Helping Children and Teens Adjust to a Loved One's Terminal Illness

Ways to Provide Support

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Children, grandchildren, and siblings are an important part of families, and they are aware of, and affected by, the illness of a family member in many ways. Therefore, including children and teens in the discussions about the changes taking place in your family is an important part of preparing them for your or your loved one's death. Giving children and teens the opportunity to participate in these discussions will help prepare them for what's ahead and will help build trust and encourage communication between them and the adults in their lives. Letting children know that they are valued family members is often best communicated through your actions and not just your words.

Yet, knowing when or what to tell children and teens about their family member's illness is sometimes difficult for families. These discussions can be emotional and challenging. Transitions LifeCare counselors, spiritual care counselors, social workers, and nurses are available to support you and your family during the illness of your family member and the changes in your family's life. No one can take away the pain of loss, but listening and communication help make this transition easier for children, adolescents, and your family.

See the rest of this packet for information on:

- Parenting strategies for assisting children and teens during this challenging time.
- How children and teens react to illness and death developmentally.
- Ideas for children and teens to stay connected to their loved one who is ill.
- What to do at the time of death and afterwards.
- A reading list of resources.

"The greatest gift you can give your children is not protection from change, loss, pain, or stress, but the confidence and tools to cope and grow with all that life has to offer them."

–Wendy Schlessel Harpham, *When a Parent Has Cancer*

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Ways to Help Children and Teens During the Illness of a Family Member

Provide Information and Communication

Give prompt and concrete information about the illness and what is happening. Describe the illness in clear, concise ways, and use simple language. It is important to name the disease (e.g., cancer, diabetes), rather than to use an all-encompassing term such as "sick." Name and point out the part of the body that is affected.

Tell children and teens about the family member's illness and condition of the illness early in the process. This information will give them the opportunity to adjust to these changes and utilize their time with their loved one. ***Avoid waiting until your loved one is actively dying to inform them that their loved one is dying.*** Use the word "die," not euphemisms such as "passing away," "be with God," or "expiring."

Teach what "hospice" means. Most children and teens are not familiar with the word "hospice." See the example in this packet on page five about how to describe this type of care. ***Clarify that even though the family member will be receiving care from the hospice doctors and nurses, the ill person will not get better and eventually will die.*** Often there is an instinct to "protect" children and teens from conversations about sorrow, illness, and death; however, this is a misguided kind of protection, as children and teens benefit more from understanding what is happening, coping with the changes around them, and having the opportunity to communicate their feelings.

Communicate the changes that are happening. Help children and teens prepare for changes in the home, family routines, and in the appearance of the family member who is ill. For example, help them to know that the ill person may be sleeping more, not eating as much, and may have mood swings. "Dad hasn't been walking very well, so we moved his bed downstairs now. He can sleep down here and won't fall going up the stairs."

Show that you understand their feelings, fears, frustrations, and behaviors. Help them know that this is a difficult time for everyone and that it is OK to have difficult feelings. It's common to experience a range of feelings, such as sadness, confusion, anger, frustration, anxiety, and even joy. It's also common for children to want to be "normal" kids sometimes, too. Find ways to express feelings together in healthy ways (e.g., playing sports, crying, hugging, taking a break).

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Ways to Help Children and Teens During the Illness of a Family Member

Create Connections

Check in regularly with children and teens. Invite your children and teens to ask questions; give honest answers in return. Ask about fears or concerns they have, or things they may be confused about. Talking to them about their thoughts and feelings validates them as an important part of the family and increases trust between you.

Involve children and teens in interacting with the person who is ill. Ask children and teens how they would like to spend their visits with their loved one, such as playing games, telling stories, or continuing special traditions. It may be helpful, for both the children and for the patient, for them to create cards or write notes to each other, or develop another special ritual together (see list of ***Ways to Stay Connected*** on page six). Give children and teens a choice about whether to visit the patient or not, and how much. If they decide to attend, prepare them for what they may see, hear, smell, and touch on these visits, and notify them of how they are expected to behave during the visit. Be mindful of the length of these visits, keeping the visits relatively brief (about 30 minutes is adequate for young children).

Engage them in simple caregiving tasks. Involve children and teens in tasks or activities that make them feel needed and useful, such as getting water or blankets for the person with the illness.

Be generous with affection and praise. Give the children and teens extra hugs or meaningful touches (e.g., rubbing lightly on their backs) and other physical signs of affection. Take time to notice their activities and efforts at home and school. Let them know you appreciate their patience and helpfulness during this difficult time. Express that you recognize that they may not be getting the same level of attention as they used to, and help them know that it will not always be like this.

Keep Structure and Balance

Keep discipline consistent. Don't overlook bad behavior because you feel sorry for the child or teen. They need, and want, structure and routine in their lives. Keep rules and routines the same. Maintaining discipline will help the child and teen to feel safe and secure.

Provide reassurance that someone will continue to care and provide for them, and that some of their lives will remain the same (e.g., going to school, playing with friends, eating dinner together).

Create balance for yourself. Although much of your family's life is changing, it is important for children and teens to know that the adults in their lives are "doing OK" and coping with these changes adequately. In order for the family and children to cope well, it's important that adults take care of themselves, too. As the adult, be sure to take breaks, get adequate rest and good nutrition, and engage in rejuvenating activities from time to time .

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Describing Hospice, Terminal Illness, and Dying to Children and Teens

The following example can be used as a guide for explaining hospice care and dying to your children and teens.

"Your Grandpa is very sick, the sickest he's ever been in his life, with an illness called lung cancer. This time is different than when Grandpa has been sick before and has been able to get better. The doctors have told us that he isn't going to get better, no matter how many medicines he takes or surgeries he gets. Over time, the cancer will cause his body to stop working and he will stop living and will die. It's not your fault that this happened. You can't catch this illness from Grandpa. We're going to continue visiting Grandpa and taking care of him, and making sure he has what he needs. This information is a big change in our family, and we all have lots of feelings about what this means, so if you have lots of feelings too, that's OK.

Grandpa will have workers from a place called hospice come and help us take care of Grandpa. Hospice will be coming to his house and checking on him to see how he's feeling, and will make him as comfortable as possible, so that they can help him have as little pain as possible. There are doctors and nurses who work at hospice that will be coming to take care of him, and also workers called social workers and spiritual care counselors who will check on him and our family, too. Remember they are helping Grandpa feel comfortable but they can't make him better. I know this is a lot of information for me to give you right now, so you can come to me at any time with questions or if you're feeling unsure of something. What do you think about what's happening? Do you have any questions right now?"

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Ways for Children and Teens to Stay Connected With Someone Who Is Sick

Sometimes it's hard to know what to say or do when someone you care about is sick. Some days your loved one may feel better than others. Below are some ideas of what you could do with your loved one and ways to continue sharing and connecting with them. Some of these ideas may help you both feel better. (Parents and caregivers, please read this list out loud to younger children.)

- Play music softly in your loved one's room.
- Read a book, chapter, religious reading, or poem out loud to your loved one.
- Make a card or picture for your special person.
- Decorate a pillowcase or blanket for your loved one's bed.
- Write a poem or letter for your loved one about all the ways he or she is special.
- Share stories about your day; ask your loved one about his or her day.
- Give your special person a hand or foot massage.
- Paint your loved one's fingernails or toenails; brush your loved one's hair.
- Ask your loved one to tell you a story about their past or when they grew up.
- Make a stepping stone out of your hand prints; or trace your hand prints together.
- Say "I love you" or "You are special."
- Say a prayer or meditation together or sit quietly together.
- Sing or hum a lullaby or special song.
- Bring flowers or a pretty object to place next to their bed, or make a mobile of pretty objects or drawings to hang above their bed.
- Look at photo albums; watch or create home movies; listen to music together.
- Interview each other about your favorite things (food, place to visit, color, hopes).
- Make special bracelets out of yarn or string for each other.
- Talk or draw a picture together about what having them be sick is like for you (and ask your loved one what it is like to be sick).
- Snuggle or cuddle in bed or on the couch together.
- Keep a special object of your loved one's in your pocket or near you. Touch it throughout the day to be reminded of the connection you share with them. (Give something to your loved one for them to have when they miss you.)
- Match your breathing together ... slowly ... in ... and ... out ...
- Talk about what heaven or the afterlife might be like.

Ways to Build Legacy and Lasting Memories and Connections

Below are some ideas that the person who is sick may want to participate in as ways to stay connected to the children and teens in their life.

- Write the children and teens in your life a letter to be read on future special occasions.
- Make a video with your family members about your daily life … or anything you choose!
- Create a video with a message that your family can watch at a later time or on a special occasion.
- Put aside mementos/belongings for the children and teens in your life for now or the future (ask them what they may want to keep).
- Share stories about your past or share wisdom you've learned in your lifetime.
- Put together a CD or playlist of your favorite music or music you've shared with your children.
- Make a list of the qualities you admire in the children in your life.
- Trace your handprints together or create a stepping stone together.

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Children's Developmental Concepts of Illness and Approaching Death
(And Ways to Support Them)

Newborns & Toddlers (newborn–3 years)	*Ways of Providing Support*
• Absorbs emotions of those around them • May be irritable and fussy • Changes in eating, sleeping, bowel/ bladder patterns • Relies on nonverbal and physical care • Does not understand death	• Show physical comfort and reassurance; hold child in your arms more, rub his/her back • Keep routines the same • Communicate and provide basic information about illness/ death • Use simple words/phrases (e.g., "Daddy feels too sick to play.")
Early Childhood (3–6 years)	*Ways of Providing Support*
• Magical thinking (believes "I caused it; it's my fault" • Regression to younger behaviors (e.g., thumb sucking, bed wetting) • Interprets world around them very literally (e.g., "Did Daddy drive to heaven?") • Fear physical changes/signs of illness • Believes people will come back to life after death	• Use pictures, books, play to help express feelings • Explain literally about illness and what death means • May need to repeat same information over again • Provide reassurance that they are safe and cared for • Emphasize that illness is not their fault; underscore that person's illness different than when they've been sick before
Middle Childhood (6–9 years)	*Ways of Providing Support*
• Fear signs of illness and death • Talking about feelings difficult • Acting out/misbehaving common • Hold emotions in their bodies (more headaches and stomachaches) • Very inquisitive about signs/symptoms of illness	• Answer their questions about illness/death directly • Provide education about the illness and its progression • Teach that their feelings are normal • Offer safe ways to express feelings (e.g., cry, take a break, scribble hard on a piece of paper)
Preteens (9–13 years)	*Ways of Providing Support*
• Concerned about being different from peers • Concerned about how their world will change; shows concern for how family members are doing • Understands basics of illness; wonders how and why it happens • School work may become affected	• Provide honest information about illness/death • Encourage safe and regular expressions of feelings • Help find supportive peers and family members • Provide education about the illness and its progression • Do not allow child to take over adult responsibilities or being a caregiver for family
Adolescents & Teens (13–18 years)	*Ways of Providing Support*
• Has concrete understanding of illness/death • Body changes amplify grief response • Increased risk taking • Questions meaning of life • May need permission to grieve • Concerns about being different than peers • May withdraw and/or avoid emotions	• Be available when they're ready to talk; don't push • Provide education about the illness and its progression • Help find supportive peers and adults • Provide gentle, consistent support • Watch for reckless or risky behavior

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Assisting Children at the Time of Death and Afterwards

At the time of a death, and in the weeks after, children can often "get lost" in the whirlwind of activities and emotions. Many families have questions about what the children should be told, what events they should participate in, and what they are able to understand. You can help them by providing needed information, allowing them to make choices, giving them comfort, and listening. There are no "perfect" answers for children and teens; each child and family is unique. What we say about death will depend on their age, their experiences, and the family belief system.

When talking with children and teens about the death, it is important to use simple and straightforward language. ***Communicate that their loved one has died, which means that their body has stopped working and they no longer need to eat, breathe, think, or feel anymore.*** It is helpful to use the word "died" rather than "passed away," "gone on a trip," "sleeping," etc. Avoid euphemisms such as, "God needed an angel," or "he was so good that God needed him in heaven." These phrases can cause children to feel afraid of being good or feel angry at God.

Talking With Children About Death

"Your mom died this morning, which means that she is no longer alive. She doesn't need to eat or sleep anymore. She's not hurting or in pain anymore. "

"Will Mom ever move again?"

"No. Dying means her body has stopped working. Remember that when someone dies, they no longer need to eat, sleep, breathe, or move anymore. They also don't feel pain, get hungry, or feel hot or cold.

Find examples of death in the natural world, such as dead bugs or animals, to explain differences between being alive and dead to children.

"Why can't they fix her?"

"Once the body dies, it stops working. It can't start again."

"Why is she cold?"

"Her heart has stopped beating. The body stays warm when it's living because the heart pumps blood to keep our bodies warm and to keep them healthy and alive. When people die, their hearts stop beating, so they feel cold to us, but the dead person doesn't feel the coldness."

"When will she come back?"

"She won't come back. People who die don't come back to life."

"Is she sleeping?"

"No. When we sleep our bodies are still working, just resting, and we can still wake up. Dying is not like sleeping."

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Frequently Asked Questions About the Time of Death, Funerals, and Afterwards

Should children or teens be present at the moment of death?

Every family and child has different beliefs and preferences about being present at the moment of death. With preparation, being present at the time of death can be a meaningful experience for children and teens, as well as help them begin to understand the finality of the death.

Explore with your child or teen before the death occurs about whether or not he or she would like to be present at the time of death. If your child or teen does wish to be present, prepare your child or teen for what that moment might be like (e.g., what they might see or hear, what others around them might be doing), and be sure that they are not alone unless they request it. Prepare your child or teen that the people around them may experience a range of strong emotions (e.g., crying, numb/no feelings, clinging, anger). Know that even despite the best preparation, it is hard to truly know what the moment of death will be like or when it will happen. Allow for changes in the plan if necessary.

Should young children attend viewings and/or funerals?

It is helpful for children to be given the choice of whether they'd like to participate in the memorial service and/or funeral or not. Prior to the service/event, children should be told what they might see, hear, and feel and then be allowed to make an informed choice.

If the child decides to attend the funeral or memorial service, involve them in the activities if possible. Allow them to select something special for the funeral or memorial service, such as choosing a flower to place in or on the casket, putting something meaningful inside the casket, or choosing something to read or share with others.

Assign a caring adult to be a "helper" or "buddy", who can take the child on a walk, sit with the child outside, or take the child home early if needed.

Should children or teens view the body before the funeral?

Viewing the body can be a peaceful and educational experience for children and teens about death; it is not inherently scary or damaging to children, teens, and adults. With adequate preparation of what they will see, viewing the body can be a way for children arid teens to begin to understand that their loved one has died and say a physical goodbye to their loved one. It is important that the child or teen is prepared for what the body looks like or how it looks different than when the person was alive (e.g., person feels cool to the touch, wearing makeup, not moving).

Children and teens often act unaffected by the loss. What are they feeling?

A child or teen may show little immediate grief outwardly, but they do indeed grieve. Children and teens experience the same feelings as adults: anger, sadness, loneliness, fear, guilt, etc. However, they express their grief differently than adults do. They grieve in short bursts and often express their grief through play, behaviors, and actions, not necessarily words.

What will help children after a loss?

Children need to be able to talk about the deceased person if they choose and share their memories with others. ***It is also helpful to allow the children to keep something that belonged to the loved one as a tangible way to stay connected to the deceased.*** Continue to provide reassurance and comfort, listen, and allow the child to express a range of feelings. Be a healthy model of grief and take care of yourself.

How much information does a child need about the death?

Children need to be told in simple, but accurate, terms what caused the death; teens also need age-appropriate information about the death. Children often believe that the death is their fault; helping them know the real reasons for the death can alleviate some of these guilt feelings. Don't assume that a child will understand what "cancer" or other medical terms are.

They also need to be reassured that serious illness and death are not contagious. Many children believe that they can "catch" cancer or death in the same way that you can "catch" a cold from another person.

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Selected Readings

Below are some reading materials that may help children and teens during this difficult time in their lives when a family member is ill.

Parent Resources

- ***How to Help Children Through a Parent's Serious Illness*** Kathleen McCue
- ***Preparing the Children: Information and Ideas for Families Facing Terminal Illness and Death*** Kathy Nussbaum
- ***Parenting Through Crisis: Helping Kids in Times of Grief, Loss, and Change*** Barbara Coloroso
- ***Raising an Emotionally Healthy Child When a Parent Is Sick*** Paula Rauch and Anna Muriel
- ***Children and Grief: Helping Your Child Understand Death*** Joey O'Connor

Teen Resources

- ***Help for the Hard Times*** Earl Hipp
- ***Facing Change*** Donna O'Toole
- ***Fire In My Heart, Ice In My Veins*** Enid Traisman
- ***When Nothing Matters Anymore: A Survival Guide for Depressed Teens*** Bev Cobain
- ***Straight Talk About Death for Teenagers: How to Cope With Losing Someone You Love*** Earl Grollman

General Books

- ***Badger's Parting Gifts*** Susan Varley
- ***When Someone Has a Very Serious Illness*** Marge Heergaard
- ***Someone I Love is Sick*** Kathleen McCue
- ***Gentle Willow: A Story For Children About Dying*** Joyce Mills

Stress/Anxiety in Children/Teens

- ***What to Do When You're Scared and Worried*** James Crist
- ***What to Do When You Worry Too Much*** Dawn Huebner
- ***Be the Boss of Your Stress*** Timothy Culbert
- ***Stress Can Really Get on Your Nerves*** T. Romain and E. Verdick

Alzheimer's Disease and Aging

- ***Animal Crackers*** Bridget Marshall
- ***Fireflies, Peach Pies, & Lullabies*** Virginia Kroll
- ***The Memory Box*** Mary Bahr
- ***What's Happening to Grandpa?*** Maria Shriver
- ***Wilfried Gordon McDonald Partridge*** Mem Fox

Cancer

- ***Butterfly Kisses and Wishes on Wings*** Ellen and Fran Waldman
- ***Daddy's Old Robe*** Shawn Alyne Strannigan
- ***My Mommy Has Cancer*** Carolyn Stearns Parkinson
- ***The Rainbow Feelings of Cancer*** Carrie Martin & Chia Martin
- ***The Hope Tree*** Laura Numeroff & Wendy Harpham
- ***Sammy's Mom Has Cancer*** Sherry Kohlenberg
- ***When Mom's Cancer Doesn't Go Away*** Maryann Makekau
- cancer.org

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