A guide for professionals

10 tips to help parents and carers with a life-limiting illness have conversations with their children

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Parents and carers with life-limiting illnesses often look to professionals for advice and reassurance on how to talk to their children about their condition. As professionals, we have a responsibility to guide and support them through these difficult conversations.

However, many professionals feel inexperienced and ill-equipped around this sensitive issue, which can impact on their readiness to start conversations with parents about their children.

We've put together these 10 tips to help you do this. The tips are based on interviews with professionals, parents, and children (up to 18 years old) from diverse backgrounds.

Having these conversations can be a challenging aspect of your role as a professional, particularly if you are a parent yourself. It may be helpful to discuss your fears and emotions with a colleague beforehand.

Contents

1. Starting the conversation with parents and carers

Acknowledge how difficult these conversations can be with parents and carers.

You could approach the conversation by saying:

> **"I'm sure this must be very difficult for you, but have you talked to your children about your illness?"**

Some parents may feel that they're protecting their children by not telling them about the illness, as they fear it will be too upsetting.

A way to approach this could be to say:

> **"Your children may pick up that something is wrong and can feel scared and unimportant if they do not know the truth."**

Parents may feel unsure when to tell their children. As a professional, you can reassure them that there is 'no right time'. Encourage parents to find a time and place to start the conversation with their children where interruptions will be unlikely, and the conversation will not be rushed.

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2. Explain that children want to be informed and involved

We know that children and young people want to be involved as much as possible when their parent is seriously ill. Usually, they sense that something is wrong. Not knowing the truth is confusing for children and can lead to them becoming anxious.

Children can get information about illnesses from multiple sources, such as the internet, which may not be accurate. They're also sensitive to what's going on around them. They may overhear whispered conversations in the home or notice visible changes in how their parent looks or behaves.

Open, factual, clear communication is best for children. Evidence tells us that children who are less prepared for the death of a parent have poorer psychological adjustment, both in the short-term and later in adult life.

By parents talking with their children, they have more control over the information that's shared and can make sure it's reflective of their situation. This can help children feel better supported and more secure at this upsetting time.

You should encourage parents to start this conversation with their children as soon as possible, perhaps by saying:

> **"Being honest with your children will allow them to express their fears and worries. Telling them the reality of your illness means they can be involved and you can support them through the process."**

3. Prepare parents for difficult questions

Children may ask challenging questions, and parents can often struggle with how to answer them. You should encourage parents to be honest with their children about the reality of the situation.

Here are some challenging questions parents may be asked by their children, with suggested responses:

Q: "Why can't the doctors make Mum/Dad better?"
A: "The doctors and nurses are doing all they can to help Mum/Dad, but the disease is still there. The doctors and nurses will make sure Mum/Dad is well looked after."

Q. "Is the illness my fault?"
A: "No, you absolutely have not caused Mum/Dad's illness."

Q. "Will Mum/Dad [the well parent] die too and who will look after me?"
A: "Mum/Dad is healthy and Granny/Grandad/Aunt/Uncle will also be there to look after you."

Q. "Is Mum/Dad going to die?"
A: "The doctors and nurses are really going to try and control the disease, but Mum/Dad is not going to get better. The really sad news is she/he is going to die."

Q. "What happens when you die?"
A: "Mum/Dad's body will stop working and when she/he dies their heart will stop beating. That means Mum/Dad won't need to eat, sleep and drink anymore."

It can also be helpful to reassure parents that it's okay to say "we don't know" to some of the questions their children pose.

4. Encourage the use of plain language

It's important to encourage parents to use plain language, so their children understand the situation. Parents can often be unsure how to explain the prognosis to their children in an age-appropriate way. Advise parents to avoid confusing terminology and euphemisms with their children, for example, encourage parents to use the word 'cancer' rather than 'lump', and 'die' rather than 'pass away'.

Parents should also inform others such as grandparents, aunts or uncles to use these terms if speaking to the children about their parent's illness.

Parents should also reinforce that this life-limiting condition is very different to illnesses that the child may have had, such as a cold, and make it clear that the parent's illness cannot be cured. Parents may draw on their religious beliefs when explaining their illness, or death. However, it's still important that children understand that the state of death is permanent.

Remind parents they may have to repeat information more than once to children, to make sure they understand it. Younger children can find 'chunks' of information at different times easier to understand.

A possible way for parents to start this conversation with their children could be:

"As you know, Mum/Dad has been getting chemotherapy for their cancer – the doctors have told us that it is not working as well as they had hoped, and the cancer is spreading in her/his body."

"The really sad news is she/he is not going to get better."

Parents should be encouraged to provide their children with ongoing information as the illness progresses.

5. Explain that showing emotion is appropriate

Sharing difficult news with the children can be overwhelming for parents. Reassure parents that it is okay for them to become tearful and emotional with their children. This is a healthy and appropriate way to respond. It helps children to understand the seriousness of the situation and gives them permission to express emotions too. Encourage parents to share their thoughts and feelings with their children.

A possible way for parents to talk to their children about emotions could be:

"It's okay at times for you to feel sad about Mum/Dad's illness – all feelings are important and right now we feel sad too."

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6. Children respond and react differently

Explain to parents that children of all ages cope with challenging situations differently. For example, some may not cry when the news of the life-limiting illness is shared with them, others may be angry about the situation or have difficulty sleeping. It's important to reassure parents that these are all normal reactions for children to have. However, parents should be encouraged to seek support from a professional if they're concerned by their child's behaviour in response to the news.

Some children may need more information about the illness and parents should encourage their children to ask questions.

It may be helpful to encourage parents to say something like:

"We know this may be very confusing for you. You can talk to us or ask questions at any time. Or if you want to talk to someone else, like your teacher, that's okay too."

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7. Encourage parents not to provide false hope to their children

It's important that as professionals we make sure parents understand the severity of the illness and that we're providing them with accurate information. Encourage parents to be clear and honest when sharing the reality of the poor prognosis with their children.

A possible way of approaching this with parents is to say:

> **"I know we want to remain hopeful, but it's important that your children know the truth about what's happening."**

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8. Encourage parents to draw on their support network

Family members, friends or people within the community often want to help when a parent has a life-limiting illness. Parents should be encouraged to make use of their support network if and when required. Drawing on these support networks may help parents manage practical day-to-day activities, such as household chores or taking their children to school.

Parents should also be encouraged to inform relevant professionals about their situation, such as school teachers and extra-curricular leaders. Faith communities, charities and schools can be particularly supportive at difficult times.

You might want to tell parents something like:

> **"I can see you have a lot on your plate right now. Is there anyone else that can give you some help or support?"**

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9. Encourage parents to maintain a routine

To provide stability, parents should be encouraged to maintain family routines and activities as much as possible. This includes the children going to school and taking part in extra-curricular and social activities. We know children benefit from taking part in social activities and spending time with friends.

It is important to encourage parents to maintain healthy boundaries in this time of uncertainty, such as usual bedtime routines.

You might want to approach this with parents by saying something like:

"It's important for children to still have fun and time away from thinking about your illness."

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10. Encourage forward planning

Parents can gain comfort from knowing their future wishes for their children will be respected. They may want to 'put-off' making preparation for the future until a later time, but this may mean they become too unwell and don't have the opportunity to do so. When parents make plans for the future it makes it easier for the family to cope after the parent has died.

Encourage parents to start making preparations for the future shortly after receiving the poor prognosis while they are still well enough. Key preparations may include making a Will, outlining funeral wishes, knowing passwords to accounts, and managing financial or legal matters such as guardianship for the children.

Some parents may also want to capture memories by taking photos, audio-recordings or videos, while others may want to document memories by writing letters and cards for the child's future.

A possible way of approaching this conversation with parents is to say:

"I understand it's very difficult for you, but it's really important to plan ahead when you are feeling well enough. This will help your family later on."

These tips have been developed to help you as a healthcare professional to empower families who are affected by life-limiting illness. We acknowledge this can be challenging and emotional for everyone. But providing families with appropriate support can have a positive impact on how their children cope in bereavement, and later life. For more information about terminal illness and bereavement, go to **mariecurie.org.uk** or read more in the publications on the following page.

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