



St. Francis Hospice



# SOMETHING HAS CHANGED

HELPING A CHILD COPE WITH ILLNESS AND DYING



Telling a child that someone close to them is seriously ill or dying is hard. Having conversations will help them feel prepared and supported - now, and through their grief. Staff from the hospice can support you starting these conversations.

Children's understanding of illness, dying and death will depend on their age and their ability to understand what is being said. There is more information about different age ranges at the back of the book.

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## Helping a child cope with the serious illness of someone they love

You might feel unsure about what to say or worry that telling them will make things worse. Children absorb information around them and often sense when something is wrong. If they're left out of the conversation, their imaginations may fill in the gaps with something more upsetting, misinformed or self-blaming.

**Be honest and reassuring:** This helps children feel secure and supported. By telling them, they will be more prepared, giving them time to process the changes and adapt, to say goodbye. They are more likely to ask questions or express their emotions if you are open with them. Younger children may need reassurance that they cannot catch the illness, and that they did not cause the illness.

**Help them express emotion:** Children may have strong emotions and don't always find the words to express them. They can be confused about the range of thoughts and feelings they have.



**You can say:** *"It's okay to feel sad, or even not know what you feel. Whatever it is, I'm here to listen."* It may be helpful to consider possible explanations for their feelings with them. For example, *"Might it be that you are scared and sad because mammy is dying?"* or *"Could it be that you are angry because you don't want daddy to die?"* It's also okay to let the child see your own emotions, this shows them that it's normal to feel and express different feelings.

If a child is struggling to talk, try texting, or drawing together, reading books about illness, or playing. A hug can be reassuring and supportive, especially when they don't know what to say.

**Watch for behaviour change:** Some children don't know what to say and may express strong feelings through their behaviour. They may also have unexplained stomach aches or other physical symptoms. They may act like younger children as they seek comfort and soothing. All this is normal, but it can be very tiring as a carer when you are dealing with your own strong emotions. Persistent changes may be a sign they need extra support.

**Routines** give a sense of predictability in children's lives. As someone becomes sicker, it can be harder to keep routines as more time is needed with the person who is sick. Sometimes friends and family members can help out.



## Start the conversation early

It is best to begin talking with a child as soon as it becomes clear that someone they love is seriously ill. This gives them time to process the information gradually and ask questions along the way. You don't need to say everything at once. Share information in small steps, using simple and honest language taking account of their stage of development.

Parents are generally best placed to tell a child. You may struggle to accept the news the person you care about is dying. If this is the case, consider someone familiar to the child like a family member or friend, who might do it on your behalf.

It is not always possible for an ill parent to tell their child that they are dying. Being able to acknowledge and accept that they are dying can be painful enough, and it may be too hard to talk to their child about this. You may need to explain this to the child when you tell them the person is going to die.

Sometimes you may need additional support outside of the family. Staff in the hospice or a member of the social work team can support you with this task.



It may help to open up a conversation by finding out what the child knows about the illness. Then, building on what they know, you may give them new information. For example, you might start with: *"Grandma is ill, and the doctors are doing everything they can."* Later, as the illness progresses, you can gently explain that the doctors can't make her better. *"The medicine cannot make her better, but it is helping her feel more comfortable."*

Sometimes, things change more suddenly. You may have to give more information over a shorter period of time to ensure the child knows what is happening and what to expect.

## Prepare them for changes

Preparing people for death is complicated by the uncertainty about the information you have been given. It is not always possible for medical staff to predict how long someone will live and the situation can change weekly or daily. But when you have been told by the medical team that someone is dying and their death is imminent, it is important to share this information. Factors such as the age of the child, the way an illness progresses, and timing can be important. Young children have a limited concept of time and sometimes when they are told that someone is going to die within the next few weeks it may leave them anticipating it daily, so you might not tell them the full extent as early as you would an older child.

At the end of your conversation with the child it helps to give them the opportunity to ask questions. Check out their understanding of what you have told them. It's ok if you don't know the answers to their questions, tell them you will find out the answers for them. Let them see your feelings, it allows them to express their own feelings. Children may ask to go play their PlayStation or watch TV. This does not mean they have not heard what you said, more that they need time to think and process what you have told them.



Keep checking in. Ask open questions like, *'How are you feeling about everything today?'* Let the child talk or be silent. Be patient as they process their grief. When you give new information, they may not talk about it, but it is still important to do. It can help if you inform their teachers or other caregivers so they can support the child too.

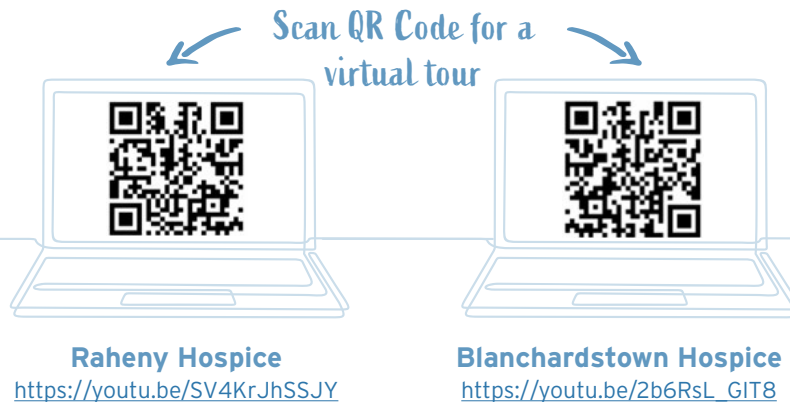
Bedtime is often a time when children can become upset or find it hard to sleep. It can help to encourage them to express their thoughts or feelings during the day when there is more time to process their feelings. Have a quiet hug time with the child. This allows them time and space to let out their feelings and stresses and may lessen the emotional disruption at bedtime.

## What about contact with the person who is dying?

Helping children have contact with the person who is dying gives them the chance to say goodbye. Preparing them for changes in the person or the environment will help them feel less fearful. Encourage them gently. Describe what they might see or hear: -

- Prepare them for any physical changes to the person who is dying. Hair and weight loss, voice tones, breathing, whether the person is awake or sleeping a lot.
- Describe the environment the person is in, including any equipment and medication in the room. Sometimes showing a photograph of the environment can help prepare children.

There are virtual tours on YouTube of our hospice in-patient units:





- Younger children may want to stay out of the room. That is okay. Allow them to be around and know it can take time for them to feel comfortable to go into the room.
- It can be helpful to guide the child on what to say. If the person is sleeping a lot, they can still talk to them.
- Let them know they can touch the person, give them a hug.
- Keep the initial visits short. Let them bring something that comforts them, like a teddy, comfort blanket or iPad. Older children may want time alone with the person who is dying.
- Give the children a small caring task such as drawing a picture, filling the water glass, reading or fixing their pillows. These tasks can help them feel included without burdening them.
- Introduce them to the nurse, doctor, carer, social worker and let them know it is okay to ask questions.
- Allow them the opportunity to ask any question about the dying process and what happens after.
- Consider activities to help say goodbye - in person, or through writing a letter or text, drawing a picture, or recording a message. This might be a conversation with the person where they tell each other how much they love each other. It may involve memory activities like doing family handprints. It might not be a spoken conversation in the room. There's no one right way.

## Explaining death

Explain that when someone dies, their heart stops beating. They no longer feel pain, hunger, or sadness. You may say there is a part of the person that you cannot see called the soul that has gone to heaven, if this fits with your beliefs. Children often have ideas about what happens, so ask them what they believe.

Remember that even when children are prepared for the death of someone close, they may still experience shock when the person dies. Knowing someone is going to die is very different from the actual experience.

## Look after yourself too

Caring for a seriously ill loved one and supporting a child is emotionally demanding. Make time for your own well-being. Talking to a friend, getting rest, or speaking with a professional can help you. Accepting help from family and friends can ease some stress. This allows you to support your child more effectively.

You don't need to be perfect - being present, honest, and loving is what matters most.

## After someone has died

It is important to include children in the rituals at the time of death and the funeral. Children need to know what happens after the person dies. Consider the following:

- **How the death is confirmed.** If the child isn't present when someone dies, consider when they will be told and who will tell them. For example, you might not wake a small child to tell them about the death, but a teenager may expect to hear as soon as the person has died if they are not present.

- **Should the child see the person laid out?**

Explain what happens: who will be there, what a coffin is, and how the person might look. Allow children the opportunity to be in the funeral home or house where the person is laid out and know it may take them some time to build up to see the person in the coffin. Some children choose not to see the person laid out, but being around everyone else is still supportive for them. Children may want to add pictures or notes to the coffin.

- **Should children go to a funeral?**

Funerals are an important part of the family saying goodbye together and celebrating the person's life. Include the child in some or all of the funeral. Talk to the child about the funeral. Listen to their worries or fears. Answer their questions honestly. Tell them about what will happen, explaining that they may feel sad and upset and that the adults around them may feel the same way.

It makes them feel part of it and gives an opportunity to say goodbye. It is also important for the future, when the funeral is spoken of that they can relate to the experience. Some children who do not get the opportunity to attend the funeral of a close relative may struggle or be angry about this in the future. Even very young children can be there with the rest of the family.

Children may also take part in a funeral by bringing up an item representing the person during the ceremony, reading a prayer or a reflection, or saying a few words about the person who died.

It is normal that children may find it hard to sit still or become upset during the funeral. It may be helpful to have a family member or friend who can care for the child during the funeral so you can be present to what is happening.

## What to say at different ages

Young Children (under 6) may not fully understand the permanency of death. They see it as temporary, like cartoon characters or like their game playing. They can sense changes and strong emotions. They need to know they are not the reason for the upset. It helps children to know that being upset is a way of showing sadness and that sometimes it helps to cry so that sad feelings aren't bottled up inside.



Use simple, consistent words. For example: *"Granny is sad because Uncle Sam is very sick"*. Repeat explanations as needed. Reassure them that they are loved and will be cared for. Hugs and attention can bring comfort and reassurance. Stable routines are helpful.

**School-age children (6-12)** often understand more about illness and the permanence of death but may still struggle with emotions. They might ask specific or even blunt questions. They may start to worry that someone else special may die. They may become anxious about their own health and their parents' health. Answer as clearly as you can and encourage them to share their worries. Reassure them that if you don't know the answers you will find out and get back to them.

They can be logical, understand rules. Children are able to take in new information and relate it to their current understandings. Children can focus on the reactions of their friends.

They may be aware of friends who have had family illness or had family members die, or they may feel different or alone if none of their friends have had these experiences. This may cause them to become withdrawn and quiet.

They may believe in an after-life. Children at this age have 'Magical Thinking'. They may think they have caused the illness by something they have thought or done, leading them to feel guilty or responsible. Assure them that nothing they thought or did could cause someone to be sick or die.

Keep an eye out for behaviour changes like eating patterns, sleeping patterns, schoolwork and friendships. This may be a sign of the child needing more support.

**Teenage years** can be a confusing time of change. Teenagers can grasp the meaning of serious illness and may want to talk about long-term impacts. Include them in family discussions about changes. They need information about who will look after them, or what will happen when the person dies.

They have the ability to understand more than they can manage emotionally. Outbursts and strong reactions to new information can be expected, as much as withdrawal and silence. They may react angrily or blame the people they are closest to, including the ill person, for causing them to feel this way. They may then feel guilty for their strong reactions or thoughts. Give them space but also let them know you are there to talk to when they are ready. Be respectful of their privacy, while offering support.

Explain that talking about feelings and worries is a helpful way of coping with stressful situations. Encourage them to engage with family members as well as spend time with their friends. Physical exercise, healthy eating and adequate sleep all contribute to their well-being.

Teenagers can both opt in and opt out of family life at different stages, sometimes focusing more on friends. This can increase when someone in the family is sick. They may have increased responsibilities within the family: to help with the care of the patient, look after younger children or take on other responsibilities. Support them to get a balance between taking on responsibilities and time with friends.

## Ongoing support

After someone dies, children may continue to grieve in waves. They might seem fine one day and very upset the next. That's normal. Keep checking in. Ask open questions like *'How are you feeling today?'* Let them talk or be silent. Be patient as they process their grief.

Inform their teachers or other caregivers so they can support the child too. You might also want to explore books, support groups, or professionals who specialises in child grief.

For further support of children and young adults experiencing a bereavement, St Francis Hospice has published two books that are available free of charge, with support from AWS in Communities:

Always in My Heart: A book for children about grieving (suitable for 9-12 year olds)



Scan QR Code  
for link



Finding Your Way Through Grief: for teenagers and young adults



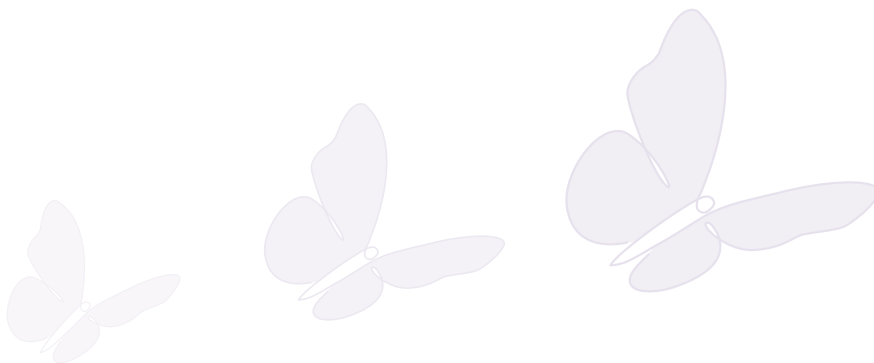
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Visit [www.sfh.ie](http://www.sfh.ie) to order your copies.

Sometimes you or the child may need added support.

Please ask a member of the hospice team about a referral to the social work team or contact us directly at [supportingchildren@sfh.ie](mailto:supportingchildren@sfh.ie).





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