

Family Support Resource

Supporting a child and young person when someone is not expected to live

When someone in the family has a life limiting illness and is not expected to live, the prospect of breaking the news to children can be difficult and daunting especially if you are upset. This is designed to help parents and carers support their child/children through this difficult process.

Dealing with the truth

Adults often underestimate children's ability to cope with the truth, not knowing can cause children and young people to feel anxious and confused. Pretending things are alright can make things worse. Children rely on the adults in their lives to help them make sense and manage, even very sad truths are better than not knowing what is happening. We cannot stop children feeling sad, we can however support them by giving them information & a safe place to share and express their feelings and voice their concerns.

It is important to answer their questions as honestly, age and developmentally appropriately as possible, it's also okay to say you don't know.

Offer reassurance

Sometimes children blame themselves for their parent's illness, it is really important to reassure them that nothing they have said or done has contributed. When a parent is too ill to care for the children, reassure them who will be responsible and care for them after the death. Knowing and understanding that there is a loving person who will continue to look after them will help them to feel secure and may alleviate anxiety.

Where do I start?

There is no right or wrong way to begin these difficult and sensitive conversations with children, however those closest to the children are usually best placed to explain what's happening. Think about how, what and when you talk to your children about your illness. If you are unsure how to begin you can start by asking the child what they think is happening, check their understanding of the progression of your illness and treatment. This is a process, a jigsaw and not a one-off conversation, avoid giving too much information in one go especially with younger children. Some children may need to be told the information on different occasions in order for them to be able to process and make sense of what they are being told.

Telling the children

Use clear language and avoid euphemisms for death and dying e.g. passing away, going to sleep or they're gone or lost, these can often be confusing & misunderstood by children. These sensitive conversations can sometimes be easier when you are doing something else, e.g. drawing, walking the dog, cooking together or any creative project. With teenagers in particular having eye contact and sharing emotions can be uncomfortable it's often better to be alongside them doing another task. Try to prepare your children for what they will see in hospitals or hospice e.g. the medical equipment, how the room or ward is set up and the person's appearance and any changes in how they communicate. Younger children may need more general information whilst older children and young people may want more details and facts. Things to tell your children:

- mum or dad is seriously ill
- the name of the illness
- your best understanding of what may happen

You may worry these conversations could lead to some difficult questions about the illness, taking the children seriously and encouraging them will help them feel included.

What if I cry?

It is okay to cry, however if when talking to the children you're concerned that you may be completely inconsolable, it may be helpful to have someone familiar to the children to support you. Children look to adults to model how to manage their feelings of sadness and loss, letting them see your emotions can show them that their responses to what is happening are normal.

How will they react?

Reactions will vary, there is no right or wrong way, it's important to let children express their feelings, whatever they feel e.g. sad, angry, frightened & love are appropriate, normal and okay. Reassurance and encouragement to talk about how they feel is helpful however talking isn't for everyone and some children may show and express how they feel in other ways. It's normal for the children to ask questions and these can range from "Did I make mummy sick?", "Can I catch it?", "Does it hurt?", "Who will take me to Brownies?" It is important that they understand they did nothing to cause the illness and cannot catch it.

Keeping children and young people involved

Children need a way to be involved, to stay in touch with the person who is ill and to be able to help in care giving. Even in small ways such as adjusting the patient's pillows, making them a card or drawing, taking them some food or drink, talking or reading to them. Ask the children if they want to help and be led by them.

Before visiting it can be helpful to ring the ward to find out how the person who is ill is doing on the day, if there any changes which will help you prepare children for seeing their parent.

Everyday routines

Keeping a degree of normality and routine is helpful for children, even when things are difficult. This may include continuing to attend school, time to play, going out with friends, keeping regular bedtimes and mealtimes or other activities such as sports or hobbies. If there are disruptions in their routine, where possible, keep children informed of the changes.

Making memories together

It is very important to make time to be together and keep communicating, even if talking about the situation or the future is too difficult. The courage it takes to talk to a child about serious illness or death cannot be underestimated. Recording special memories with your child can really support them and help in keeping the connection after the parent has died. If children would like to do this with you, encourage them to choose how they want to do it....it could be making video clips, music playlists, a memory book or memory box etc. Do what you can when you can and ask for support if you needed.

Who can help?

St Margaret's Family Support Service offers a range of support for patients and their young families under our care.

- Telephone advice, guidance and support, or meeting with you to support you in supporting your child/children (due to current crisis we are using video calls e.g. Zoom)
- Information and resources
- Meeting with families and children together or seeing the children and young people independently
- Opportunities for parents to meet and talk to other parents
- Group activities & events for families, children and young people
- Support and guidance to schools
- Signposting to other services.

For further information, contact Family Support Service: 01935 709483

Useful websites

<http://www.winstonswish.org.uk/>

<https://www.childbereavementuk.org/when-someone-is-not-expected-to-live>

<http://www.childbereavement.org.uk/>



Books

As Big As It Gets, Supporting a child when a parent is seriously ill (Winston's Wish Pub. 2007)

The Secret C: Straight Talking about Cancer (Winston's Wish Pub. 2009)