COMMUNICATING DIFFICULT NEWS ABOUT A CHILD'S HEALTH OVER THE PHONE

STEP 1: PREPARE YOURSELF

- 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.
- "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?"
- 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.

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.
- "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?"

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• 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.

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 <u>'Guide for</u> <u>Sharing the news from hospital with your child'</u> 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. Remember that the patient may be important to children; it is essential to help adults think about how to tell children 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.