

Talking to children and young people about their health condition

This leaflet is intended to help parents or carers talk to children and young people about their health condition and treatment. If you have any questions, please speak to a member of the medical team caring for your child.

Parents or carers may question:

- whether to tell a child about their health condition
- how much they should explain and when

The idea of talking to children about a health condition or future medical procedure may feel daunting, overwhelming or intimidating. It can be difficult to know what to say.

The aim of this leaflet is to give you ideas about how to approach talking about health conditions. You know your child and family situation best. This information can fit in with what you already know, and what works for you and your family. Your medical team is also here to support you and answer any questions.

Why it is important to talk about health conditions

Parents and carers often tell us that it is hard to speak to young people about their health condition or procedures. They may:

- want to protect children from information that could be upsetting or difficult to hear
- believe that their child is too young to understand
- believe that their child cannot cope with the information
- want their child to remain hopeful
- feel distressed themselves and worry that they will not be able to manage their own emotions in front of their child
- have difficult emotions like shame or guilt and avoid conversations to protect children from similar feelings
- not know what to say, when or how

These concerns are understandable, but there are various reasons why talking to your child is important and helpful. In this leaflet, we suggest different ways that parents and carers can talk to children. We also explain the types of knowledge and information that might be suitable to share at different times.

If you talk to your child about their health condition, this can help to prevent misunderstandings and worries. Children often find out small amounts of information from hospital appointments or the internet. They may overhear or listen to your conversations, and sense your anxiety. Your child is likely to be already guessing what is happening.

Talking to your child about their health condition also:

- gives them a chance to process the information, express their thoughts and feelings, and ask questions
- builds trust in your relationship
- allows them to make sense of the procedures, treatments or medicines
- gives them a greater sense of predictability, choice, control and safety
- helps them to develop knowledge and skills that they can use in the future to manage their healthcare more independently

Children are often more resilient than we might think and cope well with information, especially if they get suitable support.

Other children may ask your child questions about what is wrong or why they see a doctor. Your child may feel that they need to explain these things. If your child learns about their health, they can:

- feel more prepared to respond to others' curiosity
- decide how much information they want to share

General principles for talking to your child and sharing information

How much information you share with your child and when depends on several things, such as:

- the child's age and maturity
- what type of health condition they have
- what type of treatment they need
- other life events

You may be able to give your child information gradually or need to give them lots of information at once. Either way, your child is likely to need you to repeat the details and share more complex information as they grow up.

Preparing to talk to your child

Here are some tips for preparing to talk to your child about their health condition:

- Think about whether you have any questions or worries of your own about the health condition. It may help to find out the answers to these questions or address the worries before talking to your child.
- Plan the language that you want to use and get familiar with medical names for parts of the body.
- Try to have the conversations with your child at calm times when there will not be many disruptions or distractions.
- Decide whether it would be better to have the conversations at home or somewhere else like the hospital.
- Think about whether there is anybody who could support you with the conversations. You might find it helpful to do a role play with another adult. If you talk to a class or special educational needs and disabilities (SEND) teacher, they might give you some guidance. Depending on your child's health condition, your local authority might also offer support.
- Think about whether there is anything else that could help you with the conversations, such as having videos or drawing materials available.

Checking your child's understanding

You could start a conversation by asking your child what they already know about their health condition. If you get an idea of what your child does and does not know, this can:

- highlight any misunderstandings
- build up experience and confidence in talking for you both
- allow you to follow your child's lead

To explore your child's level of knowledge, you can ask them questions like:

- Do you know why you see the doctor?
- Do you know why you take medicines?
- Do you have any questions for the doctors or for me?

It can also be a good idea to talk to your child's teacher. They may give you feedback on your child's understanding of their health condition and attitude towards it.

You do not need to know the answers to all your child's questions. It's fine to say:

- "That's a really good question. Let's think about that together."
- "Great question. Let's write that one down for the doctor."

Try not to assume that your child will remember what you said. You need to have more than one conversation about their health condition. It is worth checking in a few days or weeks how much information they have remembered. You and your child can think about good ways to remember the conversation, such as through drawing, making stories or reading books.

You can then plan when it would be useful to have another conversation about your child's health condition. To start the next conversation, you can say something like:

- "We talked about going to the hospital the other day. Is there anything that you want to ask me about this?"
- "What do you remember from our conversation about your health the other day? Did it make sense to you?"

Language to use when talking to your child

When talking to your child about their health condition, you can use language that is familiar and comfortable for your family. However, we often recommend giving body parts their correct medical names.

You need to decide what information would be useful for your child to know based on their age and developmental level. Each child is different but here is a general guide:

- **0 to 3 years:** Babies and toddlers need a lot of physical comfort. They cannot share verbally or name how they feel. Babies and toddlers can still be soothed by gentle explanations of what is happening and why.
- **3 to 6 years:** Children develop a sense of curiosity and start to ask lots of questions. Their understanding of abstract ideas and future consequences is still limited. They can understand some simple instructions. Stories could be a useful way to introduce new ideas about their health.
- **6 to 10 years:** Children may have more complicated questions and ask why things are happening, when and what this involves. They may be encouraged or want to be more involved with their healthcare. At the same time, they may need emotional comfort for their feelings.

- **11 to 18 years:** Teenagers are likely to have complex questions, together with their own understanding or opinions, about their health condition. They can usually describe their feelings but may still be confused about them. Teenagers can think about the impact of their condition on themselves, others and important life events like going to school. However, there may still be misunderstandings.

If you give your child information at a young age, you will probably need to explain it again when they become a teenager.

Increasing your child's knowledge

Families approach the question of how much detail to give their child in different ways. A lot depends on:

- the child's personality and maturity
- what type of health condition they have
- the family's situation and beliefs

We suggest always being honest with your child. It is a good idea to think about what they need to know at any particular stage of their development.

The first conversation that you have with your child about their health condition does not need to include every detail. You may decide to share some information now and then aim to increase their knowledge with time. Your child's medical team can support you to understand their health condition.

It is important to give your child accurate information. Otherwise, there is a risk of worrying your child or damaging the trust in your relationship with them. If there is uncertainty about a health condition, procedure or issue, you could say: "We do not know exactly [about the topic]. The doctors and nurses will do their best to [tell us about the topic]."

Who to involve in conversations with your child

Who to involve in conversations with your child about their health condition, how and when depends on:

- family circumstances
- what type of health condition your child has
- your child's age

Creating a sense of community can help young people and their families to feel connected, accepted and understood. However, it may not always be safe or possible to do this. It may be necessary to find a sense of community from outside the family or your existing network.

Some families need to think carefully about what information they share with the extended family, if they do so at all. Some parents or carers prefer to let their child decide when they share personal information.

Your child's school may be able to offer support and give you an idea of how they are coping. The school curriculum may also include topics that help you talk to your child about what information to share or keep private. If you and your child decide to share information about their health condition with others, the aims should always be to:

- reduce any stigma or sense of shame
- increase your child's confidence
- help you and your child to feel more connected with others

Looking after yourself as a parent or carer

As a parent or carer, you want to protect your child as much as possible. You also want to do everything in your power to make them better. When you find out about your child's health condition or diagnosis, this can be an emotionally difficult time. It is understandable that you may find it hard to think or talk about the subject.

If you have the added responsibility of managing your child's medical appointments and giving them medicines, this can be more stressful.

It is important to look after yourself too. If you take care of your own health and wellbeing, this will help you to look after others. Parents and carers often say that it is useful to:

- contact local groups or services that can support you
- try to stay connected to, and accept help from, any existing support systems that you might have, such as family, friends or professionals
- spend time doing things that you enjoy
- get enough sleep (resting is still valuable, even if you find it hard to sleep or your sleep is disrupted)
- eat well and exercise when you can
- think about respite care (this is when you take a short break from caring while someone else looks after your child temporarily)

If you would like more help thinking about this topic or specific advice for your family's situation, please talk to your child's consultant or GP. They can give you details of services that may be able to offer extra support.

More information

We have produced some other leaflets that you may find useful:

- 'Looking after yourself', which is intended to help your child if their health needs are having a big impact on how they feel.
- 'Emotional support during or after your child's hospital stay', which explains how the paediatric psychology service can support your family.

Please ask your child's doctor for copies of these leaflets if you think that they would be helpful. You can also download the leaflets on our **website** www.evelinalondon.nhs.uk

Contact us

If you have any questions or concerns about talking to your child about their health condition, please contact the paediatric (children's) psychology service, **phone** 020 7188 4640, Monday to Friday, 9am to 5pm.

We are not an emergency service. If you have urgent concerns about your child's mental health, contact a GP. In an emergency, **phone** 999 or go to your nearest emergency department (A&E).

For more information on conditions, procedures, treatments and services offered at our hospitals, please visit **web** www.evelinalondon.nhs.uk/leaflets

Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline, **phone** 020 7188 3003, Monday to Friday, 10am to 5pm

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS), **phone** 020 7188 8801 **email** gstt.pals-gstt@nhs.net

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please contact the service your child is seeing.

NHS 111

This service offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day, **phone** 111 **web** www.111.nhs.uk

NHS website

This website gives information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing, **web** www.nhs.uk

Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, please get in touch, **phone** 0800 731 0319 **email** gstt.members@nhs.net **web** www.guysandstthomas.nhs.uk/membership



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