



Supporting Children When Someone They Love Has a Serious Illness



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Introduction

Everyone in a family is affected when one family member has a serious illness. All are dealing with the unknown and must use strengths they don't even know they have. Most of us haven't been taught how to manage when someone we love is very ill, let alone how to support children and teens during this time. Yet time and again, parents and caregivers find the strength within themselves and learn new coping and parenting skills along the way.

This booklet will help guide you during this difficult time. It describes how children of different ages understand and react to changes in the sick person, in you, and in themselves. In addition, it offers suggestions about how to talk with your children and ways to help your children prepare for the death of a loved one.

As you read this booklet, keep in mind that you are the expert on your child. What works for one child doesn't necessarily work for another. Learn from the experts, but also trust yourself, your child, and your instincts. We hope you come back to this booklet again over time as you travel this journey. And remember that we in the Grief Support Program at Hospice of Santa Cruz County are here to answer your questions and support you along the way.

What All Children Need

Gentle honesty

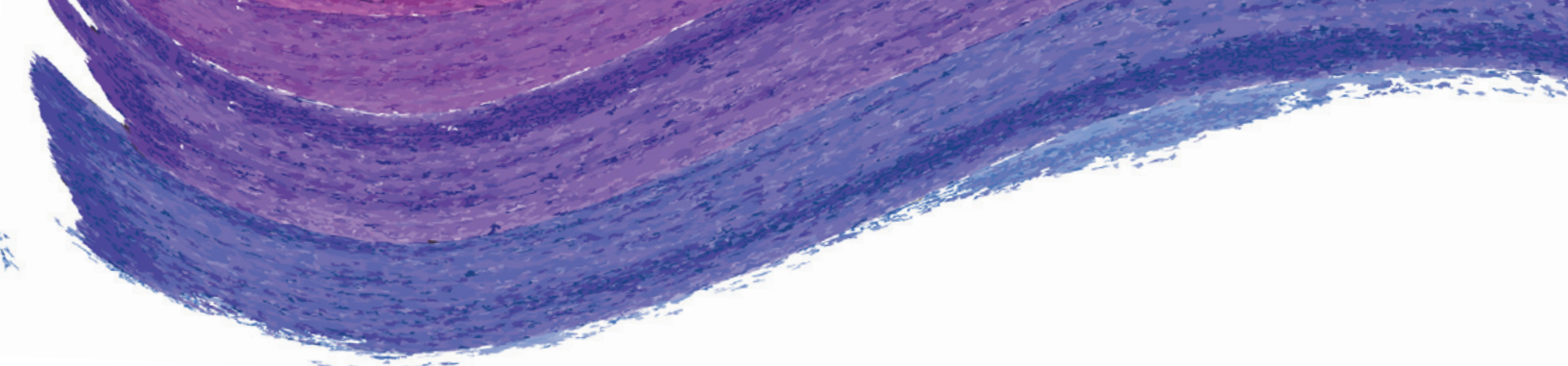
Telling children the truth as soon as possible helps them to trust and feel a sense of safety. Start by explaining what is happening in simple terms. For example, “Grandma has a sickness that makes her body tired and weak. Usually when people are sick, doctors and nurses can help them get better. Her sickness is different because the doctors don’t think that she will get better. She may die because of this sickness.”

Give children time to absorb what you have told them. Encourage them to ask questions if they are unsure or upset about anything. The words that you use don’t have to be perfect. You will find your own caring words. Try to talk with your children in a comfortable, familiar place where you can be together for a while. It’s best not to talk before bedtime, as they may need some playtime after this conversation.

Don’t shy away from using the words “dying” and “death.” Children can be confused by terms like “going away” or “gone to sleep.” Those words may create fear that loved ones won’t come back when they go away on a trip or won’t wake up when they go to sleep. When you talk about the illness, also remind your children how much you love them. Let them know that there are people who can help your family if needed. This helps children feel safe and cared for during a tough time.

It is okay to cry when you talk with them. They might cry too. It might be good to have another adult with you to support you when you talk to your children. Remind your children it is not their job to make you feel better and that you will be okay.

Being honest doesn’t always mean telling everything you know. Younger children need less information with fewer details. Older children may want more facts. The kind of informa-



tion children need varies with their age and personality. Ask “What do you think?” as you talk with children. This will let you know when they need more help understanding what you have told them.

Information at the child’s level

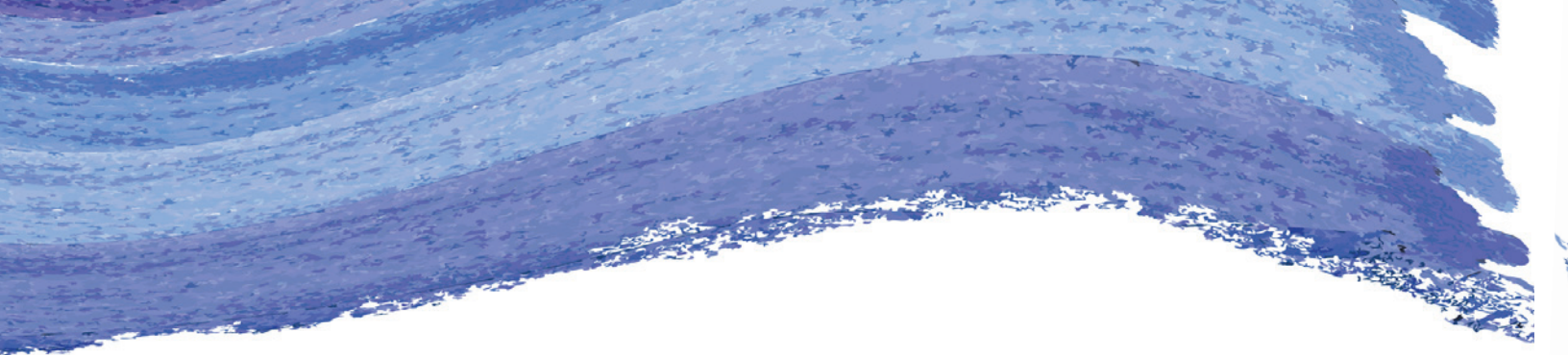
Tell your children the name of the illness and, to the best of your understanding, what may happen as the illness continues. Use honest words like heart disease, cancer, and Alzheimer’s disease. When not given truthful information, children can feel like they’ve been forgotten or lied to. They may also make up their own stories about what is happening. Honesty from you will help them cope with what is happening.



Encouragement to ask lots of questions

Children of all ages have many questions. Encourage them to ask questions about anything they are unsure about or feel troubled by. Answer questions honestly, keeping the child’s level of understanding in mind. Keep your responses short and to the point. Children understand illness and the dying process little by little. They may ask the same questions over again, and it will reassure them when they hear the same information again and again. It’s also okay to say “I don’t know” if it is true.

Children may only be able to take in a little bit at a time – and you may only be able to talk about it in brief spurts. That’s okay. Coming back to the topic later actually helps children digest it in their own way. Leave the door open for ongoing conversation. Regular updates that fit the child’s age and level of understanding can help them trust.



After providing an update: “I just gave you a lot of information and used some words you’ve probably never heard before. I’m thinking you might have some questions. What are you wondering about right now?”

“We’ve decided that we’re going to have family meetings every Thursday night so you can ask for the latest information about this illness. Of course, you can ask any question that you have at any time, but we wanted to make sure to save special time to talk as a family so we don’t get so busy taking care of things that we forget to talk with one another.”

“Anything you want to ask about Grandpa? Whenever you are ready, we’ll talk.”



A chance to share feelings

It’s normal for children to feel all sorts of feelings, including sadness, anger, guilt, confusion, frustration, and fear. Children often feel anger followed by guilt. They can be helped to express their anger safely with activities such as pounding on pillows or throwing a ball at a target. Sometimes children don’t yet have words for their feelings. Sharing your own emotions can be a model for them, reas-

suring them that others also have these feelings. It’s good to remember that many times children express and show their feelings through art and play rather than just talking about how they feel.



Reassurance that nothing they did caused the illness

Children make sense of the world from their own point of view, based on their age and ability to understand. They may think that something they did or said caused the illness. They may see the person's illness and death as a punishment for something bad they did. They also may believe that they can keep the person from dying by promising to be good. Children, especially young children, need to be reassured that nothing they did or said and nothing they will do or say is connected to the illness.

Time to play

Playing hard, laughing, and being with their friends can give children a needed break as well as reassure them that their life will continue. Give them opportunities for play and art. This helps them express themselves at their own pace in the way most familiar to them. Because children learn through play, they may act out medical scenes or want to have a funeral. A medical play kit allows a child to act out medical scenes. During pretend play, going along with the child's pretend scenes can help you get an idea of anything they may be missing or not understanding about the illness.





Routines

Children find comfort in their normal activities and schedules. They feel safe when their world is predictable and they are surrounded by caring family and friends. Try to keep routines as normal as possible. Let them continue with their out-of-school activities if possible. Have a trusted family member or a friend that your children are comfortable with help out with driving if needed. Try to have regular meals and a consistent bedtime.

Taking care of yourself

If you are also a caregiver, take care of yourself as you balance the needs of the ill person with those of children. It is okay and normal if sometimes the children's needs take a backseat to the needs of the parents. Find time to take care of yourself in the ways that help you rest or recharge. This may be through exercise, talking honestly to friends or family members, creating art, meditating, going to church, etc. Many adults, as well as children, are helped by counseling during this time.





Guidelines by Age Before Age 3

A child's age and maturity will affect how he or she reacts to the news of a loved one's serious illness. The guidelines below are broken down by age and offer ideas on how to support children at different levels.

BEFORE AGE 3

Babies and toddlers live in the moment. They feel the emotion of what is happening around them even though they don't understand illness.

Behaviors you may see:

- May be more fussy
- May be harder to soothe
- May “regress” or begin to act like a younger baby. This can include their sleeping, eating and toilet habits. For example, a toilet-trained child may return to needing a diaper again.

How to help:

Provide security and as much routine as possible

A caring presence and a regular routine help babies feel safe and secure. Try to keep a regular schedule for meals, naps, story time, and bedtime as much as possible. You may want to use simple words, like “Grandma is sick” to explain changes in a sick family member. Lots of physical contact at this time is helpful and comforting to young ones.

Guidelines by Age

3 - 5 Years Old

GUIDELINES FOR CHILDREN 3 - 5 YEARS OLD

Children ages 3 to 5 are sensitive to major changes, strong emotions, and other behaviors in their parent or caregiver. We should expect them to react to changes in their normal routines and to frequent, unplanned separations from their mother or main caregiver.

Expected behaviors:

- Brief outbursts of emotion followed by play
- Waking up very scared (“night terrors”), nightmares, and trouble sleeping
- Not wanting to be separated from parents or caregivers
- More temper tantrums and stubbornness
- May “regress” or begin to act like a younger child. This can include sleeping, eating, and toilet habits.

How to help:

Talk to the child about the illness

Use words your child understands. Children at this age take things very literally. Pick words that talk about the real illness instead of using words that avoid what is happening. Brief, concrete explanations are best. This may be something like:

“You know that Grandma is very very sick. That is because she has a sickness called heart disease.”

“Heart disease is not like a regular sickness because you can’t get it from germs, and no one can catch it from anyone else. Grandma did not get sick because of anything you did.”

“I am really mad and sad about Grandma’s illness. How do you feel about it?”

Inviting children to draw a picture or make a card for the person can be a good way to end the conversation.



Explain what they are seeing and hearing

As the ill person becomes more sick, use very simple terms to explain the changes the child may see. Explain things gradually as changes happen. For example:

“Daddy is very, very sick. That is why he’s so tired and sleepy lately. The doctors are trying to help him with his sickness, but he won’t be strong enough to play ball with you for now.”

It is important to not give children false hope. This can cause them to lose trust and be confused. If asked, “Is Daddy going to die?”, you might say something like: “People have died from the disease that Daddy has, but the doctors are doing everything they can to keep him comfortable.”

Even as the possibility of death comes closer, it’s important to talk to children about what is happening. Reassure them that they will be cared for and talk with them about how family life will continue.

Help children understand that what they are feeling is normal

It is helpful to set aside a regular time each day when children can ask questions and share their feelings. Evening can be a good time to do this. If other demands make it hard for you to find this time, you may want to ask a trusted family member or friend if they can be with the children at a regular time each day.

Children this age usually don’t ask many questions about the illness because they don’t know what to ask. Parents may think that the child isn’t affected by what is happening when the child doesn’t ask questions. The child may also use play as a way to express feelings. Realize that these are both normal ways of coping at this age and don’t mean the child is not upset.



Guidelines by Age 6 - 8 Years Old

Let children know that they are loved and will be cared for

Keeping regular routines and schedules helps reassure children. Let them know ahead of time when there will be changes to their routine. They may find it harder to separate from you during this time. Try to limit the number of different people who care for them. If possible, have the same relative or babysitter care for them when you are away. Express your love and affection often.

Allow time for play

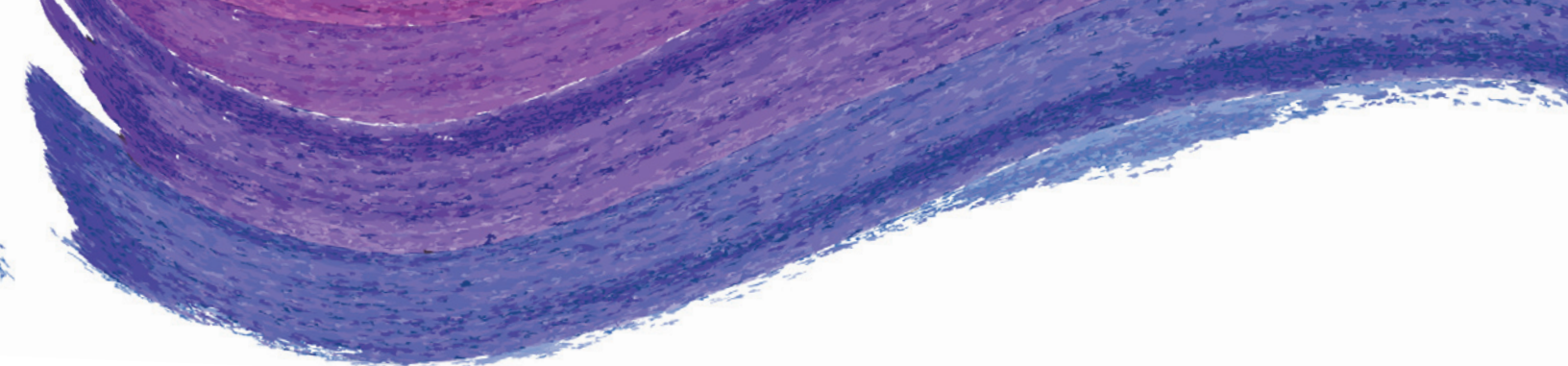
Children work through stress and emotions by playing. Play allows them to take a break in the midst of everything that is going on around them. Play also helps children make sense of all that is happening in the family. Giving children a play doctor kit, colors, markers or paint and paper gives them ways to work through their feelings. Encourage kids to be kids and play!

GUIDELINES FOR CHILDREN 6 - 8 YEARS OLD

Children between the ages of 6-8 will often feel anxious during a serious illness of a loved one. They fear being left and can feel they are the cause of family distress. They often blame themselves for bad things happening. Their actions are often tied to what is happening around them. They may feel rejected when the person who is ill is less able to be part of usual family activities.

Behaviors to expect:

- Showing many different feelings such as anger, anxiety, sadness, fear, and feeling left out or forgotten
- More conflict between siblings
- More acting out or sulking when separated from parents
- Strong requests that their personal activities not be changed and loud protests when activities are changed

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- Concern about how the sick person looks and feels. Concern about changes in the person's ability to talk or do things with them.
 - Becoming more clingy, stubborn, or demanding

How to help:

Give the child information about the disease

Name the disease and write it down. Talk about how it changes and how the sick person may look or feel over time. Talk about treatments and causes. Reassure children that nothing they did caused the disease. Let them know that it cannot be caught from the ill person. Prepare explanations ahead of time, since children this age tend to ask questions that are very exact and they often include a lot of “why” questions.


“The doctors have told me that your grandpa has Parkinson’s disease and is going to die.”

“Parkinson’s changes the way Grandpa’s brain works, and it makes him shaky and maybe more tired than before. It’s not like a cold because Grandpa can’t give it to you or anyone through his germs. This disease isn’t because of anything that you did or said.

“The doctors will work very hard to make sure your grandpa isn’t in pain. You will probably have questions about this. Remember I am here to answer any questions that you have and that I love you very much.”

Talk with them about changes in the person’s illness and treatment

Update children often. This helps them feel valued and included. When they feel close to their family members, they are better able to deal with the stress. When possible, let children talk with the doctors, nurses, and social workers caring for the ill person.



Children this age tend not to ask questions. This can be because they fear upsetting their parent or fear that the answers to their questions will be too scary. They may also worry that they will make the illness get worse by talking about it. Try not to let their lack of questions keep you from talking about it.

“The doctor has told me that the medicine hasn’t worked. This means that the cancer is growing.”

“I’m hoping that something will happen and the cancer will stop growing on its own, but I’ve heard that this probably won’t happen.”

“Remember that this cancer has nothing to do with anything that you did or said. I don’t know why I got this and I am really mad and sad about it.”

“Most of all I want you to know that I love you and I want so much to be alive and see you grow.”

Help children understand that what they are feeling is normal

Talk openly about how the situation is hard for everyone. If the person who is ill acts differently, explain that this is caused by the illness and not by a lack of love or caring. Understand that children may still be angry about the changes within the family. Even if they’re not told that the person is dying, they will often fear this and may keep that fear inside. Let them know that it’s okay to show their feelings. Allow them to see your own feelings and tell them that you will still take good care of them even though you are sad or mad or scared. If children are struggling in school, let them know that this is normal given what they are going through and that it is temporary.



Prepare ahead of time for changes in routine

Prepare children for any situations where both parents may have to leave the house unexpectedly. Talk ahead of time about the plan so they know what to expect.

“Your dad and I are going to be spending a lot of time at Grandma and Grandpa’s helping with Grandpa. We have a plan for when we aren’t able to pick you up from school. Your Aunt Sue is going to give you rides home from school and to soccer practice. She loves you very much. We’ve talked to her and she’s promised to take good care of you, just like she does with her own kids. We don’t know if this will happen, but we wanted you to know these plans just in case.”



Allow time for play or art

Play is the natural language of children and a healthy way for them to deal with stress. It allows them to feel a sense of power and control.

Be an advocate for your child

Talk with teachers and other adults in the child’s life about the illness. Try to be consistent with who cares for the child when you cannot. Try to choose

people who relate well with the child. Extra praise can help children’s self-esteem during this stressful time.

Guidelines by Age 9 - 11 Years Old

GUIDELINES FOR CHILDREN FROM 9 - 11 YEARS OLD

Children ages 9-11 are able to understand more about the illness than younger children and may ask about the details. Their desire to know these details may make it seem like they don't have a lot of feelings about what is happening. Yet getting facts to help them understand what's going on is one of the ways that they cope with scary and strong feelings.

Children this age understand that death is final and can feel sad about a future loss. They wonder how they will be impacted by illness and death and who will do the "daddy" or "grandma" things. When one parent is terminally ill, the child often fears the death of the other parent and worries about what would happen to them if both parents died. They tend to hide emotions, and it's easy to think the situation is affecting them less than it is. They may silently wonder, "Can I catch this?" "Did I do or say something to cause this?" Or they may create their own explanations when they are not given facts about what is happening on a regular basis. Children this age welcome distractions of school, activities and friends.

Behaviors to expect:

- A lot of interest in understanding the disease, treatment, and progress
- Wanting to avoid strong or scary emotions
- Not wanting to talk about or show feelings
- Anger (used to cover fear, anxiety, and grief)
- Angry and mistrustful reactions when not given the facts about what is happening
- Strong reactions to stress and normal frustrations in everyday life
- Wanting to stay active with schoolwork, sports, and outside activities
- Wanting to help care for the ill loved one



How to help:

Talk openly with the child about the disease

Watch for opportunities to talk about the illness and explain what children are seeing and hearing. Include them in discussions and updates. If children are not given enough information, they will listen in doorways or strain to hear whispered phone conversations and may jump to false conclusions.

Talk about the name of the disease, how it affects the sick person, causes, and side effects of treatments. Children also like learning things from doctors and nurses when possible. You can try to be optimistic about what to expect but not give false hope that the person will heal from the illness. So, instead of saying, “*Grandma is a fighter, and she will be cured,*” it would be better to say, “*The doctors and nurses are working hard to help Grandma feel as comfortable as possible. She may be well enough to come to your birthday party this weekend.*”

Encourage children’s natural interest in the illness by reading together and providing time to write or draw. These are some common questions:

How did she get it?

Can I get it?

How do you know I won’t get it?

What if the medicine doesn’t work?

What will happen to me when she dies?

Reassure children the illness is not their fault. Gently let them know when the person may be close to death. This will help them to make final visits and say goodbye.



Let children know that what they are feeling is normal

Let them know that the situation is hard for everyone and that the family will deal with it together. Remind them often that your moods are not their fault. Encourage them to express their thoughts and feelings about all the changes that they are seeing in themselves, in you, and in the patient. When it is time, acknowledge sadness about the possibility of death.

Prepare ahead of time for changes in routine

Children need time to prepare for changes. Talk with them ahead of time about upcoming changes in their routine as much as is possible.

Offer children ways to be helpful

Some children this age want to help take care of the sick person as a way to show their love and caring. Let them help by doing simple things but limit their responsibilities so they don't feel burdened. Children can help the patient feel loved by drawing pictures, telling the patient they love him or her, talking quietly, sharing favorite memories, etc.

Be an advocate for children

Help children stay active with after-school activities and encourage them to spend time with their friends. Let teachers and other supportive school staff know about the illness so they can provide support as needed. It is not uncommon to see a temporary drop in grades due to changes and stress at home. You may want to ask teachers for homework packets if you know children will be absent from school.



Guidelines by Age The Teen Years

THE TEEN YEARS

During the teen years children are finding their own identity and becoming more independent. They need more privacy and often withdraw from family members. This process of growing up is harder for them when someone in the family is ill. They try to balance the family's needs with their own very different needs.

Teens may show anger as they become more anxious and fearful about the illness. When much of a parent's time and attention is focused on the sick person, the teen may feel that they are being abandoned and become resentful.

As the ill person gets closer to dying, teens often are able to talk about it and cry as they express their sadness. They may also become very anxious and worry about how the death will affect their lives. Around this time, they may try harder to behave well and do what is asked of them.

Teens need as much time as possible to prepare for the death. Let them know when death is near so that there is time for them to have a final conversation and say goodbye, if possible. If they have been angry and resistant, they may become more cooperative when the death is near, but not always. Sometimes they may become even more angry as a way to protect themselves from their sadness. Teens' hostility and anger before a death may lead to feelings of guilt after the death.

Guidelines by Age

12 - 14 Years Old

GUIDELINES FOR CHILDREN 12 - 14 YEARS OLD

Teens between the ages of 12-14 can understand the illness and how it will affect their lives, yet it may be hard for them to cope with the feelings that come with it. They may not want to talk about it out of fear that they'll lose control and cry. They may act "grown up" as a way to ignore their strong feelings. This can make it seem like they don't care, which can be upsetting to parents, but this is not the case.

Teens this age can also be very optimistic that the sick person will get well and they may not want to hear otherwise. They hold on to their positive outlook by avoiding facts and feelings. This is normal for a young teen and should not be discouraged.

Reactions to expect:

- Not wanting to talk about the illness
- Feeling strong emotions but acting or saying that they are "fine"
- Holding on to the belief that the patient will get better
- Tending to argue and be more "difficult" or demanding
- Resenting chores and other demands that take them away from school and friends
- Having trouble with schoolwork, or, sometimes, trying very hard to please adults by being extremely good
- Trouble sleeping
- Anger
- Sadness





How to help:

Talk with them about the disease

Keep them up to date with what is really happening, even if they don't want to hear it. Don't assume that they understand as much about what's going on as they seem to. Let them know when death is near so that there is time for them to have a final conversation and say goodbye, if possible.

Give them a chance to talk about their feelings and concerns

It is important to talk with your teen about how they are feeling, even if only briefly and even if they don't really want to talk. Try to be as open and nonjudgmental as possible when they share their feelings. Sharing your feelings and concerns can help them feel more comfortable sharing their own. This helps them see that the feelings they have are normal and expected.

You may say, for example:

"You look kinda sad today. I'm feeling sad about this too. How are you doing with all of this?"

"Sometimes talking about what's going on helps. I'm here to listen any time that you want to talk about any of this."

It is also normal for grieving teens to have strong and often negative feelings about the person who is sick. They can feel frustrated and angry about the illness and may direct their anger towards the person. Often after having or expressing these emotions, teens can feel guilty. Help them understand that having a wide range of feelings is normal, and help them figure out ways to cope with their strong feelings.

Guidelines by Age 15 - 18 Years Old

Be understanding of the teen's reactions

Remember that if your teen pulls away from you, has lots of ups and downs, or is defensive or self-centered, this is all normal given their age. Teens often find writing, quiet time alone, and time with friends helpful as they deal with a difficult situation.

Be an advocate for your child

If possible, try to limit the teen's duties and chores at home, since pulling them away from school and friends can cause them to become angry or difficult. Understand that they may not do as well in classes at this time. Let their teachers know about the illness. Help them connect with any counseling or support groups offered by the school or local hospice. Often teens don't want their classmates to know that they are receiving counseling. Listen to your teen's concerns, offer options, and help find creative solutions to this issue.

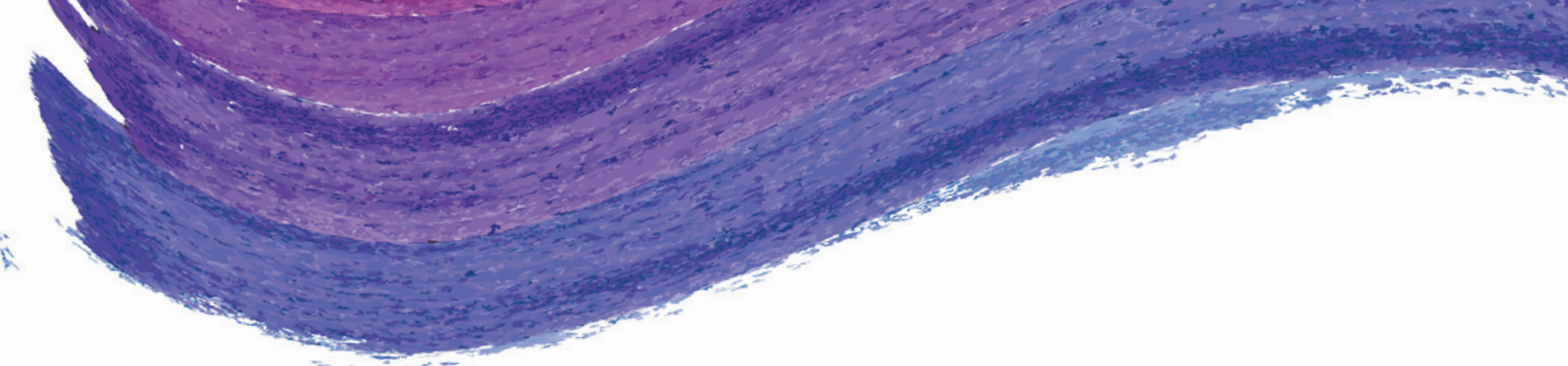
GUIDELINES FOR CHILDREN AGES 15 - 18

Teens between the ages of 15-18 can usually understand the realities of the illness and deal with their emotions. Yet at times they still may feel overwhelmed. Though they can generally talk about what they think and feel, their feelings about the illness may not be clear. Teens this age tend to be more practical in their thinking than younger teens. They may also be more considerate. Because they're more aware of the possibility of death, they may feel more grief during the illness than a younger child might.

At this age, teens want to be treated like adults and are trying to rely more on their friends than their family for support. They're able to be more concerned about the needs of their family members, though they may resent having to do more.

Expected reactions:

- Fears about the future
- Irritability
- Having strong feelings like anger and guilt toward the person who is ill

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- Trouble concentrating
 - Being torn or frustrated when having to focus on the needs of the family rather than attend activities or socialize with friends
 - Feelings of resentment, anger, and defiance

How to help:

Talk with the teen about the illness and how it will progress

Include older teens in family discussions about the illness. It's helpful if the sick person can talk directly to the teen about the illness as soon as possible. Teens this age can understand personal or spiritual thoughts and feelings, including uncertainties and unknowns, so these can be shared with them as well. Let them know when death is near so that there is time for them to have a final conversation and say goodbye, if possible.

Expect that the teen will not perform as well during this time

Keeping up grades, activities, and friendships is very important to most teens. However, during a serious illness, it's normal for them not to do as well in school, sports, etc. This can be hard for teens and parents who believe that grades will affect future opportunities. However, some teens actually do better at this time as a gift to their ill parent. Either way, be understanding of what the teen is going through.

Recognize how the stress caused by the illness can affect them

Teens this age may feel overwhelmed by the stress from the illness on top of the other pressures they feel in life. Talk with them about ways they might reduce the stress in their lives, dealing with the things that are causing them stress one at a time.

Know that they may be worrying about the future

Talk with older teens about how future plans will be affected by what is happening. Reassure them in a way that is realistic. Provide a listening ear as they share any fears they may have about their future.



Know that teens may be afraid that they too could become ill

Let older teens talk to medical professionals if possible to allow them to ask questions about the illness—how it is caused and what to expect. Talking with your teen about the actual chances of them getting sick can help them feel less fearful.

Talk with the teen about ways they can be helpful to the family

Giving the teen helpful tasks can sometimes help them feel less anxious. Look for opportunities for them to help in ways that they enjoy, such as cooking, shopping, or errands. They may also want to spend time with the patient reading, listening to music together, watching a movie, sharing food, or writing a card or letter.

Understand that the challenges of growing up are even more stressful when a parent is seriously ill

The normal process teens go through to become their own person is harder when a parent is seriously ill. It can be challenging for them to see a parent be needy. It can also be hard for them to deal with a parent wanting to control their activities and comings and goings more at this time. They might react to this with resentment or anger and then later feel guilty about it.

Be an advocate for your teen

Consider helping your teen join counseling or support groups that may be offered by the school or local hospice. They benefit from talking with understanding people who are not directly involved. They may find that friends who are usually supportive “just don’t get it.” Speak with teachers and coaches about the illness and about ways they might help support the teen.





Explaining the Final Stages of Life

The final stages of life can be confusing and scary for children if they do not understand the changes they see happening. Not all terminally ill people will go through these changes, but talking about them ahead of time can help children be prepared.

Loss of strength

The disease may weaken the body so much that the person will need lots of rest. At some point, the person may not have the strength to talk. Explain that he or she is still able to hear their voice and feel their touch.

Loss of appetite

The person will slowly lose their appetite until he or she may not eat anything at all. It is important to tell children that because of the disease, the person does not feel hungry or need food like they did before.

Pain or discomfort

The person may sometimes have pain or other discomforts from their illness. Let children know that the care team is doing all they can to keep the person comfortable.

Personality changes

Some people may act differently as the disease weakens their body. They may be more irritable, sad, or quiet. Let children know that these changes are caused by the disease and not by anything anyone in the family has said or done.



Confusion

Some diseases cause the ill people to be confused as they get closer to the end of life. They may start saying or doing things that don't make sense. This can be very frightening for children. Explain that the disease is causing the confusion and reassure children that nothing they did or said caused it.

Breathing changes

It is common during the last few days of life for breathing to change. There may be pauses between breaths, or breathing might sound loud and heavy. There may also be a sound like the person needs to clear his or her throat. Explain that these breathing patterns are like snoring – uncomfortable to listen to, but the person is not feeling any discomfort from them.

Explain to children that the family will not be calling 911 to prevent the death but will be doing everything to help the person stay comfortable.





When Death Is Near

The transition from life to death is often peaceful. Witnessing this can give children a sense of reality and comfort. If you feel comfortable being with the person as he or she is getting closer to dying, ask your children if they would like to join you. The children should decide; never force them to be there against their will. Assure children that they do not need to feel guilty if they aren't there at the moment of death. If you feel uncomfortable having your children present, you may want to tell them about it later instead.

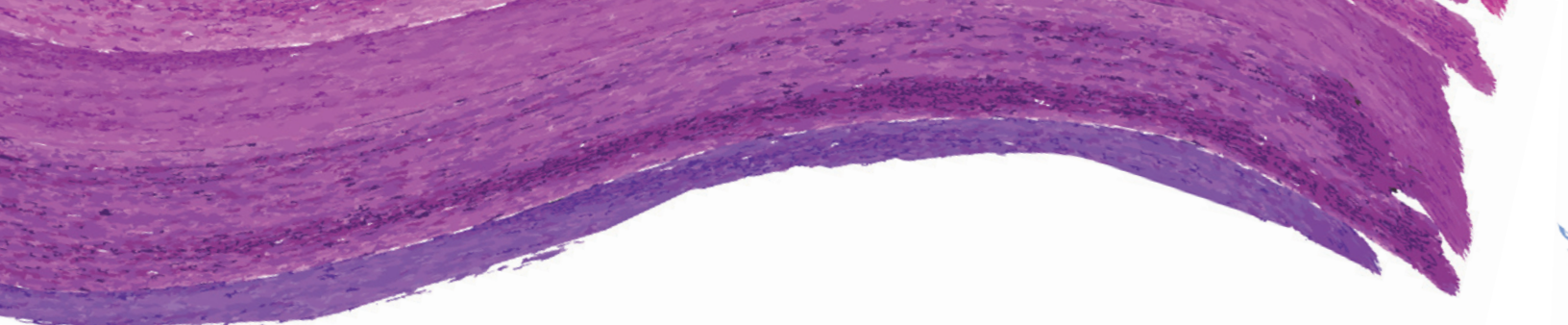
Don't promise children they can be present at the time of death. Since many people die when everyone is out of the room, being with them is not always an option. Gifts of words and art are other ways children can say goodbye.

Age-related responses to children at the time of death

Warm, loving concern should be shown to children of any age when they learn that the person has died. Let children know they can say goodbye even if they are not in the same room or house with the person who has died.

Ages 3-5 Preschool children will watch the reactions of the people around them. Their own reactions happen later, when they begin to understand that the person is gone from their life. Once this happens, they may feel sadness and disappointment or have trouble believing that the person is gone.

Ages 6-8 There are many different ways children of this age may respond to the death. They might have no response at first, or cry quietly. They may sob or scream, even if they knew that the death was coming. These responses may last a few minutes to about an hour. After this, most children usually return to what they were doing before the news.



Ages 9-11 Children this age often put on a brave face to help them deal with their strong feelings. They may look like they are not feeling grief, but this is not the case. They sometimes show anger as a way to cover up their fear, anxiety and sadness.

Ages 12-18 Adolescents are able to talk about the fact that their loved one has died and show sadness and cry. They also become anxious as they face the loss and how it will impact their life.

Remember that being patient with your child is the most helpful way you can support them at this difficult time for everyone.





Books and Resources

Books for preschoolers and beginning readers

Boritzer, E. *What Is Death? An introduction to the concept of death with examples of customs and beliefs from different religions and cultures.* While addressing children's natural curiosity, the book gently introduces themes of tolerance and identity.

Boulden, J. *Saying Goodbye.* This activity book tells a story about death as a natural part of life, the feelings that are involved in saying goodbye and the conviction that love is forever, while allowing the child-reader to draw pictures, color images, or insert thoughts on its pages.

Kohlenberg, S. *Sammy's Mommy Has Cancer.* This is a warm, sensitive, straightforward story that will help young children understand and accept the changes in their lives when a parent is diagnosed with a life threatening illness.

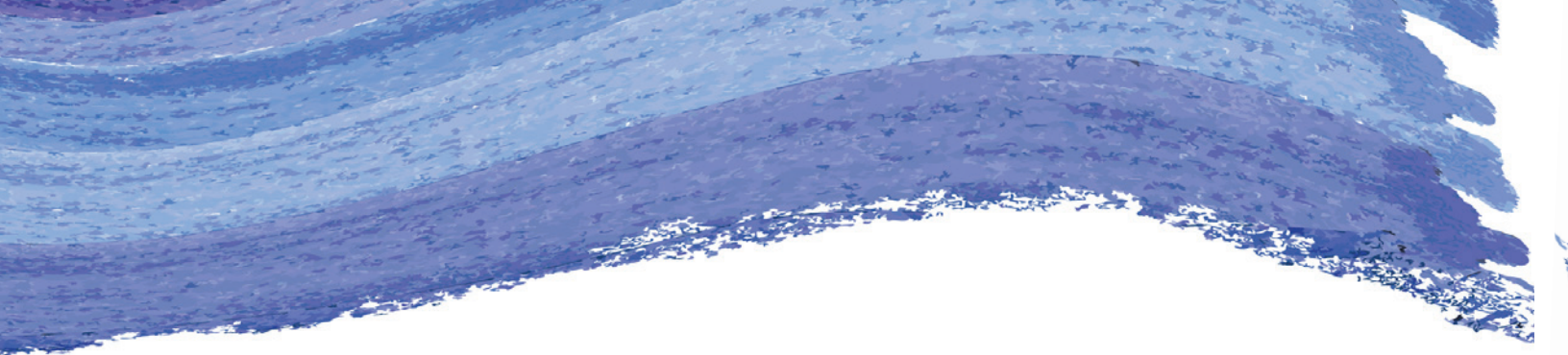
Lewis, A. *When Someone You Love Has Cancer.* Explains why a person is ill and what is happening to their bodies. It could address many unasked questions a child may have and frightening feelings they may be experiencing.

McVicker, E. *Butterfly Kisses and Wishes on Wings.* A beautifully illustrated book for children who have a loved one diagnosed with cancer. The story line, as told through the eyes of a child, gives a simple and honest picture of cancer and teaches children to realize the power they have to be an active and integral part of a loved one's cancer journey.

Primary school readers

Dougy Center. *After a Suicide.* For thousands of kids each year affected by suicide here is an activity book that sings out hope. The Dougy Center has long assisted grieving children. Here they give us a tool so we can too.

Dougy Center. *What About The Kids: Understanding Their Needs in Funeral Planning and Services.* This book addresses the best practices for funeral and memorial services with children and teens. Learn how to include children in these rituals and find creative ways to involve them in the process. You will find suggestions from children and teens about what was helpful and unhelpful about the funeral or memorial service they attended.



Grollman, E., & Johnson, J. *A Complete Book About Death for Kids*. The first section includes information about death, dying and the feelings you have when someone you love dies. The second section includes information about burial and cremation. The third section talks about the funeral and cemetery. Beautiful photos show the child what they will really see and answers the most commonly asked questions.

Heegaard, M. *When Someone Has a Very Serious Illness*. This workbook will help children deal with their own serious illness or the illness of someone they care about.

Heegaard, M. *When Something Terrible Happens*. Designed to help children cope with traumatic experiences, Heegaard gives information and healing opportunities in this art activity/workbook. Pages are given to draw out feelings.

Munday, M. *What Happens When Someone Dies*. A book for children about death and funerals. Elf-Help books address the needs of children and the adults who care for them.

Ryan, V. *When Your Grandparent Dies: A Child's Guide to Good Grief* (Elf-Help Books for Kids.) The little elves in this book explain what happens from a child's-eye view the days before, after, and beyond a grandparent's death. They explore the meaning of death and heaven, as well as how to stay close in spirit with a grandparent who has died. With ideas for action and questions for discussion, this creative guide will help you help your grieving child to create comforting memories and find closure.

Speltz, A. & Sternberg, K. *The Year My Mother Was Bald*. This book is Clare's journal and scrapbook the year her mother is diagnosed with cancer and goes through treatment. Clare tells her story, shares her feelings, and describes her family's experiences from her mother's diagnosis to chemotherapy, surgery, and radiation. Young readers will learn to understand the science of cancer and its treatments and will take comfort in knowing that they're not alone and that their feelings are normal.



High School Readers

Silver, M. & Silver, M. *My Parent has Cancer and It Really Sucks*. This book is written especially for teens to help during this tough time. Author Maya Silver was 15 when her mom was diagnosed with breast cancer in 2001. She and her dad, Marc, have combined their family's personal experience with advice from dozens of medical professionals and real stories from 100 teens—all going through the same thing Maya did. This book gives practical guidance and allows teens to see that they are not alone. It assures them that no matter how rough things get, they will get through this difficult time and that everything they are feeling is okay.

Traisman, E. *Fire In My Heart, Ice In My Veins*. This is a best-selling journal for teenagers who have experienced the death of someone they cared for. Here they can honor, record, and realize their many thoughts, feelings and questions related to the loss and to their memories.

Parents

McCue, K. *How to Help Children Through a Parent's Serious Illness*. Supportive, practical advice written by one of the pioneers of the care and treatment of children stressed by a parent's serious illness.

Okun, E. *Saying Goodbye: A Guide to Coping with a Loved One's Terminal Illness*. When someone receives a terminal diagnosis, the whole family is suddenly faced with a prolonged crisis. While medical advances have given us the gift of extending life, meaning that a loved one could survive months or even years before dying, it has also changed the way we grieve. Published in collaboration with Harvard Health Publications, *Saying Goodbye* guides you through this complex journey, offering hope and healing for those who may be “living with death” for an extended period of time.

Rauch, P. & Muriel, A. *Raising an Emotionally Healthy Child When a Parent is Sick* (A Harvard Medical School Book). Advice on how to help children cope from two Harvard psychiatrists, this book covers how you can address children's concerns when a parent is seriously ill, how to determine how children with different temperaments are really feeling, and how to draw them out and reassure the child that he or she will be taken care of.



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