

## Talking to your child about their medical condition

Talking to a child about their condition is something that goes on over many years with the aim of giving them a good understanding of it that is right for their age.

It will help your child be confident in the context of unreliable or inaccurate information, e.g. from friends or the internet. It will also help your child become involved in making choices about their condition when they can.

### What do children believe about illness?

**Infants** will be most affected by changes to routine and separations from parents.

**Pre-school** children might think illness is caused by something they have done, or by contagion or something magical. They might also think of treatments as punishments.

**Primary school** children begin to understand how disease affects the body, inside and out. They are interested in the reasons for illness, and begin to understand about germs.

**Teenagers** understand that there are many causes of illness, and that psychological factors can also influence things. They may think more about the meaning of life and have more philosophical or spiritual questions.

### What to do and say

- Firstly, find out what your child already knows about their condition. For instance you could say 'What do you think about what the doctor said?' This will allow you to plan what you are going to say to your child
- If you can, wait for the right time to discuss. It is better to give yourself time to adjust to news before you discuss it with your child
- If you have to speak to your child about their illness in a moment of crisis, repeat the things you have said later on when you are feeling calmer
- Give information in small chunks and repeat
- Check your child understands the information you have given them to avoid misunderstandings
- Share memories of what is said by doctors to help you process information together
- Seek knowledge together
- Be ready to answer questions which may come from your child at any time. If the moment isn't suitable, promise to make time to answer them later
- Get support from relevant services (details provided overleaf).

### What to avoid doing or saying

- Don't make light of difficulties your child is facing, or lay it on too thickly. Try to find a middle ground with a positive outlook
- Don't pretend illness isn't a problem - it IS an inconvenience and will affect lives
- Don't say a cure is round the corner - this may imply that life at present is not worth living

- Avoid lies and half-truths. Children can imagine something worse if not told the truth
- Don't say 'there are worse things to have' as it may belittle your child's feelings
- Try not to be upset if your child doesn't ask you questions directly. They may find it easier to talk to someone who is more removed from the situation, like a nurse, teacher or another relative.

### **Thinking about the future**

- It is important to consider the future when talking to your child about their condition and - as they grow and develop - to revisit questions they have asked so you can update them with information and check their current understanding of the situation. Your child's concerns may change at different points in their development. Be prepared to discuss these new questions and worries in years to come. Your child may have questions about life expectancy or quality of life; be ready for this and plan what you want to say.
- Remember your child's perceptions of how illness will affect them in the future will be different from your own. For example, 20 years will seem far longer to a child than it is to an adult. The far future will concern them less than you. **Children often cope better than their parents think.**
- **Useful services**
- **Paediatric Psychology and Liaison Service (PPALS)** is a specialist team that works with children and young people who require psychological support. **Contact details:** 0131 536 0535.
- **Sick Kids Friends Foundation Drop in Centre** is a facility for children and families who are affected by long-term conditions. **Contact details:** 21 Millerfield Place, Edinburgh 0131 536 0888.
- **Family Support Service** is based at the RHSC.  
Opening hours: Mon - Fri: 8.30am - 6pm; Sat - Sun: 9am - 5pm.  
**Contact details:** 0131 536 0070.
- **Kindred:** is an organisation providing advocacy and information on services available to children with additional support needs and their carers. **Contact details:** 0131 536 0360.
- **Spiritual and Pastoral Care Department:** Members of the Spiritual and Pastoral Care Team offer confidential, non-judgemental support to patients and families whatever their beliefs or life situations. **Contact details:** 0131 536 0000, ask to radio page the on call chaplain.
- **Voice of Carers Across Lothian (VOCAL):** works with carers and family members, offering specialist practical and emotional support, training, counselling and advocacy. **Contact details:** 0131 622 6666.