

## When a parent is dying

### Helping parents explain death to their children

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*You have known Sandy, Rich, and their 9-year-old son, Mike, for years. Sandy was diagnosed with metastatic melanoma 8 months ago. She and Rich know there are no further treatments available and that she is dying. You ask them what Mike knows about Sandy's cancer. They have told him only that his mother is "sick," hoping to protect him and give him as much of a "happy and normal life" as possible. Now, Sandy and Rich think it is time to tell Mike more, but they are worried about finding the "right time."*

There are few tasks more difficult and heart-wrenching than talking with children about the death of a parent. It is not something that parents can ever really prepare for until they are in that sorrowful situation. Dying patients and their spouses often ask their family physicians for guidance, and many times we also feel unprepared. This is not something that is taught in medical school or often discussed in the general medical literature.

#### The time is now

With respect to Sandy's situation, you start by talking with Sandy and Rich about how common it is for parents to wait for the "right time" but, as with most very challenging discussions with children, there rarely is a perfect moment. Given Sandy's condition, waiting for the right time could even lead to her dying before a conversation ever happens. You tell the parents that communicating openly and honestly with Mike about Sandy's cancer is important and can actually help lower any anxiety he has about what is happening in his family<sup>1-3</sup> and prepare him for the loss of his mother.<sup>4</sup> It also allows an opportunity to address any misconceptions Mike might have. Children have amazing imaginations and, in the absence of being told what is really going on, might harbour fears or beliefs even more distressing than reality. Sandy and Rich think they have protected Mike from what is happening and are pretty sure he does not know much about the illness and prognosis, pointing out that he has not asked a lot of questions. You explain that sometimes children try to protect parents by not bringing up difficult topics if they think it will be upsetting for parents. It is quite common for parents to believe that their children are fine and not emotionally affected by what is happening when, in fact, they are.<sup>5</sup>

*Rich and Sandy think about what you have said and decide to talk with Mike. They pick a time but later*

*postpone the discussion because they cannot think of the right words to use. They are worried about saying "the wrong thing" and wonder if there is anything specific to say or not to say when talking with a 9-year-old about death. They ask for your help and hope you can be there for the conversation.*

It is common for parents and health care providers to wonder about age-appropriate discussions regarding death. One can find some recommended guidelines in the literature on what to say to children in various age groups.<sup>6</sup> This information can be helpful but is not always available to parents at the time of the discussion or at the fingertips of physicians.

You inform Sandy and Rich that what is most important is to be honest with Mike about the disease and prognosis, answer his questions, and address his concerns. You also mention that it is okay to respond to a child's question with "I don't know"; they should tell the child it is a great question and they will try to find an answer. Children might ask questions for which there are no answers; these instances are opportunities for parents to teach children that not all questions have answers, yet it is still good to wonder about such questions together.

With respect to what to say about the actual illness, you inform Sandy and Rich to tell Mike that his mom has a skin cancer called melanoma. Being specific and concrete by using the name of the disease is better than saying "Mom is sick" or "Mom is ill." If, in the future, healthy parents, family members, or children themselves express suffering from a cold with "I am sick" or "I am ill," children might associate having a cold with dying.

*You meet with the family and ask Mike what he knows about his mom's illness. Sandy and Rich are shocked that Mike knows his mom has a disease of her skin and that the problem has spread to her lungs and liver. He overheard his parents' conversations with each other, his grandparents, and their friends on the telephone. He is very worried that he caused the cancer and that he might get it, as well.*

It is not unusual for children to know more than their parents think or to worry about having caused the illness. Many children also worry about "catching" cancer from a loved one. You tell Mike about the cancer, explaining that it is not contagious, and ask why he thinks he caused it.

Mike says he learned in school that the sun can cause skin cancer and he had always bugged his mom to be outside with him in the sun. He is outside a lot and is worried that he will also get skin cancer. You reassure Mike that he did absolutely nothing to cause the cancer. You tell him what he can do to protect himself against skin cancer and that you would be happy to examine him.

Listening attentively helps to discover children's fears and concerns. Addressing and not minimizing those fears and worries helps to alleviate children's anxiety. After telling Mike he can ask any question and share any worries, he asks many common questions: "What's going to happen to my mom?" "Who'll take care of me?" You explain that his mom is dying from the cancer and, although you do not know when, it could happen soon. Despite the difficulty, it is important to use the word *dying* and avoid euphemisms (eg, "not getting better" or "passing on"), as they do not translate into dying for children. It is also normal for children to worry and wonder about who will take care of them when a parent dies. You reassure Mike that his dad is healthy and will care for him.

### The inevitable

Shortly after talking with the family, Sandy is actively dying. You tell Mike what to expect and that any feelings and reactions he has to the situation are all right. Experiencing various emotions simultaneously (eg, sadness, anger, happiness when playing with friends) is common for children and is a way of coping. You also suggest that Mike have meaningful and appropriate caregiving responsibilities, such as getting fresh water to keep Sandy's mouth moist; this will make Mike believe that he is useful and is not being alienated from what is happening to his family.

### Further reading

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### BOTTOM LINE

- We cannot shield children from dying and grief.
- Do not wait for the "right time" to discuss death with children. Communicate openly and honestly.
- Actively listen to questions and concerns that indicate a child's level of understanding.
- Avoid using euphemisms, such as "not getting better" or "passing on."
- Provide emotional support.
- Involve the child in age-appropriate caregiving responsibilities.

### POINTS SAILLANTS

- Nous ne pouvons dissimuler aux enfants la mort et le deuil.
- N'attendez pas le «moment propice» pour discuter de la mort avec les enfants. Communiquez ouvertement et franchement.
- Écoutez activement les questions et les préoccupations qui indiquent le degré de compréhension de l'enfant.
- Évitez les euphémismes comme «ne pas guérir» ou «aller au ciel».
- Donnez du soutien émotionnel.
- Donnez à l'enfant des responsabilités appropriées à son âge dans la prestation des soins.

Harpham<sup>7</sup> captured the essence of how to help children when a parent is dying when she wrote, "The greatest gift you can give your children is not protection from change, loss, pain or stress, but the confidence and tools to cope and grow with all that life has to offer them." 🌿

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### Competing interests

None declared

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