SHARING THE NEWS FROM HOSPITAL WITH YOUR CHILD

STEP 1: PREPARE YOURSELF

- Thinking about talking to your child about this probably feels the hardest thing in the world. It's completely understandable to want to protect them from this news.
- If there's another adult at home with you, share the news with them first so you can talk to your child together.
- Write out a simple timeline of what your child has been experiencing recently e.g. blood test, feeling unwell etc, and then what you now need to tell your child. You can use these notes to support your conversation with your child.
- Take a minute to breathe as slowly and deeply as you can.
- Try to keep your focus on the next few minutes and how you want your child to hear this news.
- We know that even very young children (under 2 years) often know something is happening and need an explanation for what they can see around them.

STEP 2: PREPARE INFORMATION

- Take a minute to think about what your child knows about what has been happening, their understanding and experience of illness and death.
- As everyone is isolating in their houses, your child(ren) will be very aware of any phone calls and may be expecting to hear from the hospital. This means you will need to tell them the news as soon as you can, so they are not left worrying alone.
- Even though you need to talk to them as soon as possible after our phone call, it's helpful to look at <u>Talking to children</u> <u>about illness leaflet by the British Psychological Society;</u>
- It's not long and explains what children understand about illness at different ages and levels of maturity.

STEP 3: PREPARE ENVIRONMENT

- Think about where in the house you want to talk to your child.
- Depending on the age of your child and their siblings, decide whether you want to tell them together.
- Very young children can be distracted with the TV, toy or game while you talk to the rest of the family first.
- If your child has a special toy or comforter, see if you can have this to hand.

STEP 4: STARTING OFF

- Asking children to stop what they are doing and come and sit down will prepare them for the conversation to come.
- Try and speak as slowly as you can and pause between sentences. People often speak quickly when they are upset and nervous.
- Can you come here and sit with me for a minute? We need to talk together."
- "The doctor at the hospital has just called me."
- "Can we talk about what they had to say?"

STEP 5: EXPLAIN WHAT HAS HAPPENED

- Talk VERY slowly, honestly and realistically.
- If this is a new diagnosis, it may be helpful to check in with your child about what they know and understand already.
- After you have told your child the diagnosis/test result, stop for a few seconds to allow them to take in what you have said.
- Wait until you feel your child is ready for more information.
- "I'm so sorry to tell you that the tests you had at the hospital mean that [insert relevant information]"
- "I know this is really hard to take in"
- For a new diagnosis: "Have you heard of [diagnosis] before?
 What do you know about it already?"
- "Do you feel ready to hear some more about this now?"
- Be aware that their distress makes it harder for them to take in information.

STEP 6: COPING WITH CHILDREN'S REACTION TO THE NEWS

- It's ok to talk with your children about how upsetting and sad this news is for everybody.
- Sharing your feelings can be helpful, but children might find it frightening to see you completely overwhelmed with distress.
- It is useful if you name your emotion, for example explain that you are feeling sad and that you are crying because you can feel better after a good cry.
- Younger children may focus much more on the practical aspects of how the situation will change their day-to-day life; how long do I have to be in hospital, will I have to have an operation? They might not show an immediate reaction to the news (for example wanting to go and play, speaking with their friends) but this doesn't necessarily mean they didn't hear the news.
- Children can have many different reactions to the news such as:
- Crying, shouting or anger: "I know that it is very, very sad. It's hard to take it all in"
- Repeatedly saying "I don't believe you, you are wrong, it's not true": "I know it is very difficult for you to take this in."
- Go very quiet: "I know it's really hard to believe this is happening?"
- "Did you know that lots of children in this situation often feel very sad, confused or worried; how do you feel about this? Is there anything you want to say?"
- "I know that this is sad and upsetting to think about, but it's better that we share our feelings and talk about our worries, rather than struggling with it alone."
- Silence may mean your child has understood all, or very little, of the information. It's fine to check with them what they have understood. Teenagers may want some privacy to think things through by themselves.

Dr Elizabeth Rapa, Dr Louise Dalton, Helena Channon-Wells, Dr Shaun Wilson, Dr Helen Griffiths, Dr Brenda Kelly and Prof Alan Stein elizabeth.rapa@psych.ox.ac.uk | April 2020 | www.psych.ox.ac.uk/research/covid comms support

SHARING THE NEWS FROM HOSPITAL WITH YOUR CHILD

STEP 7: PREPARING FOR CHILDREN'S COMMON QUESTIONS

- It can be helpful to think about how you will answer common questions your child may ask.
- You need to think about the age of your child and what they will be able to understand. Think about what they know and understand already.
- Ask if they would like more information or have questions about the diagnosis or care plan.
- Don't be afraid of saying "I don't know" if you can't answer a
 question. Think together about how you can get the
 information they want or need.
- Children often want to know what caused the cancer and may be worried that it was because of something they thought, said or did.
- It is important to repeat that the cancer (returning) was nobody's fault.
- It can be helpful to reassure children that cancer is not something you can catch from other people.
- Children may ask you if they are going to die: "Not right now, but the treatment is not able to keep the tumour away anymore"
- "I know this is not the news we'd been hoping for. There has been a lot to take in; is there anything you don't understand or want me to explain more about?"
- "Would you like to talk to the team yourself, or shall we make a list of questions to ask the team?"

STEP 8: MAKE A PLAN

- Explain to your child what will happen next e.g.: appointments, tests or treatment.
- If possible, give an idea of the timescale, or when this will be clarified with the team.
- "Would it help to talk to someone else who's going through a similar [diagnosis]?"
- "You must let me know if anything hurts or feels funny."
- Teenagers especially can find it helpful to talk to other young people who are going through similar experiences.

STEP 9: FINISHING THE CONVERSATION

- Reassure them they will not have to manage this alone.
- It is really helpful for your children to have somebody to talk to outside of the family. Being able to share their feelings without worrying about upsetting you is important. You can help your children think about who they love and trust to support them.
- You may need to return to this conversation several times, particularly with younger children. This is very normal as they make sense of what has happened.
- "I know this feels so much right now. What I do know for sure is that I love you very much. We will get through this together, whatever the future holds."
- "Shall we think about who else might be a good person for you to talk to?"
- "Do you want to think about whether you'd like me to tell your brothers and sisters/friends, or is that something you want to do?"

STEP 10: CARING FOR YOURSELF

- It is very important that you look after yourself. These conversations are the most difficult ones you will ever have to have and are emotionally exhausting. Contact a friend or relative to talk about how you are feeling.
- http://www.clicsargent.org.uk/life-with-cancer/i-havecancer/cancer-and-treatment
- http://www.teenagecancertrust.org/get-help/ive-got-cancer
- Connect with other people, groups and organisations that can help support you and your family.