

# Serious Illness in the Family

When someone special is diagnosed with a terminal illness, families can worry about what to tell children and when. As parents or caregivers, we naturally want to protect our children from life's challenges. However, when we do this, we often under-estimate how much they need to know and how well they can cope with information we might feel is too sensitive or difficult for them to hear.

What we know is that children need clear, honest and age-appropriate explanations so that they understand what is happening and are prepared for what is to come. When they don't get this information directly, they might start to look for it elsewhere and believe things that are untrue which can be difficult and worrying for them. There is no 'magic wand' to fix what's happening for your family, and we can't prevent young people from feeling the many emotions they will experience at this time, but with open and honest communication, it's possible to strengthen their trust in caregivers, and reduce their anxiety.

#### Open and honest communication

Your child needs you to provide honest information about what is happening in their world and at their level of understanding. If you have children of various ages, speak to them together and pitch the conversation at the youngest. You can always add extra information for older children later.

### Jigsawing information

When sharing information with your child, think of it like building a jigsaw. You should begin with an initial conversation where they are told that somebody close to them is seriously ill and give the name of the illness. As changes occur, symptoms or side-effects arise, or when treatment begins, changes or stops, add in each change as a piece of information, just like adding the next piece in a jigsaw.

Only tell them about what is known. Don't project too far into what might happen in the future but reassure them that you will tell them when changes occur as this can help to manage anxiety about not knowing what is going on.

### Using concrete language

Use concrete language that all children can understand. Don't use euphemisms or metaphors, such as battling and fighting, as this can cause confusion and anxiety, especially in younger children or those with special educational or learning needs.

#### **Encouraging questions**

Encourage your child to ask questions and regularly allow time for them to do this. Be comfortable with not having some of the answers or with delaying the conversation if it feels too difficult at the time it is asked.





### Watching and Listening

Listen carefully to their fears or concerns, if they are able to share them. Where children don't or can't tell you, pay attention to their mood and behaviours as a sign that they are upset or worried.

Don't minimise their emotions by telling them not to worry, as this can lead to them still worrying but feeling unable to talk to you about it. Offer them empathy and then normalise and validate their emotions. Remind them that there is no right or wrong way to feel about what is happening.

### Offering choices

Life can feel like it is out of control when somebody in the family is seriously ill or dying and this can add extra stress or anxiety. Where possible, offering your child appropriate choices and involvement in care or family decisions can help them feel safer and more able to cope.

#### Behaviour and boundaries

Your child needs to know there are boundaries and behaviour expectations that are there to keep them safe. If we remove these boundaries, we can also remove their sense of safety which can cause difficulties with anxiety and self-regulation, potentially leading to more challenging behaviours.

Providing as much normality as possible and encouraging children to continue to participate in all of their usual hobbies, sports and social activities can help.

#### Self-care

Whether you are the person in the family who is unwell, or you are caring for someone who is, it is important that you take care of yourself as well. There is a very good reason that we are told when we board a plane, that we should put on our own oxygen mask before helping our child with theirs. We can't continue to help and support them if we collapse.

It is important to model taking time for, and care of, yourself as well as encouraging your child to do the same, whether through physical or creative activities, or with strategies such as breathing exercises or visualisation. They may like to put together a self-care bag or box containing items that will help with relaxation.





## Memory making

Finally, if you're able to, provide opportunities and resources that will encourage them to make and preserve memories of their loved one. For example, putting together memory boxes or photo albums.

For further guidance and advice and support, please visit our website: www.seesaw.org.uk



