

## STEP 1: PREPARE

- Take a moment to compose yourself. A few slow deep breaths will help you focus.
- Staff shortages may mean you feel relatively unskilled or inexperienced; this guide will support you step-by-step through this conversation. Remember, it's better for the family to hear the news than to live with uncertainty.
- Consider rehearsing/role playing what you are going to say with a colleague.
- Check you know the names of the parents/guardians, the name and age of the child, and if there are any siblings.
- Using language and content that is tailored to children's level of understanding and personalised will help the family feel cared for.
- Ask the team for any background information about the family including whether the young person is likely to be involved in this phone call.
- Ascertain if any other members of the child's wider care team e.g. paediatrician, nurse could be included in this phone call.
- Find a space where you won't be interrupted. Pass your bleep/phone to a colleague. If possible, use a landline to make the call.

## STEP 2: STARTING OFF

- Introduce yourself by name and your job title. Clearly explain which team and hospital you are calling from.
- Speak slowly with pauses between sentences. Counting to three in your head can help slow you down, particularly if you're feeling nervous.
- Check who you are speaking to and their relationship to the child. Check if they can talk privately.
- If it is not the designated contact or they ask you to call back, give a likely timescale for when this will happen (where possible).
- DO NOT leave a voicemail. If the family are driving, explain you will call them back when parked.

- *"I know that you have met Dr xx before - I am a member of their team"*
- *"Is there somewhere quiet that you can talk at the moment?"*
- *"Can I just check who is at home with you now?"*
- *"Shall I call you back in 5 minutes when you've had a chance to put the TV on/find a game for the children?"*

## STEP 3: SETTING THE SCENE

- Briefly set context for telephone call.
- Acknowledge conversation would usually take in person.
- At this point check who else they want to be in on the call e.g. partner/relative/young adult.
- Remember to speak slowly, clearly and with pauses.

- *"I'm calling to talk about the results of [child's name] recent tests."*
- *"I'd like to talk to you about what the test results mean."*
- *"As you know we've been monitoring [child's name]'s progress.."*
- *"I'm sorry we can't have this conversation in person, I know this is difficult to talk about over the phone"*

## STEP 4: SHARING THE NEWS

- Talk VERY slowly, honestly, realistically.
- Avoid euphemisms and technical jargon.
- After you have named the diagnosis/situation, STOP for a few seconds to allow the family to take in what you have said.
- Sensitively check person's knowledge and understanding of the condition.
- Listen for reactions to gauge when they are ready for more information.
- Remember pauses are important as you can't see the other person's reaction to what you are saying.

- *"Do you remember when we talked about what would happen if the [surgery/treatment] didn't work as we'd hoped?"*
- *"I'm very sorry to tell you that [share diagnosis/treatment/results update]"*
- *"Are you ready for me to tell you more about what this means?"*
- *"I understand this might be very difficult to take in...just take a few moments"*
- *"I don't know the answer to that question, but I will find out for you."*
- *"Do I need to slow down? Would you like me to go over anything again?"*

## STEP 5: RESPONDING TO THE EMOTIONAL IMPACT OF THE NEWS

- Support person with their own feelings/distress about the diagnosis/situation.
- Distress may limit their capacity to absorb information.
- Silences can feel uncomfortable and longer than they actually are on the telephone. It is difficult to know how a person is reacting when you can't see them; there may be other people in earshot including children.
- Using sounds and words, e.g. 'uh-huh', 'mmm', "take your time — I'm still here" replaces eye contact or touch, and confirms your presence.

- *"I know that normally for these conversations I would be in the room with you and be able to get a sense of how you are feeling."*
- If person is crying or shouting: *"I understand that it is very upsetting news, particularly by telephone."*
- If person repeatedly says "it's not true, it can't be": *"I understand this is very difficult for you to take this in."*
- If person goes very quiet or says 'thank you for letting me know': *"This news must be very difficult to take in; would you like me to help you think about what you want to do next?"*

## STEP 6: PREPARING PARENTS TO TALK TO THEIR CHILD

- Telling children about a diagnosis/test results is emotionally difficult - people don't want to cause distress but the child needs to know.
- Discuss the child's awareness of what has been going on.
- If person expresses fear about how to tell their child, consult 'Sharing the news' document which includes suggestions on answering children's common questions.
- Reassure it will not cause harm to tell children how adults are feeling, but careful not to over share extreme emotions.
- If parents are separated confirm who will tell: 1) the other parent 2) children
- Encourage consistent messaging by adults to avoid confusion.
- In lockdown situations there will be very little privacy and time for people to prepare themselves or get support from a friend or relative.

- "Thinking about talking to children about this probably feels the hardest thing in the world. It's completely understandable to want to protect them from this news."
- "I wonder how much you think [child's name] knows about their condition at the moment?"
- "I understand you are worried that telling [child's name] will be upsetting for them. Even very young children need an explanation for what's been going on and how they've been feeling."
- "I understand that in the current situation there is not much time or space for you to think about how you will tell [child's name]. Shall we talk through how you might do that?"
- "Would you like me to talk to [child's name] with you?"
- "It's very natural for children to feel very upset or angry, but talking is very important in helping them through this difficult time."
- "It's OK to talk with children about how upsetting and sad this news is for everybody."

## STEP 7: MAKE A PLAN

- Finish by explaining what will happen next.
- Reassure families that they will not have to manage this alone; if possible give direct number for them to contact, or a time frame for when you will call again to follow up (make sure this happens).
- If active treatment not possible, explain that symptoms will be controlled by medication to reduce pain and maximise quality of life.
- Repeat your name and which department you are calling from.
- Ask permission to send a summary and 'Sharing the news' document via email; do this straight away.
- Update patient file and tell other staff that the patient's family have been told the diagnosis/test results. Notify paediatrician.

- "Can I check how well I've explained things today? Would you like to tell me what you have understood?"
- "I know this has been a very difficult conversation and this isn't what you were hoping to hear. There has been a lot to take in; is there anything I haven't explained clearly enough?"
- Just to recap, the next steps will be x,y,z"
- "You know [child's name] better than anyone; if you have any concerns, don't hesitate to contact the team."
- "I understand that this is a lot to take in - would a call later/tomorrow be helpful? Other families have found it useful to make a list of questions they want to talk through."
- "When we next speak would you like me to talk to [child's name] directly?"

## STEP 8: CARING FOR YOURSELF

- These are emotionally exhausting conversations.
- Take a minute to check how you are feeling and acknowledge the emotions this conversation has brought up for you before you move on to your next task.
- Do you need to take 5-mins/ have a cup of tea/a snack/chat to your team? It can be helpful to 'off load' to a colleague or share your experience by talking through how the conversation went with your team.

## TOP TIPS

1. Find a quiet place. Make sure you have the key information. Use a landline if possible.
2. Speak slowly, clearly, with pauses.
3. Counting to 3 in your head can help slow you down, particularly if you're feeling nervous.
4. Silences can feel uncomfortable and longer than they actually are on the telephone. Don't feel you have to fill the silence.
5. It is essential to help adults think about how to tell children (both the patient and any siblings) as soon as possible.
6. These are difficult conversations; take time to look after yourself, it may be helpful to 'off load' to a colleague or reflect with your team.