

# Supporting Your Child

through a loved one's life-limiting illness



Grief Support for Children, Teens, Young Adults and Their Families Supporting your child through a loved one's life-limiting illness may be one of the hardest experiences you have faced as a parent, especially if you are a caregiver to the person who has an advanced illness. Here are some ways you can help yourself and your child during this difficult time.

#### Sharing the hard news

As tough as it may be, it's important to talk to your child about the person's life-limiting illness and the possibility of their death. Being open and honest fosters security and helps your child trust that you are there to help them process their feelings. Open dialogue with your child allows them to feel included in the experience and creates opportunities for their questions and clarifications.

#### Helping them understand

Explain by using easy-to-understand language about the prognosis. This helps prevent your child from filling in the blanks with their imagination. Use the words "will die from" or "dying." Avoid unclear phrases such as "won't be around much longer," "pass away" or "they are sick." Simply saying the family member is "sick" can lead to bigger fears of catching other illnesses such as a cold or flu. Naming the illness, like cancer or heart failure, helps them process the truth and will build trust with you as their caregiver.

To the best of your understanding, explain to your child what will happen in the future. This includes what could happen with the progression of the illness and what the child can expect for their care and routine. Continue to check in often with your child and provide any new information.

Invite any questions your child may have. Before offering answers, ask about their thoughts and feelings and what they already know about the illness. Consider their age and developmental level when providing answers. It's okay if you don't have all the answers. You can welcome their questions and say, *"I will try to find out."* 

#### **Grief begins**

Your loved one's life-limiting illness has likely changed your plans and dreams for your family.. Each person will have their own unique way of coping with this lifealtering prognosis. One child may want to talk about it, while another is more withdrawn. One may express their emotions, while another stays busy with activities.

Model healthy grieving by sharing how you feel with your child and inviting your child to share their feelings with you. You can cry and tell them how sad you are or how shocking this news feels for you, too. Modeling the expression of your own emotions gives your child permission to feel and express their grief, anger and feelings of injustice about the illness.

#### Provide routine, flexibility and choices

If the person who is ill plays a role in your child's caregiving, tell your child who will now take care of meeting their needs. Explain who will care for them while you are attending to your loved one. Provide routines in your home to foster predictability for your child. Consistency with mealtimes, before and after school routines, bedtimes and chores leads to stability. Offering choices, like doing their homework before or after dinner, can help your child regain a sense of control. As best as you can, provide consistent childcare when you're away at the hospital or at doctor visits. Create opportunities to be with your child when possible, and offer comfort with your physical closeness, hugs and play.

# Provide opportunities for self-expression and play

Children may express themselves through play, art and writing. Create a place in your home or other settings where they can access art supplies such as crayons, colored pencils, markers and paper. Offer ideas such as drawing their loved one a picture or writing a letter to them. Active outdoor play like running or sports can help release the big energy of worry or anger in their bodies.

As children express their feelings, invite their emotions by using reflection. If they say, "I'm scared that Mommy will die," you can say, "You feel afraid that Mommy will die." As hard as it is, you don't need to try to make it better. Your physical presence and comfort while they process this new reality helps them to attend to their emotions and find ways to cope.

Your child will not absorb the gravity of this news all at once, but rather process it in bits and pieces. You may notice their capacity for happiness alongside sadness. Offering opportunities for social connections like playing with friends provides natural relief from the intensity of their reality.

### **Hospital visits**

Allow your child to decide if they want to visit their loved one in the hospital. If they don't feel comfortable, honor their decision and offer alternatives such as writing a note or drawing a picture you can hang in their hospital room. This includes your child in a way that feels best for them.

If your child wishes to visit, describe what they will see and what their person will look like. They might see bandages, a shaved head, a breathing tube or other medical equipment. Take photos to show them the room and their person. Explain the purpose of the equipment and how it is helping, not hurting, their loved one.

Prepare your child for emotions they may feel when they see their person, such as scared, sad or worried. Give them permission to leave the room whenever they need a break. Consider bringing a friend or family member to support you, someone who is willing to drive you to the hospital and stay in the waiting room with you or your child during breaks.

During your visits, stay in the room with your child. Offer ideas and let them decide how they want to engage with their loved one, such as holding their hand, talking to them, watching a movie or playing a game. Introduce them to the nurses and doctors caring for their loved one.

Spend time with your child after the visit. Answer questions or invite them to draw a picture of their experience. Go for a walk together, play catch or kick around a ball. This creates an opportunity to talk and provides movement to help release physical energy.

### Saying goodbye

Preparing your child for the death of your loved one gives them the emotional tools they need to face one of life's most painful moments: saying goodbye. Explain to your child what they will experience when the person dies. They may notice the person's breathing changes and becomes louder, and their skin looks different. The person who is dying will often be sleeping and not able to respond or may be restless and disoriented. Explain that even if their loved one can't respond, they can still hear and sense your child's presence.

Your child will notice gradual changes if the person lives in your home. If the person is in the hospital, another home, or hospice care, take photos to show your child what they will see, especially if their loved one's medical equipment or appearance has changed. Start by showing them a picture of the door, the people caring for your loved one, then the medical equipment.

Invite your child to choose something to give to their loved one. They can draw a picture or write a letter. If they don't wish to visit, tell them where you placed the item in the room and how you think it helped their loved one.

If the child gives the item in person and their loved one is not able to respond, you can say, "Even though Daddy can't respond, he is listening and holding your love in his heart."

Invite your child to write or say goodbye with these prompts:

I wish \_\_\_\_\_

I will always remember\_\_\_\_\_

Thank you for \_\_\_\_\_

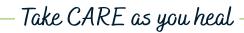
## Additional support

The support of your community can positively impact your family. Often, people may want to help, but don't know what to offer. Allowing others to support you in the ways that are most needed by you and your family nurtures your healing. Support could

include meals, running errands or doing yard work. Enlist a friend or family member to be in touch with others inquiring for updates on your loved one. Ask them to communicate regularly with your child's teacher or school counselor so they can provide extra care for your child at school.

#### Caring for you

You may be acting as a caregiver to the person in your family with a life-limiting illness. Attending to them is likely to impact how you care for yourself. Research shows that children benefit when their parents take loving care of their own physical and mental health. Remember to take **C.A.R.E.** of yourself so you can continue caring for others who need you.



**C**are for your body with healthy food, water and movement like stretching or walks outdoors.

- Accept support in the ways you find most helpful.
- **R**est often and keep normal routines as much as possible.
- Express your emotions with others as they arise.



Jessica's House offers free peer support groups for children, teens, young adults and their adult caregivers grieving a death. Each group combines therapeutic talk, play and creative expression to promote healing and hope for the future.

# For additional support and resources: jessicashouse.org info@jessicashouse.org

or we welcome your call at (209) 250-5395

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