

Talking with your child about their life-limiting condition

Coming to terms with the news that your child has a life-limiting or life-threatening medical condition is extraordinarily difficult. If the diagnosis was made recently you may find that things feel overwhelming at the moment. You may be worried about what the future holds for your child and how you can help them to live as happy and “normal” a life as possible. Many parents wish to hold off from telling their child about the prognosis/diagnosis for as long as possible, as they feel that by doing so they are protecting their child. This leaflet offers some suggestions about why it is likely to be useful to begin having these conversations early with your child and how you might go about doing so. It aims to offer you some practical advice about how to do this and address some common worries and concerns parents have.

Why should I talk to my child about their condition?

We know from research that children cope best with the realities of their condition when they are given honest, age appropriate information about their condition and the chance to ask questions. Children have an amazing capacity to understand and cope with their condition, as long as they are told in ways that they can understand and are supported to identify and learn strategies to help them manage.

“Why are they not telling me what’s going on?”

Even toddlers and pre-schoolers can sense when parents and other family members are upset or something is wrong.

“Why am I different?”

As they grow older children will be aware of changes in their condition and make comparisons between what they can do and what their peers/siblings can do. They may also be aware that they look different to other children. If they are not given an explanation they are more likely to worry about these changes and develop their own explanations about what is happening and why people are upset.

Using the internet

Increasingly, children have access to the internet from an early age. This can lead to problems as they may search for information online which may or may not be accurate. This often leads to them developing worries that they would not have if they could talk to someone and get a clearer understanding about their concerns/questions.

Why can't I wait until they bring it up?

Children will generally take their cue from you about whether they can talk about their worries. If as parents you avoid the topic, your child is likely to follow your lead. In this situation, children may conclude that it is "naughty" to talk about their condition because such talk upsets adults. Children are also often very sensitive and may feel the need to "protect" their parents and for this reason will not bring the subject up. Unfortunately, this means that they are forced to bottle up their worries and difficult feelings.

As your child gets older there will be an increasing expectation that they are going to play an active role in managing and making choices about their own medical care. If they are not informed about their condition it makes this impossible. By talking with them openly about their condition you are giving them the vocabulary they will need to talk not only with their healthcare providers but also with their peers. This in turn empowers them to manage and address any worries or concerns they have and to develop a growing independence to care for themselves.

So how do I talk about this with my child?

Children like to learn information from their parents. Generally children do best if they have these conversations with adults they are close to. For this reason, your child's medical team may typically look to you to have these conversations with your child.

Any information shared with your child should be appropriate to their age, level of understanding and experience. Children's understanding of illness may develop as a result of maturity, experience and education. When thinking about talking to your child it is useful to remember that you do not need to tell them everything in one go and in fact doing so is likely to be overwhelming.

In general, it is likely to be beneficial to think about:

- What do they already know?

Start the conversation by asking children what they already know about their condition. Ask questions to check that they truly understand.

- Do they really understand what they have been told?

Look out for misunderstandings – sometimes it can be hard to judge how much your child understands. Asking them to explain back to you what you have just told them will give you a clearer idea of their understanding.

- Explaining it's okay to talk

Tell them explicitly that they can ask you questions about their condition whenever they want. Do not presume that they know this.

- Being truthful

Answer truthfully any questions they have. If you do not know the answer, then say so. Often children just want to know that you are there and happy to listen.

- Giving the condition its name

Try and use the correct name for the condition your child has. Even for very young children having a name for something is helpful. They will become familiar with the condition over time and bit by bit, understand more about what it means.

- Telling them it's not their fault

When you first start to talk with your child about their condition make sure you explain that their illness is not the result of something anyone did, and that it isn't the type of illness that can be spread to other people. Young children are prone to misunderstandings and children under the age of five or six think in very concrete terms. This means that they can end up thinking that their condition is a result of being naughty or something they did.

- Keeping it in the present

Keep the focus on the day-to-day information they need to know now, particularly when talking with younger children.

- They don't need to know everything at once

Children will quickly feel overwhelmed if you give them too much information. When thinking about discussing your child's condition with them, it can be helpful to remember this is just the beginning of a conversation that you will repeat and expand on over time.

- Increasing information with age

As your child reaches new stages in development and new milestones (both positive ones such as entering secondary school and those associated with the progression of their condition) your child's information needs are likely to increase. If things have changed with their condition or they have upcoming hospital appointments then use these times to check in with them about how they are doing and whether they have any questions.

- Questions for the doctor - giving your child a voice

As your child gets older, ask them if they have any questions for the doctors before an appointment and check if they have any questions afterwards.

- Preparing them well for the future

As your child gets older, it is likely that they will be expected to become more actively involved in their treatment and treatment decisions. It is really important that they are prepared for this and know enough about their condition **and its prognosis** to make well informed decisions. In adult services, the young person may be asked specific questions about their wishes with regards to treatment in the future and it may be distressing for them if they are not already fully informed about their condition and prognosis. If you have any questions about your child's decision making capacity, do refer to our Factsheet on the Mental Capacity Act.



What about brothers and sisters?

Brothers and sisters are likely to have questions (and often worries) about their sibling. It can be difficult to judge how much to tell them, particularly if there is a large age gap. Generally speaking, it is important to ensure brothers and sisters do not know more about the condition than the affected child. It is a big responsibility to expect a child to hold on to this sort of information and it is rarely helpful for children to be asked to keep secrets. In general, when thinking about talking to siblings, the guidance above is still relevant. Further information is available on our Understanding Siblings Needs Factsheet.

Can anyone help me with this?

This is often a really difficult area for parents to think about. You may still feel unsure about how to go about it or when. If you would like further help thinking about this or specific advice for your family's situation, your child's consultant paediatrician (or community children's nurse, if you have one) can assist you with this. Some teams also have access to specialist psychological support that may help too. Children's hospices also offer this support to families. If you want to find out where your local

hospice is, please refer to our Children's Hospice Factsheet or call our Helpline on 0808 8088 100.

Glossary

Prognosis – the likely course of a medical condition

The Family Factsheets mentioned above can be found at togetherforshortlives.org.uk/familyresources

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Together for Families Helpline
10am-4pm, Monday-Friday

0808 8088 100

info@togetherforshortlives.org.uk

www.togetherforshortlives.org.uk

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