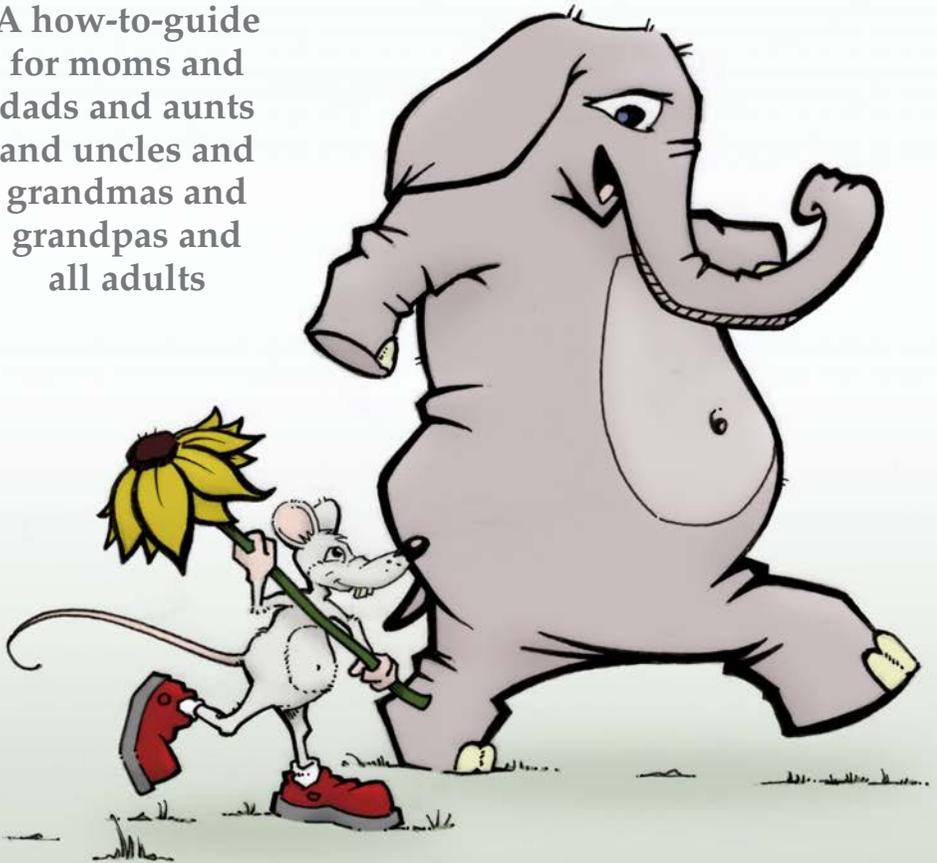


Simple Talk for Tough Times

Talking with Children About Cancer

A how-to-guide for moms and dads and aunts and uncles and grandmas and grandpas and all adults



Allina Health

Simple Talk for Tough Times

Talking with Children about Cancer

Developed by Allina Health

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Acknowledgements

Simple Talk for Tough Times is dedicated to the extraordinary courage, determination and hope of the families we serve.

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At the Allina Health Cancer Institute, we provide cancer care that is connected, compassionate and convenient. Our health care providers work closely with you on a personalized care and treatment plan that meets your specific needs, from the initial diagnosis and every step of the way. Learn more at allinahealth.org/cancer.

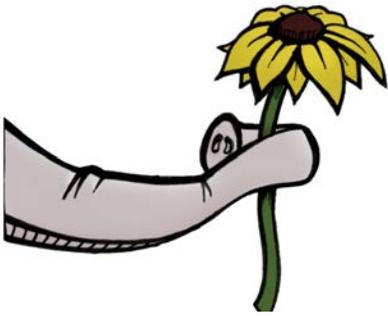
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Introduction

*“Sometimes the questions are complicated and the answers are simple.”
~ Dr. Seuss*



A cancer diagnosis shakes up your life and the lives of your family in ways you might never expect. Nothing feels quite the same. It is hard enough to accept the news yourself, but how can you possibly tell your child? What should you say? When is the right time to tell your child?

The diagnosis acts like an “elephant in the room.” It is something big that everyone is aware of, but no one wants to talk about. So you try to ignore it, usually because you do not know what to say or how to say it.

Simple Talk for Tough Times

Simple Talk for Tough Times is designed to help you talk with your child about the “elephant in the room” and help him or her learn to cope with the changes that often come with a cancer diagnosis. The hope is as you talk with your child and cherish your time together, your relationship will blossom in ways you never thought possible.

In addition to general advice and suggestions, this book looks at each phase of childhood development and offers specific ideas for what to say, do, and watch for when talking with your child.

Understanding your child’s emotions at each phase of development and how he or she may be affected by the changes in your home will help you prepare and manage the challenges that come with a cancer diagnosis.

Children often have concerns about their parent’s health as well the changes that are happening in their homes. It would be of concern if they did not react to a major event in their family.

But, most children doing well with school, friends, and at home before their parent's diagnosis of cancer continue to do well while you go through treatment. Those children who were having a hard time in one or more of these areas before a parent's illness are likely to have trouble dealing with the challenges now as well.

Communication is important in your relationships. It takes on different forms in different families. Communicating can be talking or doing things together. This guide encourages both talking and doing – spending time together to help your family learn ways of communicating through these tough times.

As you read this book, think about how this information fits with your family. Children mature at different speeds. They may be more or less mature than their actual age. To meet your child where he or she is in his or her development, you may want to read the pages of more than one age category for your child. Then choose the age that best corresponds to your child's maturity.

Simple Talk for Tough Times is organized into four sections. The first two sections give general information for all ages, as well as talking points for each age group. The third section talks about special situations within some families dealing with a cancer diagnosis. The last section gives ideas and resources for more information and support.

This book can also be a guide for support groups. It allows you to share any worries you may have and learn from others going through the same situation. You can attend a support group to meet other parents, share experiences and talk about the information in this book.



Breaking the News



Breaking the News

Preparing Yourself

*“We are always communicating, even when we do not speak.”
~ Virginia Satir*

Read through this section and find the pages for different age groups. You will find more specific ideas for what to say, do and watch for with your child on these pages. There are also resources for each age group in the *Ideas and Resources* section.

Setting the Stage

- Take time to understand and accept your diagnosis. Talk with others, especially your partner, if you have one. Think through and even name your own feelings. Know that your thoughts and feelings will change with time and working through them will be an ongoing process. Take your time but remember that your child already realizes something is wrong and needs your support.
- Recognize the size of the “elephant.” As hard as it can be for you to accept your cancer diagnosis, it can be even harder for your child. Some parts of the message are bigger and harder to describe than others. You don’t have to talk about everything at one time.

*“Pace yourself. An elephant can be swallowed only one bite at a time.”
~ Anonymous*

- Pay attention to your child’s attention span. Children have varying attention spans, and so do you. There will be times that are better than others to talk to your child about what cancer means to your family. Use the metaphor of the elephant if it helps. Don’t worry if your child tunes out after just a few minutes. Ask what he or she is feeling as you talk.



- Choose times to talk when your child is more open or ready to talk. There will never be a perfect time. It helps to plan times to talk when your child is not too hungry, tired or busy with his or her own issues with friends or school. If you are married or have someone else involved with your child, it is good to do this together. Sometimes you have to “make a date” with your child.
- Be as natural as possible. Talk with your child, not at him or her. Use familiar language.
- Tell the truth as you know it. Your child needs to know that you can be trusted to tell the truth. If something is not clear to you, tell your child you will let them know as soon as you understand.

Talking About Cancer

- Share your feelings, but focus on your child’s feelings more than your own.
- Put two of the most common fears of children at ease: Say, “You cannot catch cancer and you did nothing to cause it.”
- Use the real name of your cancer.
- Ask your child what he or she already knows about cancer. Don’t be afraid of talking over his or her head. Give your child credit. He or she understands more than you realize.
- Tell your child your best understanding of what will happen and when. Children need to have anchors, even dates and times, if possible. Making a calendar with medical appointments listed can be helpful.
- Children want life to be predictable. Let your child know some things may change and how that might look. Reassure your child that he or she will always be cared for. Explain that things that will not change in his or her life.
- Encourage questions, but realize you may not always know all the answers. You can say, “I don’t know but I will find out.” Follow your child’s lead as to how much he or she wants to know.



- Allow yourself and your child to express emotions. Hug each other, cry, be angry or express frustration together. Your role is to show that it is alright to say and feel emotions. Don't be afraid to ask for your child's hugs, too.
- Let your child know that you believe in his or her inner strength and resilience.
- Call on the expert resources available to help you, including your doctor, hospital social workers, counselors at school and in the community, clergy, and others.

Keep in Mind

Every child is unique.

*Children sense changes in their environment
and know when something is wrong.*

*A child's known problems may continue
and sometimes worsen with change.*

Children absorb as they are able.

Honesty is better than secrets.

*Providing structure and
predictability is important.*

*Look through the eyes
of your child.*

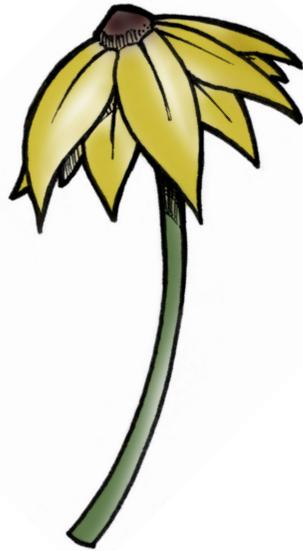
*Be curious about your
child's experience.*

*Mistakes made with love
are easier to correct.*

Simplify, simplify, simplify.

Not all children will have questions.

*Follow your instincts.
You are the expert on your own children.*



Breaking the News

Infants to 2 Years

*"My name is 'NO NO' but Grandma calls me 'Precious'!"
~ Unknown*

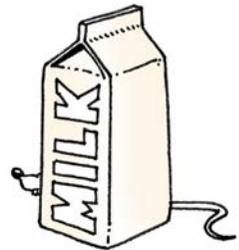
Developmental Factors

Trust, Mistrust and the Beginning of Independence

At this age there is little understanding of what is happening. Infants and toddlers are very sensitive to the emotional environment of the home. They sense change and react to the emotions of those around them. They listen to your tone, watch your eyes and feel the slightest tension in your touch. While most often infants and toddlers cannot tell you in words what they are feeling, they may become more irritable and need more holding, stroking, reassurance and calming.

Cancer can cause the environment to feel less secure and less trusting. It is important to provide confident and consistent reassurance for your child. One- and two-year-olds are working toward more independence, but when they feel stress and changes in the environment, they may become more dependent, stubborn or run away.

Changes in the environment and overlooking your child's basic needs can create a sense of mistrust in your infant or toddler. Healthy and consistent doses of affection will make sure that your child's view of the world is one of trust and security.



What to Say

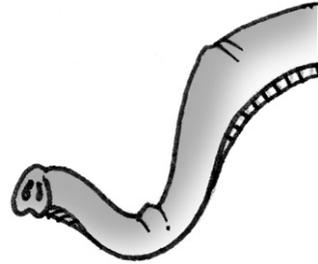
- Actions speak louder than words with infants and toddlers. Your voice itself will be reassuring. You might even say what is happening. Even though your child may not understand the words, he or she will sense your feelings.
- Sing songs that calm and comfort your child, especially familiar ones. This might even benefit you, too. Nursery rhymes that offer comfort can help. If it has a softness or tone of happiness it will be helpful, especially if it is familiar.
- With toddlers you can use words to describe cancer. Some parents give their cancer a name or use a shape or something familiar to describe the cancer.
- Try using dolls, stuffed animals or puppets to help show where the cancer is and how it will be treated. Let your child act out how he or she might help the doll or animal get better.
- Let your child know who will care for him or her at times you cannot.

“For infants and toddlers learning and living are the same thing. If they feel secure, treasured, loved, their own energy and curiosity will bring them new understanding and new skills.”

~ Amy Laura Dombro

What to Do

- Keep your child in his or her own home or in environments that are familiar, if possible.
- Try to keep routines the same as much as possible — meals, naptime, playtime and bedtime.
- Create a safe, blocked-off area where your child can play and explore without needing to be chased or kept from touching things. Then sit with him or her and enjoy playing.
- Ask a known family member or friend to comfort your child, if you or your partner are not able to do it. Remind that person of the words and sounds your child finds comforting.



- Limit the number of caregivers helping with your child as much as possible. Encourage caregivers to follow your child's usual routine.
- Use the same friends or relatives to care for your child if overnight stays become needed. This will lessen feelings of insecurity that may come from traveling from place to place.
- Try to avoid or reduce introducing new things. This includes weaning off the bottle, toilet training or giving up a comfort toy or pacifier — especially during the early stages of the diagnosis.
- Offer comfort in every way you know your child loves — music, toys, blankets, stuffed animals, familiar books, clothing, voices (even a long-distance call to a relative), food, baths, walks, rides and other things you know are calming to your child.
- Reassure your child by using all five senses — sight, sound, touch, smell and taste.

What to Watch for

Changes in behavior for infants and toddlers during stressful times are normal. They may return to less mature behaviors. Some behaviors you may see include:

- not sleeping well
- wanting to nurse or drink from a bottle more than normal
- becoming more irritable
- crawling instead of walking
- eating too little
- less interest in playing
- less emotions or eye contact.



It is important to pay attention to any behavior that is out of character for your child, especially if the behavior appears more intense or often, or if you sense that something is wrong. This is the time to talk to a professional such as your doctor or pediatrician, a child development specialist or counselor.

Breaking the News

3 to 5 Years

“Grown-ups never understand anything for themselves, and it is tiresome for children to be always and forever explaining things to them.”
~ Antoine de Saint-Exupery

Developmental Factors

Independence and Sense of Self and Initiative

This is the age at which children are first learning about independence. Three- to five-year-olds see the world revolving around themselves. Separation is wanted and feared at the same time. This is sometimes called, “first adolescence.” Because a parent’s illness may force a child to be more independent, he or she may resist because it is not his or her choice. It is important to set firm, loving limits.

Magical thinking is common with children of this age as well as a certain sense of power. Children may confuse fantasy and reality. However, children of this age also think very concretely. Their sense of trust is still growing. They begin to take initiative and learn how to get along with others.



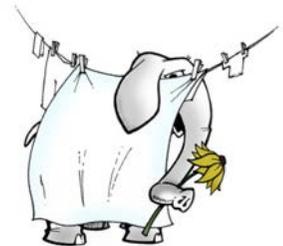
Children continually look to their parents to see if they are being understood and to see if they will be OK. For parents, it is important to learn to have your facial expressions match your feelings. Look into your child’s face to see if you are communicating well.

What to Say

- Use language your child will understand. For example, avoid saying, “Mommy will lose her breast.” A child may think it will be found again. Instead say, “Mommy’s doctor may have to remove the part of mommy’s breast that has the cancer.”
- Your child may wonder how you get cancer. A simple answer is, “No one knows exactly why some people get cancer and others do not. We are learning more about cancer all of the time.”
- Keep telling your child he or she cannot catch cancer and he or she did nothing to cause it.
- If you find a time that you need help in caring for your child, tell him or her, “If/When I am sick, I will still take care of you. Mommy/Grandma/etc. may have to help a little. But we will keep everything going as much the same as we can.”
- Be clear about behavior changes. For example, “Daddy needs to sleep a little more to feel better. Sometimes when you have a good nap it makes you feel better, right?”
- Get your child ready for possible changes in your appearance, such as loss of hair. Tell your child there might be changes in your household. If he or she knows what is coming, it can be easier to deal with the changes.
- Acknowledge fear and difficult feelings by naming them.
- Allow humor to help your child to face fears and talk about them. Try the elephant metaphor, “This seems like it is a big deal – as big as an elephant, doesn’t it? How big does this cancer seem to you? We cannot talk about it all at once can we? So, let’s just talk about a part of it — like the ears.”

What to Do

- Make up a story about the cancer or use one of the resource books. Story-telling helps fit together confusing parts of what is happening.
- Read your child's favorite books to him or her. Your child will find comfort in the familiar stories. Go to the *Ideas and Resources* section for suggested books for children of this age group.
- Snuggle together. Find a new blanket in a color your child loves to use as a special comfort blanket.
- Let your child help you foster his or her growing independence. "You can be a big help to mommy/daddy/ etc. at this time. I know you like to help." Then suggest something specific for your child to do, and offer praise when he or she does it.
- Draw or paint pictures with your child about the cancer and his or her feelings toward it.
- Try using dolls, stuffed animals or puppets to help show where the cancer is and how it will be treated. Let your child act out how he or she might help the doll or animal get better.
- Look at pictures or draw them together showing what chemotherapy and radiation might look like.
- Allow other adults in your child's life (such as pre-school teachers, etc.) know what is going on at home.
- Give your child an opportunity to express feelings of anger constructively, such as drawing in bold colors, finger painting or punching pillows.

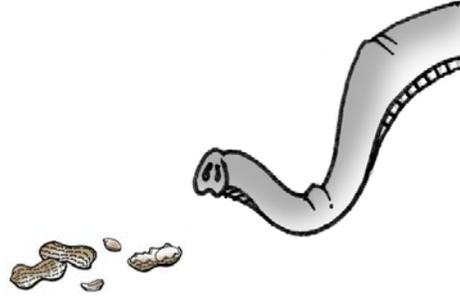


What to Watch for

Changes in behavior for children during stressful times are normal. They may return to less mature behaviors.

Some behaviors you may see include:

- thumb-sucking or wanting a pacifier
- wetting the bed or potty accidents
- not being able to sleep
- curling up in a corner
- clinging
- whining
- not being able to pay attention
- increased anger
- stress from being apart.



It is important to pay attention to any behavior that is out of character for your child, especially if the behavior appears more intense or often, or if you sense that something is wrong. This is the time to talk to a professional such as your doctor or pediatrician, a child development specialist or counselor.

Breaking the News

6 to 9 Years

*“Tell me I’m clever. Tell me I’m kind. Tell me I’m talented.
Tell me I’m cute. Tell me I’m sensitive, graceful and wise.
Tell me I’m perfect – but tell me the truth.”
~ Shel Silverstein*

Developmental Factors

Industry and Competence

These are the ages when children are interested in real things and may be less interested in fantasy. Following rules is important, and children will often make up complex rules for games.

Children’s attention spans increase. They stick more with a task and enjoy working at things. Doing things right is important. Working and playing together is more common. Children in this age group like to master things and feel good about themselves.

This is also a social stage when children can have low self-esteem, especially if they feel different about themselves or the changes in their family. The neighborhood and school are becoming important, and family is a little less the authority.



What to Say

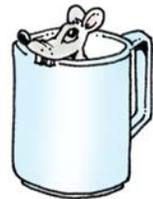
- Since children at this age are thinking more logically, you can explain cancer in a more straightforward way. Use some of the real words and help your child pronounce them.

For example, “I have colon cancer. The colon is the part of your body that carries waste from our food out of the body. Cancer is a disease of the cells of our bodies. The cells grow faster than normal and a tumor formed in my colon and had to be removed. Now we are trying to stop the cells from growing again by using medicines called chemotherapy.”

- Tell your child the schedules you will be keeping for treatment, and who will be caring for him or her during those times.
- Keep telling your child that he or she cannot catch cancer and they did nothing to cause it:
- Show-and-tell is an important way for children to share with classmates in school. A picture or story about the cancer might help your child deal realistically with the cancer and normalize your family. For the older end of this age group, writing a research project or book report about cancer might help.
- Tell your child what to expect, “I may be a little sick after the chemotherapy. My stomach may feel upset and I may not feel like eating. I may get tired more easily than before, but taking naps will help me to feel better.”
- If your child is feeling fearful or anxious about your illness when you are apart, you might say, “If you feel like you need to talk to someone at school when you get scared, let me know and I will ask someone to help you.”
- Children may become self-conscious if a parent is noticeably sick, has hair loss or if life at home is different. Talk these feelings through and be sensitive to them.
- Children at this age often understand that death is real. You may need to talk about death. Children often think of death as caused by something outside the body, not inside. Read more about this in the *Facing Uncertainties* section.

What to Do

- Talk with your child's school. Make sure they know what is going on at home. Ask if there is someone who will talk with your child and a place for him or her to get away if it is needed.
- Try to simplify after-school schedules. Talk with your child about which activity is his or her favorite and which one may be put on hold for a little while, if needed. It is better for your child to be present at one favorite activity regularly than to irregularly attend several.
- Address your child's curiosity about where you get your chemotherapy or radiation treatments. Explain what he or she will see, and arrange a visit with staff. Allow your child to ask questions while you are there and be sure to ask what the experience was like afterward.
- Draw pictures together or write a story or poem about the experience of cancer in your family.
- Recognize that anger is part of resistance to the changes. Encourage your child to express anger by pounding on some clay, having a pillow fight, painting with bright colors, etc. For some, anger is hard to express directly. These activities can be very healthy and satisfying for both or all of you. (One father shared throwing ice cubes with his son into the bathtub while it was empty.) Be creative!
- Talk with your child about his or her fears and sadness, since anger can often drown out these other emotions. Ask, "You were pretty angry when you were throwing those pillows, weren't you? Are you scared or sad, too?"
- Acknowledge and accept your child's disappointment if you are not able to attend his or her school or community activities.
- Look at pictures of the human body and point out where the cancer is. See the *Ideas and Resources* section.
- Take time to snuggle and look at pictures together. Don't worry if your child's need for attachment is stronger now or if your child is afraid to get close. Talking about the feelings often allows the real needs to surface.



- Take a trip to the library or the hospital's resource center to find some books about cancer.
- Encourage your child to lie still and imagine bubbles dissolving the cancer or some other images he or she is able to understand. Use imagery and relaxing music to help them calm down.
- Keep certain expectations clear, such as, "My job is to get better from my cancer. Your job is to go to school and keep working and playing as you have before." Your child may not want to go to school for fear something may happen to you. Reassure your child that you will be alright while he or she is in school.
- Limit time spent socializing with well-wishers during family time (after school to bedtime). Your child wants your valuable attention during family-only times.

What to Watch for

Changes in behavior for children during stressful times are normal. They may return to less mature behaviors.

Some behaviors you may see include:

- thumb-sucking
- wetting the bed
- not being able to sleep
- withdrawal/isolation
- misbehaving
- irrational fears (fears that don't seem to "make sense")
- obsessive-compulsive or ritualistic behaviors (repeated behaviors done to lower stress)
- physical complaints related to emotional issues
- tics (twitching, especially in the face)
- harmful behaviors
- eating too much or too little
- acting like the parent (needing to be Mom or the "man of the house").



It is important to pay attention to any behavior that is out of character for your child, especially if the behavior appears more intense or often, or if you sense that something is wrong. This is the time to talk to a professional such as your doctor or pediatrician, a child development specialist or counselor.



Breaking the News

10 to 13 Years

“Don’t laugh at a youth for his affectations; he is only trying on one face after another to find a face of his own.”
~ Logan Pearsall Smith

Developmental Factors

Curiosity about Sexuality, Reliance on Friends and Developing Independence

During these preteen years, children are vulnerable as they move toward independence. They still feel a need for parents and a need to know that their parents are in charge. It can also be a time of great stress for parents as they allow their children to grow up while still feeling the need to protect them.

Children of this age are going through confusing changes in their bodies and body image. They may begin to have mood swings. Preteens begin looking up to role models and may have crushes on others. They may be dishonest and try to trick people so they feel important or in control.

Since fitting in is important for preteens, it is hard for them to have a family that is “not normal,” which is likely how they view a cancer diagnosis. And since they are having a hard time separating but still wanting and needing parenting, they may feel lost.

“Mother Nature is providential. She gives us twelve years to develop a love for our children before turning them into teenagers.”
~ William Galvin

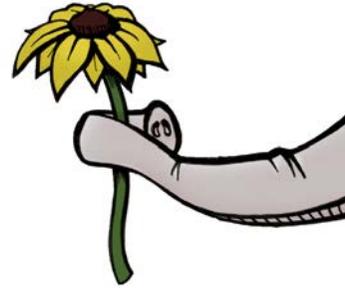


What to Say

- It is important to try to see the world through the eyes of your child. Ask what he or she thinks about the cancer. Listen carefully. Repeat what you hear to make sure you understand and your child feels like he or she is being heard.
- Explain your cancer as clearly as possible. Tell your child what cancer is and what it is not. Reassure your child that he or she cannot catch your cancer and he or she did nothing to cause it. Ask your child what he or she wants to know about cancer and your treatment.
- Give your child short articles about cancer to read. Books or pamphlets with too many words may overload his or her attention span.
- Encourage the use of chat rooms for children of parents with cancer. See the *Ideas and Resources* section.
- Acknowledge your child's need not to feel different, and how scary the cancer and the changes it may make will be.
- Tell your child you will be there for him or her as much as possible. Tell your child that when you are not able to be there, he or she will still be well cared for.
- Go to your child's events whenever possible. If you are not able to go, show interest by asking about your child about the events. Acknowledge and accept your child's sadness if you are not able to attend.
- Praise your child for specific things he or she does that you like or appreciate.
- Don't overreact when your child says he or she doesn't care about the cancer or says something unkind or hurtful. Accept that anger is a common response to stress and fear.
- Ask your child if he or she has a friend or someone who will listen to his or her feelings. Talk about "the elephant in the room." One good friend can usually be enough to help your child feel better.
- Ask for what you need from your child, and what your child needs from you.
- Encourage your child to spend time with another adult – the well parent, a close relative or family friend.

What to Do

- Try to keep home and school routines as normal as possible.
- It may be helpful to post a weekly schedule for your child to check that includes everyone's activities, tells who the daily go-to person will be at home and who will be providing carpooling or other supports.
- Make after-school schedules as simple as possible. Talk with your child about which activity is his or her favorite and which may be put on hold for awhile, if needed. It is better for your child to be present to one favorite activity regularly than to irregularly attend several.
- Hug your child when he or she needs it – and when your child does not.
- Enjoy some fun, quality together time. Play a game or watch a movie together.
- Talk openly about both of your fears.
- Look over old pictures and point out stories of your child's strengths and good times.
- Read about cancer together or give your child an assignment to find out something specific about your cancer.
- Invite your child to come to an appointment with you and talk about it afterward.
- Draw, paint or write together or separately about the cancer and how it affects your family. Compare notes and drawings.
- Try to understand some of the fantasy books or games that interest your child – or at least parts of them. Let your child teach you or explain what he or she likes about the book or game.
- Continue to be involved, or have your partner or a friend be involved in what is going on with your child. Talk to school counselors and teachers about his or her work. If it is OK with your child, share about what is going on at home.



- Encourage your child’s expression of frustration through sports, games, writing and drawing.
- It can be hard at times to have a face-to-face conversation with your child. Find communication tools they are familiar with, such as texts, emails or notes.
- Limit time spent socializing with well-wishers during family time (after school to bedtime). Your child wants your attention during family-only times.

What to Watch for

Changes in behavior for preteens during stressful times are normal. They may return to less mature behaviors. Children in this age group are having a hard time because they are not sure how to react to the changes in their life.

It can be hard to know what behaviors are normal or abnormal for your child. Some behaviors you may see include:

- increased anger or withdrawal
- poor schoolwork
- crying more than usual
- eating too much or too little
- mood swings
- spending less time with friends or not having many friends
- fears and insecurities
- being caught up with fantasy
- needing to always be by a parent, relative or close friend
- physical complaints related to emotional issues.



It is important to pay attention to any behavior that is out of character for your child, especially if the behavior appears more intense or often, or if you sense that something is wrong. This is the time to talk to a professional such as your doctor or pediatrician, a child development specialist, or counselor.

Breaking the News

14 to 17 Years

*“Adolescents are not monsters. They are just people trying to learn how to make it among the adults in the world, who are probably not so sure themselves”
~Virginia Satir*

Developmental Factors

Separation, Identity and Devotion to Friends and Causes

This is the age when an adolescent begins to act as an independent person and seeks his or her own identity as a person and sexual being.

Adolescents may have a hard time communicating with others in this stage. They also may find it hard to figure out where they stand with their own personal beliefs. Adolescents may withdraw from responsibilities and family members in order to be alone or as a way of “putting one’s foot down.”

Adolescents feel stress as they try to separate from their family and gain independence. Yet, they often feel all-powerful and all-knowing.

They are loyal to causes and their friends.

Adolescents continually experiment with new ideas and skills. Being successful at one or two of them builds their self-esteem and confidence. It is important to support them in their efforts, even in interests you may not be familiar with.

What to Say

- Explain the cancer clearly. Let your child read about it and go to health care appointments with you, if that feels comfortable.
- Use words that accurately describe what is going on with you. Talk openly and don't keep important information from your child. He or she is capable of understanding much more than you might think.
- Ask your child to tell you what scares him or her about the cancer, if able to. Fear of death is often a large part of your child's concern.

Adolescents are afraid of death, yet they feel nothing could possibly harm them. They may begin doing unhealthy behaviors when trying to deny or block this fear. Tell your child what you know today and what remains unknown. See the *Facing Uncertainties* section.



- Your child want things to be normal. Talk about the idea of a new normal for your family, but make sure to let him or her know that you want to keep things outside of the family as normal as possible.
- Discourage your child from using the “cancer card” inappropriately. Cancer can become an easy excuse for everything that is not going well.
- Adolescence is the age of independence and figuring out one's identity. Yet, cancer may challenge and confuse these normal instincts.

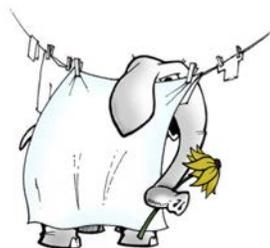
Your child may be afraid to hurt your feelings or leave you, and still he or she feels the natural draw to do so. You may get mixed messages. Ask your child if he or she might be feeling confused and offer permission to do things without you.

- Some adolescents may “disappear,” finding comfort in friends and other activities. Let your child know that you understand it is hard to live face-to-face with cancer.

- Ask your child if he or she is uncomfortable about anything having to do with your illness, such as your wig, energy or medical equipment. Then let your child talk.
- Adolescents need an outlet for their anger. Try not to take your child's uncaring words too personally. Ask your child what is causing his or her anger — usually it's fear and sadness. Remember, you can love someone and still be angry at him or her.

What to Do

- Provide consistent structure, limits and expectations for your child. Tell your child to continue to do his or her chores and homework as well as other responsibilities. Choose your battles carefully, and make sure they are worth it.
- Connect your child to recommended Internet sites. Help your him or her find online cancer chat rooms and encourage your child to talk with other teens facing the same issues. See the *Ideas and Resources* section. Let your child become educated about your cancer.
- Watch a movie or play a video game together, especially if you don't have as much energy as usual. Lighthearted "chill" time is a great way to spend quality time together.
- Encourage activities that your child might do at home with friends.
- Be aware of your child's role with younger siblings. Your child will need permission to have his or her activities without feeling he or she is being selfish. At the same time, finding ways he or she can provide emotional support to younger siblings is a powerful lesson about love and responsibility within a family. Be aware that adolescents who feel the need to move into parenting roles may also over-parent their siblings.



- It can be hard at times to have a face-to-face conversation with your child. Find communication tools he or she is familiar with, such as texts, emails or notes.
- Try to keep a lively sense of humor, if you are able.
- Encourage favorite relatives and adult friends to drop by and/or call your child. Don't be jealous of their relationship. Encourage them.
- Provide a place for your child to play or listen to music. Music is a great way to relieve stress and express one's emotions.
- Encourage and take interest in the creative ways in which your child expresses his or her feelings through poetry, journaling or artwork. Be interested, but respect your child's need for privacy.
- Take your child with you to appointments and ask him or her to write down what the health care provider says and ask questions as a way of helping you.
- Recognize that adolescents still love things to cuddle, like soft fleece blankets and stuffed animals.
- Plan for future events with your child, such as a vacation, a birthday, family get-together or driver's test.
- Give your child something that symbolizes his or her courage or hope. Perhaps it is a special rock, feather, picture or other family keepsake. Its meaning can be known by only the two of you.
- Hang posters or pictures of encouragement, humor and inspiration.
- Look at old pictures together and remind your child of his or her strengths and good times. Share stories about his or her childhood.
- Identify cancer support groups and encourage your child to attend. See the *Ideas and Resources* section.



What to Watch for

Changes in behavior for adolescents during stressful times are normal. They may return to less mature behaviors. This age group usually shows a wild mix of emotions and challenges.

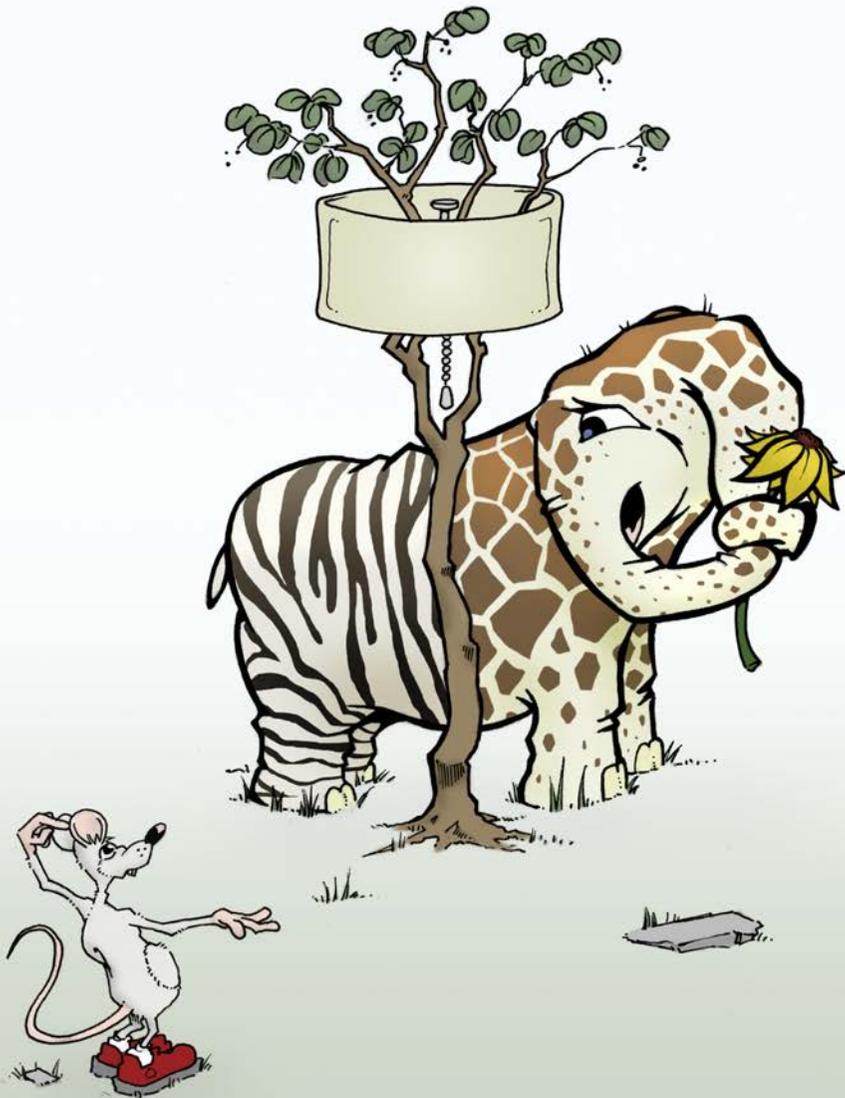
Stay tuned in to your child's behavior and feelings. It may seem that nothing is normal. Some behaviors you may see include:

- increased anger or aggression
- withdrawal or isolation
- depression (feeling “down in the dumps”)
- eating too much or too little
- losing interest and energy for life
- getting poor grades and having behavioral problems in school
- spending less time with friends or not having many friends
- showing addictive, unhealthy or dangerous behaviors
- sleeping too much or too little.

It is important to pay attention to any behavior that is out of character for your child, especially if the behavior appears more intense or often, or if you sense that something is wrong. This is the time to talk to a professional such as your doctor or pediatrician, a child development specialist or counselor.



Facing Uncertainties



Facing Uncertainties

*"I wanted a perfect ending. Now I've learned the hard way, that some poems don't rhyme, some stories don't have a clear beginning, middle and end. Life is about not knowing, having to change, taking the moment and making the best of it, without knowing what's going to happen next."
~ Gilda Radner*

The most challenging times in your life may be when you feel overwhelmed by uncertainty, mystery or doubt. Cancer turns your life into a state of unknowns. Your doctors, the books you read, experts on the Internet and well-meaning friends try to tell you what you will face and how you should face it. Yet, the only thing you are certain of is your uncertainty.



Becoming comfortable with mystery and learning to live in the moment are lessons that are learned and forgotten and learned again. Trying to hold onto hope with one hand while you wrestle fear with the other is never easy. It is normal to want to protect your child from cancer's challenges but it is not possible. Your children can sense your fear and insecurities. Instead of trying to hide it from your child, face the uncertainties together.

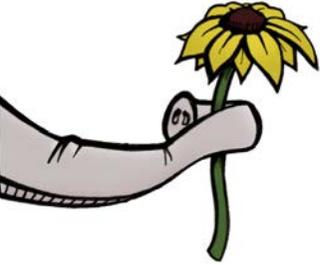
*"Uncertainty will always be part of the taking charge process."
~ Harold S. Geneen*

Remember that your uncertainties may be different than your child's. How you cope with uncertainty will affect how your child will deal with it. You don't need to turn all unknowns into knowns. Allow the uncertainty to settle around all of you and try to become comfortable with not knowing.

Sometimes a leap of faith will help you and your child get beyond the uncertainty. Sometimes focusing on something else positive and out into the future will help. And sometimes screaming and yelling will relieve frustration.

If you can identify and talk about your uncertainties and doubts, so can your child. Together, you can learn to live with uncertainty. Hope does not always mean cure. You can hope for many things in the middle of uncertainty. You and your child can learn to live in hope. Holding hope in one hand and uncertainty in the other is possible. Focusing on hope can get you and your child through the challenges of cancer.

*“Once you choose hope, anything’s possible.”
~ Christopher Reeve*



Facing Uncertainties

Three Inevitable Questions

There are many uncertainties with cancer, but three questions seem to be the unspoken “elephants in the room.”

- Will life ever be normal again?
- Will the cancer be cured?
- Will you die?

This section offers answers to these three questions you are almost certain to hear from your child, followed by five simple steps to successfully face the uncertainties of your illness together. There are also pages that provide specific age-appropriate ideas for what to say, do and watch with your child. A list of resources for each age group is in the *Ideas and Resources* section.



Will Life Ever be Normal Again?

The most common expression heard from cancer patients and their families is, “I just want things to go back to normal again.”

But life does not go back to normal.

Instead, you learn to live a new normal.

And each child needs to learn how to adapt to the new normal.

You, as the parent, lead the way into this time. Your acceptance of the changes will make it easier for your child.

“The only normal people are the ones you don’t know very well.”

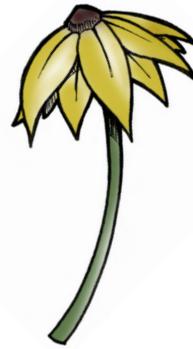
~ Alfred Adler

Some parts of life will still be the same and it is important to emphasize those for your child. Find a name for the new normal in your home and family, such as LAC (Life after Cancer) or LWTE (Living with the Elephant). Name the things that will stay the same. Explain the plan for the parts that will have to change. Encourage your child’s help with this task.

Will Your Cancer be Cured?

This question begins at diagnosis and returns often. Your child will ask if you are better now and if the cancer is gone. When you don't have an answer for this, or if the answer is no, tell the truth. Don't sugarcoat it as children can see through it. Allow time to let the truth sink in and for the feelings to be shared among your family members.

If you believe you will be cured even though your doctor may express concern, tell your child what you believe to be true. Even if you don't believe you will recover, let your child know that you both should continue to hope for the best and try to be ready for the changes that might come.



Your child needs to understand the difference between your hopes for the future and the reality of your disease or what is likely to happen. You can hope to live forever or beat the cancer, but be sure you are being honest with yourself and your child. Whether your cancer will or will not be cured, there is always hope.

Your child needs to know if and when your hope for a cure changes. You may still keep a firm grip on hope, but you may have taken some of your "hope eggs" out of the "cure basket." Put your hope on achievements that can be more easily reached. For example, being at your child's first soccer game in the spring, attending a family member's wedding, going fishing again or simply having a good laugh.

*"Locking onto one kind of hope shuts the door on other possibilities."
~ Ted Bowman*

The next related question your child will ask is, “What will happen next and what will change?” As with your description of the new normal, let your child know what you know. Put it in his or her language. Predict only what you can and leave the rest alone.

Some cancers come back and some stay with us. Many types of cancer are being seen as chronic (long-lasting) illnesses. Your child needs to know how you both might recognize if the cancer comes back. For example, are there tests that can be done, or what symptoms might show that it has returned?

Share any ideas you may have with your child about what you might do if it does come back, such as treatments you may have or surgery that may be needed. Again, let your child know what the possible outcomes may be. Children of all ages, just like adults, do better when the possible outcomes have been talked about.

Children also need to know that the more serious effects of cancer will not always be visible. “Cancer may still be in mommy, but we will live with it. It will be a part of our lives.”

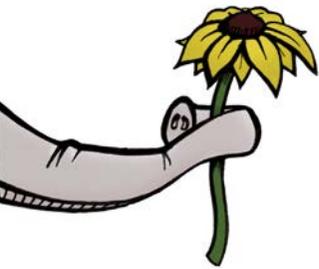
It is true, and can be said, that cancer research is going on all the time and new treatments are being developed, possibly while you are dealing with your cancer. And sometimes, cancer really does seem to miraculously go away. You can tell your child that you will hope for a new treatment or that your cancer goes away, but you will also deal with what is real today.

*“I am not afraid of dying. I just don't want
to be there when it happens.”
~ Woody Allen*

Will You Die?

Death is a universal uncertainty and very real fear for most people. People gradually come to terms with death throughout the course of their lives. Their answers and feelings vary at different stages of life. Cancer puts this subject right there in the room like an even bigger elephant.

Parents sometimes struggle the most with the concept of death when they think about leaving their child too early. Conversations about death are often minimized or even ignored. When a loved one is near death, fear of talking about dying can make the loss even harder for the rest of the family.



Death needs to be talked about just like all the other tough issues. Your family can work through the fear they are experiencing as you talk about death together. There is such a thing as a good death.

Children learn about death at early ages. They see dead birds, insects and animals

lying by the road. Often they have lost a pet and, most certainly, many see death on television. They hear about it in fairy tales and in nursery rhymes. Some experience it in their own families or neighborhoods. Children's understanding of death depends on their experiences, their maturity, their parents' acceptance and communication and the beliefs the family holds.

Ask your child what he or she knows about dying and death. Be with your child when he or she is scared, angry or doesn't show interest or concern. There is no right way to understand death, nor is there only one way of coping with it.

There may be times of hospitalization and changes in the home environment with increased medical needs that create a clear sense that things are getting more serious.

Children need to be included, but not forced to be a part of this. Watch for opportunities to talk with your child about fears that may arise from these changes and what might happen next. Prepare him or her for the changes with conversations, examples or even pictures.

See the *Ideas and Resources* section for materials and resources to help children whose loved one is dying.

*“You cannot change the direction of the wind,
but you can adjust your sails.”
~ Anonymous*

Five Basic Steps to Facing Uncertainties Together

1. Accept the uncertainties. Take your child with you on your journey through cancer treatment. Tell him or her what you know and what you don't know. By sharing your uncertainties, your child can tell you his or her own. It is OK to be uncertain.
2. Begin by naming the uncertainty you share.
For example, "We don't know if the cancer will come back."
3. Reassure your child that even if the two of you don't know an answer, you will be OK. Children have a harder time accepting the unknown, but more importantly they need to be reassured that even if the answers are not clear, they will be OK and that someone will be with them every step of the way.

For example, you may say, "That is something I don't know the answer to now, but I do know that we will look for the answer together. Even if we don't find the answer, we will be alright. There are lots of things we don't know; like if it will snow tomorrow. Even when the weatherman says it will snow, sometimes it does not."

4. Talk about your family's beliefs and practices. For some families there is comfort in spiritual beliefs or religious practices. There are many books that deal with uncertainty for children, some that are religious and some that are not. Look through them to see what might fit for your family and child.
5. Keep the communication lines open. Conversations about cancer take time and often need to be talked about many times as doubts and uncertainties come and go.

*"Hope is the thing with feathers
That perches in the soul,
And sings the tune – without the words,
And never stops at all..."*
~ Emily Dickinson

Keep in Mind

Talking about the hard stuff will not make it happen anymore than not talking about it will keep it from happening.



If it is mentionable, it is manageable – like the “elephant in the room.”

Your uncertainties and those of your children may be different.

Know there are times when words just do not work — but being together does.

Facing and talking about fear is better than living in fear.

Children face tough stuff slowly and need time to adjust.

Children will be more resilient when someone believes they can be.

Some things will never be understood.

Find what gives you and your children energy; avoid what drains energy.

Children don’t always appear to be listening, but often they are.

There is laughter amid sorrow and sorrow amid joy.

Be in the moment with your children, whenever you can be.

Be careful about putting all your “hope eggs” in the “cure basket” – there are many things to hope for.

Most children are good at hope... and wishing and dreaming.

Facing Uncertainties

Infants to 2 Years

Developmental Factors

Trust, Mistrust and the Beginning of Independence

In these early years, your child is developing a sense of trust. It is important that you be honest, strong and try to be confident – even when you are not feeling your best.

In the first two years of life, infants and toddlers change and grow quickly. There is something new every moment. Enjoying your child's development can be the best medicine for keeping your mind off your worries and symptoms. The warm, safe environment you provide your child will benefit you as well.

“Children know from a remarkably early age that things are being kept from them; that grown-ups participate in a world of mysteries.”
~ Anthony Hecht



What to Say

- For infants and toddlers, it is important to communicate security by being as present as possible for them. Keep a positive tone in the home and maintain your child's routines, such as meals, naptime, playtime and bedtime.
- Try to keep your focus on what is the same and positive, not what is different.
- Talk about the changes positively but be ready for your child's reactions. Let the feelings be cried about and talked about. Remain loving, supportive and firm.
- Offer stories about things that change, such as a caterpillar changing into a beautiful butterfly. Most importantly, try to be with your child each time a major change happens. Providing comfort and structure will help relieve the uncertainty of change.

- Use simple, easy-to-understand language when talking with your child.
- Death is not something that toddlers grasp very well. They may have some tears if it is talked about, but they will not fully understand its meaning. Tell your child that he or she will always be cared for and loved. This may be harder for you than for your child.

What to Do

- Add small positive things to make any changes easier for your child. Toddlers and infants will adjust to new routines when they are added alongside things that are still being done in the old normal.
- Comfort, comfort, comfort. Use every possible comforting idea — food, toys, music, baths — all the things your child finds calming.
- Allow sadness and uncertainty to be expressed in tears or as tantrums. Allow your child's emotions to come out; then keep the comfort coming.
- Make or buy something that is soothing — a special blanket, doll, stuffed animal or book.
- Record your voice reading stories that your child can listen to at bedtime or when you cannot be there to read.
- Put together a little box of treasures that can be carried with your child. Collect items that are special to your child and include something personal of yours.
- Think of who you want to be important in your child's life if there are big changes coming or if you may die. Try to have that person with your child as often as possible to help them bond.
- Cry together – and be tough together. Sometimes parents need to cry with their children, be held, soothed and touched by their children.



What to Watch for

Changes in behavior for infants and toddlers during stressful times are normal. They may return to less mature behaviors. Some behaviors you may see include:

- not sleeping well
- wanting to nurse or drink from a bottle more than normal
- becoming more irritable
- crawling instead of walking
- eating too little
- lack of interest in playing
- lack of emotions or eye contact.

It is important to pay attention to any behavior that is out of character for your child, especially if the behavior appears more intense or often, or if you sense that something is wrong. This is the time to talk to a professional such as your doctor or pediatrician, a child development specialist or counselor.



Facing Uncertainties

3 to 5 Years

Developmental Factors

Independence, Sense of Self and Initiative

This is the age at which children are first learning about independence. Three- to five-year-olds see the world revolving around themselves. Separation is desired and feared at the same time. This is sometimes called, “first adolescence.” Because a parent’s illness may force a child to be more independent, he or she may resist because it is not his or her choice. It is important to set firm, loving limits.

What to Say

- Your child needs to know that he or she didn’t do anything to cause your cancer, or to make it return or get worse (this is geared towards the possibility of the cancer returning). Your child also needs to know that there is nothing he or she could have done to prevent it.
- Uncertainty is a breeding ground for fantasy and unrealistic thinking. As long as you help your child knows the difference, sometimes letting him or her make up stories or having you make them up helps him or her to cope and to hope.
- Tell your child what will be different and what will stay the same.
- Ask your child questions about how he or she feels and what he or she thinks is happening. Ask open-ended questions so he or she is encouraged to offer a full answer. For example, “How did you feel when Mom went back to the hospital?”
- Keep your language simple, clear and direct, without using euphemisms. For example, calling your cancer a “boo boo” or an “owie” can cause confusion and worry the next time your child scrapes his or her knee.



- Above all, tell the truth. Even if the truth is not fully understood today, in time this will help your child to be more trusting.
- If death is a real possibility, talk about it. Listen to and understand your child's thoughts of what death is. Encourage him or her to talk about what he or she is feeling. Let him or her know it is normal and good to get the sadness out. Tell your child how he or she will be cared for when you die. The *Ideas and Resources* section offers a variety of sources to help you talk with your child about death.

What to Do

- Draw pictures of what is known and unknown, what is feared and what is comforting to your child.
- Help your child make special "get well" cards and gifts for the parents that has cancer.
- Cook together, if you are able. Sometimes pounding cookie or bread dough, or stirring something can be a good release of frustration, as well as fun.
- Sing together, cry together and be angry together.
- Prepare your child for a visit to the hospital with pictures of mom or dad or pictures from a book. Describe what might be seen and how the child might feel. Don't force, but encourage him or her to visit.
- Make the time to create things with and for your child, especially if death is near. Draw pictures of what you both like. Write letters to him or her. Record yourself talking with him or her and reading stories. Make special notes using a page of stickers to show him or her the things you liked and those you did not like.
- Remember that all losses – big and small – are sad. Ask your child what he or she misses since the cancer has been with the family. Encourage your child to talk about the losses.



What to Watch for

Changes in behavior for children during stressful times are normal. They may return to less mature behaviors.

Some behaviors you may see include:

- thumb-sucking or wanting a pacifier
- wetting the bed or potty accidents
- not being able to sleep
- curling up in a corner
- clinging
- whining
- not being able to pay attention
- increased anger.

It is important to pay attention to any behavior that is out of character for your child, especially if the behavior appears more intense or often, or if you sense that something is wrong. This is the time to talk to a professional such as your doctor or pediatrician, a child development specialist or counselor.



Facing Uncertainties

6 to 9 Years

Developmental Factors

Industry and Competence

These are the ages when children are interested in real things and are less interested in fantasy. Following rules is important, and children will often make up complex rules for games.

Children's attention spans increase. They stick more with a task and enjoy working at things. Doing things right is important. Working and playing together is more common. Children in this age group like to master things and feel good about themselves.

This is also a social stage when children can have low self-esteem, especially if they feel different about themselves or the changes in their family. The neighborhood and school are becoming important, and family is a little less the authority.



What to Say

- At this age, more detailed explanations are more important and the desire for logic is stronger. This makes uncertainty even harder. Tell your child what you know and what you don't know. Remind your child that you will tell him or her any new information as soon as you learn it.
- Be understanding of how frustrating it is to not know.
- Prepare your child for the physical and emotional changes that your cancer may bring. Talk about what might happen with your illness, and what the signs and symptoms of change might be.
- Take advantage of teachable moments. A scene in a TV show or an ambulance racing past your car may be the perfect moment to talk. For a child who cannot pay attention for a long period of time, these short talks are often better than long, planned conversations.

- Encourage your child to express his or her feelings of frustration and sadness.
- Tell your child that he or she will be well cared for by those who love him or her.
- If death is a real possibility, talk about it. Ask your child what he or she thinks death is about. Share your own thoughts too. Encourage your child to talk and share his or her feelings. Your child will likely not only worry about your death, but he or she will worry about his or her own death, as well. Take the time to talk about that, too. Tell your child who will care for him or her and how he or she will be cared for. The *Ideas and Resources* section offers a variety of sources to help you talk with your child about death.

What to Do

- Give your child the freedom to be away from you and to be on his or her own. Tell your child it is OK to have fun!
- Encourage your child to play with other children. Let the parents of your child's playmates know about your illness and what to expect, so that visiting children are not surprised or scared.
- Create some special routines you share only with your child, such as after-school snack time, a made-up bedtime story, or a special handshake.
- Make some memories with your child by crafting boxes of photos, mementos, poems or drawings of things you have done together.
- Make a recording of yourself reading a book or singing a favorite song with your child.
- Find a special charm that your child can carry with him or her for comfort, such as a stone, a good luck piece, a ring or even a family keepsake.
- Talk about ways your child can help you.
- Encourage your child to talk about his or her feelings with a trusted teacher, counselor or social worker at school.



- Find out if there are other children your child's age whose parents have cancer. Connect with them personally, by email or in a chat room.
- Be available, even by phone, if your child needs to talk to you about his or her fears, whenever he or she needs to talk.

What to Watch for

Changes in behavior for children during stressful times are normal. They may return to less mature behaviors. Some behaviors you may see include:

- thumb-sucking
- wetting the bed
- not being able to sleep
- withdrawal/isolation
- misbehaving
- irrational fears (fears that don't seem to "make sense")
- obsessive-compulsive or ritualistic behaviors (repeated behaviors done to lower stress)
- physical complaints related to emotional issues
- tics (twitching, especially in the face)
- harmful behaviors
- eating too much or too little
- acting like the parent (needing to be Mom or the "man of the house").



It is important to pay attention to any behavior that is out of character for your child, especially if the behavior appears more intense or often, or if you sense that something is wrong. This is the time to talk to a professional such as your doctor or pediatrician, a child development specialist, or counselor.

Facing Uncertainties

10 to 13 Years

Developmental Factors

Curiosity about Sexuality, Reliance on Friends and Developing Independence.

During these preteen years, children are vulnerable as they move toward independence. They still feel a need for parents and a need to know that their parents are in charge. It can also be a time of great stress for parents as they allow their children to grow up while still feeling the need to protect them.



Children of this age are going through confusing changes in their bodies and body image. They may begin to have mood swings. Preteens begin looking up to role models and may have crushes on others. They may be dishonest and try to trick people so they feel important or in control.

Since fitting in is important for preteens, it is hard for them to have a family that is “not normal,” which is likely how they view a cancer diagnosis. And since they are having a hard time separating but still wanting and needing parenting, they may feel lost.

What to Say

- Explain what is going on as truthfully and completely as possible. Let the questions come naturally.
- Ask open-ended questions about feelings that need more complete and thoughtful answers. For example, “When you see me cry, how do you feel?”
- Talk about the possible return of your cancer even though your child may not stay focused for very long. Prepare him or her for what you know might happen.
- Talk with your child about his or her friends, and whether he or she feels comfortable talking about your cancer and the changes it is causing in your home.

- Address your child's need for life to be normal again. Identify what is still normal and explain that things can be both normal and different.
- Allow your child to express his or her anger about the changes that are happening in the family and home. Allow him or her to be sad over what he or she feels may have been lost.
- Identify at least one other adult family member, school teacher, neighbor or friend your child can talk with about his or her feelings. Explain that this person will spend time with him or her away from the uncertainties of home. You may ask one or several people to support your child in these ways.
- If death is a real possibility, talk about it as early as possible. Ask what his or her understanding and feelings are about death and dying. Let your child tell you what he or she is struggling with most about your possible death. Share your fears and sadness with each other, and hold each other through that time. Make sure your child understands your plans for who will care for the family. The *Ideas and Resources* section offers a variety of sources to help you talk with your child about death.

What to Do

- Let your child's school know about the progress of your cancer and changes that he or she is facing at home. Make sure, too, that your child knows you are talking with the school. Encourage him or her to ask for help when needed.
- Persuade your child to spend time with friends. Have your child invite friends into your house. Ask him or her to tell his or her friends of your cancer and how it is affecting your family.
- Encourage your child to share his or her feelings and experiences in reliable Internet chat rooms or at teen support groups with other young people who are facing similar situations in their families. See the *Ideas and Resources* section.



- Acknowledge and accept your child's disappointment when you are unable to attend his or her activities or events.
- Start a daily check-in time. Set aside five to 10 minutes every day to hear about the details of his or her day. Ask about schoolwork and afterschool activities. Invite sharing about successes and frustrations, as well as questions about how things are going now or what to expect in the future. Most importantly, listen.
- Allow your child to help you. Be careful not to let him or her overdo it. He or she may begin to feel obligated and build resentments. Balance is important.
- Communicate with your child. Use texts, emails or any other tool your child prefers. Sometimes writing about the uncertainties is easier than talking with him or her, and still provides a positive way of communicating. Journaling is also a good idea for you and your child.
- Encourage your child to use art, music and sports to express his or her feelings, frustrations or confusion.
- Ask your child to teach you something you don't know how to do.
- Dig out old photo albums, so you can relive happy times and funny experiences together.
- Make some special memories together. Take a short road trip, go to a concert or find some quiet moments when you can talk about the future. You can even dream wildly together by planning an imaginary trip to some far off, exotic location.



What to Watch for

Changes in behavior for preteens during stressful times are normal. They may return to less mature behaviors. Children in this age group are having a hard time because they are not sure of how to react to the changes in their life.

It can be hard to know what behaviors are normal or abnormal for your child. Some behaviors you may see include:

- increased anger or withdrawal
- poor schoolwork
- crying more than usual
- eating too much or too little
- mood swings
- spending less time with friends or not having many friends
- fears and insecurities
- being caught up with fantasy
- needing to always be by a parent, relative or close friend
- physical complaints related to emotional issues.

It is important to pay attention to any behavior that is out of character for your child, especially if the behavior appears more intense or often, or if you sense that something is wrong. This is the time to talk to a professional such as your doctor or pediatrician, a child development specialist or counselor.

Facing Uncertainties

14 to 17 Years

Developmental Factors

Separation, Identity and Devotion to Friends and Causes

This is the age when an adolescent begins to act as an independent person and seeks his or her own identity as a person and sexual being.

Adolescents may have a hard time communicating with others in this stage. They also may find it hard to figure out where they stand with their own personal beliefs. Adolescents may withdraw from responsibilities and family members in order to be alone or as a way of “putting one’s foot down.”

Adolescents feel stress as they try to separate from their family and gain independence. Yet, they often feel all-powerful and all-knowing.

They are loyal to causes and to their friends.

Adolescents continually experiment with new ideas and skills. Being successful at one or two of them builds their self-esteem and confidence. It is important to support them in their efforts, even in interests with which you are not familiar.

What to Say

- Even if your child does not seem to be listening, what you say is important.
- Talk from your heart and let your child know you understand that the cancer and the changes it creates are hard to accept.
- Explain in detail what is happening now and what could happen in the future. Reinforce that you will continue to be truthful.



- Allow your child to express his or her feelings. Remember that if your child is showing anger, it is usually an outward expression of sadness and fear.
- Ask your child open-ended questions about what he or she is thinking and feeling. For example, “What do you think about my cancer coming back?”
- If talking becomes hard, use other forms of communication to express yourselves, such as texts, notes, letters and emails.
- Find at least one other adult family member, school teacher, neighbor or friend your child can talk with and who will spend time with him or her away from the uncertainties of home. You may ask one or several people to support your child in these ways.
- If death is a real possibility, talk about it as early as possible with your child. Ask your child what he or she understands and feels about death and dying. Let your child tell you what he or she is struggling with most about your death. Share your fears and sadness with each other and hold each other through that time. Explore ways in which you may create some meaningful times together. Share regrets and forgiveness, if needed. Tell your child your plans for who will care for him or her and the rest of the family. The *Ideas and Resources* section offers a variety of sources to help you talk with your child about death.

What to Do

- Search for ways to make the times you have with your child count.
- Do what gives you energy, not what drains your energy.
- Continue to set limits for your child, but once in a while make an exception.
- Dig out old photo albums. You can relive memories of good times, including stories of his or her childhood and yours.
- Allow your child to help you and your family. Be clear about setting limits to avoid resentments. Thank your child for his or her efforts.
- Make time to enjoy relaxing, everyday activities together. This could include playing games, watching TV and movies, listening to music, or making things together.
- Drop little personal notes where he or she can find them to let him or her know you are interested in him or her activities.



What to Watch for

Changes in behavior for adolescents during stressful times are normal. They may return to less mature behaviors. This age group usually shows a wild mix of emotions and challenges.

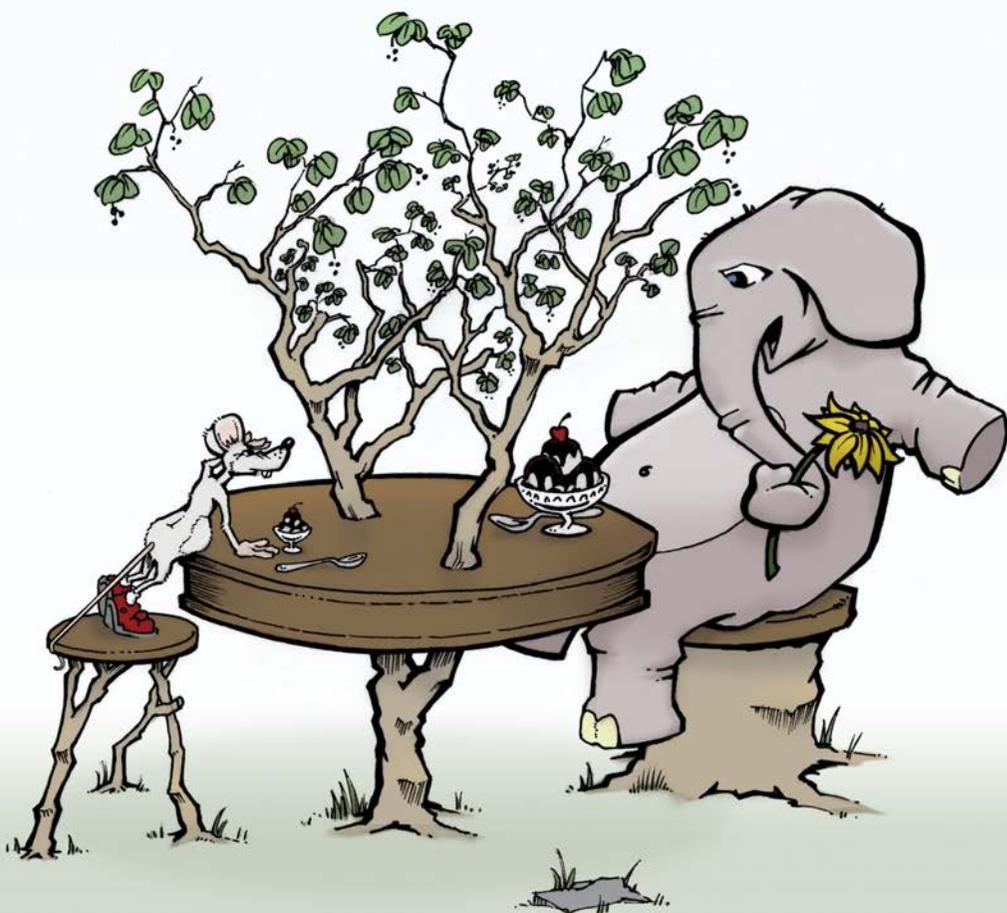
Stay tuned in to your child's behavior and feelings. It may seem that nothing is normal. Some behaviors you may see include:

- increased anger or aggression
- withdrawal or isolation
- depression (feeling “down in the dumps”)
- eating too much or too little
- losing interest and energy for life
- getting poor grades and having behavioral problems in school
- spending less time with friends or not having many friends
- showing addictive, unhealthy or dangerous behaviors
- sleeping too much or too little.

It is important to pay attention to any behavior that is out of character for your child, especially if the behavior appears more intense or often, or if you sense that something is wrong. This is the time to talk to a professional such as your doctor or pediatrician, a child development specialist or counselor.



Special Circumstances



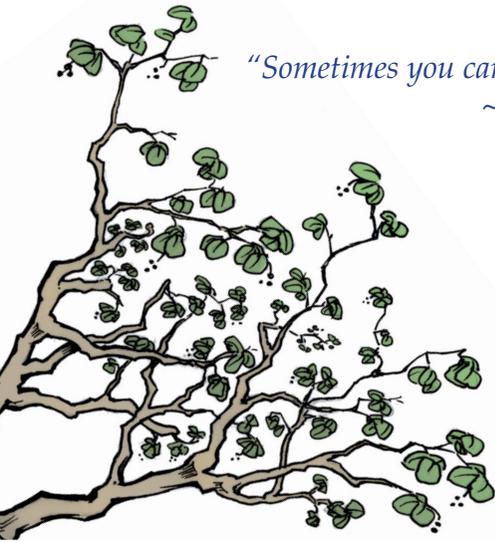
Special Circumstances

The challenges a family was dealing with before the diagnosis of cancer usually don't go away. This can make it even harder to cope with a cancer diagnosis. Unfortunately, the original challenges may even get worse during this new crisis. For some families dealing with difficult situations, the added crisis draws family members closer together. This section will address some of the more challenging special situations, including:

- children and family members with special needs
- single-parenting through cancer
- death and non-death losses.

These circumstances have to be worked through. It may feel like there are too many obstacles in your path.

This section may give you some ideas for how to overcome the obstacles and succeed in facing their challenges.



*"Sometimes you cannot see the forest for the trees."
~ Anonymous*

Keep in Mind

Life is not fair.

*You cannot always change circumstances,
but you can change your response to them.*

*Putting yourself first is not selfish, but a means to caring for others.
In other words, “put your own oxygen mask on first.”*

Asking for help is not a sign of weakness.

*People who depend on you can be helped to transfer their dependence
to others, and sometimes learn to do some things for themselves.*

You have power and choices even in difficult circumstances.

*The best way out is always through –
face the “elephant in the room” directly.*

*Naming problems can be the first step to making them more
manageable, especially the difficult ones.*

*Try to focus less on the stress and more on finding meaning
and purpose in your life.*

*Some people drain energy and can be toxic to the healing process.
Spend time with the people who give you energy.*

When you are in a hole, stop digging.

Sometimes lowering your standards can be healthy.



Special Circumstances

Children and Family Members with Specialized Needs

You may be coping with a child or another adult in your home or family circle with special needs or circumstances. These situations can make focusing on your cancer and communicating your needs harder.

If you live with a child or adult with a mental or physical illness, you have already learned about loss and grief, and the courage it takes to cope. You already know that life is not fair. Yet, you have found ways to work around the obstacles and adapt your life to change. You have grown in the knowledge of what is truly important in your life and what is not. You have probably learned that there are silver linings in dark clouds. But no matter what you think you already know, a crisis like cancer can threaten the balance in your family.

You may be worrying about a close family member or maybe an aging or ill parent. This also adds to your stress level. You cannot always be there and you worry that you may not be there in the future. It makes putting your needs first almost impossible.

The ways you coped in the past will help decide how you will cope now, what your child can expect and what you can expect from him or her. Hard situations you coped with in the past will help to strengthen you for the new stressors in your life.

If you have coped poorly with challenges in the past, now is the time to seek the help you need to face these new challenges successfully. If you can look back and see some of the strength you called upon before, it will be there again.



If you are like most caregivers, your first thought is about the impact your cancer will have on the person whose needs you to look after. It can send a wave of panic through you. How will my loved one get the care he or she needs if I am sick? How can I deal with my own cancer and the treatment and still care for my family?

And your loved ones are worrying about you, even if they don't show it.

Suggestions

- Put your own oxygen mask on first. You need to have enough strength to help someone else.
- Allow yourself time alone (or with a good friend) to think your situation through and notice how you are feeling.
- Recall the skills you learned through caring for others. The courage and power that helped you through the tough times before will help you through it again.
- If your goal has been to empower the loved one who is mentally and/or physically impaired to live independently, your illness may cause you to focus more on reaching that goal.
- Identify other caregivers who can give you a break.
- Try to involve the person who has limitations in your conversations and activities. He or she most likely senses what is going on and wants to be a part of it even if the words are not fully understood.
- Don't lose sight of those in your family who are healthy. While it may be harder to recognize, they need your attention too.
- Keep everyone in the family informed, so they know how to help you. Use the CaringBridge website (caringbridge.org) or other Internet sites to keep family members and friends updated. See the *Ideas and Resources* section for more websites.



- If you attend support groups related to your special circumstances, continue going to the meetings and make use of the groups' resources. If you don't currently attend a support group, look into joining one. Then make use of a sponsor, mentor or buddy you can call.
- Make a list of the friends who give you energy, as well as those who drain your energy. Try to avoid or limit time with those who drain your energy during this time.
- Recognize the things that bring you peace, calm you and reduce your stress level. Include more of them more often into your life. Take hold of those things that give you energy, such as music, nature, art, books, movies, fishing or gardening.
- Learn to recognize when you are becoming more stressed and ask for help.
- Seek community-based or personal options for respite care for your child or loved one, and make use of them.
- Write down your frustrations and fears, as well as the joys of life for which you are grateful.
- Scream in places where no one hears you – in the car, in the woods or in places where it is already too noisy, such as at athletic events.
- Find legal counsel if you need to think ahead about where and how your loved one will be cared for.
- Increase the activities that you and your loved one like to do together, the things that bring both of you joy.
- Accept what you cannot change.

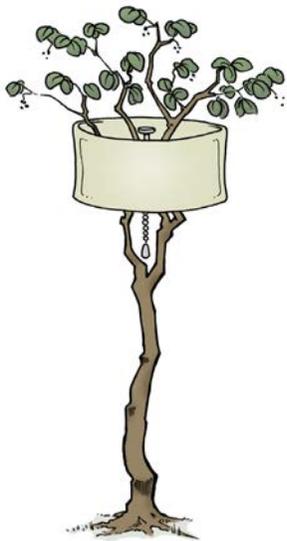


Special Circumstances

Single-Parenting through Cancer

*"If I don't put effort toward creating what I want,
I have to put effort toward coping with what I get."
~ Unknown*

How and when you became a single parent may impact the ways in which you and your children cope with your cancer. If a child is used to the parenting arrangement he or she has, it will make it a little easier to adjust to the new reality of your cancer. A recent divorce or death will likely make it harder for your child to face the challenges of your cancer.



Because you and your partner are no longer together, your child may worry even more about losing you to cancer. Your child's concern is very real and he or she will need your reassurance.

The ways you coped in the past will set the course for how you cope now and what your child can expect. This will still be a crisis for all of you, but past coping experiences help strengthen you for new stressors.

If you have coped poorly with challenges in the past, now is the time to seek the help you need to face these new challenges successfully. If you can look back and see some of the strength you called upon before, it most likely will be there again.

Though you may have talked with your child about your cancer from the very start, it is important to take as much time as needed to continue answering his or her questions. Before you begin these conversations, sort out your feelings with someone you trust. You may want to have that person present when you talk with your child. You don't need to say everything at once.

Don't be afraid or embarrassed to let your child see your emotions. Let your feelings show; even name them. For example, "Mom/Dad is sad right now, but that is a feeling we all have. And it will come and go." Try to regain some control over your emotions, so that your child knows it is good to let the sadness out, but that it does come and go. Reassure your child that he or she will be well cared for.

While most people who are single were single before their cancer diagnosis, sometimes the diagnosis contributed to their partner leaving. Your child senses this and may be confused about their relationship with the absent parent. It is important to not blame your partner in front of your child. He or she likely knows already, but the absent parent is still his or her father or mother figure. Your child's relationship with that person will always be important and maybe even more important now.

Suggestions

In addition to the age-specific suggestions in the earlier pages of this book, here are some general suggestions for single-parenting:

- You may want to have a close friend or family member with you when you break the news of your cancer diagnosis to your child.
- Be ready to answer clearly and thoroughly the important question about who will take care of your child if or when you are too sick.
- Let your child know that you understand if he or she is afraid to lose you.
- If your partner died, your child will naturally worry more about you dying. Your child will need you to tell him or her all that you know and what it will mean for him or her. Remember you are not dying; you are living until you die.



- If you have a shared custody arrangement or have a relationship with someone who provides your child care, talk to that person about your needs and your child's needs for more support during this time.
- If you know the cancer will involve difficult treatment, it will be important that you make arrangements with others, such as school counselors, ministers, therapists or family members, to offer your child a shoulder to lean on and an ear to listen.
- In addition to school and community support, find one person – a close, trusted family member or friend – your child can go to for support.
- Try to keep your child's routine as regular as possible.
- Ask your child to help in ways that make him or her feel valued and appreciated.
- Be gentle to yourself and your child. Accept that you may not be able to do all that you could before.
- Get counseling for yourself to get more support. This will help you to process your emotions.
- Treat yourself to alone time.
- Think “outside the box” for creative solutions to your situation.
- Talk with hospital and clinic social workers for help with financial and other practical day-to-day issues.
- Pay attention to feelings of being overwhelmed. And don't hesitate to ask for help!

As mentioned before, watch your child for signs of trouble with coping with the changes. Ask for and get help for yourself and your child if the signs are unusual and go on for awhile. Your stress level is higher, so be careful not to misinterpret what has been normal behavior for your child in the past.



Special Circumstances

Losses: Death and Non-Death Losses

There are many kinds of losses – some small and some large. Some represent the physical loss of a loved one while others are characterized by the loss of dreams. (See the booklet, “Loss of Dreams” in the *Ideas and Resources* section.) These become more noticeable when a cancer diagnosis is made.

For you, and for your child, a cancer diagnosis may remind you of a loved one who died from cancer or even from another cause. There are all the dreams and imagined losses your child will expect, “Will you be there to see my soccer championship, when I graduate, when I get married or when I have children?”

As a cancer patient who has already experienced the death of a parent, sibling, friend or loved one, your fears and the fears of your child are even more real, especially if the death was cancer-related.

*“He that conceals his grief finds no remedy for it.”
~ Turkish Proverb*

Loss of any kind must be grieved by you and your child. Everyone grieves differently. Some losses, such as the death of a loved one, are harder. You may feel it is impossible to fill the void. Others, such as the loss of a job, an income, a friend or a home, may seem less overwhelming, yet their impact may be every bit as challenging. A cancer diagnosis creates its own set of personal losses. This may include things such as the loss of energy, hair or a part of one’s body. Sometimes the diagnosis can cause a job loss or the loss of friends who unexpectedly disappear from your life. Dreams, plans and pictures of the way you imagined life to be may be lost. Your child, like you, will feel these losses. When these losses multiply, as they can with cancer, you will need to deal with them.

*“Grief is itself a medicine”
~ Willaim Cowpers*

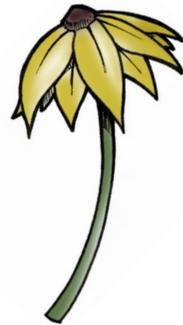
When you feel a loss, it is important to grieve its passing. Unfortunately, there is not always a fast or direct route through this process. It will affect you emotionally, mentally and spiritually. Take the time to learn about grief, its stages and pathways. See the *Ideas and Resources* section.

Find someone you can share your loss and the feelings it creates. Naming your grief allows you and your child to better manage it. Anger, sadness and feelings of hopelessness are common. You may return to these feelings several times. During the process you may experience and express many difficult and painful emotions. Postponing or trying to ignore them may only make the process harder. Your feelings may simply come back at another and perhaps less appropriate time.

Use the following steps and the resources in the back of this book to help you and your child grieve your losses. Grief is never a neat and easy process; it comes and goes. Over time, the energy it requires will lessen and life will begin to find its way to a new kind of normal.

Suggestions

- Tell each other your real and imagined losses, all of them – from the biggest and worst to the smallest and silliest.
- Name the feelings you are having as a result of your losses.
- Find ways to set free your grief and its emotions, such as sadness, fear, anger and confusion.
- Be patient because grieving is a process and takes time.
- Remember that no two children or adults grieve in the same ways.
- Connect with others, including friends, support groups, counselors and clergy. Be willing to share your feelings, no matter how painful. Openness and honesty are vital.

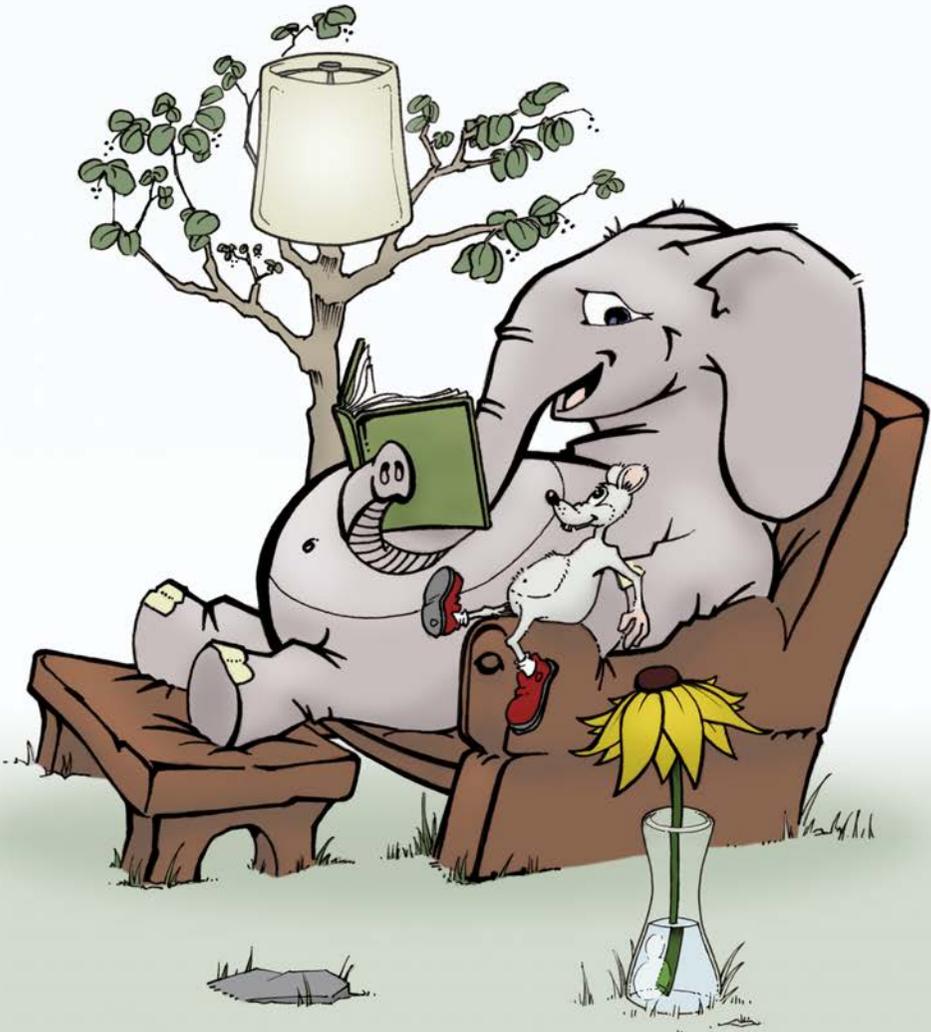


- Begin to dream and hope while you are grieving.
- Identify things you and your child can hope for together.
Make a list of your hopes and keep adding to it over time.
- If grief leaves you feeling deeply depressed and it does not improve with time, talk to a professional counselor.

“Life is no brief candle to me. It is a sort of splendid torch which I have got a hold of for the moment, and I want to make it burn as brightly as possible before handing it on to future generations.”

~ George Bernard Shaw

Ideas and Resources



Ideas and Resources

*“Medicine for the soul.”
~ Inscription over the door of the Library at Thebes*

Selected stories, guidebooks and other resources created by parents, patients, counselors, teachers and writers – those who understand.

When facing a cancer diagnosis, a simple story often communicates better than a textbook, pamphlet or medical article. This section highlights a collection of resources that have been selected to help you and your family better understand and cope with a cancer diagnosis and the range of emotions that go with it. Like any resource list, it will never be complete. Explore what you find here, but do search beyond these pages.

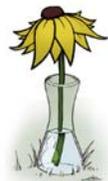
Most of the books and resources in this section can be found in libraries, bookstores or are available from online retailers, such as amazon.com and barnesandnoble.com.

An Introduction to the Resources

Children’s Books

These books are often as helpful and informative for parents as they are for children. They are easy to read and provide a springboard for talking and thinking for all of you. Children’s books often speak a truth in a simple, insightful or clever way. And they are not a strain on your child’s or your short attention span.

Some of the children’s books recommended are about cancer and some address the types of feelings your children may experience. Some are classics and some are new stories. While most are written for children younger than 12 years old, many can be enjoyed by teenagers and adults.



Teen Books

The number of books written about cancer specifically for teenagers is small. Yet, some will still enjoy reading the children's books. Teenagers also tend to be attracted to more active resources, like watching movies, surfing the Internet, and getting into music. Explore all of these resources with your child.

Guidebooks

These books are packed with detailed clinical and practical information, and tend to be written more for adults. They present different and overlapping points of view about talking with children about cancer. Many can be reviewed in sections or by topic, and can be easily picked up and put down.

Storytelling

You and your children may enjoy writing or telling your own story. You may dream up a story using your children as the central characters. Telling stories can help you heal. Many of the authors listed here write from their own experiences, having lived the story they write about. The resulting books are actually a part of their family's healing process.

"If there's a book you really want to read but it hasn't been written yet, then you must write it."

~ Toni Morrison

Tips for Reading Stories to Young Children

- Look over the story first before reading it to your child. Be sure it feels right for you and your child.
- Find a comfortable and cozy place where you and your child can read and talk about the story.
- Allow, and even encourage, your child to imagine himself or herself in the story.
- Use your natural voice as you read.
- Try not to speak down to your child while reading. Let the meaning and feelings of the story enter you as well. Allow yourself to take the journey with your child.
- Share the images and ideas that you each envision.
- Try not to make a moral judgment or conclusion from the story.
- Relax and chat about how you both liked or disliked the book when you are finished.
- Children of all ages (and adults) like to have someone read to them! One is never too old to hear a story read aloud.
- If a book is too deep for a child or his or her interest stops, pause, talk about it a little to understand the discomfort and try another time or another book.



“A book is the only place in which you can examine a fragile thought without breaking it, or explore an explosive idea without fear it will go off in your face.”
~ Edward P. Morgan



Children's Books About Cancer

Preschool – Early Elementary

“Someone I Really Love Has Cancer” by Dana Cohn and L.E. Murray

Cartoon/illustrated color book about a boy named Charlie and his friends who help him understand his feelings about his Mom’s cancer.

“My Own Human Body” by Giovanni Caviezel

This charming board book explains the human body in a series of words and pictures that will make sense to preschool boys and girls. As children turn the pages, they observe the human body’s interior and learn about the functions of muscles, lungs, the skeleton, and the stomach and intestines. This book is a wonderful tool to help young children see and understand how the human body looks inside, and is easy to use in pointing out where the cancer is.

“Butterfly Kisses and Wishes on Wings: When Someone You Love Has Cancer” by Ellen McVicker and Nanci Hersh

The story, told through the eyes of a child, offers a simple and clear understanding of cancer, cancer treatments, treatment side effects, and the many feelings that families face with a loved one’s cancer. Most important, however, is the lesson that teaches children to realize the power they have to be an active and integral part of a loved one’s cancer journey.

“Can I Catch Cancer?” by Cristine Thomas

This book explains cancer in terms and illustrations children can easily understand. Gently and playfully guides the child through the process of a cell growing into a tumor. Includes interactive pages so the child reading this book can understand and visualize by coloring and drawing the cute and clever characters in the book.

“Life Isn’t Always a Day at the Beach: A Book for All Children Whose Lives Are Affected by Cancer” by Pam Ganz and Tobi Scofield

A cartoon illustrated workbook for kids to color, to help learn and understand their feelings about a parent’s cancer.

“The Rainbow Feelings of Cancer: A Book for Children Who Have a Loved One with Cancer” by Carie Martin and Chia Martin

This book is written gently and with simple language that young children can understand.

“Tickles Tabitha’s Cancer-Tankerous Mommy” by Amelia Frahm

This book helps children deal with the mood changes that a parent with cancer might go through. It portrays family life in a humorous way.

“When Someone Has a Very Serious Illness: Children Can Learn to Cope with Loss and Change” by Marge Heegaard

Cartoon-illustrated workbook for kids to color themselves to help understand feelings when their parent is ill.

Elementary Ages

“Promises” by Elizabeth Winthrop and Betsy Lewin

Story of a young athletic mom who has cancer, told from the perspective of her child.

“Upside-Down Cake” by Carol Carrick, illustrated by Paddy Bouma

A nine-year-old boy tries to come to terms with his grief and anger when his father develops cancer, gradually becomes weaker and weaker, and then dies.

Elementary - Early Teens

“Becky and the Worry Cup: A Children’s Book About a Parent’s Cancer” by Wendy Schlessel Harpham, MD, and Jonas Kulikauskas

Wendy Harpham, MD, wrote this book and another guidebook to describe her personal experience helping her children deal with her diagnosis of cancer. “Becky and the Worry Cup” talks about chronically tired parents, parents who have to go away for awhile for treatment, low blood counts, etc. It suggests ways children can overcome some of the helpless feelings they experience when a parent is sick.

Late Elementary - Early Teens

“Can I Still Kiss You? Answering Your Children’s Questions About Cancer” by Neil Russell

Diagnosed at age 47, when his children were 11 and 13, this is the emotional account of the cancer’s life-changing impact on the author and his family. It is both an informative narrative and interactive journal; it will help parents speak to their children about the cancer that has come into their lives.

“The Year My Mother Was Bald” by Ann Speltz and Kate Sternberg

This book helps readers identify with a child experiencing her mother being diagnosed and treated for breast cancer, and the various steps and consequences that go hand-in-hand with an extensive modern treatment course.

Teens

“When Your Parent Has Cancer: A Guide for Teens” by National Cancer Institute

This pamphlet offers step-by-step information for teenagers to help understand and cope with a parent’s cancer and the challenges it may bring. The pamphlet is available free of charge from cancer.gov or by calling 1-800-4-CANCER.

“What About Me? How Teenagers Feel when Someone in the Family is Ill” by Cancer Family Care

Solid and sensitive information for teenage children of cancer patients. It includes testimonials from teens who have found themselves in this situation.

All Ages

“H is for Hair Fairy: An Alphabet of Encouragement and Insight for Kids and Kids at Heart with Cancer” by Kim Martin and Wend Boomhower

An uplifting and encouraging book that helps cancer patients feel less scared and confused, and recommended for anyone, young or old, who is dealing with cancer or knows someone who has been affected by it.

**“Kemo Shark” by H. Elizabeth King, PhD, Mitchell McGough,
and Diane Williford Steele**

Kemo Shark is the hero of a sixteen-page color “comic book” designed to help children understand the psychological and physiological changes in a parent with cancer who undergoes chemotherapy.

“My Mom Has Cancer” by Sheri Lichtenstein

A book written by a 10 year-old with children’s drawings.

**“Once Upon a Hopeful Night” by Risa Sacks Vaffe,
Troy Cramer, and Risa S Yaffe**

This book accomplishes the hard and often painful task of revealing to your kids that you have cancer in a sensitive and simple way. It is a caring book to read to your children or anyone else in a crisis. Good for all ages.

“Our Family Has Cancer Too” by Christine Clifford

This book has pages of cartoons that show the humorous and serious side of cancer in the family.

“The Paper Chain” by Eliza Blanchard, and Kathy Parkinson

A beautiful, cartoon-illustrated book that tells the story of how one family coped while their mother was in the hospital during her cancer treatment.

“Snowman on the Pitcher’s Mound” by Jamie Reno

This is a book written for both parents and children about loss from a young boy’s perspective. It provides a guide for teachable moments that parents can use to help them relate to their children when faced with serious illness or loss.

**“What is Cancer Anyway? Explaining Cancer to Children
of All Ages” by Karen L. Carney**

This book includes an extended family (parents, kids, grandparents) and talks about cancer simply and directly; addressing a few emotional concerns such as “can I kiss Grandpa?” and “will I get sick, too?”

Children's Books About Uncertainties

Elementary Ages

"Angel Kisses" by Katie Dorn, Ginny Kelley and Amanda Garcia

This is a lyrical story that helps make religious sense of cancer.

"Drawing Together to Learn About Feeling" by Marge Heegard

This expressive workbook covers the strong feelings that children experience in life but sometimes have trouble identifying. Through drawing, children can express and release deep emotional feelings in safe and appropriate ways.

All Ages

"Bridge to Terebithia" by Katherine Paterson and Donna Diamond

This is a story of friendship, imagination, love and loss written about two fifth-graders.

"Fall of Freddie the Leaf" by Leo Buscaglia

The focus of this story is about love, and how love enables us to face some of life's most difficult challenges. It is a book about change, death, and transition.

"Sad Isn't Bad: A Good Grief Guidebook for Kids Dealing with Loss" by Michaelene Mundy and R.W. Alley

A story of the normal process and feelings associated with loss, and how natural they are.

"Tear Soup" by Pat Schweibert, Chuck DeKlyen

This book is wise and insightful, both for a grieving person as well as someone who loves a grieving person. Loss of any type is addressed in this book. It is perfect for children as the illustrations are stunning and it is written simply, but adults will experience the book more deeply as they will see its wisdom and understand its nuances.

Adult Books About Uncertainties

Teens – Adults

“Finding Hope when Dreams Have Shattered” by Ted Bowman

Learn to dream again after loss. This is a beautiful and practical guidebook for rekindling hope again after any kind of loss.

“Kitchen Table Wisdom” by Rachel Naomi Remen

Excellent book of stories told to the author by cancer patients. Inspiring and easy to read.

“Loss of Dreams” by Ted Bowman

This book is about dealing with non-death losses including dreams. A practical and poetically resourced book that provides perspective on a topic not often anticipated or talked about.

“When Bad Things Happen to Good People”
by Rabbi Harold Kushner

This book is about the “why” question and ways to respond to “bad things.” It offers a perspective on God, life and suffering.

All Ages

“The Next Place All Ages” by Warren Hanson

This illustrated book poses thoughts about what might happen in the next life for children, parents and adults alike. It’s a simple but profound way of explaining death to a child without making it seem frightening or overtly religious.

“Healing a Child’s Grieving Heart: 100 Practical Ideas for Families, Friends & Caregivers” by Alan D. Wofelt

This book provides a great list of things to do for families and individuals of all ages as they travel the process of loss.

Adults

“Helping Children Grieve When Someone They Love Dies”
by Theresa Huntley

Divided into sections by ages from elementary through teens, this book provides parents and other adults with timeless information to help children face the loss of a loved one.

Children's Books About Feelings

All Ages

“Alexander and the Terrible, Horrible, No Good, Very Bad Day”
by Judith Viorst

This book helps children (and adults) express their feelings of frustration when things go wrong. This author has a number of titles that are helpful in dealing with emotions. All ages find this book to be fun and sensitive.

“My Many Colored Days” by Dr. Seuss

The best benefit of this book is not necessarily for kids to understand themselves, but to help kids understand grown-ups' moods – why Mommy is tired after a long day at work or why Daddy is frustrated when he burns dinner. I can tell my daughters that I am in a 'gray' mood, and all becomes crystal clear!

“Where the Wild Things Are” by Maurice Sendak

This book is about joining in with the wild things to help lessen the fear about them.

Elementary Ages

“The Grouchy Ladybug” by Eric Carle

This book allows parents to talk with their kids about right and wrong behavior, about cooperation and conflict, and about standing up against bullies. It is a very unique book that starts conversations between parents and kids.

“I Was So Mad” by Mercer Mayer

This book is for very young children about frustration and anger.

“The Very Lonely Firefly” by Eric Carle

This book follows a lonely firefly on his search for other fireflies that leads him to other sources of light such as light, candle, and flashlight. A good book for conversations on what we feel like when we are feeling lonely.

Elementary – Early Teens

“There’s a Nightmare in My Closet” by Mercer Mayer

From the perspective of a young boy, this book tells the story of how a child confronts his fears and learns that they might not be as scary as he once thought.

... and a Few Books About Elephants

All Ages

“Babar” by Jean de Brunhoff

Stories about a young elephant called Babar who leaves the jungle, visits a big city and returns to bring the benefits of civilization to his fellow elephants. He returns to become the king of the kingdom.

“Dumbo” by R. H. Disney

This is a lovely story about a physical symbol or good luck charm (feather) that is released when courage comes from within.

“The Magician’s Elephant” by Kate DiCamillo

The Magician’s Elephant is a haunting fable about trusting the unexpected and making the extraordinary come true. The tale is somber, but the overall message of the story is hope. The characters are quirky and magic lingers on every page.

“My Friend is Sad” by Mo Wilems

From the Elephant and Piggy series, this book about friendship discusses the emotion of sadness through the use of humor.

“The Saggy Baggy Elephant” by Kathryn Jackson
and Byron Jackson

The story of a baby elephant who is lost in the jungle and is made fun of by other animals for the way he looks. Then he’s found by a great herd of gray elephants who tell him he’s a perfectly wonderful little elephant.

Guidebooks for Parents and Families

“Cancer in the Family” by Sue P. Heiney, Joan F. Hermann, Katherine V. Bruss, Joy L. Fincannon

This book details the necessary steps to help children understand what happens when a parent has been diagnosed with cancer. It also includes a special illustrated workbook designed just for children and adolescents to help them record their thoughts and feelings so they can learn how to better navigate this emotional time.

“Coping When a Parent Has Cancer” by Linda L Strauss

This book thoroughly describes cancer and its current treatments, including pointing to improving long-term survival rates and cures. Then it talks about the many challenges a cancer diagnosis can present to families, including financial concerns, altered household responsibilities, the need for care of both patient and children, living with uncertainty, and more. The book is filled with valuable practical information on a wide range of topics, including how to find a teen support group and why to join, what a hospice is, how to behave with a dying person and at a funeral, and anticipating the stages of grief.

“Facing Cancer: A Complete Guide for People with Cancer, Their Families and Caregivers” Edited by Theodore Stern and Mikkael Sekeres

This book is uniquely supportive of the emotional, social and familial aspects of living with cancer. Written by leading doctors in their respective fields of psychiatry and oncology, it is the only reference that combines top-tier medical information and compassionate counsel on cancer. The book is ideal for anyone whose life is affected by a cancer diagnosis.

“Finding Your Way: Families and the Cancer Experience: A Guidebook” by Gail A. Noller, MA

This comprehensive guidebook deals with the emotional impact of a cancer diagnosis on an individual and all those that surround that person. Ask about the companion video series. The book is more appropriate for adults, but the companion video, with some parental screening, can be helpful to children.

“Healing Stories: Picture Books for the Big and Small Changes in a Child’s Life” by Jacqueline Golding, PhD

With over 500 hand-picked titles, “Healing Stories” recommends carefully selected books essential for any adult looking to help children cope with their growing pains through reading.

Featuring the long-established children’s classics and the most recent library sensations, these hand-picked stories address kids’ struggles – from everyday to life-changing events – while offering adults the information they need to make the right choices for their kids.

Also includes useful tips to make reading fun and helpful for both adults and children. This is a great guide to finding additional lists of books that help children cope and grow.

“How to Help Children Through a Parent’s Serious Illness” by Kathleen McCue, MA, CCLS, and Ron Bonn

This book offers supportive, practical advice from a leading child-life specialist, including what to tell a child about an illness, how to recognize early-warning signs in a child’s drawings, sleep patterns, schoolwork and eating habits, and when and where to get professional help. Complete with illustrations and Calvin & Hobbes cartoons.

“The Human Side of Cancer” by Jimmie Holland, MD

This is a well-respected text that talks about the real life aspects of cancer, emotions, relationships and healing. It is written by a psychiatrist with years of experience talking to cancer patients and their families.

Dr. Holland shares what she has learned from all of them about facing their life-threatening illness and what truly helps along the cancer journey. This book is the next best thing to sitting in Dr. Holland’s office and talking with her about the uncertainty and anxiety elicited by this disease. And it is a book that inspires hope -- through stories of the simple courage of ordinary people confronting cancer.

“The Human Body Book and DVD” by Steve Parker

This is a highly recommended anatomy book which can be useful for you and your children as you learn about where your cancer is and how the human body functions.

“Their Cancer: Your Journey A Traveler’s Guide for Caregivers Including Families and Friends” by Ann Orchard

This book offers direct advice and reflections for caregivers, family members and friends who are dealing with a loved one’s cancer.

“Vanishing Cookies: Doing OK When a Parent Has Cancer” by Michelle Goodman, MD

This book is written by a psychologist with the special needs of 7 to 12 year-olds and their families in mind. It emphasizes the value of open communication and normalizes feelings. This item is available in the free “Kid’s Kit” from the American Cancer Society.

“When a Parent Has Cancer / Becky and the Worry Cup” by Wendy Schlessel Harpham, MD

This is typically a two-book package, written by a physician who is also a parent and cancer survivor. It offers clear, direct and sympathetic advice about the issues that arise during the long months of treatment. Important points for parents are in bold for easy reading, and it includes a chapter on teens. “Becky and the Worry Cup” is a wonderful companion piece for children.

“When a Parent is Sick: Helping Parents Explain Serious Illness to Children” by Joan Hamilton

This book reviews a child’s understanding and response to serious illness at different stages of development. It provides suggestions of how adults may help the child cope with their feelings and the daily disruptions the illness has created. Joan Hamilton is a clinical nurse specialist in cancer care in Halifax, Nova Scotia. She has worked with cancer patients and their families for more than 20 years.

“When a Parent is Very Sick” by Edna LeShan

This book talks about typical feelings and a child may have when a parent is seriously ill or injured, as well as how it affects the entire family. The book suggests healthy ways for children to deal with these situations.

DVDs and Videos

Daughter to Mother: Teenage Girls Whose Mothers are Living with Recurrent Breast Cancer Share Their Experiences

In this 15-minute documentary, four teenage girls whose mothers are living with recurrent breast cancer express their thoughts and feelings. This DVD was developed to encourage teens and their mothers to share difficult emotions. The DVD is available from the producer, Cancervive, at cancervive.org.

Kids Tell Kids What It's Like When a Family Member Has Cancer

Cancer affects everyone in the family. In this award-winning 115-minute documentary, children talk about their hopes, fears and the adult burden placed upon them when cancer strikes a parent. The film is faithful to the kids' point-of-view and validates the children's emotions. The DVD is available from the producer, Cancervive, at cancervive.org.

Parenting Through Cancer

The Minnesota Angel Foundation's Parenting Through Cancer DVD addresses one of the most difficult concerns a parent has when diagnosed with cancer—how to talk to their children about it. Whether newly diagnosed or in recurrence, this DVD provides the basis for opening up healthy lines of communication, addressing family needs and providing tools for the family to become strengthened by the experience. Easy-to-navigate chapters address the needs of different age groups, and wonderful interviews with a panel of experts, parents and children, provide practical advice for facing the challenges of cancer together as a family. The DVD is available from the Angel Foundation at 612-627-9000 or at mnangel.org.

Talking About Your Cancer: A Parent's Guide to Helping Children Cope

This 18-minute film was produced by Philadelphia's Fox Chase Cancer Center to help guide parents in conversations with their children. It can be ordered from Fox Chase Cancer Center at 1-888-369-2427 or fcc.edu.

We Can Cope: When A Parent Has Cancer

This is a set of three videos, including a manual for parents. The parent video features seven parents talking about how their families coped. The teen video features a group of teenagers talking about their parents' cancer and how they coped. The child video features three young children expressing their feelings. The program can be ordered from Inflexxion Inc. at 1-800-848-3895 or wecancope.com.

Websites

cancer.org

The official site of the American Cancer Society provides a wealth of cancer-related information, including diagnostic and treatment information for all types of cancer, statistics, a treatment decision guide, current research activities, and much more. Its Community section provides information on local resources, support groups, presentations and activities near your home. Discussion boards allow people with various types of cancer to exchange thoughts with cancer survivors. The site's My Planner lets patients maintain a personal calendar for appointments and reminders, make a to-do list, save links to articles, and contact other registered users of the site. The ACS has also created the Circle of Sharing, a unique, free program that helps cancer patients and their caregivers get personalized information about the disease, and share that information securely with family and friends..

cancer.gov

This is the site of the National Cancer Institute, part of the U.S. National Institutes of Health. It offers volumes of reliable and up-to-the-minute cancer information and support options, including articles on a wide range of cancer topics, types of cancer, treatments, statistics, and clinical trials and research.

cancer.org

This large national nonprofit site offers a broad range of 100% free programs and resources for anyone affected by cancer: people with cancer, caregivers, children, loved ones, and those who have lost someone to cancer. CancerCare programs, provided by professional oncology social workers, include counseling, support groups, Connect Education Workshops, publications, financial assistance and practical help. CancerCare also sponsors a companion website: lungcancer.org.

cancerhopenetwork.org

This independent nonprofit site matches cancer patients and their families one-on-one with trained volunteer cancer survivors who have recovered from similar experiences. The volunteers' personal cancer experiences give them a unique perspective and understanding of the questions and fears that only individuals who have gone through it can have. The matching process helps provide support and hope, to help patients and family members look beyond the diagnosis, cope with treatment, and start living life to its fullest once again.

caringbridge.org

This is a free, personalized website for easier communication with family and friends during a health crisis. You or a loved one can update your story and friends can write notes to you on the site. It conserves energy and saves phone calls.

kidskonnected.org

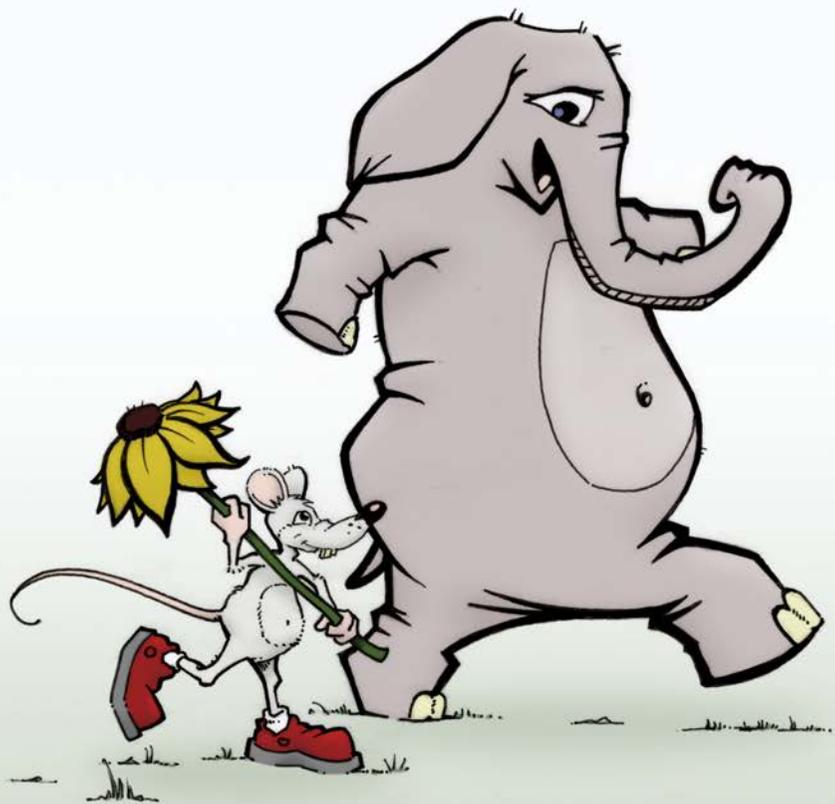
The mission of the nonprofit Kids Konnected is to provide friendship, understanding, education and support for kids and teens who have a parent with cancer or have lost a parent with cancer. Developed on the premise that when a parent gets cancer the entire family is affected and the needs of the children must be addressed, Kids Konnected offers support and services for kids (ages 4 to 12), teens, parents and professionals; including a 24 hour kids' hotline, monthly support group meetings for parents and children, summer camps, a moderated chat room, and a host of educational services and materials.

livestrong.org

The LIVESTRONG Foundation's mission is to unite people to fight cancer; believing that unity is strength, knowledge is power and attitude is everything. Its website provides support and services ranging from educational programs and articles to the latest in clinical trials findings to one-on-one support through its Survivor Care program.

*"Acceptance of what has happened is the first step
to overcoming the consequences of any misfortune."*

~ William James





Allina Health

allinahealth.org