

Supporting children and teens when a family member has an advanced serious illness



Explaining that someone has a life-limiting illness to a child or teenager can feel overwhelming and daunting. These tips may help you have that hard conversation and know better how to support your child during the challenges of living with a family member who has an advanced serious illness.

BEGIN THE CONVERSATION

Giving children difficult news is not an easy task, though your child will likely have already sensed that something has shifted within the family. Knowing that it will be painful for a child to hear that a parent or other family member has an illness that they may ultimately die from often leads caregivers to wait for the “right” time to share challenging, life-altering news. However, rarely is there a “perfect time” to have these conversations with children. Waiting can lead to hurried exchanges that provide too little information or that comes too late in the illness for children to best cope and be included in the experience. The “perfect time” then, is the one that is created by you which leaves ample space for questions, reactions, and clarification.

USE OPEN, HONEST, AND CLEAR COMMUNICATION

Be honest and give clear accurate information. Euphemisms like “not getting better,” “won’t be here much longer,” or “passing on” can be confusing. Use the words “will die from” or “dying” when speaking to children and teens. If the only thing a child has been told is that the family member is “sick,” they can become fearful or anxious of being sick with a cold or flu. Name the disease. Young children need basic concrete information regarding the illness, what will happen in the immediate future, and specifics about how their care and routine will be maintained. Adolescents and teens appreciate having more detailed

information, especially as the family member’s health declines. Being open in your communication models for your children their ability to also be open and creates a level of trust with your child as they realize you will tell them the truth, even when it is really hard.



VALIDATE FEELINGS AND THOUGHTS

It is important to listen to a child’s responses without interrupting or minimizing fears. Validate the experience your child is sharing with you. Tell them that it is normal to have many different feelings and thoughts when someone in the family has an advanced serious illness. Children often worry that they can catch the disease, or that they either caused or in some way contributed to their family member’s life-limiting illness. Reassure your child by being clear that their family member’s illness is not contagious nor did they cause it. An adult can also validate the experience of a child by sharing similar feelings/thoughts, affirming that each reaction is normal, and giving them permission to express those feelings and thoughts.

COMMUNICATE OFTEN

Make time to have check-ins with your child. Use this time to inform your child when there is new information regarding the illness, treatment and procedures, changes in appearance or functioning of the person, or changes in routines. Ask your child if there are questions, concerns, or thoughts they would be willing to share with

you. Even if there is no update, just carving out the time to share openly will reaffirm the message that you care. Communicating often with your child will build trust and help prepare for what's immediately ahead.

MODEL BEING OKAY WITH NOT KNOWING.

Be honest if you don't have an answer. It's okay to not know. Appreciate your child's question then assure them that you will tell them if and when you have an answer. Validate that it's important to ask questions even when no answers are to be had. Much in life is unknown to us and that is certainly true when a family member is living with a life-limiting illness. Being able to ask questions and be patient in the unknown is an important life skill.

PROVIDE STRUCTURE AND ROUTINE

Life is constantly changing and often seems very unstable when a family member has an advanced serious illness. Providing structure with flexibility will help a child regain some sense of safety and control. Predictable morning and night time routines provide consistent bookends that will support your child in starting and ending their day. Additional important routines to consider are consistent childcare when you're unavailable, planned time-limited hospital visits, continued participation in school/sports activities, and spending time with friends.

GIVE CHILDREN TASKS AND RESPONSIBILITIES

Think about assigning your child some of the household tasks, with consideration of their age and other commitments. Having some responsibilities can help a child or teen feel useful and needed, feel included in the family, and reduce feelings of helplessness during

this very difficult time. Your family is a team with each person having an essential role with given tasks to complete. Age appropriate household responsibilities may include putting the dishes away, doing laundry, or vacuuming. Helping with their ill family member may include bringing water, fluffing the pillow, or reading to their family member. Whatever the assigned duties may be, it is important to remember that the tasks are age appropriate and that your child is a helper and not responsible for the burden of caretaking.

PROVIDE TIME TO BE A KID/TEEN

It's important for your child to spend time with and play with their peers. This invaluable time provides your child some normalcy, a physical outlet, social connection and can be a supportive coping strategy when your child is overwhelmed with all the other changes that are occurring at this time. Kid/teen time gives your child a brief but much needed reprieve from the worries and burdens they are carrying.

ADVOCATE FOR YOUR CHILD

Inform your child's teacher or school counselor about what is happening at home, how your child has been responding, and any fears or anxieties your child has that may be expressed at school. Many teachers and school counselors have little if any training on supporting grieving kids. It may be helpful to provide school staff with literature and resources so they can best support your child. Look to your palliative and hospice care staff, child's pediatrician, hospital social workers, and support organizations like Dougy Center for helpful information to give to your child's school.



The National Grief Center
for Children & Families

Our Mission

Dougy Center provides grief support in a safe place where children, teens, young adults, and their families can share their experiences before and after a death. We provide support and training locally, nationally, and internationally to individuals and organizations seeking to assist children who are grieving.

Dougy Center Bookstore/Resources

Dougy Center has been helping children, teens, young adults and their parents cope with grief since 1982. Our practical, easy-to-use materials are based on what we have learned from more than 60,000 Dougy Center participants. To order online, visit dougy.org or dougybookstore.org, or call 503.775.5683.

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