

When someone is not expected to live: supporting children

Telling a child that someone important to them is not expected to live, and supporting them, may be very daunting, especially when you are distressed, in shock or grieving yourself.

For a parent who is seriously ill, the thought that their children will grow up without them is devastating. Or families may be facing the loss of a child, and the prospect of having to talk to the child and any siblings. To protect children, and themselves, parents or carers may want to avoid the subject for as long as possible, especially when it is not certain what will happen, and how family life will be affected.

However, children watch adults closely and overhear adult conversations. They are usually aware that there is something seriously wrong, even when adults think they have successfully hidden the signs. Children who are seriously ill often know more than their adults realise. Even very young children tend to sense that something is wrong, as they pick up on signs of tension and distress.

Children sense when important things are not being shared with them and this can lead to anxiety, confusion and feeling excluded. Their security is based on trusting the people who care for them. Avoiding the subject may leave them too worried to ask questions, afraid that they have done something wrong or are in some way to blame for what's happening. They need direct reassurance that this is not the case.

What do I tell the children and when?

Give clear, simple and accurate information, appropriate to the child's age and level of understanding.

Every situation is different. However, you could start giving a child more information when you know that the person's illness or injury means that they are unlikely to get better, or when the child is clearly showing that they need to know more, by asking questions or by showing their distress or anxiety.

Give information bit by bit, allowing them time in between to process and make sense of what they've heard and ask you any questions. Only give them the information they need at the time, and add more later.

Explaining the illness or situation

For young children, it is helpful to explain the illness or situation in basic terms, for example:

"Daddy's illness is called cancer. Because of it, his body can't work very well. You haven't done anything to make this happen, and you can't catch cancer like some other illnesses".

"Eddie was driving his car and it crashed. He was badly hurt and is in hospital, but he is so hurt that the doctors can't make him better."

Some children may ask directly if the person is going to die. It is best to be honest and support children in the reality of what is going to happen rather than try to protect them with false hopes, which can lead to them not trusting you later.

Telling a child that someone is going to die

The following is one approach that you could adapt, and this can be done in stages, over the course of different conversations:

- If the child knows something already, acknowledge this:
“You know that Joe has been ill for a long time, and the doctors have been trying to make him better.”
- Their response may help you to understand how much they already know. Ask what they’ve noticed about Joe recently. They might say something like *“he’s too tired to play with me.”* They may go on to say more about what they think is happening.
- Guided by what they say, you could say something like:
“Joe’s illness has got a lot worse and the doctors have tried everything they can. There isn’t anything more they can do now to make him better, and that means Joe won’t live for much longer. This means that Joe will die. We don’t know when this will be but the doctors think it could be very soon.”
- Allow children to express how they feel about what is happening. It is OK, and can be helpful for them, for you to show some of your feelings: *“I am sad and worried too, but you can still talk to me”.*
- Reassure them that there is nothing they did to cause the person’s illness or injury, and that they will be looked after.
- Acknowledge their grief, and support them emotionally by saying you (and others) are there for hugs, time to talk and to do things together. You can also ask them how they want to support the person.

Children’s reactions and answering questions

How children react will depend on their age, their life experience, their emotional maturity and their family’s culture and beliefs. Children under six years old may not understand the permanence of death, and will take everything that is said in a very literal way. They may ask lots of questions as they try to make sense of what is happening, and will need answers repeated frequently with sensitivity and patience. Older children understand that death is permanent and an inevitable part of life for all, including themselves.

There is often uncertainty about when someone will actually die. Some people die much sooner than expected and others live longer than anyone thought they would, surviving treatment after treatment. Young children often only understand things in very concrete terms, and being unable to provide them with a definite answer is hard. The family may have had to live with uncertainty for many months, or years, and may have prepared for the worst several times. In such circumstances it can be hard to believe that the person is actually going to die, and so children may not be willing to accept what is now being said to them. It may help to acknowledge how they feel, and encourage any questions they have.

As adults, we might fear the questions children may ask. They may be the very questions we dread or can’t bear to think about, but it is vital to try to respond to children at the right time for them and don’t put them off, as opportunities to support them may then be lost. Answer any questions honestly and simply, and check that they have understood what you have said. If you don’t know the answer, it is OK to say *“I don’t know, but if I find out, I’ll tell you”.*

When a child asks *“What happens when people die?”*, a simple answer that can be understood by most children is: *“when someone dies, their heart and breathing stops, and their body doesn’t work anymore”.*

You can also acknowledge that this is a good question that can be hard to answer, and ask the child what they think. This can help you to find out the child’s level of understanding and correct any misconceptions they may have. It can also be a chance to share thoughts according to family culture and beliefs.

Just as adults seek to protect children, so children may try to protect the adults around them by not showing their feelings. Also, children can switch quickly in and out of feelings, as they are not able to stay with very difficult feelings for long. However, they are still very much affected, and still need support.

Managing everyday life

Each child is likely to react in a different way. How they respond will be affected by their personality, age, level of understanding and the nature of the relationship they have with the person who is dying. Young children's thinking is often very self-focused, and it is not unusual for them to have practical concerns, such as 'Can I still go to football practice?' or 'Who's going to have his bike?'

Ways to support children include:

- **Time together as a whole family**, including the person who is dying if possible, and if this reflects their needs and wishes.
- **Time and space** for children to think and ask you questions.
- **Familiar routines** which help children to feel secure and comforted at a time of upheaval. It will help them if you can be honest and clear about what routines will continue and what may not be possible for a time. Older children and teenagers are likely to want more detailed information as their thinking and emotional understanding develops. They may ask searching questions about the impact of what is happening in the family, and what may happen in future.
- **Keeping contact with school** - telling your child's teachers what is happening at home can help them support your child appropriately while they are in school, where they spend a considerable amount of their daily life.
- **Keeping in mind the child's (and your) physical health** - such as eating and sleeping as well as possible during this difficult time, and continuing treatment for any medical conditions.
- **Continuing normal levels of discipline** can help a child feel safe within known boundaries. Children's feelings often show through their behaviour and their play. They may be more naughty or disruptive than usual with angry outbursts, or they may become quieter or more helpful than usual. These are normal reactions to an event in their life that feels anything but 'normal'.
- **Noting unusual behaviour** - children who are anxious may show behaviour changes, including not wanting to leave their parents, not being able to sleep, or behaving as if they were younger. Such behaviour often settles down with reassurance and support. If it continues over a long period of time, and is affecting how they function in daily life, it may be helpful to seek some additional support.

Keeping children involved

Children can offer a lot of support to family or friends who are seriously ill, by playing normally with them, or by simply keeping them company. Some people who are very ill, including children, can benefit greatly from 'normality' in those around them. Children feel more involved, and their self-esteem is boosted, by being able to help in care-giving, even in small ways such as adjusting the person's pillows or making them a card.

Where possible, ask children what they would like to do to support others, and provide them with the information they might need to make that choice. Being involved in making decisions can give children some control in a world where so much feels out of control.

It is very important to make time to simply be together and keep communicating, even if talking about the situation or the future is too difficult.

Support for you as parent, carer or professional

The courage it takes to talk to a child about serious illness or death cannot be underestimated. This is an enormously difficult time for the whole family and for those supporting them. Meeting the needs of children alongside your own emotional or practical needs may seem impossible at times. Use whatever support is available to you, and don't expect too much of yourself. You can call our confidential helpline on 0800 02 888 40 for further help and guidance.

Resources and further reading

Child Bereavement UK information sheets

Children's understanding of death at different ages

How children and young people grieve

What helps grieving children and young people

Books to read with a child

Available from bookshops or online booksellers, unless otherwise stated.

My Brother and Me

Courtauld, Sarah; illustrated by Rebecca Cobb

Picture book story about a sibling's serious illness, his stays in hospital, and how his brother copes with different emotions and feelings. The story ends with the brother being back at home and OK for now, whilst acknowledging uncertainty about the future. For children aged 4 – 10 years.

Only available from Child Bereavement UK.

When your Mum or Dad has cancer

Ann Couldrick; illustrated by Graham Jeffery

A short book for children and young people aged 7 and older. Including an introduction for parents, it explains cancer in a simple way children can relate to. It also covers many questions children ask, such as will the person die and what exactly happens, but tackles the answers with insight and honesty.

Available from Child Bereavement UK.

As big as it gets

A short and practical booklet by Winston's Wish which aims to help families cope with the serious illness of a parent or child. It includes a range of ideas to help you explain to a sibling what is happening and suggestions of what to say.

The huge bag of worries

Virginia Ironside; illustrated by Frank Rodgers

Picture book about Jenny whose worries grow into a huge bag of worries that follows her everywhere.

Jenny decides they will have to go. But who can help her?

For professionals

Available from bookshops or online booksellers.

Sibling loss across the lifespan: research, practice, and personal stories

by Brenda J. Marshall & Howard R. Winokuer