

When a close family member has a life-limiting illness, it is challenging to know the right things to say and do for the children affected. Telling your child that an important person in their life is going to die is one of the most difficult conversations you will have. However, children need information to begin to understand the changes that will be coming for themself and their family. As well, they need opportunities to experience and process the feelings which are part of anticipating the death of an important person in their life.

When is the right time to tell my child that the person is seriously ill?

Many parents/guardians fear that talking about the life-limiting illness too early will raise a child's anxiety. However, children are perceptive. They often sense when something has changed in the family. Sensing that something is wrong but not having information can be more anxiety provoking than knowing the truth. While the decision about when to share the news with a child is unique for every family, ideally it is good to start in the early days of the illness, long before the person is palliative.

When a life-limiting or terminal diagnosis has been confirmed.

While every family situation is unique, the following is important to consider when talking with your child or teen about the life-limiting or terminal diagnosis:

• Before sharing the news with your child, seek out support for yourself. Talking with a family member, friend, social worker or health professional can be helpful in several ways. It can provide you an outlet for your own feelings and to find the strength needed to deal with the challenging days ahead. It can also be helpful to talk through and plan what you will say, so that you feel more prepared to support your child and answer their questions.

• When sharing the news with your child, have the conversation in a place that feels safe for them, where there won't be interruptions and your child won't feel embarrassed to express feelings. If possible, have another caring adult with you for

the first conversation with your child, in case you become emotionally overcome.

To prevent confusion, use simple, truthful language and the specific name of the illness rather than describing it as a 'sickness'.

• Offer for your child to ask you anything about the illness or changes they are witnessing in the person who is seriously ill. This will send the message that it is emotionally safe for them to you come to you in the days, weeks, or months ahead when questions or concerns arise. If you don't have an answer to their question, it is okay to say so. Wonder about it together, and offer to put the question to the doctor.

• It can be difficult to explain to younger children why the person is going to die. Using examples from nature can help to explain who and what is living and non-living. Sometimes children can understand death more easily when the body is described as a having special parts that must be working in order for the person to be alive, as in the parts of a machine. For example, while doctors can usually repair the body, sometimes a part of the body becomes too broken to fix. In situations where the seriously ill person is elderly, it can be helpful to explain the death as a part of the natural cycle of life. For families who hold religious or spiritual beliefs that include an afterlife, this may be a way to comfort your child.





• Check in with your child occasionally regarding whether they have more questions or concerns about the person's medical condition.

How will my child react when told about the serious illness?

Every child has their own unique personality and natural ways of coping, so there can be a wide range of reactions. Some respond with no emotion and may want to guickly leave the situation. They may need time to process the information, or already sensed the truth, or because they are very private with their emotions. Other children may immediately express a lot of physical upset, anger or sadness. Still other children and teens respond with calm but ask a lot of questions. There is no right or wrong response to hearing the news that a close person has a life-limiting illness. Reassure your child that there will be support for them, that it is okay to ask guestions and express their concerns. Keeping them informed as the circumstances change, will help prepare them for what may come.

When illness and impending death are so much a part of daily life, It is also important for children to have time and space away from thinking about the situation. Respect and encourage your child's need to focus on activities that provide distraction and maintain their social connections. For younger children, imaginary play is a way they process thoughts and feelings. For older children and teens, time with friends is important for connection. Sports and hobbies are often good outlets for stress.

Gifts from the person who is seriously ill It can be very difficult for the person who has a life-limiting diagnosis to confront their own death. Once they are able to accept the diagnosis, they are more likely to be able to focus on the child's needs. When emotionally ready, they can provide very important gifts of their thoughts and memories for the child. If the seriously ill person keeps a journal about their own childhood and adult life experiences, this will provide your child information and insights that will likely be cherished into adulthood. Writing letters to the child, writing down memories of their time with your child can be a precious gift. If they person living with the life-limiting condition feel comfortable being videoed, this will help provide the child a powerful continuing connection long after the person has died. If they feel comfortable being being videoed, this will provide the child a powerful continuing connection long after the person has died.

Supporting the child in the final days

Many families are uncertain whether to have their child visit the hospital or bedside in the final days before the person is expected to die. Again, this is a personal decision and your family's cultural and spiritual beliefs are to be respected. Lighthouse children often share that having choices is helpful. Children usually want to see the person but feel nervous or fear the unknowns. To help your child be prepared, provide a mental picture of what they will encounter. This includes the sights, sounds and smells in the room, describing the medical equipment attached to the ill person and its purpose, as well as the person's condition (ie groggy, agitated, sleeping, unconscious, able or not to speak). Your child may want to see the person but remain near the door. They may or may not be comfortable touching or hugging the person, who will likely look very different and a little scary compared to when well.

Often a child is at a loss for how to interact with the seriously ill person. Before the visit encourage your child to think about something they would like to talk about and share with the seriously ill person.



Finding the words to express feelings verbally can be difficult especially for younger children. Drawing a picture for the person or writing them a letter which can be read may help prevent later regrets for your child about thoughts and feelings they wished they had expressed.

Should I include my child in the end-of-life ceremony?

Children often want to be included. The key is in providing your child information about what to expect, giving them choices about how involved they will be on the day of the ceremony, and where possible including them in the planning. Helping with decisions such as the clothing, pictures items and music for the ceremony, helps your child to begin processing the loss and gives them some control over an otherwise helpless situation. If there is a casket, this is another opportunity for your child to place a special private message or drawing with the person. You may help your child to purchase two identical keepsakes such as stuffed animals, charms or other small items, placing one in/at the casket, the other to keep. You might help your child feel connection to the person who died on such a difficult day.

The funeral or memorial service can also be a good opportunity for receiving stories and memories by people who knew the person who died. Some families have a book available for adding memories at the end-of-life ceremony. Others ask that friends and family email the stories or post on a social media page that you set up. Asking people to write their stories and forward them for your child or teen helps to build a larger bank of memories of the person who has died. This can also help encourage your community of family and friends to remain connected to you and your child.

READING LIST

- When a Parent is Sick helping parents explain life-limiting illness to children by Joan Hamilton
- As Big as it Gets by Stokes, Crossly and Stubs via
- the Winston's Wish centre • What do We Tell The Children: Talking to kids
- about death and dying by Joseph Primo
- When a Parent is Very Sick by Eda LeShan
- A Tiny Boat at Sea: How to Help Children Who
- have a Parent Diagnosed with Cancer
- by Izetta Smith
- Expected Loss: Coping With
- Anticipatory Grief by Dr. Alan Wolfelt

<u>Children</u>

- When Dinosaurs Die -
- by Laurie Brown and Marc Brown

- Miss You A First Look At Death by Pat Thomas
 Lifotimos by Brian Mallonia
- Lifetimes by Brian Mellonie
- When Someone Has a Very Life-limiting illness by Marge Heegaard
- Tell me, Papa: a family book for children's questions about death and funerals by Joy and Marv Johnson
- Someone is Sick, How do I Say Goodbye by Jill Johnson

<u>Teens</u>

- You Are Not Alone: Teens Talk About Life After The Loss of A Parent *by L.B. Hughes*
- Healing Your Grieving Heart For Teens: 100 Practical Ideas *by A.D. Wolfelt*
- You Just Don`t Understand: Supporting Bereaved Teenagers by Winston's Wish, Helen Mackinnon

Created by the Lighthouse For Grieving Children - Updated 2024

<u>Adults</u>