



Sibling Support

Paediatric
Palliative Care



PalliativeCare
AUSTRALIA

Sibling Support



Parents often express concerns about how to talk to their children about the diagnosis of a life-limiting illness. While there are a number of things to think about when deciding how to discuss the diagnosis, open communication can help children to feel included, respected and listened to. It may be helpful to speak with a member of your care team who can help answer questions and provide support.

Coming to terms with your child's diagnosis

Hearing the news that your child has a life-limiting illness that will shorten their life is devastating. Dealing with your own feelings, as well as coping with new, challenging and practical matters can be difficult. The thought of sharing this news with your children can be overwhelming. Some parents may think it's better for siblings not to know about the illness and extended family and friends often encourage this approach. However, talking to children early on will help them to cope better in the long term.

Building trust

Sometimes children who aren't sure what is going on, or who feel that something is being kept from them, may try and find out the truth in some other way. They may have overheard you talking and picked up a little bit of information. They may go searching for their own answers — talking with friends or looking on the internet. It's easy for children to fill in the gaps for themselves and possibly get things wrong. It's always best if your children hear things from you as parents, the people they love and trust. Children cope much better when this happens.

How do siblings feel about their brother or sister?

As parents you instinctively know when something is bothering or worrying your children. Similarly, your children can easily pick up on how you are feeling. Even if they don't know what is going on, they can pick up on the signs and know when you are not happy or when something just doesn't feel "right". Siblings may experience all kinds of emotions and feelings when they hear about their brother or sister's health. They may feel sad, angry, confused, guilty or fearful about the future. They may feel protective or loyal towards their sibling. They may worry about how it will change things, or worry that they may get ill too.

Children will need support in coming to terms with the news and it is important to help children express their feelings. Talking with them and finding special time for them will help. Often children, especially older ones, will understand that you have new demands and that time is precious. Some children will not want to bother you, or feel bad about taking your attention when they know you are busy. They can sometimes feel guilty about being able to do things their sibling can't.

Worrying about talking to your children

Many parents worry about how they can share their child's diagnosis with their other children. Perhaps you are worried about how they will react. You may want to protect them from the truth. You might not feel emotionally strong enough to say the words you need to, or worry about crying in front of your children. You may be concerned about using the right words to describe what is happening to their brother or sister.

Often there is so much happening at this time. You may have constant hospital appointments and lots of meetings with professionals involved with supporting your child. Balancing this with family life and work as well as finding time to talk to your children is hard. Giving as much attention as you can to all your children will help to reassure them. If they know what's going on, it's easier for them to adjust to changes in family life. These are all normal feelings. You might find some of your fears start to fade when you start opening up to your children.

Finding the right words

Being truthful may be painful, but it can save a lot of pain and misunderstanding in the future. It also builds the trust between you and your children. Some sibling's worries can be easy to address. They might worry that they could "catch" the same health condition or worry unnecessarily about dying. If you are worried about how to start the conversation or what words to use, there are lots of people you can talk to. We have included some key contacts at the end of this factsheet.

If you are in touch with your local children's hospice, you could talk to them about explaining things to your children. You can also talk to your GP or another professional who is supporting you. You might find it helpful to talk to your spiritual advisor or religious leader, or to other parents who have had similar experiences. You might not always know the answers to questions your children ask, but it's ok to be honest and say you don't know. Some parents find it easier to talk to siblings in the presence of a trusted professional, such as a counsellor or palliative care nurse, who can answer difficult questions and offer emotional support. Other parents will want to do this in the privacy of their own home, without anyone else present.

Finding the right time

Try and find a time that is right for you and your children. A moment when you know you have time and space and nothing will disturb you or when you know that you won't be distracted by other commitments. You might choose a regular time when you would normally talk to your family about important things. If you have a partner, husband, wife, friend or relative who is supporting you, take time to talk things through together. This may help you to find the right words and think through some of the issues that could come up. It also helps if you both know what you are going to say; that way there will be no mixed messages.

Finding the right approach

All children deal with things in different ways. Go at their pace and allow time for them to get used to the news. Keep things open so they know they can ask questions when they are ready. Be open, honest and encourage them to talk. Talking to very small children and toddlers can be difficult and you may prefer to explain things as they happen. For example when your child asks questions such as: "why can't my brother have dinner like me?" or "why is my sister always sick"? Reassure them that although there are new things to get used to, family life will carry on and there are lots of special family things that won't change.



Siblings will have their own unique relationship with their brother or sister. Having a disabled or seriously ill sister or brother can help to build strong sibling relationships. There are lots of ways to involve your children in caring for their brother or sister. Having a special role can make them feel included. Maybe there are games they can play with their sibling, or perhaps they can help you care for them. Try and involve all your children along their brother or sister's care journey, talking to them about changes and explaining the care or treatment that they need. Give siblings choice about how much they want to be involved and acknowledge the things they do to support their brother or sister. It will help your children if you make sure that key people in their life know what is going on at home. Talk to your children's teachers, nursery or day care staff and close family friends. It's a good idea to have regular meetings at nursery, day care, school or college so that sibling's teachers and support staff understand any changes that might affect them.

How siblings may respond

On hearing the news or having their suspicions confirmed about their brother or sister's health, siblings react in different ways depending on their age and personality. Some become quiet and want to be by themselves, some ask if they can go out to play, others get very upset and cry or get angry. Negative changes in behaviour may make parents feel that they have done the wrong thing, however it is normal for things to get worse in the short term and then get better.

"If you are worried about how to start the conversation or what words to use, there are lots of people you can talk to."

Remember that you are not alone

There are organisations and support available:

Siblings Australia

Siblings Australia is a national organisation committed to providing support for brothers and sisters of people with special needs; including disability, chronic illness and mental health issues. They provide workshops, print and web-based resources and networking opportunities for families and providers across Australia and overseas.

siblingsaustralia.org.au

Your General Practitioner/Area Health Service

Your General Practitioner (GP) and your area health service will help you link into supports.

Headspace

Provides early intervention mental health services for 12–25 year olds.

headspace.org.au

Canteen

Support for siblings 12–25 who have a sibling affected by cancer. Provides information, online resources & support.

canteen.org.au

Redkite

Provides information and emotional financial support to parents and families whose child has cancer.

redkite.org.au

Children's Hospice

Your local hospice may have a comprehensive sibling support service for siblings of children with life limiting illness whom access the service.