Principles to assist health-care professionals in communicating with children, adolescents, and parents about life-threatening conditions before, during and after consultation.

	Details	Challenges	Suggested Phrases
Prepare yourself	Examine your own comfort levels and beliefs. Use of supervision or consultation and peer support can be invaluable. Ensure that when you meet the child, they can see you as a calm and focused person who is able to hear and tolerate their distress and provide emotional support.	Time limitations due to pressure of work. Managing own distress about talking to the child about their illness. Managing own experience of bereavement or loss.	
Prepare information	Plan what you need to communicate; prioritise key information. Check you know the name of the child and members of the family. Check relationships between the child and family (eg, step parents).	Missing or inadequate information in child's health record.	"Is there anyone else who is important to you, who could be here to support you?" "My name is insert your name, can I just check I know everyone's name and who is here today?"
Prepare environment	Identify a quiet and private area. Consider who is with the child and who should be included in consultation, including relatives, advocates, or other health-care professionals well known to child or family. Make arrangements to care for other siblings as appropriate, or if they are to be present, consider their needs (eg, organising toys or colouring).	Availability of childcare for siblings to best support those taking part in conversation.	"Would it help if we found someone to look after your younger children while we talk?"
Development	Check the age of the child and any known neurodevelopmental problems or communication impairments. Consider child's understanding of language to be used in consultation (find interpreter if appropriate). Consider child's likely developmental understanding. Consider how to make information relevant to child's everyday context and culture. Choose developmentally appropriate language; accessible but not patronising. Consider use of universal communication tools –ie, picture charts and things such as faces or symbols to gauge happy, sad, good, bed, etc.	Facilities to support children with communication difficulties (eg, deafness, blindness, and interpreters) might be limited or unavailable.	"How much do you feel your child understands about the world around them and about their condition and care?" "Are there any tools you use in communicating with your child that we could make use of in this conversation?"
Prepare the parents	Discuss with parents the importance of communicating with the child about the diagnosis.	Parent might be reluctant to involve child in consultation, or wants to tell the child or assumes it is someone else's job to tell the child.	"I wonder how much you think insert child's name knows about their health at the moment?" "Thinking about talking to insert child's name about this probably feels the hardest thing in the world. It's completely understandable to want to protect them from this news. But we do know that children are very good at picking up on changes around them, and helping children understand what is going on can help them feel less frightened and alone. It will also enable you to support them without having to pretend." "We are here to support you with this."
Build a relationship	Patients and parents value respect, trust and empathy. Use the child's name when talking to the child and family (ensures consultation feels personal despite being in a large hospital or busy clinic). Respect parents' and patients' existing knowledge around the condition, care, or situation and treat them as an equal, respecting their own expertise in their personal lives and experiences.	Parents might share a different understanding of events or symptoms leading up to the consultation.	"Are there any questions that you feel are important for us to try and answer today?"

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Communication with children and adolescents about the diagnosis of their own life-threatening condition
Alan Stein, Louise Dalton*, Elizabeth Rapa, Myra Bluebond-Langner, Lucy Hanington, Kim Fredman Stein, Sue Ziebland, Tamsen Rochat, Emily Harrop, Brenda Kelly, Ruth Bland, Communication Expert Group†*

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	Details	Challenges	Suggested Phrases
Listen first	Elicit the child and parent's story. Determine what the child knows already. Ask the child what they think is happening. Use this information to evaluate the child's level of autonomy and independence so that information can be directed accordingly – eg, adolescents might want to take the lead in consultations. Children and adolescents should be given the opportunity to talk to the health-care professional alone to allow them to raise subjects they do not wish to share with their parents. Note that even older adolescents and young adults might appreciate the involvement of their parents in consultations.	Acknowledge that child might not want to speak at the moment. A challenge when time-limited to allow sufficient time to listen. Appreciate that some older children and young people talking on certain topics might not want their parent(s) present. Might need to use different approaches to conversations with different children. Children might have little confidence and self-advocacy skills.	"Tell me a little bit about what's been happening recently, leading up to being here today?" "Tell me what Mum or Dad told you about why we're meeting today?" "What do you know about what's happening to you? How do you feel about this?"
Language	Decide beforehand if you will name the life-threatening condition and consider implications of decision (consider age of child). Be consistent. Use clear language and avoid euphemisms or technical jargon, this prevents children feeling excluded or patronised by language they do not understand or feel is not tailored to them. Explain technical terms and jargon where necessary. After you have named the condition, stop for a few seconds to allow the family to take in what you have said. Then, sensitively check the family's knowledge and understanding of the condition.	Parent or child might google name of diagnosis. Child may want to talk to peers – eg, in a ward setting.	"Have you heard of insert name of condition? What do you understand or know about insert name of condition?" "What name do you usually use for your condition?" "What do you already know about your condition?"
Information delivery in a timely fashion	Be honest and realistic.	Uncertainty might exist about prognosis (if so, acknowledge this uncertainty). Children and their families vary in the timescale over which they wish to receive information. Parents and children might want different amounts of information. Parents might feel anxious about talking about prognosis in front of their child.	"Is there anything you would like me to expand on right now?" "Would you like to know everything in detail now? If not, how do you prefer to find out about things?"
Pace of information delivery	Provide simple, measured pieces of information. Allow the family and child time to assimilate what you have said, especially important after you name the diagnosis. Look for child or parents' reactions to gauge when they are ready for more information. Communicate on child's terms and with support from parents. Identify child's priorities and tailor information accordingly – eg, some young people's primary concern will be hair loss or whether hospital admission will interfere with a forthcoming social event, rather than treatment options.	Few cues from child or parents. Restrictions on time available for discussion. Be aware of emotional distress, fatigue, or pain that might limit capacity to absorb information.	"Have you heard of insert diagnosis before?" If so, "What do you understand about insert diagnosis?" "Do I need to slow down? Would you like me to go over anything again?"
Sources of information	Provide visual and verbal information. Provide details of other sources of information (eg, support group, useful websites or resources. Give child information to take away. Consider options to connect with another family with similar experiences to help guide them through (based on family preference).	Avoiding information from unreliable websites or unhelpful social media.	"Would it help if I wrote down some of the things that we talked about today?" "Would a picture be helpful to understand what we talked about?" "Shall I show you some photographs to explain what I mean?" "Would it help to talk to someone else with a similar illness?"

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	Details	**Challenges**	**Suggested Phrases**
Pay attention to emotional understanding	Follow the child's cues about their emotional understanding of the information. Allow child to express their feelings and explain these are normal in this situation.	Child's silence may indicate that they have understood all or very little of the information. It is important to check with the child what they have understood. Possibility of misinterpretation of behaviour.	"Did you know many other children often feel very sad, confused or frightened; how do you feel about this? Is there anything you want to say?"
Acknowledge quantity of information given	Reassure the family that feelings of shock and distress are normal and make it very difficult to process information.	Religious, spiritual, and cultural beliefs might need to be taken into consideration. Limited opportunities to talk to the family again.	"Do you feel ready to hear some more about this now?" "Would you like me to write anything down for you?"
Ask child and parents what they understood about what has been said	Check if the family are familiar with any medical terms used and whether there are local or cultural meanings that need to be recognised. Try to gauge understanding of all involved to ensure no one is getting lost in the conversation. Check understanding throughout the conversation. If possible, ask the child what they understood. Provide parent and child with opportunity to ask questions. Reassure child and family there will be further opportunities to ask questions.	Important to ensure communication at correct developmental level. Some parents and young people are very familiar with medical language and procedure, whereas others are not.	"I know that it can be difficult to take this all in." "Is there anything you do not understand or would like me to explain further?" "Can I check how well I have explained things today? Would you like to tell me what you've understood so far?" "Some families find it helpful to write all their questions down and bring them to their next appointment."
Make a plan	Explain to family what will happen next. Give family an idea of timescale for next steps, or, if unclear, when timescale will be clarified, including when their next appointment will be. Reassure families they will not have to manage this alone – if possible provide telephone and email contact details. If appropriate or available explain that symptoms can be controlled by medication, especially pain. Consider other sources of support for family – eg, community health-care professionals. Communicate with other health-care professionals involved – eg general practitioner.	Challenges in resource-limited settings including absence of phones and difficulties attending health clinic appointments.	To the child: "You must let us know if anything hurts or feels funny." To the parent(s): "We know that you know your child inside and out. If you have any concerns, feel they are in pain or something is wrong, then don't hesitate to contact the team. We appreciate you are the expert in your child and we will always work with you."

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