

## Understanding Siblings' Needs

**This family factsheet has been written for parents and carers of a child who has been diagnosed with a life-threatening health condition or a condition that will shorten their life. It has been designed to help parents who are worried about talking to siblings about their brother or sister's diagnosis and how this will affect them. We hope that this factsheet will provide reassurance around worries or anxieties about broaching this difficult conversation with siblings.**

### **Coming to terms with your child's diagnosis**

Hearing the news that that your child has a health condition that is life-threatening or will shorten their life is devastating. Dealing with your own feelings, as well as coping with new and challenging practical matters can be hard to bear. The thought of sharing this news with your children can be overwhelming. Some parents think it's better for siblings not to know or be told, and extended family and friends often encourage this approach. 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 protection or loyalty towards their sibling. They may worry about how it will change things, or worry that they may get ill too.

It's important to help children express their feelings. They will need lots of support in coming to terms with the news. 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 getting on with their own lives.

## Worrying about talking to your children

Many parents worry about how they can share their child's diagnosis with siblings. 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 is hard and finding time to talk to your children is hard as well. But 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 have started 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 siblings' 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, then 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 palliative care nurse, who is available to answer difficult questions and who can 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 really open so they know they can ask you questions when they are ready. Be open and honest and encourage them to talk. Talking to very small children and toddlers can be tricky. Maybe 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 ill"? 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 journey 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 of involving 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 their brother or sister. 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 staff and close family friends. It's a good idea to have regular meetings at nursery, school or college so that siblings' 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.

## Remember that you are not alone

There are lots of organisations and support available.

### Sibs

Sibs supports siblings who are growing up with a brother or sister with any disability, long term chronic illness, or life-limiting condition. They can provide parents with phone support on talking to siblings about diagnosis, as well as activities for explaining disability or illness to siblings.

[www.sibs.org.uk](http://www.sibs.org.uk)  
Tel: 01535 645453  
Email: [info@sibs.org.uk](mailto:info@sibs.org.uk)

### Young Carers

YCN is a UK-wide interactive site dedicated to young carers, offering information, advice, email support and supervised message boards and chat sessions.

[www.youngcarers.net](http://www.youngcarers.net)  
Tel: 0844 800 4361  
Email: [youngcarers@carers.org](mailto:youngcarers@carers.org)

### Winston's Wish

Winston's Wish is the childhood bereavement charity that provides services to bereaved children, young people and their families.

[www.winstonswish.org.uk](http://www.winstonswish.org.uk)  
Tel: 0845 203 0405  
Email: [info@winstonswish.org.uk](mailto:info@winstonswish.org.uk)

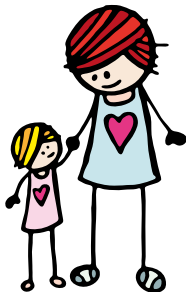
### Child Bereavement UK

Child Bereavement UK supports families and educates professionals both when a child is dying or has died, and when a child is bereaved of someone important in their life.

[www.childbereavementuk.org](http://www.childbereavementuk.org)  
Tel: 01494 568900  
Email: [support@childbereavementuk.org](mailto:support@childbereavementuk.org)

Many children's hospices also offer specialist sibling support sessions and activities. Contact our Family Support Hub for further details:  
0808 8088 100

Thanks are due to the UK charity Sibs for all their help and support in developing this family factsheet.



**Family Support Hub**  
Helpline & Live Chat: 9am-4pm, Monday to Friday

**0808 8088 100**

[info@togetherforshortlives.org.uk](mailto:info@togetherforshortlives.org.uk)  
[www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)



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