff involved in the care of the child.

Every bereaved family should be allocated a Lead Health Professional ie the child's lead Consultant and a Key Worker who acts as a single point of contact for the bereaved family. Both these professionals should guide the family through the national and local pathways.

### Good practice points

- Initial notification to your local CDOP.
- Involving the parents in the process by asking them for any outstanding questions they may have.
- Attending the CDR meeting for a child who you were involved with.
- Feedback to the parents via a meeting, after the CDR meeting.

## 3.11 Registration of death

Any death needs to be registered within five working days in order for the certificate of registration of death (death certificate) to be issued. An appointment will need to be made for this, which can now be done online. 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 who found 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 baby 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, if no family or friends are able to help the parents, 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.

33. Smith J (2004).

## The following are needed to register a death

- The child's full name, 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/young person'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 about their relationship to the deceased child, whether they were present at the time of death and 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 so that the funeral can 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).

### 3.12 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. 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 <https://nafd.org.uk> provides good advice and lists funeral directors locally. Funeral directors should be licensed with the British Institute of Funeral Directors.

Choices about burial, cremation and the funeral are a central part of grieving over the death of a child<sup>34</sup>. 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.

In England the new Children's Funeral Fund has been set up to provide free burial or cremation for children [www.gov.uk/government/publications/childrens-funeral-fund-for-england](http://www.gov.uk/government/publications/childrens-funeral-fund-for-england). In other UK countries 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.

### 3.13 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 will enable parents to make informed decisions about 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.

### 3.14 Moving the body and repatriation

If a body is to be moved out of the country, the coroner (or Procurator Fiscal in Scotland) 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 copies of the death certificate (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. 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.

### 3.15 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)<sup>35</sup>. The law governing cremation in Northern Ireland is the Cremation (Belfast) Regulations (Northern Ireland), 1961<sup>36</sup>, and Scotland, the Cremation (Scotland) Regulations (2003). 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

There are a number of forms that will need to be completed before a cremation:

- 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 post-mortem 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, but if you wish to scatter ashes on private land, or in a river, you should get consent from the landowner. Although UK law allows ashes to be taken abroad, many countries have strict rules on this and it is important to check before travelling. When a 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 directors and crematorium and ensure parents are aware of this in advance.

### 3.16 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.

34. Dent A, Stewart A (2004).

35. The Cremation Regulations (2008).

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



Families are increasingly arranging funerals that take account of environmental 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 as well as information about 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).<sup>37</sup>

### Key resources

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

### 3.17 Further support for the family and in the community

Once the immediate preparation of the child's body has been completed, staff should 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 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.

It may be that siblings were not with the child at the time of death, and families may need support in telling them about what has happened. It is important to go at the family's pace and to read their behaviour to decide what feels right. 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 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 the 'further resources' section.

Grandparents often 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 lives. In addition, they carry the added dimension of supporting their own son or daughter through their grief<sup>38</sup>. Support for grandparents is therefore important, and staff will need to be guided by them as to any support they may need.

It is also important to think about the support needed by the wider community such as the child's school or other groups that they attended.

### 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.

### Reflective question

How is your service addressing the NICE Quality Statements?  
Please refer to page 5.

## Section 4 Bereavement support

37. Wadey A (2010).

38. Young C & Dowling T (2012).

## 4.1 Overview

**Bereavement support is not 'one size fits all' and should be offered in response to individually assessed need. It does not necessarily require a specialist practitioner, but all staff should be guided 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. It's important to adopt an integrated approach to supporting bereaved families in which careful attention is paid to assessing their risk factors and individual coping styles<sup>39 40</sup>.**

As well as caring for the family in the days leading up to the funeral, 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 their location and resources. Dedicated bereavement charities or organisations with an extended family support or bereavement team may be able to offer regular post-bereavement sessions. Others may help families to find support within their own community. Whichever model issues, there are a number of key principles and basic guidance to follow, based on good practice in bereavement care.

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.

## 4.2 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.

## 4.3 Spiritual support

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

Most families will want to celebrate their child's life. Carefully chosen words, songs (or hymns) and readings 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 diverse ways in which families choose to respond to death and remember their child.

## 4.4 Making memories

Collecting memories that are meaningful can help to provide a 'life story' of the child. This can be undertaken before or after death. 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 many different ways to support families in creating memories, for example:

- A small lock of hair.
- Handprints and footprints or hand and foot sculptures.
- Decorating plates or other objects.
- Keepsake jewellery or ribbons.
- Memory boxes.
- A book of remembrance – a formal record that is often held at the hospice.

- 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 – which can include pathways, stones, trees and water features that have meaning for the family.
- A memorial service.
- Cards for significant dates, birthdays, anniversaries, religious festivals etc.

## 4.5 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. It is very important to involve the family support team, chaplain, funeral director, celebrant 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 ways to remember a child within a service, whether religious or non-religious. The key choice for families is whether to have a cremation or a burial, but with so many options for coffins, cars, readings and music, it can be difficult for a family to decide how to proceed. Families should be encouraged to draw on the resources of their local community to help them with planning the service.

## 4.6 Family follow up

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. Many children's services 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. There are also national organisations which provide ongoing bereavement support (see 4.7).

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

### Good practice point

- Be prepared to be guided by the individual needs of the family in planning for the funeral and in supporting them through bereavement.
- Carry out a clinical and a separate emotional debriefing after all child deaths, along with supervision.

### 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)
- Parents and Bereavement (Young 2012)
- A Guide to developing good practice in childhood bereavement services (The Childhood Bereavement Network, 2006)
- The Irish Childhood Bereavement Care Pyramid

[www.childhoodbereavement.ie/professionals/childhood-bereavement-care-pyramid/](http://www.childhoodbereavement.ie/professionals/childhood-bereavement-care-pyramid/)



39. Relf M et al (2010).

40. The Irish Childhood Bereavement Care Network (2014).



#### 4.7 Further bereavement resources

The following websites provide useful information on bereavement for families and professionals.

**Bliss** gives vital support and care to premature babies in the UK: [www.bliss.org.uk](http://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](http://www.childhoodbereavementnetwork.org.uk)

**Child Bereavement UK** supports bereaved children and provides training to professionals across the entire spectrum of child bereavement: [www.childbereavementuk.org](http://www.childbereavementuk.org)

**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](http://www.childdeathhelpline.org.uk)

**The Compassionate Friends** support bereaved parents and their families: [www.tcf.org.uk](http://www.tcf.org.uk)

**CRUSE** is a national charity offering free, confidential help to bereaved people. It produces booklets on coping with grief that you can buy online: [www.cruse.org.uk](http://www.cruse.org.uk)

**Education Scotland Support Around Death** supports healthcare staff who are working with patients, carers and families before, at, and after death: [www.sad.scot.nhs.uk](http://www.sad.scot.nhs.uk)

**Winston's Wish** is a childhood bereavement charity providing services to bereaved children, young people and their families in the UK: [www.winstonswish.org](http://www.winstonswish.org)



## Section 5 Staff support and supervision



## 5.1 Overview

It is well documented that working with dying people is very demanding. The loss and sense of helplessness when a person dies can also be experienced by the team caring for them. Senior managers have a duty of care that carries with it a 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 both pre-brief before and debrief sessions following the death of a child either internally or with a wider multi-professional team. Debriefs aim to provide emotional support and a time of reflection and an opportunity for professionals to process and manage the emotional and spiritual distress of death. In addition, they provide an opportunity to learn from our experiences, from our patients and from each other, so we can reinforce strategies that work and change the ones that do not.

## 5.2 Training and professional development

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 and confidence 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, development opportunities should be offered, for example in verification of death.

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 provides opportunities to reflect back on the care given so as to develop a holistic approach to practice.

### Good practice point

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

### Key resources

RCN Competencies for Children's Palliative Care  
[www.rcn.org.uk/professional-development/publications/pub-007033](http://www.rcn.org.uk/professional-development/publications/pub-007033)

Skills for Care & Hospice UK Competencies  
[www.skillsforcare.org.uk/Learning-development/ongoing-learning-and-development/end-of-life-care/End-of-life-care.aspx](http://www.skillsforcare.org.uk/Learning-development/ongoing-learning-and-development/end-of-life-care/End-of-life-care.aspx)

### Reflective question

How can you effectively promote and use supervision individually and/or across your organisation?

# Section 6 Glossary and references



## 6.1 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.

**Coroner's Officer:** A person who works on behalf of the Coroner and is the main point of contact between a family or professional.

**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.

**The Health Care Inspectorate:** The regulator of quality of care in Wales.

**Rapid response team CDOP:** 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 confirmation of death.

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## Section 7 Practice Prompts

The following pages are designed to provide useful information on a particular topic relating to a child's end of life care that you can use for your own practice and reflection. They are also designed to be easily photocopyable resources for staff training sessions.



## 1. Care before death: Overview

This sheet gives an overview of the main things to think about when working with a child in the immediate period before their death. The following prompts should help trigger any considerations you need to make at this stage of caring for a child.

- The child's needs should be assessed, and a plan of care should be discussed and developed with the child and their family. The child and family's beliefs and choices should be incorporated into the end of life care plan.
- Families and carers should be given appropriate written information to back up discussions and plans. Information should be provided for the child, siblings and parents in a way that is appropriate for their age and understanding.
- The child's current medication should be re-assessed. If appropriate, you might want to discontinue any medication which is 'non-essential'. Consider whether to discontinue inappropriate interventions at this stage such as blood tests, intravenous fluids and routine observation of vital signs.
- It is important to anticipate and prescribe for a range of possible symptoms such as pain, agitation, nausea and vomiting and respiratory tract secretion, ensuring that 'as required' subcutaneous and other medication is prescribed according to an agreed symptom management protocol.
- Ensure that the family has up to date emergency contact details for relevant staff and agencies. The GP practice, care team (eg community children's nursing services, consultants) and others (eg ambulance trust), including out of hours services, should be made aware that the child is now at their end of life phase.
- The family should be given the opportunity to discuss their plans for after death care including information about who to call, what needs to be done immediately and what can wait. Help the family to think in advance about support systems available after their child has died.
- Family members, including parents or carers, siblings, grandparents and others should have their needs considered at this stage.

**These overview prompts should be used alongside more specific end of life prompts on *Difficult Conversations* and *Advance Care Planning*.**



## 1a. Care before death: Difficult conversations

Good communication is key to providing care to children and their families, especially at end of life. By carefully listening and responding, you can help by providing information, comfort and understanding at a difficult time. This also helps identify problems and develop management plans to enhance the delivery of good care.

**The following prompts should help you think through your approach to difficult conversations with families during their child's end of life phase.**

- Work through your own reaction to the news before preparing yourself to share this with someone else – put aside your own 'baggage' and personal feelings.
- 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 without interruptions.
- Know your facts and 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. Think about how and where you are getting your support from after these conversations.
- Have a framework for the conversation and consider rehearsing with a colleague beforehand. Active listening skills should be used to really listen to what is being said and asked by the parents and child. The conversation should be led by their questions rather than a professional agenda.
- 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 understand everything you are telling them.
- Always be open and honest.
- Give feedback to all who 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.

**You may also be interested in reading our prompts relating to *Advance Care Planning*.**



## 1b. Care before death: Advance Care Planning (Anticipatory Care Planning in Scotland)

An Advance Care Plan (ACP) sets out what actions should be taken when a child develops potentially life-threatening complications of their illness and provides an opportunity to discuss and agree these actions with the child (when appropriate) and the child's family. It is important that children and their families have choices in the care they receive as they approach the end of their life. Advance Care Planning can help minimise inappropriate admissions and interventions, as well as facilitate choice.

The following prompts should help you think through Advance Care Planning and consider the issues surrounding it.

- An Advance Care Plan can be helpful for families of children or young adults who have chronic and life-limiting illnesses to think about choices at the end of life, at the time of death and beyond.
- 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.
- Find out if the family have already discussed an Advance Care Plan or have thought in advance at all about their wishes for their child's end of life phase.
- The ACP should address issues of resuscitation and care in the case of acute deterioration of the child's condition. In Scotland, the Children and Young People's Acute Deterioration Management (CYPADM) Plan will be completed in conjunction with the ACP.
- Ideally you should have conversations about organ and tissue donation in advance as this affects decisions about place of death.
- A symptom management plan should be in place. You may find links with a symptom management team helpful in providing additional advice and support.
- The ACP should address the question of preferred place of care at the time of death, and after death, and explore the family's preference for caring for their child's body after death.
- Talk to families about their religious and cultural practices that will inform the care of the child before and after death.
- Families may want to start thinking about organising a ceremony prior to the death of their child.
- Sensitive communication and good information and advice for the family are essential in cases where post-mortems are required.

You may also be interested in reading our prompts on *Difficult conversations*.

## 2. At the time of death: Overview

These prompts give you an overview of the main things to think about when caring for a child at the time of their death. At such a significant time, it is essential to provide sensitive and meaningful support that meets the needs of each individual family.

The following prompts should help trigger any considerations you need to make at this stage of caring for a child.

- Joint planning should take place with the family, which includes discussion about the preferred place of care and death for their child.
- Always refer to the child's end of life plan at the time of death, where one already exists.
- Think about whether you are aware of the family's wishes for care at the time of death – if not, try and have a conversation as soon as possible to discuss this.
- The family's religious and cultural wishes should be considered at all times, and nothing should be assumed.
- Any wishes regarding organ donation or post-mortems need to be considered at this time.
- Think about whether there are any investigations, post-mortems or organ donation that needs to be carried out after death.
- Plans should be in place regarding who will verify and certify the death.
- Ensure you are aware of all the relevant legal and regulatory issues around death when a child in your care dies. If you're not sure, consult a colleague.
- Families' wishes for the moments before and after death should be respected, and you should try to facilitate the presence of the people they want around them at these times.
- It is important that families know who to contact after the death of their child, and when they need to do it. You can help advise them of this, and maybe write a list so they don't forget.
- Make sure you know what support is available for the family following the death of their child and through their bereavement, so you can let them know at appropriate times.

These prompts should be used alongside more specific end of life prompts on *Practical issues, Legal issues and Verification of death*.



## 2a. Care at the time of death: Practical issues

Predicting death in children is not easy and it can be an intensely emotional time waiting for a child to die. Throughout this very difficult time it is always best to ask the parents what they want at each stage. Many parents need guidance on what they are able to do, for example holding their child or lying on the bed with them. They may want to sleep for a while before doing anything else. When a child dies, there are many decisions and arrangements that need to be made and dealing with the practicalities can feel overwhelming.

**The following prompts should help you when considering the practical issues that will need to be attended to at the time of a child's death.**

- When you think a child has died do not feel you have to immediately verify the death – you do not have to rush to do anything.
- 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.
- Parents may wish to be involved in the personal care of their child after death, and this presents an opportunity to recognise cultural 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 and you may need to repeat this information several times.
- You may find some families prefer information in written format so that they can refer back to it.
- Enabling parents to do things in their own time and at their own pace is important. They should not feel rushed into any decisions or feel pressured to move things forward before they are ready.
- You should inform families about the choices they have in the care of their child eg their child can be taken to a chapel of rest and remain there until the funeral, or their child can be taken to a chapel of rest and then return home at any point before the funeral, or their child can remain at home until the funeral, or local hospices may be able to offer care in their cool room or special bedroom.

**You may also be interested in reading our prompts on *Legal issues and Verification of death* which should also be helpful at the time of a child's death.**



## 2b. Care at the time of death: Legal issues at the time of death

When a child dies, there are a number of legal requirements that need to be met. These include the process of verification, certification and notification of death and also the registration 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. Professionals should be mindful of the need to advise parents about post-mortems where applicable and to request cremation certificates. 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. The death certificate must be signed by a doctor and should be given to parents straight away wherever the child dies.

**The following prompts should help you think through the legal issues that need to be considered when a child dies.**

- You should anticipate and plan as far as possible how to manage the death of a child with a life-limiting or life-threatening condition, in order to avoid any unnecessary distress to the family and to ensure that correct processes are followed.
- You should be aware of the law and policies to be followed in your local area and help ensure that agreed procedures are followed by all involved.
- It is important to recognise the distinction between expected and unexpected death. If death is unexpected or suspicious in any way, you must report this to the doctor. It is advisable to notify the doctor and coroner/Procurator Fiscal simultaneously.
- Make sure you have received sufficient training to understand good practice at the time of death and legal issues at the time of death eg role of the coroner, the difference between verification, certification and notification of death.
- You should work with the family and encourage them to gather the information they need to register the child's death. Many families worry about what they 'have to do' when their child dies – there are only two legal requirements to fulfil: obtaining the death certificate and registering the death.
- Work with the family to ensure that the relevant organisations and professionals are informed of the child's death, that equipment is removed from the home at an appropriate time and that controlled drugs are disposed of in accordance with local policy.
- Contact your local register office to find out whether the Tell Us Once programme is operational in your local area, which helps families tell government agencies just once about a person's death.

**You may also be interested in reading our prompts on *Practical issues and Verification of death*, which should also be helpful at the time of a child's death.**



## 2c. Care at the time of death: Verification of death

Verification of death is an integral part of end of life care. It can be achieved sensitively and helps avoid delays. It enables families to continue to care for their child and carry out their choices and wishes after death. Verification of death is a relatively new role for many children's nurses.

**If you have been trained to undertake verification of death and the child's death is expected, the following prompts should help you think through the process.**

- You should ensure that there is clear, sensitive, and effective communication with the family.
- You should be aware of the policy and processes that are in place to support Registered Nurses in the verification of death. You must ensure that verification of death is only undertaken in accordance with the law and local policy and know when verification of death is not possible.
- You should have received training to ensure you have the knowledge, skills and competence to undertake the verification of expected death and understand your accountability in practice.
- Early conversations and planning about who is going to undertake verification of death means families know in advance what is going to happen.
- The child and family should continue to be respected and treated with dignity throughout the process.
- You should be aware of the clinical signs and assessment for confirmation of death (circulatory, respiratory and cerebral).
- Documentation of the verification of death is essential; you should ensure that this is completed appropriately and in a timely manner.
- You should notify the appropriate agencies and individuals in accordance with local policy following the verification of the child's death.

**You may also be interested in reading our prompts on *Practical issues* and *Legal issues*, which should also be helpful at the time of a child's death.**



## 3. Care after death: Overview

These prompts give you an overview of the main things to think about when working with a child and family after the child's death. Care of the child and family after death includes the consideration of many areas of care, support and regulatory requirements.

**The following prompts should help trigger any considerations you need to make at this stage of caring for a child.**

- You should be aware of the policy and procedures locally and within your organisation when caring for a child after death.
- You should ensure the family are given appropriate information, resources and advice and, if appropriate, give them information about access to a cool room or borrowing cooling equipment for the ongoing care of their child's body following death.
- Families may require guidance and information around registration of their child's death and you should check that they have appropriate support with funeral planning.
- Sensitive and thoughtful communication is essential at all times when supporting families after their child has died.
- Consider all of the child and family's needs including their spiritual, religious and cultural needs.
- Ensure that siblings are included and involved, and that grandparents are cared for and supported along with other family members, as well as friends that are important to the child and family.

**These prompts should be used alongside more specific end of life prompts on *Care of the body* and *Preparation for a ceremony* and *Bereavement support*.**





### 3a. Care after death: Care of the body

Alongside the emotional and spiritual care of the family at the time of death, there are a number of practical aspects of care that need to be considered. The choice of where to provide care after death may include a combination of options including the hospital ward, the hospital mortuary, the funeral directors, at home or at a children's hospice.

**The following prompts should help you think about the various aspects of caring for a child's body after their death.**

- You should care for the child and family with dignity and respect at all times.
- You need to be aware of organisational and local policies in caring for a child after death.
- You should ask the family what their needs and wishes are and work with them at an appropriate pace – it is essential for parents to retain control and choice in the care of their child, for example they may wish to wash and dress their child. Siblings may also wish to be involved in any aspect of caring for their brother or sister.
- Think about any religious requirements involved in caring for the body.
- You should be knowledgeable and informed about changes to the child's body and the best way to deal with this and to be up to date with new technologies in caring for a child after death. Families will need to be made aware of likely changes to their child's body.
- You should ensure continued care of the body, the eyes, mouth, skin and attention to any leakage or bleeding.
- You should be aware of the correct policy and procedures for discontinuing controlled drugs, any IV or subcutaneous infusions and medication. Following verification of expected death it is acceptable, if parents agree, to remove other medical equipment, cannulas, nasogastric tubes, gastrostomies and tracheostomies. You should be prepared for there to be some leakage. If in any doubt about this aspect of care, seek advice.
- Moving the child in to the coffin can be a poignant moment – it needs careful planning and support from the funeral director. You should be aware of the needs and wishes of the family and whether they wish to be present at this time.
- It is essential that the importance of cooling the body whether this is at home, a hospice or at the funeral directors is recognised.
- You should seek continued support and regular supervision when caring for child at the end of life and after death.

**You may also be interested in reading our prompts on *Preparation for a ceremony* and *Staff support and supervision* which may also be useful after a child has died.**



### 3b. Care after death: Preparation for a ceremony

Planning a funeral, or other ceremony, is a task that many families immerse themselves in, but do bear in mind that others find the task overwhelming and may distance themselves from it. Many families want to ensure that the service captures the very essence of their child and the memories they hold. 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.

**The following prompts should help you when preparing to talk to a family about planning for their child's funeral or other ceremony.**

- Find out how much discussion of the child and families wishes regarding a ceremony have taken place before the child's death.
- Be sensitive to the cultural and spiritual wishes of the family. Customs vary widely between cultures, and between religious affiliations within cultures. The most important thing is to ask the family what they want, and not make assumptions.
- Recognise the importance of choices for families, enabling them to make informed decisions.
- You may need to direct and signpost families to advice and information – it is good practice to have a folder of useful information available for families to look through.
- Try as much as you can to support families with a number of practical tasks eg service sheets and choosing flowers.
- You need to ensure that the family have an established relationship and are comfortable communicating with the funeral directors.
- You should provide families with a named person that they can contact in the days and weeks following the funeral.
- It is good practice to make a follow up telephone call about six weeks after the funeral, to see how the family are doing, and what sort of support is needed on an ongoing basis.

**You may also be interested in reading our prompt sheets on *Care of the body* and *Bereavement support*, which may also be useful after a child has died.**



### 3c. Care after death: Bereavement support

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

**The following prompts should help you when thinking about how you will support a family after the death of a child.**

- Parents should feel in control of events before and after death and should be able to follow their own choices and wishes. Help them to avoid being rushed into decisions or activities that they don't feel ready for.
- Reassure family members that whatever they feel or do will probably be 'normal', and it is important to try and respect their own instincts and those of others also grieving, about what is right for them as individuals.
- Recognise that every child and family's experience is different and they will need different levels and types of care during their bereavement eg some will need immediate support, whereas others may need support years later.
- Find out about the many sources of help and support available, both locally and nationally so that you can help to signpost families to the services that are most appropriate for them.
- Bereavement support should be offered based on assessed need.
- The bereavement needs of siblings, grandparents and the extended family should be recognised and support offered.
- Staff support is essential. Debriefing, ongoing staff support and supervision should be readily available.

**You may be interested in reading our prompts on *Care of the body* and *Preparation for a ceremony*, which may also be useful after a child has died.**



### 4. Staff support and supervision

Working in children's palliative care can sometimes be a highly stressful environment. Professionals have to cope with the emotional and spiritual dimensions of working with those who are suffering, dying and bereaved. They need diverse and strong personal coping strategies in order to deal with the demands of the job.

**The following prompts should help you think about whether you are receiving sufficient support and supervision in your job.**

- Be confident that your experience has made you an expert in how to be empathic, understanding and able to communicate with children who are sick or dying, and their families.
- It is important for you to acknowledge and accept when you cannot 'save' someone.
- You can help build resilience in yourself by setting boundaries that are strong enough for personal protection but flexible enough for when circumstances change.
- Maintain your health and energy by eating, sleeping and exercising well.
- Try to maintain an optimistic approach, seeing the best rather than the worst in things.
- Try and nurture relationships with others so that you don't feel isolated. Other people can make you feel appreciated, they can help put things in perspective, and they can offer someone to talk to.
- Remember the importance of teamwork in order to provide good children's palliative care.
- Make sure you have a proper appraisal or review. It's important to reflect on where you are and plan where you are going.
- Get adequate supervision, as this provides a system for talking through difficult cases, sharing problems and planning the way forward.
- Make sure you have debriefs following the death of a child.







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