

Supporting a child or young person when someone has a life-limiting illness

It can sometimes be hard for parents and carers to know how to best support their child. This leaflet is designed to help you through that process



Be open and honest

Don't pretend that everything is alright when it isn't. Children depend on the adults around them to help them understand and cope, so give them as much information as they need. This will vary according to a child's age and developmental level of understanding. Younger children may need more general information while an older child may want more detail and ask lots of questions. Answer questions as honestly as you can. If you don't know the answer, say so. In our experience children often know much of what is happening even though no-one has explained things to them. If nobody talks to them about it, they can be left feeling isolated and unable to share their worries.

Offer reassurance

Children and young people normally need to know what will happen to them if their parent or guardian becomes too ill to care for them and after they have died. Being

reassured that there is a known and loving person who will continue to look after them is important to help them feel secure.

Where do I start?

Those closest to the child are usually the best ones to explain what is happening. If you don't know where to begin, start by asking the child/young person what they think is happening. Approach it as a process rather than a one off conversation. Avoid giving too much information in one go, especially with younger children. Some children may need to be told the information on several occasions to be able to take it in.

What do I say?

Use clear language and avoid euphemisms for death and dying (passing away, going home, going to sleep) which are likely to be misunderstood by children. It's sometimes easier to have difficult conversations when you are doing something else like

cooking, or taking the dog for a walk. This is particularly true with older children who may feel uncomfortable having eye contact or showing emotions. Prepare a child for what they may see. For example if visiting in hospital, the medical equipment they may see, but also changes in a person's appearance or in how they communicate.

What if I cry?

You don't have to protect children from your sadness. Children look to you to model how to manage sadness and loss. However if you feel that you will be completely inconsolable consider having someone familiar to the children with you for support.

How will they react?

In any number of ways but it's important to let them express their feelings, whatever they are and reassure them that whatever they feel – sad, angry, frightened – is okay and quite normal. Try not to ask them to be strong, not to cry, or tell them that they shouldn't be angry. Encourage them to talk about how they feel if this is what they want to do. Emotions may seem to come and go. You may find that a child is in the depths of grief one minute and happily playing minutes later – this can feel bewildering but children often (although not always) grieve in this way.

Involving Children and Young People

Children need a way to keep in touch with the person who is ill and when the time comes, to have an opportunity to say goodbye in a way that is appropriate to their age, understanding and relationship with the person. Ask them what they would like to do. They may like help with writing a card or a letter. Every child is different but some children will want to be there when the person dies, to see their body after they die or to attend and take part in the funeral. Our experience is that it is usually

important for children and young people to have the opportunity to attend the funeral, unless they really don't want to. We often hear regrets from older people who didn't attend the funeral of a loved one.

Making Memories Together

Recording special memories together can support your child in keeping a connection to the person once they have died. Ask children if they would like to do this and for their ideas of how to do it. This could include talking about photographs together, making a video clip, creating a memory box or looking through treasured items. The adult who is ill may want to write letters into the future for the child, create a journal or complete a little box of thoughts.

Everyday Routines

Children and young people need a degree of normality and routine, even when things are difficult. This is likely to include continuing to attend school, time to play, going out with friends, keeping regular bedtimes and mealtimes or other activities such as sports or hobbies.

Who can help?

Dorothy House Family Support Team offers a range of support for patients and families under our care

- Telephone support and advice and/or meeting with you to help support you in supporting your child.
- Books, leaflets, memory boxes, box of little thoughts that an adult can prepare for a child.
- Meeting with parents, families and children together and/or seeing children and young people individually
- Opportunities for parents to meet and talk to other parents
- Groups and activities for children and young people
- Support and advice to school staff
- Signposting to other services

For further information, contact the Family Support Team: 01225 965 803
Alternatively, contact the Clinical Coordination Centre: 0345 0130 555