

How do I talk to my child about their
CHRONIC/LIFE-LIMITING ILLNESS?



For many parents, after their child has received a diagnosis, their biggest worry can be “how do I talk to my child about their illness and its treatment?” It can be hard to know what to say and how to say it.

This toolkit is designed to help you navigate conversations with your child about their illness.



THINGS TO REMEMBER

We know that young people often:

- 1 understand more than adults think
- 2 benefit from being involved in their care
- 3 feel safer when they know what is going on
- 4 are resilient as well as vulnerable
- 5 can overcome difficulties and adversity with support, love and a future filled with hope



Top tips and strategies

Speak honestly and simply

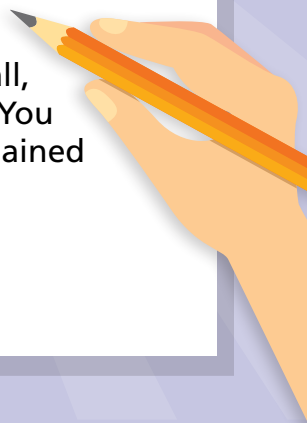
When speaking to your child about their illness, be truthful. Use age appropriate language and tell them things that they will be able to understand.

Ask what they already know about their illness

We know that sometimes children and young people mishear things or come to conclusions that are not correct. It can help to find out what they already know about their illness. Once you know what they know and don't know, help to fill in the gaps so that they have a better understanding of their illness and of the treatment involved.

Give information in stages, not all in one go

It's important not to overload your child with information. Gradually give them small, manageable bits of information at a time. You may need to repeat some of what you explained at later dates.



Don't force them to talk if they don't want to

After speaking to your child about their illness, don't be surprised if they don't say much at that moment in time. Let them know that you are here to talk to them whenever they would like. They might come back to you at various times with different questions. This may happen at times such as during play.

Ask if they have any questions which they haven't felt like they could ask

Remind your child that it's okay for them to ask questions but don't worry if you don't always have the answer. Just try to respond as honestly and simply as you can.

Use storybooks

If you are struggling to find the right words to talk to your child about their illness, children's storybooks about illnesses can help to give you an idea on how to explain things simply and clearly. You might even like to sit down with your child and read through the book together.

Help prepare your child for answering questions their friends might have

Your child might get questions from friends and other children about their illness. Help them to think about their illness in a normalising way, so that when they are asked questions, they can respond. For example, if a friend asks why they take tablets, your child could respond "I need them to help my tummy work better, just like some people need glasses to help their eyes work better".

Keep on having conversations as they grow up

Your child might forget things you told them when they were younger. It's important to revisit the conversations you had, so that your child can continue to understand about their illness as they grow up.

Help them live a fulfilling life

Try not to focus on the life-limiting aspect of their illness but help your child to focus on living a fulfilling life.

As well as supporting your child, make sure you find support for yourself

Children and parents have different ways of responding to illness. It's important you both get appropriate support surrounding your child's illness.

WHAT SUPPORT IS AVAILABLE?

Please talk to the play specialist or clinical psychologist if you would like any help in supporting your child in hospital and when at home. The nurse looking after you will be happy to contact them for you.

Useful links

Together for short lives is a charity which supports children who are expected to have short lives and their families.

Website: www.togetherforshortlives.org.uk

Tel: 0117 989 7820



WHAT SUPPORT IS AVAILABLE?

Rainbow Trust children's charity offer a wide range of support for families who have a child with a life threatening or terminal illness.

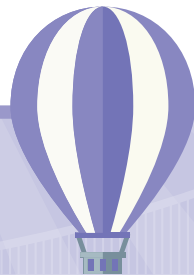
Website: www.rainbowtrust.org.uk

Email: enquiries@rainbowtrust.org.uk

Tel: 01372 363438

The website Little Parachutes sells a collection of story books that help children cope with worries, health issues and new experiences.

Website: www.littleparachutes.com



These toolkits have been written by NHS clinical psychologists and neuropsychologists working for University Hospitals Bristol. They have been co-designed with service users and healthcare staff. These toolkits are only intended to provide general advice and information. Please discuss your individual needs with your doctor or specialist nurse. If you would like more information about psychology services please go to:

<http://www.uhbristol.nhs.uk/patients-and-visitors/support-for-patients/psychological-health-services/>

We would like to thank patients and other healthcare staff for their contributions to this toolkit.

For access to other patient toolkits please go to the following address:

<http://www.uhbristol.nhs.uk/patients-and-visitors/support-for-patients/psychological-health-services/resources/>

For this leaflet in large print, audio or PDF format, please email patientleaflets@uhbristol.nhs.uk

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