



**University
Hospitals Sussex**
NHS Foundation Trust

Supporting a child when someone in the family has a serious illness

Neuro-oncology

Patient information

The diagnosis of a serious illness and subsequent treatment process can be a frightening and difficult time for any patient and their family.

For families with young children or teenagers there are additional concerns about how children will re-act to being told and how they will cope with the changes the illness will bring into their lives.

We hope that the following information will help you start those difficult but important conversations. This leaflet is for parents, carers and family members dealing with a serious illness.

How does talking help children?

Children who are not given the opportunity to talk about things openly may:

- Feel frightened because they do not understand what is happening.
- Feel alone.
- Think that they are not important enough to be included.
- Imagine something worse than the reality.

Trying to protect children from things that will hurt them is natural. However, children of all ages often know more about what is happening than adults realise.

It is important to give your child the chance to talk openly about their fears and worries. It shows you trust them and it helps them to understand that it is alright to have feelings of anger, fear, sadness and hope when a person they are close to is seriously ill.

You may be struggling with the news yourself but not explaining what is happening may make your child feel even more vulnerable. You may find that by giving yourself a chance to get used to the news before you begin to talk to your children may help.

How should children be told?

There is no right or wrong time or way to do it. As a parent, you are the expert when it comes to your child: you understand how to communicate with them, how they might react and what support they may need.

Some children may prefer to discuss things while you are driving, gardening, on the way to school or while they are in the bath. Don't be surprised if after being told some children ask no questions at all!

Things to think about when telling a child

- Be honest. If they think you are hiding something they will find it hard to believe that they are being told the truth.
- If you have more than one child, it is best to tell them together if you can. If you are telling them separately, do it as close together as possible. Try to avoid only telling the older children as this can put a burden on them.
- See this conversation as a part of a jigsaw. This is only the start.
- There may be lots more pieces to put together and depending on the age of the child, these pieces may be added over minutes, days, weeks or even months.
- Provide small amounts of information to help them adjust to the news. Use words that you know they will understand.

- Allow the conversation to be directed by your children's reactions and check that you understand their questions so that you can explain exactly what they want to know.
- Give them space and time to digest the information.
- Wait until they come back to ask before adding information.
- It is fine to say that you don't know if you cannot answer all of their questions. Tell them that you will try to find out and let them know.
- Teenagers may ask for more information about the diagnosis and what it means to family life. They may find it harder to cope. Just at a time when they want their independence, they feel that they ought to be at home.
- It is okay to cry. Allowing children to see you show your emotions is a good way for them to learn not to be afraid of their own feelings. Explain why you are feeling upset or anxious.

Children's common misunderstandings: what should I say?

Children need reassurance that:

- They are not to blame.
- Diseases such as cancer are not like a cold and you cannot catch it. It is okay to sit close, have a hug or a kiss.
- That there will always be someone there to look after them.
- They can always ask you questions and talk to you about how they feel.
- It is okay to laugh and play. That they can still go to school and see their friends.

What are the three key things to tell them?

- That the person is seriously ill.
- The name of the illness.
- Your best understanding of what might happen. If you talk about what you know right now then this can be updated as the illness or treatment changes. Remember to be consistent and honest.

How might a child react to being told that someone they love is seriously ill?

How children might react to the news that someone is ill will vary greatly according to their age and/or development. They may be distressed or angry. They may not seem to react at all and ask 'what's for tea' or 'can I go out to play?'

This doesn't mean that they don't care. When children feel overwhelmed they instinctively try to protect themselves by withdrawing from emotion. They will need time to understand the information.

We have added several useful websites at the end of the leaflet where you will find information about possible reactions at different stages of a child's development and recommended books for all age groups.

How can I look after myself?

Try to remember that super parents/carers do not exist. You are doing the very best that you can. You can't support others if you are overwhelmed yourself. Make sure that you call on any help available from family and friends.

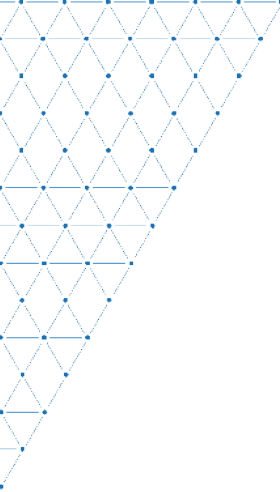
Access support offered to you by Health Professionals. You do not have to do this on your own. If you have been assigned a Nurse Specialist, talk to them.

But most importantly, you are doing the one thing that will help and that is involving the children.

Who can I contact for further information or support?

There is no right or wrong way to access helpful information. Please see below just a small selection of recommended websites/apps. There are many more. By looking around you can find the right information for you.

Good grief an app where grieving people can privately connect, chat, and support each other in finding a new normal. It's available on iOS, Android and the web	https://blog.goodgriefapp.com/our-story/
Macmillan cancer support	https://www.macmillan.org.uk/cancer-information-and-support/diagnosis/talking-about-cancer/talking-to-children-and-teenagers
Cancer Research UK	https://www.cancerresearchuk.org/about-cancer/coping/dying-with-cancer/coping-with-the-news/supporting-children
Winston's Wish	https://www.winstonswish.org/
Child bereavement UK website and app	https://www.childbereavementuk.org/
University College London Hospitals a short film to share with your children when talking about cancer.	https://www.uclh.nhs.uk/OurServices/ServiceA-Z/Cancer/CSS/MCIC/Pages/Talkingtochildrenaboutcancer.aspx
Riprap for teenagers	http://www.riprap.org.uk/
CRUSE	https://www.cruse.org.uk/get-help/for-parents/how



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