

## When a child dies – questions parents ask

This factsheet has been developed to support families and carers preparing for the death of a child. The death of a child is devastating, and every experience is unique. There may never be a good time to approach this and talk about a child's end of life. But having information about what to expect and knowing where to go to for support can help families prepare and ensure that they are able to spend time together as a family. Families will need time to explore their wishes and access good support from health and social care professionals caring for their child.

Here are some responses to some questions often asked by parents. It's not intended to replace any face-to-face support offered by a child's care team, but may act as a useful prompt to inform families.

### **How will I know that my child is facing the end of their life?**

When a child with a life-limiting or life-threatening condition is dying, it can be difficult to recognise when they are moving towards their end of life. Their symptoms can fluctuate and it can be difficult to know when a deterioration in their condition will result in the child's death. This is a very distressing time for families and means that end of life care for children can be complex for the care team around the child and for the family to manage. It's very difficult to predict what will happen next. Even if a child is thought to be at their end of life, it's important to have multiple plans in place – an end of life plan and a plan to ensure the ongoing care of the child or young person in cases where they survive. Doctors and nurses often refer to this as parallel planning. Honest, open and sensitive communication between the family and their child's care team is vital. Ideally, there should have been open communication over time, before the last weeks, days or hours of the child's life. These conversations should enable plans to be made in advance so that families have realistic expectations of what may happen.



### **What about our wishes for our child's end of life?**

Professionals caring for seriously ill children often talk about an Advance Care Plan or an end of life plan. Sometimes these plans have other names, for example an end of life wishes document.

An end of life plan captures the discussions between families and professionals about a child's care and brings together a family's wishes and the needs of their child into a practical plan relating to care at the time of death. Having this plan in place ensures the best quality of life for the child, and the best possible death. If you are not sure about what plans are in place, do talk to those professionals who are caring for your child.

### **Do we have a say on where our child dies?**

Every child's needs will be unique, and choices about where end of life care will be provided depends on many factors

including the child's individual care needs, the family's preferences and doctor and medical team's opinion about treatment, and where the care can be delivered safely. At all times professionals will ensure that decisions taken are in the child's best interests and that the child's welfare is central to all considerations. However, the family's preferred choice of the place of their child's end of life care may be limited by local resources and the child's condition.

It's important that when the time comes, loved ones are close by, with privacy and space, whether the death occurs in hospital, at home or in a children's hospice.

Options for where end of life care may take place should be discussed as part of the end of life planning. It is important that families discuss their wishes with the team caring for their child. Every effort should be made to support the family (parents, siblings, grandparents and other extended family) to spend time together, caring for

their child and building memories that they can cherish in the months and years to come.

### **What happens after their death?**

Families need to have time and privacy with their child in the hours and days following their death. They need to know that almost anything they decide is possible, including moving the child's body to another place. There are special cooling mattresses that can be used to enable a child's body to be taken home. Some families may choose to use the 'cool room' at a children's hospice. It's important for families to explore what's possible with the team caring for their child. It can be helpful for families to care for their child's body during the hours or days after their death. This may be the only time when they feel that they can truly 'parent' their child, free from medical equipment, tubes and monitors. Some families may wish to take a lock of their child's hair, make hand or footprints and some like to take photographs of their child at peace.

Some families will want to carry out cultural rituals or have spiritual wishes which are individual to them. These needs should be discussed and the family supported to achieve these important rituals which can help to bring healing and closure.

Whether a child's death was expected or not, it is important to understand why children die. Following the death of a child, a [Child Death Review](#) is undertaken when information about the circumstances of their death is collected and summarised from records held by ambulance services, hospitals, community health services, schools, police, children's services and other agencies.

Discussions about post-mortem may need to take place and families will need sensitive and clear information to help them with any decisions about this. There are a number of reasons for a post mortem to be carried out, whether this is the choice of the family, a coroner's request or a request from professionals caring for the child.

### **What support will be available for bereaved families?**

Bereavement is unique to every individual. Families start to grieve from the moment they find out their child is likely to die young and they will need bereavement support throughout their child's life, death and beyond.

No one knows how they will feel or react after the death of a child. People describe a 'rollercoaster' of emotions, ranging from numbness to furious anger, profound sadness to perhaps a certain relief. Some parents may wonder if they will ever feel positive or happy again. It is important for families to trust their own instincts about what is right for them as individuals. Other family members and friends may experience or express grief differently, which can be difficult. Children grieve in different ways to adults and the bereavement needs of brothers and sisters and other children should be recognised and supported.

Children's hospices offer bereavement support to families and there are lots of specialist bereavement charities. Visit Together for Short Lives' website or call the Helpline to explore what support is available locally.

## Where can I find more information?

Together for Short Lives has produced a booklet for families called "[Caring for your child at end of life](#)".

There is further information to support families and carers, including a Family Companion and a range of factsheets. You can find them on the family section of our [website](#).



**Together for Families Helpline & Live Chat**  
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