

# Supporting children and teenagers when someone has a life-limiting illness



Information and guidance  
for families

# Supporting children and teenagers when someone has a life-limiting illness

Supporting children and teenagers through life-limiting illness and loss is not easy especially as parents, caregivers and family members are coping with their own feelings about the situation. Knowing how best to communicate with children while also wanting to protect them can feel incredibly difficult. This leaflet provides families with guidance for those with a life-limiting illness supporting children.



# I've a life limiting illness – how do I tell my children?

Finding the right moment to tell your child you have a life-limiting illness may feel impossible. You may find the conversation happens spontaneously; or you need to set aside some time; however it is best to avoid bedtimes.

Children, even when very young, can often sense when something is wrong and will feel more secure when told the truth. Children will often try and make a complete story and not having information can cause misunderstanding. Although it's natural to use terms like a sore tummy or poorly head, it is advisable to name the illness "Mummy is very poorly, she has a brain tumour" Doing this avoids a child worrying that someone who has for example a headache, has the same illness.

Children may feel responsible when things go wrong. It is important they are given reassurance that they are not to blame for causing a person's illness.

Try to avoid making promises you can't keep. Providing updates about appointments, treatment and changes in the person's physical appearance will help your child to feel included and reassured. Some children will not want to know all this information; they will lead you in what is and is not helpful for them.

It's helpful to keep to normal daily routines as far as possible, and while it's understandable to want to protect your child it's also good to maintain the same boundaries you have as a family. Additionally, it is advisable to tell your child's school or college. It may be that your child has a particular teacher they feel comfortable with and can be given the opportunity to spend 1-1 time with them.

# Telling a child that someone is going to die

When it is apparent that a person is becoming more unwell and is going to die, telling your child will probably be the most difficult conversation you will have with them. However, preparing them for the death enables them to spend time with the person and say goodbye. Some people find it helpful to have another family member supporting them; others prefer a professional for example a nurse or doctor. It can be helpful to start the conversation by checking out how much your child already knows and understands. Be led by your child and keep the information bite-size, simple and factual.

“I have something very sad to tell you. You know that Mummy has been poorly with cancer for a while now...”

“Well, the doctors and nurses have been trying very hard to make her well again, but all the things they have been doing aren’t helping her. Which means they can’t make Mummy better and she is going to die. We are not sure exactly when, but it will be soon. This isn’t your, mine Mummy’s or the doctor’s fault she is just too poorly.”

Clearly a child’s age will influence how you talk with them; however, whatever the age it is important to use the word die so they understand what is happening.



Your child may experience many feelings, for example anxiety, shock, scared, numb, withdrawn, guilt, relief, sad. Sometimes younger children will appear not be affected or have practical worries like “who will take me to football practice” Alternatively they may need to ask the same questions repeatedly. It’s okay to not know the answer to every question but let your child know you will find out the answer for them. Being open and reassuring is most helpful at this time.

Older children and teenagers are likely to want more detailed information and to ask more searching questions. They can think more deeply about the impact of a parent’s death, and they too need opportunities to discuss things with someone they trust, especially when they have had some time for the news to sink in. Spending time with their peers may be an important source of support for them.



Children need the opportunity to spend time with the person with the knowledge they are going to die. Although watching the physical deterioration of someone so special can be frightening, with support and guidance, children can manage this. Offering updates about any changes in the ill person's physical appearance will help children to feel further involved and prepared.

Spending the last few days with someone you love is inevitably heart-breaking but allowing your child to be part of this will help them in their grief.

Some children will find it too difficult to spend time with the person who is ill. Although this can be upsetting for family members, there are other ways a child can maintain links with that person: phone calls, cards, pictures, flowers or suggesting your child creates a playlist of the person's favourite music for them to listen to.

Children and teenagers may feel they have to be brave and can worry about being an extra burden. While they need to know you are there to care for them, it can be reassuring for them to know that you are sad too and sharing this sadness and being able to cry is natural and okay.

## Children with additional needs

As your child's parent or carer you will know them best and how you share information with them will be appropriate to their developmental age and additional needs. It may be they will need extra help with their understanding and ways to express feelings. Although it may not be possible to understand what a child or a young person with profound and multiple learning disabilities understands when someone significant dies, they will certainly be aware of that person's absence and of the impact on their daily life that may result.

# Looking after you

As a parent or carer you will be experiencing your own grief whilst trying to keep everyday life going. If possible, try to have some space for you – whether this is accepting offers of practical help or talking to a friend or with a professional.

If you would like to arrange a counselling session please ask to be referred to the Family Support Service at St Michaels Hospice or contact us directly on **01256 848892** or email **family.support@stmichaelshospice.org.uk**

## Useful organisations

### **Child Bereavement UK**

Tel: 08000288840

[www.childbereavementuk.org](http://www.childbereavementuk.org)

### **Riprap**

Website providing information for young people who have a parent with cancer. Includes a section on bereavement support for young people.

[www.riprap.org.uk](http://www.riprap.org.uk)

### **Simon Says**

Providing counselling, guidance, information on and resources for families of bereaved children living in Hampshire. Also facilitates monthly support groups for children up to 11 years old.

Tel: 023 8064 7550

[www.simonsays.org.uk](http://www.simonsays.org.uk)

For recommended reading please see our website:

[www.stmichaelshospice.org.uk/our-care/bereavement-service/](http://www.stmichaelshospice.org.uk/our-care/bereavement-service/)

### **Sources:**

Rowan's Hospice

Child Bereavement UK



St. Michael's Hospice (North Hampshire), Basil de Ferranti House,  
Aldermaston Road, Basingstoke, Hampshire, RG24 9NB | 01256 844744  
[info@stmichaelsospice.org.uk](mailto:info@stmichaelsospice.org.uk) | [www.stmichaelsospiceorg.uk](http://www.stmichaelsospiceorg.uk)  
SCT/02/22