

# How do I tell my child that I HAVE A SERIOUS ILLNESS?





Many parents worry about how to tell their child about their illness and knowing what is the right thing to say. We know that sharing information can help your child to cope, start to adjust and feel more safe and secure. As their

parent, you may already be thinking about what feels right to tell them and when. Talking to you child can help them feel included, and gives them the opportunity to ask questions and tell you about any

worries that they may have.

#### How can you use this toolkit?

This toolkit is designed to help you think about how to talk to your child. There are no rights and wrongs but the toolkit includes some tips and ideas that might help you. At the end of the toolkit there are links to further information if you wish to explore this area in more detail and gain more support to do so.

### General principles of the topic to consider

Telling your children about your illness is a process; it is likely that the initial conversation will serve as a starting point for you and your child to discuss more information and address questions or concerns following this.

There is no 'right' way of discussing this information with your children, you are the expert on your child and what works best for your family. This information is a starting point for you to plan how to have these discussions with your children and others as appropriate.

As these discussions progress, so can your encouragement of your child to share their thoughts, feelings and questions about what you have told them. Asking open ended questions, such as "how do you feel about...?" or "what do you think about...?" can be a good way of encouraging a discussion.

#### Top tips and strategies

Here are some techniques to help you tell your child if you have a serious ilness:

Decide what you feel important to tell your child and why. You may want to rehearse what you want to say. Try to be consistent with what's said between parents/other adults

sharing the news with your child.

Choose a time when you're feeling fairly calm and use a setting which is familiar and comfortable for you all, where you won't be interrupted. Try to tell all siblings together if you can.

Start by asking the child what they understand about what has been

happening. This helps you to identify and correct any misunderstandings that they may have and gently bring them up-todate with the situation.

Try to give information to match your child's age and ability. Young children

especially will likely have a short attention span and so will not be able to absorb lots of information at one time. Let your child know that they are able to react and say how they feel. By seeing the sharing of this information as a process, revisit the discussion with your child when they are ready to know more and/or ask you questions or discuss their feelings regarding this.

Parents can worry about getting upset in front of their child – be reassured that although it can be a little upsetting for children to see their parents distressed, seeing them show feeling, and having that moment pass can be helpful.

Use simple language to help ensure that your children understand what they're being told. Demonstrate with age appropriate discussion, media e.g. pictures or toys for younger children.

Give your child the opportunity to ask questions and be aware that these may arise at other times following your conversation. Try to give clear answers; if you are unsure, it's better to say "I don't know, but I'll try to find out" than to guess or lie.

Assure your child that no matter what happens, they will be safe and loved.

Encourage your child and family to focus on their normal activities and continue to do things which they enjoy.

## WHAT SUPPORT IS AVAILABLE?

Speak to your healthcare team if you feel concerned about holding these conversations, they may help to advise you on how to answer certain questions that your child has and/or may be able to direct you to services where you can access further quidance and support.

Some teams in the hospital have a psychologist and/or counsellor as a member of

their team, who can speak to patients and their families about how to discuss their diagnosis and treatment with their children – ask a member of your healthcare team who knows you well, such as your Clinical Nurse Specialist, if they can make a referral on your behalf.

If you are a patient or family member of a patient of the Bristol Haematology and

Oncology Centre (BHOC), there is an information and support centre in the main entrance which has lots of leaflets which can help you if you need some more information and advice.

There are additional resources on the UH Bristol website for managing common concerns, such as overcoming worry, please refer to these guides for more information and support.

#### Links to appropriate resources

- 1. Winston's Wish is a UK charity which supports bereaved children, young people and their families. The charity produces publications, has an interactive website and offers individual, group and residential support and activities. Visit the Winston's Wish website for more information: http://www.winstonswish.org.uk/
- 2. Macmillan Cancer Support have a wide range of information and advice, either online, printed resources, telephone helpline and support groups. Resources include 'talking to children when an adult has cancer.' Visit their website for more information: http://www.macmillan.org.uk/information-and-support/coping/talking-about-cancer/talking-to-children or telephone the Macmillan helpline on: 0808 808 2020
- 3. Marie Curie is a UK charity which offers care and support for people living with a terminal illness, and their families. They have free online resources, including advice on talking to children about illness https://www.mariecurie.org.uk/help/terminal-illness/family-friends/children as well as a free telephone line: 0800 090 2309, online chat service and leaflets.
- 4. You may also find additional resources on the associated charity website for your health condition, such as the British Heart Foundation: https://www.bhf.org.uk/informationsupport/support/health-and-emotional-support/telling-your-children



These toolkits have been written by NHS clinical psychologists and neuropsychologists working for University Hospitals Bristol. They have been codesigned 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** 

© University Hospitals Bristol | Published: 05/10/18 | Expires: 31/10/21 | DOTS/PHS/TLKTAD/CHILD/OCT18 |

