



Talking with Children and Youth about Serious Illness

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Explaining the serious illness of a family member or friend to a child or youth can seem overwhelming. Adults who are themselves feeling emotions related to a family member's illness may want to protect children from feeling the hurt that comes from knowing that someone you care about is very sick, and may die.

However, even very young children can sense when something is wrong within the family. As a result, if you try to hide your feelings, you are not likely to be successful. Children who are shielded from the truth are likely to worry, rely on overheard bits of conversation, or make up something in order to make sense of the unusual behaviours they're observing. Many experts who work with children and youth believe that young people are better able to cope with situations if they know what is happening and feel comfortable asking questions.

When you provide children and youth with information about what's happening within the family, you may be giving them the opportunity to:

- work through their feelings with other family members who are experiencing the same emotions;
- feel less isolated;
- learn to trust what adults are telling them;
- learn to trust their own perceptions.

The challenge you may face is to provide children and youth with information that is honest, timely, and appropriate to their age and stage of development.

If you are uncomfortable talking about death and dying, as many of us are, you may find yourself struggling for the right words to explain what is happening. After reading the general suggestions here, you may want to ask for support from members of a palliative care team who have special expertise in working with children, youth and families.

Start the conversation

Children know when others are anxious, or when something has changed in the family. Telling them about the seriousness of the illness lets them know it's okay to ask questions and helps them understand why family members seem to be unhappy or are crying sometimes.

Children become aware of death at a young age – they may see insects, animals or pets die, and they may see death portrayed in books, on television or in movies. You could draw upon these previous life experiences to start a discussion about what's happening. You will probably want to be up front about the fact that someone they know is expected to die. It's okay to use the words "death" and "dying" in these discussions. Avoiding these words may only cause confusion.

For a very young child, you will want to keep things very simple in language they can understand:

"Grandpa has a disease called cancer. The disease is taking away his energy to do things. It's making him weaker and weaker. One day he won't be able to get out of bed anymore. And then he'll be so weak that his heart will stop working and he will die."

After this explanation, you will want to listen carefully and observe the child's reaction. As children go through different developmental stages, their understanding of death and dying will change quite dramatically.

You may find yourself wanting to explore how a child is feeling about a family member's illness, but are unsure how to begin that conversation. A starting point can be to connect with what they've likely been noticing:

"You've probably been noticing that Grandpa has been more tired lately, and hasn't been able to do as much as he used to. I'm wondering if you've been thinking about that, and if you'd like to talk about that..."

When speaking with children or youth, it is vital to respond in an open and honest way to questions they may have. No matter how difficult a situation seems, children and youth are remarkably able to cope and integrate illness and death into their lives.

Clear up misunderstandings

Even before you share the details of what's happening with a child, you may want to find out what they know about the situation. They may be feeling anxious about things you haven't even considered. For example, one person's illness may cause worry that other people in the family are also at risk of dying. You may want to start the discussion by addressing these concerns.

Not all questions will be answered in one conversation. Encourage children and youth to come back to you when they think of new questions. Other people might also give them different information than what you have given them. This can be confusing. You might want to let them know that you're available to try to help sort things out.

Listen for cues

You might wonder how much detail to provide children and youth about the seriousness of the illness. The best approach may be to take your cues from the child and give only as much information as they seem to be able to take in or want to know.

Like adults, children and youth need time to let things sink in. If they want additional explanations, they will usually ask questions about things they are wondering about.

Children should be allowed to determine the pace of information that they receive. They will often set this pace without any prompting from you. They might ask questions that seem to come out of the blue, and then abruptly shift their attention back to something else, such as playing. This may seem like the child doesn't understand how serious things are, however the child is pacing the amount of information, and taking the time needed to think about it.

Reassure the child or youth that you will give them regular updates as to what is happening and how the ill person is doing. Let them know that they can come to you (or another trusted adult) at any time with questions or to share how they are feeling.

Provide information about what to expect

Knowing what to expect helps to ease the fear of the unknown. Children and youth also may have to adjust certain behaviours because of the physical limitations of the person with illness.

You might want to share information about any of these:

- treatments;
- where the person will be cared for (home, hospital, other environment);
- side effects that might occur as a result of medications or procedures. For example, you might let the child know that the person with illness may be more tired than usual, may look different, or may not be able to participate in activities;
- symptoms of illness. For example, if the person with the illness has back pain, the child should be aware that a cuddle while sitting on the adult's knees may not be possible.

Prepare for visits to new environments

Describing the health care environment in advance of a visit helps children and youth make sense of what they will see. Imagine yourself as a child...what will you see and notice as you walk into a room? If the patient is using any medical equipment (such as oxygen, a ventilator or an intravenous line), describe what the equipment looks like and explain its purpose.

If children or youth need to behave in a certain way, prepare them for this too. For example, visitors to an intensive care unit will need to remain quiet, as there are usually several patients being cared for in one area.

When visiting someone who is ill, keep in mind that visits should not be too long, especially if the person is quite tired. If the children are not close family members, check with the patient or the patient's family about whether it's all right to bring children or youth to visit. They may welcome your desire to normalize this experience for the young person, or they may prefer to stop visits at a certain point during the illness.

You may wonder how involved your child should be as someone becomes more ill. If the child or youth is not distressed by the patient's changes and symptoms, and the visits are still welcome, then there is no reason to stop visiting. Often families do not want children to be around someone who is dying. However, this avoidance may lead to more questions and possibly some fears developing about illness and the end of life. Making death a natural part of life for children and youth will help them integrate this experience into their lives.

Discuss changes to routine

Children and youth may be very concerned about who will look after them, and how someone's illness may affect their usual routines. This happens especially when the person with the illness is a parent or primary caregiver. Try to clarify who will be looking after them, where they will be cared for, and what changes might occur in their day-to-day routines. If you can, continue to maintain a regular schedule, as structure is important for both children and youth.

Speaking to more than one child

If there are several children in the family, you may want to bring them together for discussions. However, there may be times when you want to set aside some time to talk to each of them individually. If you have children or youth who are particularly sensitive, you may find you have better discussions when they can explore their feelings without their siblings present. You will likely have a sense of what will work best in your situation.

If groups of children or youth are affected by someone's illness, such as a classroom of students, a team, or members of a club, it may be helpful to hold serious discussions as a group. You may want to have someone come along to support you in the discussion of these difficult issues.

Check in frequently

Check in with children or youth frequently by asking them if they have any questions about what is happening or want to talk about how they may be feeling. This will let them know that they can talk to you about their feelings. Exploring why they have these feelings can also be helpful. You may also want to discuss how you're feeling and that's okay. Children and youth will recognize that the situation is sad, and it can be helpful for them to know that adults are experiencing the same emotions that they are.

Developmental stages

Your child's understanding of illness and death is shaped by many things, including their:

- previous experiences with death and illness
- verbal abilities
- exposure to popular culture (television, films, internet, games)
- cultural and ethnic background
- spiritual or religious beliefs and practices.

As children develop and age, their understanding of the world around them begins to expand. Knowing how children interpret illness and death at various stages of their lives may give you some clues about how to reach out to them in a way they can understand.

The ages here are rough guides to the stages of development, as children mature at different rates.

Very young children (infant – 2 years)

Children younger than two will have a very limited understanding of illness and death. Their verbal skills are developing, and they experience the world primarily through their senses. Even young children can be aware of changes in their environment. If someone is not present, such as an important family member, a child may recognize this absence. They seem to be affected by the emotions of those around them, and often sense that things are not as they normally have been.

Very young children are often comforted by the presence of the familiar. They respond to being held, having someone close to them, maintaining their routine, possessing their favorite toy or blanket, as well as being in familiar surroundings.

Young children (2 – 6 years)

Children of about two to six years of age are beginning to develop an awareness of illness and death. They may view death as something that is reversible and may not understand its permanency. This can lead to misunderstandings about the finality of death. You may find that for quite some time you are repeating details and clarifying what has happened.

Children this age may ask questions about the person who is ill or who has died. These questions often come up at random times. It is important to answer these questions honestly. If you don't have an answer, then let children know that you don't know, but that you will find out. Some questions may cause you to become emotional. It's all right to show your sadness to children. It will let kids know that sadness can be a part of the grieving experience.

Be aware that young children can have active imaginations and may not fully understand what illness means. They may not understand the rituals that families or communities have around death. If children express thoughts that are not accurate, you can gently comment that their view is interesting. You can also explain in simple, concrete terms what the reality of the situation is.

Sometimes children feel that they have caused the death. A child might remember saying *"I wish you were dead!"* and feel completely responsible for the illness or death. Children at this age need to be persuaded that their words and actions cannot influence someone's health.

It is important to realize that children can be affected deeply by an illness or death, and yet continue to participate in normal childhood activities, such as play. This does not mean that they are not acknowledging the illness or are not grieving; it means that they are integrating the illness or death into their lives. When dealing with stress or new things, some children may fall back in terms of their developmental progress. This is normal and no cause for alarm.

Activities that may be helpful for younger children to express their emotions or discuss illness and death may include reading storybooks, playing or participating in art activities.

Older children (6 – 12 years)

Older children around ages six to twelve are beginning to understand how the body works and what it means to have an illness. They are coming to realize that illnesses may not be directly caused by something external to a person. They can also start to understand how the body functions and how illness can result from a part of the body not working properly.

Older children are starting to develop an awareness of the world around them and recognize that death usually occurs in older adulthood. They understand that life has a beginning and an end. Between the ages of six to nine, children begin to understand the permanency of death. Starting at around nine years old, children recognize that death is permanent and that it can happen to anyone.

These children are beginning to develop reasoning skills and a higher level of understanding about illness and the world around them. They are recognizing that people are individuals, who respond to situations in different ways. Some children are very curious and may ask questions about specific details relating to customs, rituals and the physical preparation of a body when someone dies.

Activities that may be helpful for older children to express their emotions or discuss illness and death may include reading, playing, art therapy, support groups, workbooks or writing (keeping a journal).

Youth (13 – 18 years)

By the time adolescence is reached, children have likely experienced the death of someone they know. These earlier life experiences will shape how death is viewed in the present. Teenagers and young adults understand that death is final and personal. They realize that death is universal and that it will happen to all living things.

The illness or death of someone close can have quite an effect on the day-to-day life of an adolescent. Their mood, usual behaviors, attitude, sleep and eating patterns, and school work can all be affected.

The teenage years are a time of self-exploration. Adolescents want to be older and do older things, but at the same time they may envy younger children who have no hesitation in seeking out hugs or cuddles. This struggle can bring out volatile emotions when someone dies, including anger.

As parents and other adults reaching out to adolescents, you'll probably need to make repeated offers to help. Young adults will process a death in their own way and there is no rushing it along.

By the age of 13 and older, peers have become an important part of life. Because of this, support groups can be a great place for adolescents to meet others in similar situations. They realize they are not alone and can find support in others who are experiencing similar circumstances. At the same time, they may not want to stand out as being different from their peers, so they may avoid talking frankly with their friends about their feelings.

Keeping a journal may be a way for adolescents to express themselves. Music may be another way for them to express or relate to their feelings.

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