

Principles to assist health-care professionals communicating with parents and children about parental life-threatening conditions.

	Details	Challenges	Suggested phrases for parent/children
Prepare yourself	Examine your own comfort levels and beliefs. Ensure parents can see a calm and focused person who is emotionally available. Use of supervision or consultation and peer support can be invaluable. Consult relevant disease specific guidelines if available.	Time pressures and work.	
Prepare information	Try and establish if patient has children. Consider what ongoing input you can offer parents and children (eg, availability for direct contact with children). Check that you know the names of the parents and names and ages of children to ensure language and content is developmentally appropriate. Addressing family members by name will make the consultation more personal. Consider how to initiate the conversation about patient's children.	Might be difficult to establish if adult patient has children (eg, in the Accident and Emergency department). Adult clinicians might feel unskilled or inexperienced talking about children.	Parent: "Can you tell me about your family?" "Who lives at home with you?"
Prepare environment	Consider suitable location (quiet or private) and timing of conversation with parents (both if possible) and children.	Private or quiet space might not be available.	Parent: "Let's move to this quieter space so that we can spend some time talking together."
Explore parents' views about talking to their children	Acknowledge concerns that parents might have about telling their children. If parents express doubt about talking to their children explain that they might have already noticed changes – eg, physical and emotional changes, and absences – which lead to children's distress. Suggest it is better to talk to children so they are not alone with their worries, or find out the diagnosis from another source, especially if ongoing treatment and changes in physical state. It might be helpful to discuss their children's developmental understanding of illness. Acknowledge emotional aspects of a parent telling their child about their condition and desire to limit child's distress. Explore parental fears or barriers to talking to their children. Problem solve around perceived barriers, while respecting parent's role, wishes, and beliefs.	Parents might feel reluctant to talk to their children; reassure parents that it is not uncommon to feel this way. It can be helpful to tell parents there is no hurry to decide, that they can give this decision some thought, and another meeting can be arranged in a few days.	Parent: "Talking about talking to your children about this probably feels like the hardest thing in the world. It's completely understandable to want to protect them from this news. Are there particular things that make this even harder for you?" "I wonder if your children have noticed that you've been losing weight or have been unexpectedly away from home a lot recently?" "We know from experience that sometimes when we don't share things about illness with children, they often realise something important is happening. They have active imaginations and what they imagine can even be worse than the reality." "We know that you know your child inside out. We appreciate you are the expert in your child and we will always work with you."

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Communication with children and adolescents about the diagnosis of a life-threatening condition in their parent

Louise Dalton*, Elizabeth Rapa*, Sue Ziebland, Tamsen Rochat, Brenda Kelly, Lucy Hanington, Ruth Bland, Aisha Yousafzai, Alan Stein, Communication Expert Group†

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	Details	Challenges	Suggested phrases for parent/children
Prepare the parents	<p>Acknowledge and support parent with their own feelings and distress about their diagnosis.</p> <p>Prioritise key information for parents – they might struggle to assimilate information because of fatigue, pain or emotional distress.</p> <p>Discuss with parent timing of information about life-threatening condition.</p> <p>Encourage parent to ask the child how much they know about the life-threatening condition and pace subsequent information in response to children’s emotional reactions and wishes; the conversation might need to take place on several different occasions.</p> <p>Discuss with parent how best to describe the life-threatening condition; suggest simple phrases or narratives the parent could use to explain the life-threatening condition to their children, including the name of their life-threatening condition, what they might observe, and what they should expect.</p> <p>Encourage parent to only convey information that is true and can be elaborated in due course; this is important to maintain the children’s trust in their parents or caregiver.</p> <p>Suggest to parents they might find it helpful to prepare a script and practice this before talking to their children.</p> <p>Suggest parent might find it helpful to include their partner, a family member or friend in their conversation with the children.</p> <p>Highlight to parents themes from literature about what children report is important in communication about life-threatening conditions.</p> <p>Offer parent resources (eg, leaflets, story books, or web resources) to share with their children.</p> <p>Encourage parent to check children’s understanding of what has been communicated and importance of repeating key messages.</p>	<p>If parents are separated, discuss with parents who will tell the children and the involvement of the other biological parent.</p>	<p>Parent: “Would you like to sit and talk with me now about how you will tell your children and what words you could use? If you like, we can then practice this together.” “I know you are worried that telling your children will be upsetting for them. Yes, it is likely they will be upset or even angry. These are natural emotions and responses to have. Be assured that talking to children is important in helping them through this difficult time.” “Younger children might focus much more on the practical aspects of how the life-threatening condition will change their day to day life; who will take me to school? They might not show an immediate reaction to the news (for example wanting to go and play) but this doesn’t necessarily mean they didn’t hear the news and distress can be shown in other ways.”</p> <p>Children: “Today we went to the clinic because Dad hasn’t been feeling well. Shall I tell you a bit more about what the doctor told us?” “You know that Mummy hasn’t been feeling well and we needed to find out what was wrong. We went to the hospital where the doctors did some special tests to try and find the problem. Today the doctors told us Mummy is ill because she has an illness in her blood called cancer.” “The doctors are giving Dad some strong medicine called chemotherapy to try and treat the cancer. We hope this will help him get better, but it will also make him feel very tired.” “The doctors and nurses are trying very hard to make Mummy better and I really want Mummy’s medicines to work but sometimes medicines do not work.”</p>
Reassurance for parents that discussion will not cause more problems	<p>Reassure parent it will not cause harm to share some of their emotion with children but that openness does not mean sharing full expression of their own grief.</p> <p>Encourage parent to consider how they can or want to model for their children in responding to the life-threatening condition (eg, sharing emotions, possibly using humour).</p> <p>Labelling emotions (eg, sad, scared, or angry) is useful and allows modelling of emotional sharing and expression.</p> <p>Help parent feel confident to reassure their child that they will be loved and looked after no matter what the future holds.</p>	<p>Alert parent to children’s common reactions – eg, sadness, anger, and reassure parent that these are normal responses and does not mean the parent has done the wrong thing, or that the child does not want further information at a later date.</p>	<p>Parent: “It’s ok to talk with your children about how scary and sad this news is. 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 sometimes you feel a bit sad and you feel better after a good cry.”</p> <p><i>Continued on next page</i></p>

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			<p>Children: “I know that this is sad and scary to think about, but it’s better that we share how we are feeling and talk about our worries, rather than having to struggle with it by ourselves.”</p>
Common questions	<p>Support parent to nurture children’s confidence to initiate conversation and ask questions. Anticipate common questions that children might ask. Parents might benefit from rehearsing with answer these questions at a developmentally appropriate level; this also provides an opportunity for you to check parents’ own understanding of their condition. Encourage parent to reassure their children that their distress is normal and acceptable. Discuss ways parent can encourage children to ask questions as they arise and review their children’s feelings regularly. Discuss with parent the possibility older children might independently seek further information online which might be of varying factual quality Encourage parental dialogue with their children about online information.</p>	<p>Questions about the possibility of parental death are disease and stage specific. Answers need to consider child’s age and level of understanding.</p>	<p>Parent: “Children often want to know what caused the illness and are worried that it might have been their fault.” “Your children might ask you if you are going to die, who will look after them and whether they can catch it. Shall we plan how you might deal with these questions at home?” “Would it be helpful to have a session with you and your children together?”</p> <p>Children: Would you like to talk to the doctors; you can come with me one of my clinic visits?”</p>
Future thinking	<p>Discuss with parent how they can involve children in day-to-day aspects of the life-threatening condition. Encourage parent to establish a new normal while maintaining boundaries and hobbies where feasible. Encourage the parent to share the practical and emotional burden with the well parent, family, and friends. If parents are separated, discuss the benefits of maintaining a consistent message for their children. Identify who else knows about the life-threatening condition and who the child can talk to. Explore the importance of children’s teachers and school. Identify ongoing sources of support and community resources (eg, parent groups, voluntary sector, online forums or websites, written story books and other online resources). Discussion might need to include consideration of who will care for the children if the parent is hospitalised, or for single parents, custody arrangements.</p>	<p>Challenges in resource-limited settings including absence of phones and difficulties attending health clinic appointments.</p>	<p>Parent: “If you can, do accept offers of practical help or emotional support from friends and family with whom your children feel comfortable, to keep their day to day routine.” “Children spend a large amount of time at school and so it is important for the school to understand what your child is going through. School can also be a really helpful source of support for your child. Try to keep the school up to date.” “It will be 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 really important.”</p> <p>Children: “I know it can feel scary when you don’t feel sure about what’s going to happen. I feel that way sometimes too. What I do know for sure is that I love you very much. We will work through this together as a family, whatever the future holds.”</p>

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