

End of life planning series

1. Care before death

This sheet gives you 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.



1. Care before death

- ⦿ 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 and ensure that 'as required' subcutaneous and other medication is prescribed according to an agreed protocol to manage symptoms.
- ⦿ Ensure that the family has up to date emergency contact details for relevant staff and agencies. The GP practice, care team (e.g. community children's nursing services, consultants) and others (e.g. 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.



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Difficult conversations

Good communication is key to providing good 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 by allowing enough uninterrupted time.
- ⦿ 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.
- ⦿ Have a framework for the conversation, 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 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 end of life prompt sheet on *Advance care planning*.

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Advance care planning

An Advance Care Plan sets out what actions should be taken when a child develops potentially life-threatening complications of their illness. Actions will be discussed and agreed by 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 (ACP) 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 ACP, 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.
- ◉ Ideally you should have conversations about organ and tissue donation before the child's 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.
- ◉ 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.



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2. Care at the time of death

This sheet gives 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.



2. Care at the time of death

- 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 exists.
- You need to 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 transplants that need 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.



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Practical issues

Predicting death in children is not easy and it can be an intensely emotionally 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 may 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 e.g. 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 end of life prompt sheets on *Legal issues and Verification of expected death* which should also be helpful at the time of a child's death.

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Legal issues

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 e.g. 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 end of life prompt sheets on *Practical issues* and *Verification of expected death* which should also be helpful at the time of a child's death.

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Verification of expected death

Verification of expected 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 expected death is a relatively new role development for many children's nurses and further information and descriptions are included in *Verification of expected death in childhood: Guidance for children's palliative care services*, Together for Short Lives, 2012, which is part of this End of life planning series.

The following prompts should help you think through the process of verification of expected death, and should help you decide if you are the right person to verify the death.

- 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 expected 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.



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3. Care after death

This sheet gives 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.



3. Care after death

- ⦿ 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 and access to a cool room 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 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.
- ⦿ The bereavement needs of the whole family should be assessed and support provided to meet these needs.



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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, a cool room at home or 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 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. Parents 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.
- Families will need to be informed of any changes to their child's body and you should make them aware of likely changes.
- You should be aware of the correct policy and procedures for discontinuing controlled drugs, any IV or SC 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 any leakage and if in any doubt about these or other equipment, seek advice.
- 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.
- You should ensure continued care of the body, the eyes, mouth, skin and attend to any leakage or bleeding.
- Moving the child into 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 end of life prompt sheets on *Preparation for a ceremony* and *Bereavement support* which may also be useful after a child has died.

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Preparation for a ceremony

Planning a funeral, or other ceremony, 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 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 preparing for their child's funeral or other ceremony.

- ◉ Find out how much discussion of the child and family's wishes has already taken place regarding a ceremony before the child's death.
- ◉ You need to ensure that the family have an established relationship, and are comfortable communicating with the funeral directors.
- ◉ 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.
- ◉ You should provide families with a named person that they can contact in the days and weeks following the funeral.
- ◉ Recognise the importance of choices for families, enabling them to make informed decisions.
- ◉ 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 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 e.g. service sheets and choosing flowers.



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

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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 their 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 aspects of care during their bereavement e.g. 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.



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4. Staff supervision and support

Working in children's palliative care can sometimes be a highly stressful environment. Professionals have to cope with the emotional and spiritual dimension, generated by 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.



4. Staff supervision and support

- ⦿ 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 family members.
- ⦿ 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 team work 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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