



Creating Connections

*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—the implications now, and on down the road.

Eventually the reality of what your family is facing begins to dawn. It takes different forms over time; sometimes it feels different from one day to the next. And complicating matters even more is the constant uncertainty of how the illness and the prognosis 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—this struggle of figuring out how to keep on living when one of you may be dying.

And the struggle is even more intense for the children. How can you help them understand and manage what is happening?

What we have heard from families who have gone through this experience themselves is that what they cherished most of all was anything that helped to strengthen the connection between the children and the person who was ill. Creating memories helps build that connection now, and helps keep that connection alive after the person they love is no longer present to the children.

Talking with the children is one way of strengthening these connections. (See the companion brochure, *“Telling the Children: Talking With a Child When a Family Member Is Diagnosed With a Life-Limiting Illness,”* for more about talking with children.)

Another way of connecting and creating memories is through engaging in a number of activities together.

Building Connections

There are many ways to create lifelong connections with a child. Listed throughout this brochure are a number of options that may help to bring your family closer and create memories that can last for the rest of the child’s life.



Possible Activities for the Family to Share

Messages From You

You or your family member can write in a journal or you can record yourself in audio or video to share messages for each of the children. If you are not sure of what to write or say, you might reflect on questions or ideas like these:

- What was it like the day the child was born?
- How is the child like you?
- What is your favorite food, color, thing to do, television show, type of music, song, book, movie, etc.?
- Write a story about something that you remember from your childhood.

Stories From the Child's Point of View

Children can create their own special story of their "life and times" with you or your family member. This can be done by creating a scrapbook or memory album with photos of them and the ones they love. They could also create a story book with the pictures, which you or other members of the family can put together with them.

Collages

The children can create a collage with pictures and words that describe themselves, you or your family member, and/or your relationship with one another. They can do this alone, or with you or another adult. Be sure to set time aside for them to share what they've done.

Favorite Songs

If you or your family member don't already have a favorite song, help to choose one that the child can remember as "our song." Play, sing and/or listen to it with them now—make it even more special and dance to it. You or your family member can let them know that whenever you hear it, you always think of them.

Letters

Create a "Words to Live By" letter that the children will follow and embrace. This type of letter may involve some quotations (yours or your family member's, or those of someone famous) that describe the values that the children could follow.

For example, some quotations that could be offered to children are:

- "Follow the Golden Rule—Do unto others as you would have them do unto you."
- "Believe in yourself."
- "Words can be like arrows—once you let them loose, they never return."

Both children and teens especially treasure *handwritten* letters.

You or your family member might want to explain why a particular quote is important—perhaps it was passed down from a parent or grandparent, or maybe there is some story behind why this quote represents such an important way to live your life. Anything you or your family member adds will be another way of connecting with them in the years to come.



Jewelry and Other Material Items

Pieces of jewelry can be chosen or purchased and then given to each child on a certain future birthday or event (a graduation or wedding). The jewelry might be engraved with a message. Or a child might be given a watch or a ring, a jacket or a favorite hat. None of these things need to be expensive or valuable in themselves—it's the connection they make with you or your family member which will be meaningful to the children through the years.

Messages

Brief messages can be written to be given to the children on landmark days in their lives such as a bat or bar mitzvah, confirmation, graduation, wedding or the birth of a child. Although you might think that this could make them sad, grown children and adults who have received such messages treasure the fact that their family member was thinking of them long ago for this very special day.

Future Hugs

Take a picture of you or your family member hugging the child, then place it in an envelope that says on the outside, "Open this whenever you need a hug."

Memory Boxes

Create a "Memory Box" with the child that would include photos, small keepsakes, letters, drawings—anything that represents special memories between the child and the family member.

Spending Time

One of the most treasured things you can do to create moments to remember is to simply spend time with the children. It doesn't have to be some well-planned event or a "best vacation ever."

As one teenager said: "One of the best memories I have with my dad is just sitting there with him, listening to music. Just sitting there, talking and listening to my dad hum along with me."



What Other Families Have Said

1. Your family is in this together.

This is a family affair. All of you will change—as individuals and as a family. Children see themselves as part of a family. In fact, family is at the very core of a child's universe. Now that someone in the family is seriously ill, that core has been shaken. They need to know that the foundation of their family will survive even though it will change.

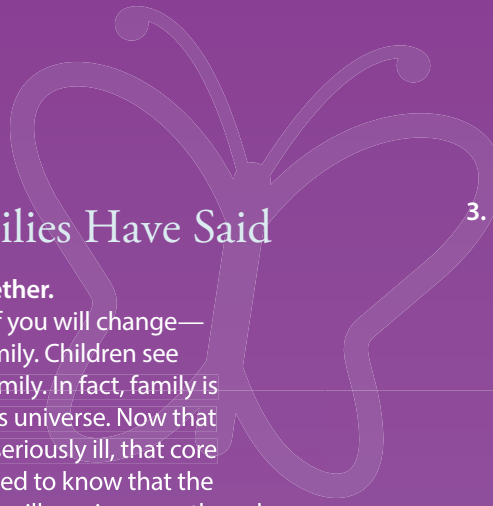
2. Be honest.

As hard as it will be, and as much as you want to protect the children from the harsh reality ahead of them, it is far better for them if you are truthful about the illness and possible impending death, in ways that are appropriate to their age. Parents who didn't tell their children want you to know that if they had to do it all over again, they would let their children know sooner rather than later.

3. There's no time like the present.

Many parents have stressed that before you place all of your energy into staying well for as long as you can, or in helping your family member in the same way, use this precious window—right now—to create lifelong connections with the children. Soon you and/or your family member will be swept up in the whirlwind of doctor's appointments and treatments, so take the time today to:

- Record your or your family member's voice. Children and teens never want to forget that voice. They're happy with even a short message that they can play again and again. They especially love hearing their name in that voice.
- Handwrite a note. This really doesn't need to be something very long or the "perfect" message.
- Take a photo of just the child and that person. You may already have photos of you or your family member alone with each of the children, but if you don't, then take that photo now. This is the photo they'll cherish for the rest of their lives.





Creating Lifelong Connections

Each one of us will create a unique legacy for the children in our lives, and they in turn will form their own “life story” of their relationship with all of the important people around them. Those life stories go on, throughout the lives of the children who create them.

They go on through memories. Memories help keep the relationship—and the person himself or herself—alive in those who love them still. Memories help keep love shining in the hearts of the children who have built these memories.

Remembering helps the children know that the people they love, even when they don’t see them physically, live on in their hearts. The remembering helps brighten the darkness.

As we said at the beginning, what the families who have gone through this experience have said they cherished most of all was anything that helped to strengthen the connection between the children and the person who was ill. It’s the creating of memories which helps build that connection now, and helps keep that connection alive after the person they love is no longer present to the children.

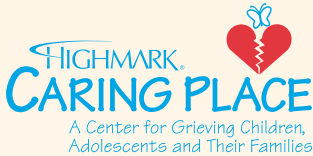
Memories that were made in love cannot be taken away by anyone.

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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