



Telling the Children

Talking With a Child When a Family Member Is Diagnosed With a Life-Limiting Illness

A Life-Limiting Illness

Receiving the news that you or a member of your family has a life-limiting illness is shocking. At first, it feels impossible to comprehend it, to believe it, to understand the meaning of what is happening.

Eventually the reality of what your family is facing begins to dawn. Complicating matters is the constant uncertainty of the prognosis and how the illness will progress, and the many unknowns your family will have to navigate.

The grief this news brings is as real as the grief we feel when someone dies. And the struggle is just as real. It is a family struggle as much as an individual one.

The struggle is even more intense for the children. How can you help them understand and manage what is happening? When a family member has a life-limiting illness, more than anything, those in the family want to make sure the children will be OK.

One way of helping the children is by connecting with them and creating memories together. (See the companion brochure, *“Creating Connections: When a Family Member Is Diagnosed With a Life-Limiting Illness,”* for more about building these connections.) Another way of helping them is by talking with them about what is going on.

Will the Children Be All Right?

Understandably, this is a difficult and confusing time. Families want to know what to say, and when and how to talk to their children about the seriousness of the illness. Parents and caring adults want to protect their children from the sadness they will experience, yet they want to do what is best for their children.

What we have heard over and over from these adults themselves, and from surviving spouses and children, is that what is most important is to:

- Talk with the children sooner rather than later.
- Be honest with the children. Remember that the whole family is experiencing this illness together.

When to Tell the Children

Most experts, along with parents and family members who have gone through this experience themselves, encourage those with a life-limiting illness not to put off telling the children the reality of what is happening.

Even though your instincts may be to shelter the children from the pain of that reality, children trust parents and other adults to tell them the truth, from the littlest things in life to life's greatest lessons.

Their trust in you lays the foundation for future relationships with other adults, their future spouse and the surviving parent(s).

In addition, this reality can't be hidden.

After all, most children, no matter what their age, will soon sense that something is amiss.

They may not be able to say it in words or put their finger on it, but they realize that life as they have known it is changing. They'll pick it up in hushed voices and they'll see it in your eyes.

In very concrete ways, the comfort of daily routines will be disrupted as you become caught up in doctors' appointments, hospitalizations and caregiving.

Friends and relatives may be taking them to school, carpooling them to activities and preparing dinners, while new faces from hospice or home health care show up in your home.

Honesty and following your heart are what your children will trust and appreciate long after you've had this conversation.

What to Tell the Children

Many adults become very concerned over saying the “right words” about their own or their family member’s life-limiting condition. They are so afraid of saying something they think will harm the children for the rest of their lives that they may hesitate to say anything at all.

But please be assured that what’s most important is the fact that you are telling them. Your love and sincerity will speak louder than the words they will hear.

Explain the disease or condition in terms appropriate to the age of the children, teaching them what it is and what it will do to the body of the person who is ill. Use the name of the condition.

Despite how hard it may be to **say the word “dying,”** it is important that the children hear the word. Children will not be able to read between the lines when you tell them someone is “seriously” or “gravely” ill. For preschoolers, describe how the person’s body will change and that someday their heart will stop and their body will shut down. They will die.

If you find this task too difficult to do by yourself even with a loved one beside you, then seek the assistance of a hospice nurse or other supportive adult.

Especially for younger children, be sure to **explain that this is different from just being “sick,”** as children will think that whenever they hear that someone is sick then they will die. They may also think the same thing whenever they are sick. So, if the condition or disease has a name, use it and refrain from using the term “sick.”

Let them know that they did not cause the illness. It is no one’s fault. Explain that, *“I’m trying very hard to do everything possible to stay well and keep my body going for as long as possible. The doctors are working very hard to help me, too. But this is something that will not go away. There is no cure, and it’s no one’s fault.”* (Obviously, this can be adjusted if you are speaking on behalf of another family member who is ill.)

Tell them that the illness is something they will not catch—it is not like getting a cold or the flu. (If you or your family member has an infectious disease, then explain the precautions the children will need to take.)

Give them permission to still be a child—or to still “have a life” by letting them know that it makes you feel good—and it makes the person who is ill feel good—to see them working hard as a student, continuing to be involved in activities and hanging out with their friends just like they did before the person became sick.

If you are a parent, advise the children that you and your spouse or loved one will remain doing the “parent things” like paying bills and running the household so these are things they do not need to worry about. Identify who will be taking care of them in ways like helping with homework, preparing meals, and taking them to and from school and activities while you are busy with your own or your family member’s treatment and doctors’ appointments. Do not encourage a teen to believe that they should start acting as the “man or woman” of the house because they need to start filling your shoes.

Assure them that you will be checking in to see how they are doing and they can do the same with you. Everyone also has permission to say, “Can we talk about this another time?”



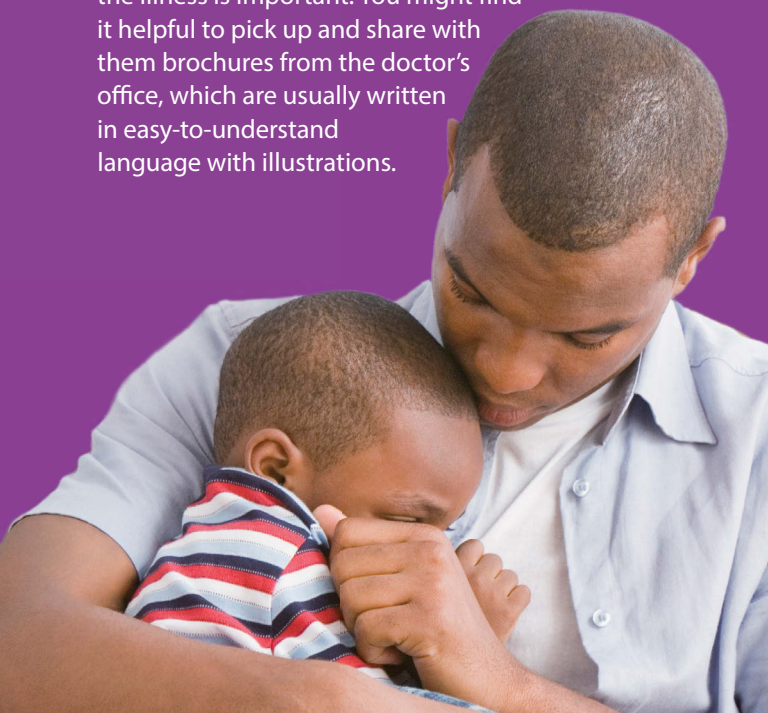
How to Tell the Children

Telling children as a family sends a reassuring message that “we are all going through this together” and that everyone is being given the same message. Reserve a time where there are no visitors and no phone calls to interrupt your conversation with them.

At the end of your family meeting, allow each child to ask questions and to do whatever feels most comfortable: Younger children may go off and play, a teen may go to his or her room and ask to be left alone, while a twelve-year-old may call a best friend. Don't expect an immediate response or one that may make sense to you. They'll need time to process what they have just learned.

Pictures or drawings used to explain the illness and what is happening to your or your family member's body may be beneficial for young children. Very young children will respond well to a simple “show-and-tell” approach using dolls or teddy bears.

Answering questions posed by older children and teens wanting to understand the process and cause of the illness is important. You might find it helpful to pick up and share with them brochures from the doctor's office, which are usually written in easy-to-understand language with illustrations.



Creating a chronology of events explaining the illness—including a beginning, middle and end of the “story”—might be helpful. You could start off with describing symptoms (what things felt like over time), doctors and tests at different points in the process, what's being done now to help the family member stay well, and what will continue to be done on into the future.

Be sure to prepare the children, especially younger ones, for what they will see during a hospital visit. Beyond describing medical equipment like intravenous lines, it would also be helpful to describe how their family member is feeling and looking: *“Mommy is pretty tired because of the medicine she is taking to fight the cancer cells, so she might look kind of pale and will be lying in bed. She probably won't talk a lot, but she will be so happy to see you. Just knowing you are near her will make Mommy feel better.”*

Double-check with the children, once you have had a discussion about the illness, to make sure they accurately understand what you've explained to them. There are a number of ways you can approach this:

- Ask them, “How would you explain what I just told you to a friend?”
- Ask, “Can you put into your own words what I just said?”
- For very young children, you might ask them to show you what's wrong with the family member by using a doll or a teddy bear.

Remember:

- There's no time like the present.
- Be honest with the children.
- This is a family affair.

About the Highmark Caring Place

The Highmark Caring Place is dedicated to making a difference in the lives of grieving children.

It is the mission of the Highmark Caring Place:

- To raise awareness of the needs of grieving children
- To provide programs to address those needs
- To equip the community to support those children who have experienced the death of a loved one



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