

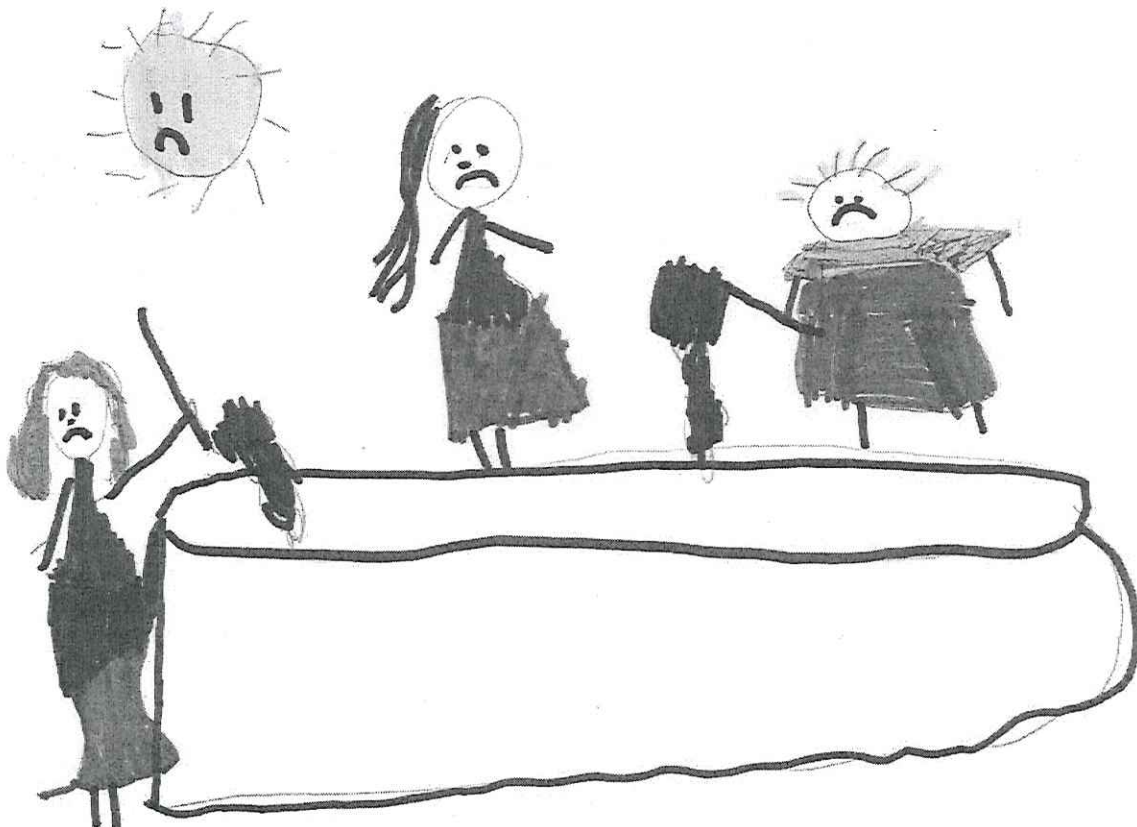
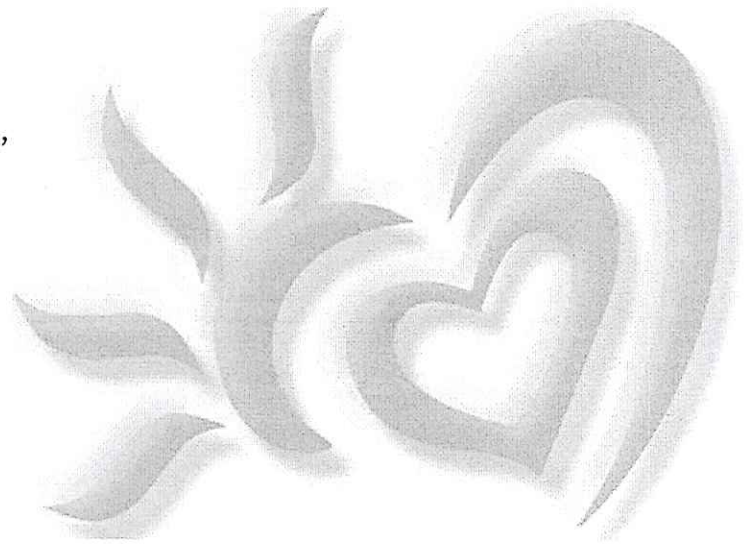


Talking with Young People About Illness and Dying

Supporting children and teenagers when a loved one is dying or has died is one of the most difficult tasks for adults at this trying time.

Family members, friends and caregivers who are helping a child to understand and grieve – when they themselves are also grieving – often feel overwhelmed and helpless. Despite these feelings, you can help.

When a loved one is dying, we may wish we could “fix” the situation or prevent children from suffering. But we can best support kids in their struggle to live with and make sense of what is happening by talking with them frequently and including them in the experience. We hope that the following ideas will help you to do this.



Talking openly, honestly, and often: A framework for discussion

Be honest when answering questions and providing information. Kids can sense when they are not being told the whole truth. They may become anxious and make up inaccurate explanations about the illness.

Use the words *dying*, *died*, and *dead*. To a child, phrases like “there’s nothing more we can do” and “he’s not going to get better” do not mean the same thing as “he’s going to die.” Children may think their loved one will live a long time in their current state. Avoid confusing phrases like “passed away” or “gone to a better place.” Do not refer to death as being like sleep. This can lead children to fear falling asleep because they think it might lead to death. Explain that when someone dies, their whole body stops working. They stop breathing, their heart stops beating, and their brain stops working. This means that their body can’t think, hear, see, smell, taste, or feel. Dying is what happens as a person’s body stops working. Talking about the physical aspects of death also provides an opening to discuss spiritual beliefs.

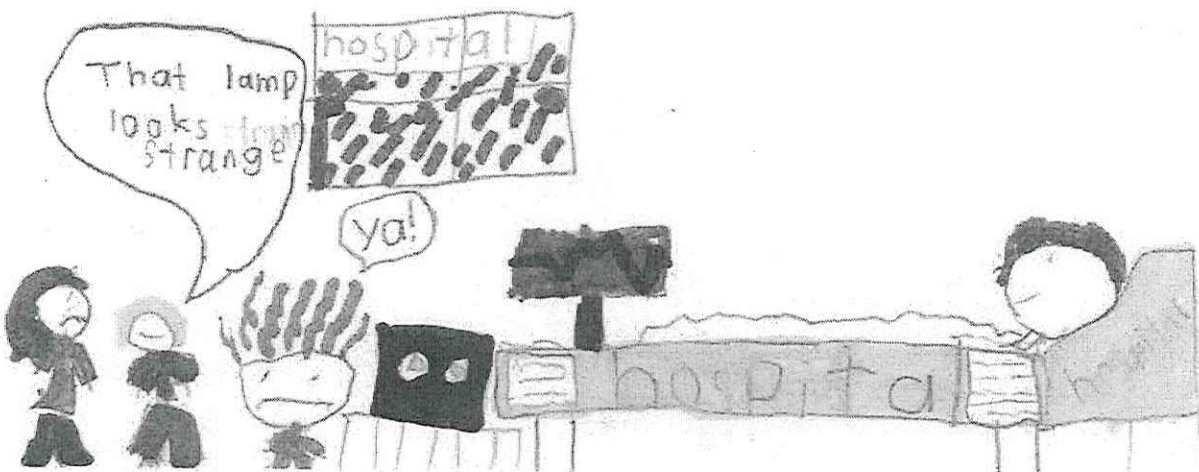
Ask if they’re wondering or worrying about anything. Kids often try to protect their parents, so it is important to reassure them that any questions or worries they have are okay. Kids may have feelings and ideas that surprise you or seem strange, but it is important to take a child’s concerns seriously. Even when these things are hard to talk about and may be upsetting for you or the child, it is good to bring them to light. When kids ask hard questions, answer honestly and thank them for being open with you. Children may ask the same questions over and over when they are trying to make sense of something complex or abstract. Be patient when you need to repeat yourself.

Pay attention to how they react to what you say. For example, if they cry, fidget, or look surprised while you are talking, or even afterwards, identify the reaction you are seeing. Ask them to tell you what it was that made them respond that way. Although some children may not be able to explain the reasons for their reactions, it’s important to be attentive to what is happening for them.

Don’t be afraid to say “I don’t know.” Tell them you’ll ask someone who might know the answer, like a doctor or family member. When discussing serious illness and death with kids, they may have questions for which there are no answers. Discuss with them that some things in life cannot be explained and let them know that it can be helpful to talk to others about any mysteries that they have been wondering about. Exploring a young person’s imagination about these issues and spiritual beliefs is an important part of talking about death.

Show them you are there to support them. Children feel stronger knowing they can share their thoughts, questions, and concerns with loving and supportive adults. They need to know that there are no wrong or bad feelings or thoughts, and that they don’t have to “be strong” or “hold it together.” Explain that it is common to feel a range of emotions and it is important to share them. Encourage healthy ways for kids to express their feelings such as through sports, art, crafts, music, dancing, writing, or talking to someone they trust.

Check with them often. Ask them if what you have told them makes sense, or if they want it explained again in a different way. Throughout the discussion and over time, keep asking if they have new questions or concerns.



Talking about illness and dying: A step-by-step approach

Ask them to describe what they know about the situation so far. If children use medical terms like “seizure” or “cancer,” ask them what they think those words mean. Clarify any misunderstandings. Describe the illness and how it works using clear, concrete language.

Always identify the illness by name. Some people avoid words like “cancer” or “tumour” because they think that it is less scary for children to hear the word “sick” or to call a tumour a “bump.” This is confusing for children. They may worry that the next time someone else gets “sick” – including themselves – they could die from it. Even children who are too young to understand what “cancer” or “tumour” mean can understand that it is different than having a cold or getting a bump on the head from a fall.

If the disease is not contagious, reassure them that they cannot “catch” it. Helping children to understand how the disease works reassures them that this is true.

Emphasize that the illness is not anyone’s fault. Kids often feel responsible for what is happening around them. Some children may believe they accidentally wished or caused the illness to happen, that they made it worse, or that it is punishment. Even if kids don’t appear to feel responsible for the illness, it is very important to assure them that there is nothing they could have done to cause, avoid, or cure it.

Explain the treatments that have been tried, and how we know that the treatments aren’t going to cure the disease. Refer to changes that the child has seen in the ill person, such as a loss of strength or change in abilities. If there are no visible changes, explain that medical tests show a cure is not possible. This information is important proof of a decline in health and of the efforts made by the medical team and the family to help the person they love. Reassure children and teenagers that the dying person has done everything possible to stay alive to be with them.

Reassure kids that there are still medicines that can help with symptoms. Even though these medicines will not cure the disease, they can help control headaches, nausea, and pain. If their loved one is receiving palliative care, explain that the care focuses on keeping people comfortable and minimizing suffering. This means helping them to “feel” better rather than “get” better. It is a comfort to know that their loved one will be cared for even though the disease cannot be cured.

Talk about ways they can help the dying person. Children and teenagers often struggle with feelings of helplessness when they cannot change the situation, but it is valuable to find ways for them to be involved in the care of the dying person. Explain to them that spending time with the person, doing familiar activities, expressing their feelings, and making things for them are all very meaningful ways of offering care.

Understanding how children grieve: Ways you can help

Children grieve in “chunks.” They may seem to be sad or angry one minute and happy the next, and their play will often express these themes. Children use play to make sense of and express their feelings and may shift between different feelings or activities quickly. This is a natural and healthy way for children to grieve and is an outlet when they don’t have the words to speak about what is happening for them.

Grieve together. To protect kids, adults often hide many of their emotions related to grief. This behaviour teaches kids that such emotions shouldn’t be seen or shared, which can have long-lasting impacts on them. It’s important for kids to know that all the feelings they are experiencing are okay, and that adults experience them too. Don’t hesitate to cry together, be mad together, and be sad together. Children learn how to grieve by watching those around them. Grief can include feeling sad, angry, lonely, guilty, numb, confused, and many other feelings. Support them to express their feelings in healthy ways. Explain the difference between emotions (what we feel) and behaviours (what we do). Although some behaviours are not acceptable, such as hurting themselves or others, there is nothing wrong with having the emotions that lead to those behaviours. Kids just need help finding healthy ways to let those feelings out, like through talking, music, art, drama, play, and physical activity.

Kids' common concerns

"What will happen to him/her?" Kids wonder what will happen to the person's body and their spirit or soul after they die. Explain what will happen physically in clear and concrete terms, emphasizing that it will not hurt or be uncomfortable to be buried or cremated because the body has no feelings after death. As for their spirit, ask the child what he or she believes, describe what you believe, or talk about ideas that others have. It's okay not to have answers to these questions; it is extremely valuable for kids to wonder aloud with you.

"What will happen to us?" Many kids wonder "What happens if you die too?" Whether or not they actually ask the question, don't assure them that it won't happen. Instead, discuss with kids who would take care of them if their parents or caregivers were to die. Also use this honest approach to address kids' common practical concerns like "Will we have enough money?" and "Will we have to move?"

"I don't want to lose him/her." Reassure kids that their loved one will still be their father/mother/ grandparent/sibling and that death does not end that relationship. Talk about ways to keep precious memories alive and continue to honour their loved one such as by celebrating their birthday, continuing to practice something their loved one taught them, or making a memory book.



Attending to your own grief: Self-care for caregivers

Taking care of a grieving child or youth can be an emotionally exhausting and physically draining experience. By taking responsibility for your health and well-being and attending to your own grief, you will be able to support your grieving child more effectively. The following web sites will help you attend to your own grief-related needs: www.bereavedfamilies.net and www.virtualhospice.ca.

The Max and Beatrice Wolfe Children's Centre at the Temmy Latner Centre for Palliative Care offers education, counselling support, and medical care in the community and at the Centre to children and families where a child is dying grieving the dying or death of a family member. We also provide consultation and education for healthcare professionals, children's mental health providers and boards of education.

You can find more information on how to support children and youth through grief in *Living Dying: A Guide for Adults Supporting Grieving Children*, a book produced by our Centre. The book is for adults who know young people, who will experience, or have experienced, the dying and death of a loved one. To order your copy of *Living Dying* e-mail max@bea@tlcpc.org or call 416-586-4800 ext. 6664.

In order to provide this free service to grieving families, we rely entirely on donors like you. To help us continue to support families in need, here are different ways you can donate:

- Visit www.tlcpc.org
- Call 416-586-8203 ext. 3936
- Use a credit card for a monthly or one-time gift
- Send a cheque to the Mount Sinai Hospital Foundation of Toronto at 1001-522 University Avenue, Toronto ON, M5G 1W7