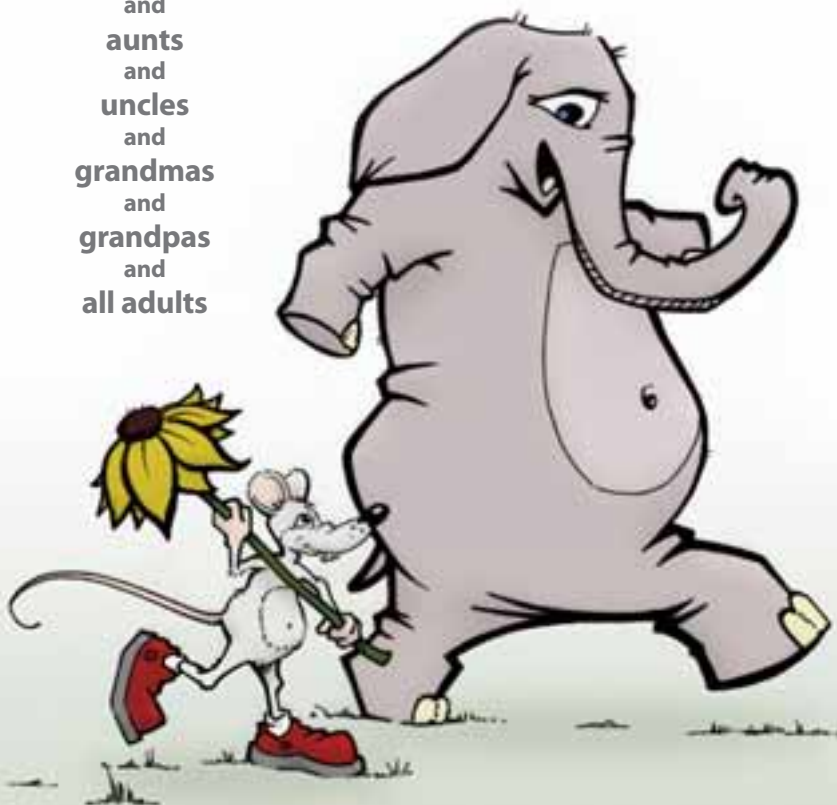


Simple Talk for Tough Times

TALKING WITH CHILDREN ABOUT CANCER

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



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 children? What should you say? When is the right time to tell them?

The diagnosis looms like the proverbial “elephant in the room” – an age-old expression used to describe something big that everyone is aware of but no one wants to talk about. So we try to ignore it, usually because we just do not know what to say or how to say it.



Simple Talk for Tough Times is designed to help you talk with the children in your life about the “elephant in the room” and help them learn to cope with the enormous changes that often accompany a cancer diagnosis. We hope, as your conversations grow and you cherish your times together, you and your children will blossom in ways you’ve never before imagined.

We have gathered and simplified information from many resources (most of which are referenced in the last section of this book), as well as our own experience with parents and their children.

In addition to general advice and suggestions, this book explores each phase of childhood development and offers specific ideas for what to say, what to do and what to observe when talking with your children about the “elephant in the room.” Understanding the

emotional milestones associated with each phase of development and how your children may be affected by the changes in your home, will help you prepare and manage the challenges that arise.

Children and adolescents alike tend to have concerns about their parent's health as well the changes that are happening in their homes. It would be of concern if they had no reaction to a significant event in the life of their family. But, most children doing well with school, friends, and at home prior to their parent's diagnosis of cancer continue to do well through treatment. Those children who were struggling in one or more of these areas prior to a parent's illness are likely to have extra difficulty weathering the disruptions and worries of their parent's illness.

Communication is important and it takes different forms in different families. Doing things together is a way of communicating, as is talking. This guide encourages a combination of both talking and doing – real together times that will help your family learn ways of communicating through these tough times.

Take from this book what is relevant to your family and the developmental behavior of the children in your life. Since all children mature in their own times, it is important that you meet your child where she is developmentally. Children may be more or less mature than their actual age, so you might like 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 provide general information for all ages, as well as talking points organized by childhood developmental age groups. The third section discusses special circumstances facing some families and children. The final section offers ideas and resources for more information, support and assistance.

This book can also serve as a companion guide for our support groups, allowing you to share concerns with other adults and children, and learn together. We encourage you to attend a support group to meet other parents, share experiences and talk about the information in this book.

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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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- the Virginia Piper Cancer Institute – Abbott Northwestern Hospital
- the Virginia Piper Cancer Institute – Unity Hospital
- Mercy Hospital
- Buffalo Hospital
- Cambridge Medical Center
- New Ulm Medical Center
- River Falls Area Hospital
- St. Francis Regional Medical Center
- United Hospital
- various Allina Medical Clinic locations.



Breaking the News

Preparing Yourself

“We are always communicating, even when we do not speak.”

~ Virginia Satir

Read through this section and then locate the accompanying pages for different age groups. On those pages you will find more specific ideas for what to say, what to do and what to observe with your children. 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 your peers, 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 keep in mind that your children are already sensing something is wrong and need your explanation and reassurance.
- Recognize the size of the “elephant.” As hard as it can be for you to get your own arms around your cancer diagnosis, it can be even more challenging for your children. Some parts of the message are bigger and harder to describe than others. So, you do not 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 children’s attention spans. Recognize that children have varying attention spans, and so do you. There will be times that are better than others to talk to your children about what cancer means to your family. Use the metaphor of the elephant if it helps. Do not worry if children tune out after just a few minutes, but do ask them what they are feeling when they do.
- Choose times to talk when your children are more open or ready to talk. There will never be a perfect time. It helps to plan times to talk when your children are not too hungry, tired or preoccupied with their own issues with friends or school. If you are married or



have someone else involved with the children, it is good to do this together. Sometimes you have to “make a date” with your children.

- Be as natural as possible. Talk with your children, not at them. Use familiar language.
- Tell the truth as you know it. Children need to know that you can be trusted to tell the truth. If something is not clear yet to you, tell them you will let them know as soon as you know.

Talking About Cancer

- Share your feelings, but focus on your children's feelings more than your own.
- Put two of the most common fears of children at ease: Tell them, “You cannot catch cancer and you did not do anything to cause it.”
- Use the real name of your cancer.
- Ask your children what they already know about cancer. Do not be afraid of talking over their heads. Give them credit. They understand more than we realize.
- Tell them 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 noted can be helpful.
- Children want life to be predictable. Let them know that some things may change and how that might look. Reassure them of the things that will not change and that they will always be cared for.
- Encourage questions, but realize you may not know the answers to all of their questions. You can say, “I don't know but I will find out for both/all of us.” Follow your children's lead as to how much they want to know.
- Allow yourself and your children 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 their hugs, too.



- Let your child know that you believe in his inner strength and resilience.
- Do not hesitate to call on the expert resources available to help you, including your physician, hospital social workers, counselors at school and in the community, clergy and others.

Breaking the News

Infants – 2 Years

“My name is ‘NO NO’ but Grandma calls me ‘Precious!’”

~ Unknown

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.



Developmental Factors

Trust, Mistrust and the Beginning of Autonomy (Independence)

At this age there is little rational understanding of what is happening. But infants and toddlers are exceptionally 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 require more holding, stroking, reassurance and calming.

Cancer can cause the environment to feel less secure and less trusting, so confident and consistent reassurance is critical. One- and two-year-olds are working toward more independence, but when they feel stress and changes in the environment, they may revert to increased dependence, run away or become more stubborn.

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 ensure 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 infant or toddler may not understand the words, they 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 them act out how they might help the doll or animal to get better.
- Let toddlers know who will care for them 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 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 toddler can play and explore without needing to be chased or restricted from touching things. Then sit with her and enjoy playing.
- Call upon another known family member or friend to comfort your child, if you or your spouse is unable 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, and encourage caregivers to maintain your child’s usual routine.
- Use the same friends or relatives to care for your child if overnight stays become necessary, to lessen feelings of insecurity that may arise traveling from place to place.
- Attempt to avoid or reduce introducing new things, such as weaning, toilet training, or giving up a comfort toy or pacifier — especially during the early stages of 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 beloved 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 Observe

Changes in behavior for children, adolescents and adults during stressful times are normal. These changes may include regression or returning to less mature behaviors. Some behaviors which may occur include:

- Not sleeping well
- Wanting to nurse or drink from a bottle more than normal
- Becoming more irritable
- Crawling rather than walking
- Not eating
- Lack of interest in play
- Lack of expression of feelings (listlessness) 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 frequent, or if you intuitively sense that something is wrong. This is the time to consult a professional such as your physician or pediatrician, a child development specialist, or counselor.



Breaking the News

3 – 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 desired and feared at the same time. It is sometimes referred to as the “first adolescence.” Because a parent’s illness may force a child to be more independent, she may resist because it is imposed and not her choice. It is important to set firm, loving limits.



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

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

What to Say

- Use language your child will understand clearly. 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.”
- Continually reinforce to your children that they cannot catch cancer nor did they do anything to cause it.

- If you find a time in which you need help in caring for your children, tell them, "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, such as, "Daddy needs to sleep a little more to feel better. Sometimes when you have a good nap it makes you feel better, right?"
- Prepare your child for possible changes in your appearance, such as loss of hair, or in the set-up of the household. If children know what is coming, it can be easier for them 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." Or even give the cancer your own name.

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 books and comforting stories, especially favorite ones, to keep the familiar strong. Refer 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 your special comfort blanket.
- Let your child help you foster 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 she does it.
- Draw or paint pictures with your child about the cancer and his 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 she might help the doll or animal to 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 (pre-school teachers, etc.) know what is going on at home.
- Give your child an opportunity to express feelings of anger constructively—drawing in bold colors, finger paint, punching pillows.

What to Observe

Changes in behavior for children, adolescents and adults during stressful times are normal. These changes may include regression or returning to less mature behaviors. Some behaviors which may occur include:

- Thumb-sucking/wanting a pacifier
- Bedwetting / potty accidents
- Sleeplessness
- Curling up in a corner
- Clinging
- Whining
- Inattention
- Angry outbursts
- Aggression
- Separation anxiety



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 frequent, or if you intuitively sense that something is wrong. This is the time to consult a professional such as your physician or pediatrician, a child development specialist, or counselor.

Breaking the News

6 – 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 are less engrossed in fantasy. Following rules is important, and children will often make up elaborate 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 prevalent. Children in this age group like to master things and feel competent.

This is also a social stage when children can feel inadequate, especially if they feel different in terms of themselves or 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 now thinking more logically, you can explain cancer in a more straightforward way. Use some of the real words and help them 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 was 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 children the schedules you will be keeping for treatment, and who will be caring for them during those times.

- Continually reinforce to your children that they cannot catch cancer nor did they do anything 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 them deal realistically with the cancer and normalize their family. For the older end of this age group, writing a report about cancer or reading a book about cancer and reporting on the book 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 us know and we will ask someone to help you."
- Children may become self-conscious if a parent is noticeably sick, has lost hair 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. A discussion about death may be necessary as children often think of death as caused by an external force not something internal. See more about this in the *Facing Uncertainties* section.

What to Do

- Communicate with your child's school. Make sure they know what is going on at home and will provide a person for your child to talk with and a place to get away when it is needed.
- Try to simplify after-school schedules. Talk with your child about which activity is a favorite and which may be temporarily put on hold, 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 will see, and arrange a visit with staff. Allow him 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 her anger by pounding on some clay, having a pillow fight, painting with bright colors, etc. For some, anger is hard to express directly, so using clay, paint or pounding pillows can be very healthy and satisfying for both or all of you. (One father related throwing ice cubes with his son into the bathtub while it was empty.) Be creative!
- Talk with your child about 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 in your inability to attend his 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 photographs together. Do not 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 she is able to comprehend. 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. Yours is to go to school and keep working and playing as you have before." Children may not want to go to school for fear something may happen to you. Reassure them that you will be alright while they are 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 Observe

Changes in behavior for children, adolescents and adults during stressful times are normal. These changes may include regression or returning to less mature behaviors. Some behaviors which may occur include:

- Thumb-sucking
- Bedwetting
- Sleeplessness
- Withdrawal / isolation
- Acting out
- Irrational fears
- Obsessive-compulsive or ritualistic behaviors
- Psychosomatic complaints
- Tics (localized and habitual twitching, especially in the face)
- Destructive behaviors
- Over-eating or not eating
- Acting like the parent (needing to be Mom or the “man of the house”)
- Psychosomatic complaints

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 frequent, or if you intuitively sense that something is wrong. This is the time to consult a professional such as your physician or pediatrician, a child development specialist, or counselor.



Breaking the News

10 – 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 “tween” years children are vulnerable as they move toward independence; while still feeling a need for parents and a need to know that their parents are in charge. It can also be a time of great strain and conflict for parents, allowing a child 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. There are significant mood swings. Preteens develop heroes and heroines, and have crushes on others. They are prone to manipulate others as a means of gaining a sense of importance.

Since fitting in is important for preteens and teenagers, it is difficult for them to have a family that is “not normal,” which is likely how they view a cancer diagnosis. And since they are struggling to separate but still want and need 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 these young people. Ask them what they think about the cancer. Listen carefully. Repeat what you hear to be sure you understand, and to validate they are being heard.



- Explain your cancer as clearly as possible. Tell your preteens what cancer is and what it is not. Reassure them that they cannot catch your cancer, nor did they cause it. Ask them what they want to know about cancer and your treatment.
- Give your preteens brief articles about cancer to read. Books or pamphlets with too many words may overload their attention spans.
- Encourage the use of chat rooms for children of cancer patients. See the *Ideas and Resources* section.
- Acknowledge their need not to feel different, and how frightening the cancer and the changes it may make will be.
- Tell them you will be there for them as much as possible. Reassure them that when you are not able to be there, that they will still be well cared for.
- Attend your children's events whenever possible; and when you cannot, show interest by asking about them. Acknowledge and accept their sadness if you are unable to attend the events.
- Reassure and praise them for specific things they do that you like or appreciate.
- Do not overreact when your preteen says she doesn't care about the cancer or blurts out something unkind or hurtful. Accept that anger is a common response to stress and fear.
- Ask your preteen if he has a friend or someone who will listen to his feelings and talk about "the elephant in the room." One good friend is most often sufficient.
- Ask specifically for what you need from your children, and what they need from you.
- Encourage your preteen 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 stable as possible.
- Post a weekly schedule for your child to check that includes everyone's activities and indicates who the daily go-to person will be at home and who will be providing carpooling or other supports.

- Simplify after-school schedules as much as possible. Talk with your child about which activity is a favorite and which may be temporarily put on hold, if needed. It is better for your child to get to one favorite activity regularly than to irregularly attend several.
- Hug them when they need it – and when they do not.
- Enjoy some fun, quality together time. Play a game or watch a movie together.
- Talk openly about fears – theirs and yours.
- Look over old photographs and point out stories of their strengths and successes.
- 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 its influences on 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 they like about the book or game.
- Remain engaged, or have your partner or a friend be engaged, in what is going on with your preteen. Talk to school counselors and teachers about her work. If it is okay with your child, share the circumstances at home.
- Encourage your preteen's expression of frustration through sports, games, writing and drawing.
- Exchange e-mails or notes with your preteen, as sometimes face-to-face conversations are difficult.
- 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 Observe

Changes in behavior for children, adolescents and adults during stressful times are normal. These changes may include regression or returning to less mature behaviors. Young people in this age group are struggling with uncertainty. It can be challenging to discern normal from abnormal behaviors, as there is increased volatility and vulnerability in these years. Some of the behavioral changes you should look for include:

- Excessive anger or withdrawal
- Poor schoolwork
- Frequent crying
- Refusal to eat or over-eating
- Dramatic mood-swings
- Lack of friendships
- Uncomforted fears
- More than usual pre-occupation with fantasy
- Clinging
- Psychosomatic complaints

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 frequent, or if you intuitively sense that something is wrong. This is the time to consult a professional such as your physician or pediatrician, a child development specialist, or counselor.



Breaking the News

14 – 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 a child begins to act as an independent person and seeks her own identity as a person and a sexual being.

It is a time of struggle with social interactions and moral issues. In their struggle, adolescents may withdraw from responsibilities and family interactions in order to be alone or as a way of “putting one’s foot down.”

Adolescents are restless as they struggle to separate from family and strike their independence. Yet, they are idealistic and 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 increases their self esteem and confidence. It is important to encourage and support them in their efforts, even in interests with which you are unfamiliar.

What to Say

- Explain the cancer clearly. Let them 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 do not withhold important information from teens. They are capable of understanding far more than we might expect.
- Ask your teens to verbalize what frightens them about the cancer, if they are able. Fear of death is often a large part of their concern. Adolescents fear death, yet they feel immortal. They may escape into unhealthy behaviors when trying to deny or repress this fear. Tell them what you know today and what remains unknown. See the *Facing Uncertainties* section.

- Teens want things to be normal. Talk about the idea of a new normal for the family, but reinforce that you want to keep things outside of the family as normal as possible.
- Discourage your teens from using the “cancer card” inappropriately. Cancer can easily become the scapegoat for everything that is not going well.
- Adolescence is the age of separation from parents and the time to strike individual identities. Yet, cancer may challenge and confuse these normal instincts. Your teen may be afraid to hurt your feelings or leave you, and still she feels the natural draw to do so. You may get mixed messages. Ask your child if she might be feeling confused and offer permission to do things without you.
- Some adolescents may “disappear,” finding solace in friends and other activities. Let your child know that you understand it is hard to live face-to-face with cancer.
- Ask them if they are uncomfortable about anything regarding your illness, such as your wig, your energy or medical equipment. Then let them talk.
- Adolescents need an outlet for their anger. Try not to take their uncaring words too personally. Ask them about what is fueling their anger — usually fear and sadness. Remember, you can love someone and still be angry at them.



What to Do

- Provide consistent structure, limits and expectations for your teen. Expect him to continue to do chores, homework and fulfill his other responsibilities. Choose your battles carefully, and be sure they are worth it.
- Connect your teens to recommended Internet sites. Help them find online cancer chat rooms and encourage them to talk with other teens facing the same issues. See the *Ideas and Resources* section. Let them become experts on your cancer.



- Watch a movie or play a video game together, especially if you do not have as much energy as usual. There is no substitute for lighthearted “chill” time.
- Encourage activities that your teen might do at home with friends.
- Be aware of your teen’s role with younger siblings. Your teen will need permission to have her activities without feeling she is being selfish. At the same time, exploring ways she can provide emotional support to her younger siblings is a powerful lesson about love and responsibility within a family. Be aware that children who are thrust into or feel the need to move into parenting roles may also over-parent their siblings.
- Exchange e-mails or notes with your teen, as sometimes face-to-face conversations are difficult.
- 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 teen. Do not be envious of their relationship. Encourage them.
- Provide a place for your teen to play or listen to music. Music is a tremendous release for stress and emotions.
- Encourage and take interest in the creative ways in which your teen expresses her feelings through poetry, journaling or artwork. Be interested, but respect your teen’s need for privacy.
- Take your teen with you to appointments and ask him to write down what the physician or nurse says and ask questions of the staff as a way of helping you.
- Recognize that teens still love things to cuddle, like soft fleece blankets and stuffed animals.
- Plan for future events with your teen, such as a vacation, a birthday, family get-together, driver’s test, etc.
- Give your teen something that symbolizes his courage... or hope. Perhaps it is a special rock, feather, photograph or other heirloom. Its meaning needs only be known by the two of you.



- Hang posters or photos of encouragement, humor and inspiration.
- Look at old photographs together and remind your teen of her strengths. Share stories about her childhood.
- Identify cancer support groups and encourage your teen to attend. See the *Ideas and Resources* section.

What to Observe

Changes in behavior for children, adolescents and adults during stressful times are normal. These changes may include regression or returning to less mature behaviors. This age group typically demonstrates a wild mix of emotions and challenges. Stay tuned in to your child's demeanor, behavior and feelings. It may seem that nothing is normal. Some of the behavioral changes you should look for include:

- Extreme anger or aggression
- Withdrawal / isolation
- Depression
- Eating too much or too little
- Apathy
- Failing grades and behavioral problems in school
- Friends pulling away or your child pulling away from friends
- Addictive or risky behaviors
- Sleeplessness or too much sleep

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 frequent, or if you intuitively sense that something is wrong. This is the time to consult a professional such as your physician or pediatrician, a child development specialist, or counselor.



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 our lives may be when life is shrouded by uncertainty, mystery or ambiguity. Cancer casts one’s life into a constant state of unknowns. Our physicians, the books we read, experts on the Internet and well-meaning friends try to tell us what we will face and how we should face it. Yet, the only thing we are certain of is our 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 we wrestle fear with the other is never easy. It is normal for us to want to protect our children from cancer’s challenges. But it is not truly possible. Children can sense our fear and insecurities. It is instead time to clasp hands and face the uncertainties together.

“Uncertainty will always be part of the taking charge process.”

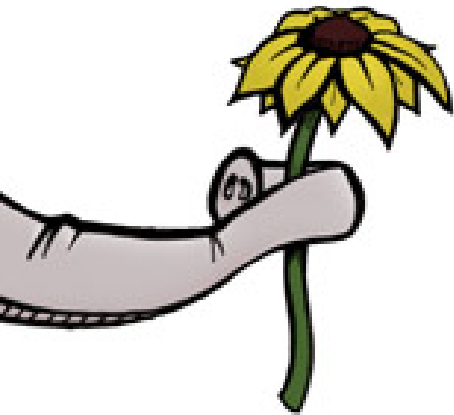
~ Harold S. Geneen

Remember that your uncertainties may be different than your children’s. How you cope with uncertainty will deeply influence how your children will deal with it. You do not need to turn all unknowns into knowns. Allow the shreds of uncertainty to settle around all of you and try to become comfortable with not knowing. Sometimes a leap of faith will transport you and your children beyond uncertainty. Sometimes focusing on something else positive and out into the future will help. And sometimes screaming and yelling will vent the frustration.

We know that if we can identify and talk about our uncertainties and doubts, so can our children. Together, you and your children can learn to live with uncertainty. Hope does not always mean cure. You can hope for many things amid uncertainty. And we can all learn to live in hope. Holding hope in one hand and uncertainty in the other is achievable. Focusing on hope can get you and your children through the adversities cancer presents.

“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 loom as the main unspoken “elephants in the room;”

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

In this section we offer answers to these three looming questions you are almost certain to hear from your children, followed by five simple steps to successfully face the uncertainties of your illness together. Subsequent pages provide specific age-appropriate ideas for what to say, do and observe with your children. There are also numerous resources for each age group in the *Ideas and Resources* section.

Will Life Ever be Normal Again?

The most common expression we hear 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 children.

“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 underscore those for your children. Find a name for the new normal in your home and family, such as LAC (Life after Cancer) or LWTE (Living with the Elephant). Identify the things that will stay the same. Explain the plan for the parts that will have to change. Have your children help with this.

Will Your Cancer be Cured?

This question begins at diagnosis and returns frequently. Your children will ask if you are better now and if the cancer is gone. When you do not 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 the family members.

If you believe you will be cured despite your physician's concern, tell your children what you believe to be true. Even if you do not believe you will recover, let your children know that you and they should continue to hope for the best and try to be ready for the changes that might come. Children need 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 certain you are being honest with yourself and your children. Whether your cancer will or will not be cured, there is always hope.

Children need 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." Refocus your hope on more readily attainable achievements, such as being at your child's first soccer game in the spring, attending Aunt Lynda's wedding, going fishing again or just having a good laugh once today.

"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 children know what you know. Put it in their language. Predict only what you can and leave the rest alone.

Some cancers come back and some just stay with us. Many types of cancer are being viewed as chronic illnesses. Children need to know how you and they might recognize if the cancer comes back. For example, are there tests that can be done, or what symptoms might announce its return? Share any ideas you may have with your children about what you might do if it does come back, such as treatments you may pursue or surgery that may be required. Again, let them know what the possible outcomes may



be. Children of all ages, just like adults, do better when the possibilities have been discussed.

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 just seem to miraculously go away. You can tell your children that you will hope for a new treatment or that your cancer just goes away, but you will also deal with what is real right now.

"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 a very real fear for most of us. We gradually come to terms with death throughout the course of our lives. Our answers and feelings vary at different stages of our lives. Cancer puts this subject right there in the room like an even bigger elephant.

Parents often struggle the most with the concept of death when they think about prematurely leaving their children. Frequently, discussions are ignored or at best minimized. The fear of addressing death can make the times when death is very near even harder and the loss more difficult for everyone.

Death needs to be discussed just like all the other tough issues. As it is confronted, the fears can lessen some as the uncertainties are addressed. 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 developmental level, their parents' acceptance and communication, and the beliefs the family holds.

Ask your children what they know about dying and death. Be with them in their fears, in their indifference and in their anger. 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 discuss fears that may arise from these changes and what might happen next. Prepare them for the changes with discussions, examples, even pictures and photographs.

See the *Ideas and Resources* section for materials and resources to help children whose parent 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 children with you on your journey through cancer treatment. Let them know what you know, as well as what you don't know. By sharing your uncertainties, they can verbalize their own. It is okay to be uncertain.
2. Begin by naming the uncertainty you share, such as, “We do not know if the cancer will come back.”
3. Reassure your children that even if the two of you don't know an answer, you will be okay. Children have a harder time accepting the unknown, but more importantly they need to be reassured that even if the answers aren't clear, they will be okay and that someone will be with them every step of the way. For example, you may say, “That is something I do not know the answer to now, but I do know that we will look for the answer together. Even if we do not find the answer, we will be alright. There are lots of things we do not 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, both religious and secular. Look through them to see what might fit for your family and children.
5. Keep the communication lines open and the dialogue ongoing. Discussions take time and often require repetition as doubts and uncertainties reappear.

“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 any more 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 – 2 Years

Developmental Factors

Trust, Mistrust and the Beginning of Autonomy (Independence)

The dictionary defines trust as “reliance on the integrity, strength and ability of a person or thing; confidence.” In these early years, your infant or toddler is developing a sense of trust. So it is particularly important that you be honest, strong and strive to be confident – even when you are not feeling your best.

In the first two years of life, babies change and grow so rapidly. There is something new for you to notice from one moment to the next. Enjoying your child's development can be the best medicine for keeping your mind off your worries and symptoms related to your illness or treatment. The warm, secure and stable environment you provide your infant or toddler 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 your child, keeping a positive tone in the home and by maintaining your child's routines (e.g., mealtimes, playtimes, sleeptimes, etc.).
- Try to keep your focus on what is the same and what is positive, not what is different.
- Talk about the changes positively but be prepared 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 occurs. Providing comfort and structure will help ease the uncertainty of change.
- Make explanations short and simple.

- 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. Reassuring them that they will always be cared for and loved is most important. This may well be harder for you than for your children.

What to Do

- Add small positive things to make any changes more interesting and desirable. Toddlers and infants will adapt 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 infant or toddler finds calming.
- Allow sadness and uncertainty to be expressed in tears or as tantrums. Recognize the need for the emotions to come out; then keep the comfort coming.
- Make or buy something that is particularly 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 present 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 present as often as possible to help facilitate bonding.
- Cry together – and be tough together. Sometimes parents need to cry with their children, be held, soothed and touched by their children.



What to Observe

Changes in behavior for children, adolescents and adults during stressful times are normal. These changes may include regression or returning to less mature behaviors. Some behaviors which may occur include:

- Not sleeping well
- Wanting to nurse or drink from a bottle more than normal
- Becoming irritable
- Crawling rather than walking
- Not eating
- Lack of interest in play
- Lack of expression of feelings or eye contact
- Listlessness

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 frequent, or if you intuitively sense that something is wrong. This is the time to consult a professional such as your physician or pediatrician, a child development specialist, or counselor.



Facing Uncertainties

3 – 5 Years

Developmental Factors

Independence, Sense of Self and Initiative

This is the time when children are learning about independence. Three- to five-year-olds see the world as revolving around themselves. Separation is wanted and feared at the same time. Some child development experts view this time as the “first adolescence.” Because illness may force your child to become more independent, he may resist it as it has been imposed upon him and is not his choice. It is important to set firm, loving limits.

What to Say

- Children of this age need to be reassured that neither they nor anyone else did anything to cause your cancer, or to make it return or worsen. They also need to know that there is nothing they could have done to prevent it.
- Uncertainty is a breeding ground for fantasy and unrealistic thinking. As long as you help your child realize the difference, sometimes letting her make up stories or having you make them up helps her to cope and to hope.
- Tell your child what will be different and what will be the same.
- Ask your child questions about how he feels and what he thinks is happening. Ask open-ended questions so he is encouraged to offer a fuller answer.
- Keep your language simple, clear and direct, without using euphemisms. Calling your cancer a “boo boo” or an “owie” can create confusion and worry the next time your child scrapes her knee.
- Above all, be truthful. Even if the truth is not fully understood today, in time this will nurture your child’s trust.
- If death is a real possibility, talk about it. Listen to and understand your child’s thoughts of what death is. Encourage him to talk about what he is feeling. Let him know it is normal and good to get the



sadness out. Tell him specifically how he 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 ill parent.
- 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 photos of mom or dad or pictures from a book. Describe what might be seen and how the child might feel. Do not force, but encourage 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 her. And record yourself talking with her and reading stories. Make special notes using a page of stickers to show her the things you liked and those you didn't like.
- Remember that all losses – big and small – are grieved. Ask them what they miss since the cancer has been with the family and encourage them to talk about the losses.

What to Observe

Changes in behavior for children, adolescents and adults during stressful times are normal. These changes may include regression or returning to less mature behaviors. Some behaviors which may occur include:

- Thumb-sucking / wanting a pacifier
- Bedwetting / potty accidents
- Sleeplessness
- Curling up in a corner
- Clinging



- Whining
- Inattentiveness
- Angry outbursts
- Aggression
- Separation anxiety

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 frequent, or if you intuitively sense that something is wrong. This is the time to consult a professional such as your physician or pediatrician, a child development specialist, or counselor.



Facing Uncertainties

6 – 9 Years

Developmental Factors Industry and Competence

These are the ages when children become more interested in real things and less engaged in fantasy. Following rules is important, and children will often make up elaborate rules for games. Their attention spans are growing longer, and they tend to stick more with a task and enjoy working at things. Doing things right is important. Working and playing with others is now more common. They like to master things and need to feel competent.

Six- to nine-year-olds are becoming more social and desire to be a part of all that is going on. Yet, they can also feel inadequate, especially if their family or their own lifestyle seems different from others. The neighborhood and school are growing in importance, while the family's authority is somewhat less than it once was.



What to Say

- Because more detailed explanations are more important at this age and a child's desire for logic is stronger, uncertainty can be even more difficult. Tell your child what you know and what you do not know. Reinforce that you will tell her of any new information as soon as you learn it.
- Be understanding of how frustrating it is to not know.
- Prepare them 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.
- Seize the teachable moments whenever they arise. A scene in a TV show or an ambulance racing past your car may present the ideal moment to talk. For a relatively short attention span, these spontaneous flashes of communication are often better than long, planned conversations.
- Encourage your child to express his feelings of frustration and sadness.
- Give large doses of reassurance that your child will be well cared for by those who love her.

- If death is a real possibility, talk about it. Ask your child what he thinks death is all about. Then share your own thoughts. Encourage him to talk and share his feelings. He will likely not only worry about your death, but he will worry about his own death, as well. Take the time to talk about that, too. Reassure him of who and how he 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 her own. Tell her it is okay 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 frightened.
- Create some special rituals you share exclusively 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 for comfort, such as a stone, a good luck piece, a ring or even a family keepsake.
- Identify and discuss ways your child can help you.
- Encourage your child to talk about her feelings with a trusted teacher, counselor or social worker at school.
- Find out if there are other children of your child's age whose parents have cancer and connect with them personally, by e-mail or in a chat room.
- Be available, even by phone, if your child needs to talk to you about his fears, whenever he needs to talk.



What to Observe

Changes in behavior for children, adolescents and adults during stressful times are normal. These changes may include regression or returning to less mature behaviors. Some behaviors which may occur include:

- Thumb-sucking
- Bedwetting
- Sleeplessness
- Withdrawal / isolation
- Acting out
- Irrational fears
- Obsessive-compulsive or ritualistic behaviors
- Psychosomatic complaints
- Clinging / separation anxiety
- Tics
- Destructive behaviors
- Over-eating or not eating
- Acting like the parent (needing to be the 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 frequent, or if you intuitively sense that something is wrong. This is the time to consult a professional such as your physician or pediatrician, a child development specialist, or counselor.

Facing Uncertainties

10 – 13 Years

Developmental Factors

Curiosity about Sexuality, Reliance on Friends
and Developing Independence.



The early teen years are a time of curiosity and confusion. As they move toward independence, preteens are particularly vulnerable. While they would rather not admit it, they still feel a need to know that their parents are in charge. This is also a time of great strain on parents, as they are torn between allowing their child to grow up while still feeling the need to protect him.

Preteens are undergoing confusing changes in their bodies and body image. There are significant mood swings. They look up to heroes and heroines, and have crushes on others. They manipulate others to gain a sense of importance.

By its very nature, early adolescence is full of uncertainty, as the process of developing a sense of self begins. The added uncertainties of a parent's serious illness makes it especially challenging for a preteen to find his place at home. While he does not want to be as close to his parents as before, he still yearns for the reassurance and love of home.

At the same time, early adolescence is a time when understanding and abstract thinking are possible, so detailed explanations of your disease and more involved discussions of the unknowns are possible.

What to Say

- Explain what is going on as truthfully and completely as possible and let the questions come naturally.
- Ask open-ended questions about feelings that beg more complete and thoughtful answers.
- Talk about recurrence of your illness even though your child may not stay focused very long. Prepare her for what you know might happen.
- Speak with your child about their friends, and whether he feels comfortable talking about your illness and the changes it is causing in your home.

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

What to Do

- Let your preteen's school know about the progress of your illness and changes that he is facing at home. Make sure, too, that your child knows you are informing the school, and encourage him to ask for help when he needs it.
- Persuade your child to spend time with friends and to have your child invite friends into your house. Ask her to tell her friends of your cancer and the circumstance surrounding it.
- Encourage your preteen to share his 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 her activities or events.



- Establish a daily check-in time. Set aside 5–10 minutes every day to hear about the details of his day. Ask about schoolwork and afterschool activities. Invite sharing about successes and frustrations, as well as questions about any aspect of how things are going now or what to expect in the future. Most importantly, listen to him.
- Allow your child to help you. Be careful not to let her overdo it as she may begin to feel obligated and build resentments. Balance is important.
- Write notes, letters and e-mails to your child. Sometimes writing about the uncertainties is easier than talking with him, and still provides a positive way of communicating. Journaling is also a good idea for you and your child.
- Encourage your preteen to use art, music and sports as outlets for frustration and confusion.
- Ask your preteen to teach you something you do not 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 roadtrip, go to a concert, or just 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 Observe

Changes in behavior for children, adolescents and adults during stressful times are normal. These changes may include regression or returning to less mature behaviors. Young people in this age group are struggling with uncertainty. It can be challenging to discern normal from abnormal behaviors, as there is increased volatility and vulnerability in these years. Some of the behavioral changes you should look for include:

- Excessive anger or withdrawal
- Poor schoolwork
- Frequent crying
- Refusal to eat or over-eating
- Dramatic mood swings
- Lack of friendships
- Uncomforted fears
- More than usual preoccupation with fantasy
- Clinging / separation anxiety
- Psychosomatic complaints

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 frequent, or if you intuitively sense that something is wrong. This is the time to consult a professional such as your physician or pediatrician, a child development specialist, or counselor.

Facing Uncertainties

14 – 17 Years

Developmental Factors

Separation, Identity and Devotion to Friends and Causes

This is the age when your teen begins to act as an independent person and seeks his own identity as an individual and a sexual being. It is a time of struggle with social interactions and moral issues. Teens may withdraw from responsibilities and family interactions in favor of being alone or as a way of “putting ones foot down.” They are restless, and seek to separate themselves from family. Adolescents tend to be idealistic and readily substitute ideals for experience. They are devoted to friends and causes. Mastery of a skill is crucial to their self esteem and identity.

While this is a time when adolescents try to distance themselves from family, it is also a time when limits and the reliability of family are important. A seriously ill parent compounds this dilemma. They are torn by their desire to be at home and to be helpful, while being drawn to break away. The result can be increased confusion and inner turmoil.

“Me-centeredness” is commonplace. Teens may express anger at the illness and the changes and uncertainties it causes. Above all, adolescents want to feel like they belong, while needing to have their own identities. They may try out a variety of identities in search of their own, including sexual identity and relationships.

Cancer, and its uncertainties, may force a child to become independent earlier than normal, to regress and remain dependent, or to rebel and find a place to belong away from family.



What to Say

- Even if your adolescent does not seem to be listening, what you say is important.
- Talk from your heart and let your teen 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 teen to express his feelings, and remember that anger is usually the outward expression of sadness and fear.
- Ask your teen open-ended questions about what she is thinking and feeling.
- If talking becomes difficult, utilize other forms of communication to express yourselves, such as notes, letters and e-mails.
- Identify at least one other adult family member, school teacher, neighbor or friend your child can talk with and who will spend time with him away from the uncertainties of home. You may ask one or several people to support him in these ways.
- If death is a real possibility, talk about it as early as possible with your teen. Ask her what she understands and feels about death and dying. Let her tell you what he 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. Exchange regrets and forgiveness, if necessary. Reaffirm your plans for who will care for her and her siblings. The *Ideas and Resources* section offers a variety of sources to help you talk with your teen about death.

What to Do

- Search for ways to make the times you have with your teen count.
- Do what gives you energy, not what drains your energy.
- Continue to set limits for your teen; but once in awhile make an exception.
- Dig out old photo albums, so you can relive memories of good times, including stories of his childhood and yours.
- Allow your teen to help you and the family. Be clear about the limits of your expectations to avoid resentments. Thank her for her efforts.
- Make time to enjoy relaxing, everyday activities together, such as playing games, watching TV and movies, listening to music and making things together.



- Drop little personal notes in your child's lunch bag or backpack to let him know you are interested in him and his activities.

What to Observe

Changes in behavior for children, adolescents and adults during stressful times are normal. These changes may include regression or returning to less mature behaviors. This age group typically demonstrates a wild mix of emotions and challenges. Stay tuned in to your child's demeanor, behavior and feelings. It may seem that nothing is normal. Some of the behavioral changes you should look for include:

- Extreme anger or aggression
- Withdrawal / isolation
- Depression
- Eating too much or too little
- Apathy
- Failing grades and behavioral problems in school
- Friends pulling away or your child pulling away from friends
- Addictive or risky behaviors
- Sleeplessness or too much sleep

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 frequent, or if you intuitively sense that something is wrong. This is the time to consult a professional such as your physician or pediatrician, a child development specialist, or counselor.

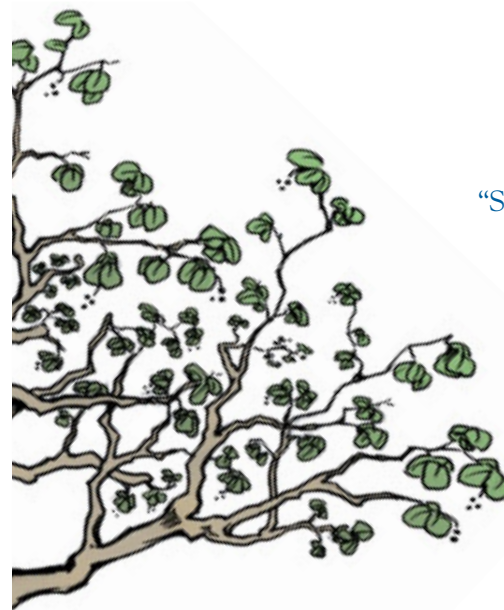


Special Circumstances

The challenges a family was dealing with prior to the diagnosis of cancer typically remain, often making it even more difficult to cope with a cancer diagnosis. Unfortunately, the original challenges may even worsen 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 around and through. Often 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 own illness and communicating your needs more challenging.

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, 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. Ultimately, it makes putting your needs first an almost insurmountable task.

The ways you coped in the past will help determine how you cope now, what your children can expect and what you can expect from them. We know that past coping skills help strengthen us against new stressors. If you have coped poorly with challenges in the past, now is the time to seek the help you need to face your new trials 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 look after. It can send a wave of panic through you. How will my loved one get the care he/she needs if I am sick? How can I deal with my own cancer and the treatment, and still care for my children and family?

And your loved ones are worrying about you, even if they do not show it.

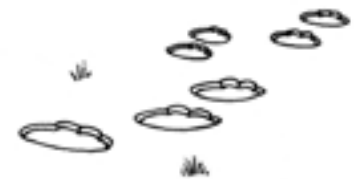


Suggestions

- Put your own oxygen mask on first. You need to have enough personal strength to help someone else.
- Allow yourself time alone (or with a good friend) to think your circumstances through and identify what 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, your illness may hasten you toward your goal.
- Identify other caregivers who can give you a break.
- Do not underestimate the understanding and need for involvement of the person who has some limitations. He/she most likely senses what is going on and wants to be included in discussions and activities, even if the words are not fully comprehended.
- Do not 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 web site (CaringBridge.org) or other Internet sites to keep family members and friends updated. See the *Ideas and Resources* section for more sites.
- If you attend support groups related to your special circumstances, continue attending and make use of the groups' resources. If you do not currently attend a support group, consider attending 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 whose energy-sapping traits you should avoid.



- Recognize the things that bring you peace, calm you and reduce your stress level, and incorporate more of them more often into your life. Take hold of those things that restore your energy and perspective, such as music, nature, art, books, movies, fishing, gardening, etc.
- Learn to recognize when your stress is increasing and ask for help before it shows up in unwanted forms.
- Seek community-based or personal options for respite care for your child or loved one, and make use of them.
- Maintain a journal in which you can detail 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 illness. If a child is accustomed to the parenting arrangement he has, it will make it a little easier to integrate the new reality of your illness. A recent divorce or death will likely complicate the challenges facing you and your children.

Because you and your spouse are no longer together, your children may worry even more about losing you to cancer. Their concern is very real and they will need your reassurance. You can tell them that you will do all you can to stay with them, but if circumstances change, you will tell them.

The ways you coped in the past will set the course for how you cope now and what your children can expect. This will still be a crisis for all of you, but we know that past coping experiences help strengthen us 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 your new trials successfully. If you can look back and see some of the strength you called upon before, it will be there again.

Though you may have talked with your children about your cancer from the very start, it is important to take as much time as needed to fully discuss your diagnosis and treatment with them. Before you begin these discussions, sort out your feelings with someone you trust and consider having that person present when you talk with your children.

Take time to catch your breath and think through all that you want to say. You do not need to say everything at once. Try not to minimize this additional stress. The elephant is in the room and it needs to be discussed.

Do not be afraid or embarrassed to let your children see your emotions. Allow your feelings to surface; even name them,



“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 children know it is good to let the sadness out, but that it does come and go. Reassure your children that they will be well cared for.

While most people who are single were single prior to their cancer diagnosis, sometimes the diagnosis contributed to you or your spouse leaving. Your children sense this and may be conflicted about their loyalty to you and their absent father or mother. It is important to not blame your spouse in front of your children. They likely know already, but the absent spouse remains their father or mother, and their relationship with that person will always be important and perhaps 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:

- Consider having a close friend or family member present when you break the news of your cancer diagnosis to your children.
- Be prepared to answer clearly and thoroughly the important question about who will take care of them if or when you are too sick.
- Let your children know that you understand they are afraid to lose you.
- If your spouse died, your children will naturally worry more about you dying, and will need you to tell them all that you know and what it will mean for them. 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 children’s needs for additional support during this time.



- If you know the cancer will require aggressive treatment, it will be important that you make arrangements with others, such as school counselors, ministers, therapists or family members, to offer your children a shoulder to lean on and an ear to listen.
- In addition to school and community support, identify one person – a close friend or family member – who can serve as a trusted confidant to your child.
- Strive to keep your children’s routines as consistent and stable as possible.
- Ask your children to help in ways that make them feel valued and appreciated.
- Be gentle to yourself and your children. Accept that you may not be able to do all that you could before.
- Seek counseling for yourself to gain additional support and understanding, and to process your emotions with minimal exposure to your children.
- Treat yourself to alone time.
- Think “outside the box” for creative solutions to your situation.
- Talk with hospital and clinic social workers for assistance with financial and other practical day-to-day issues.
- Pay attention to feelings of being overwhelmed. And do not hesitate to ASK FOR HELP!

As mentioned previously, watch your child for signs of difficulty in coping with the changes. Ask for and seek help for yourself and your children if the signs are uncharacteristic and persistent. 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 evident to us when a cancer diagnosis is made.

For you, and for your children, a cancer diagnosis conjures the memory of a loved one who died from cancer or even from another cause. There are all the dreams and imagined losses your children will anticipate, “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 children 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 by your children. Each of us grieves differently. Some losses, such as the death of a loved one, are more profound, creating a seemingly impossible void. Others, such as the loss of a job, an income, a friend or a home, may appear less overwhelming, yet their impact may be every bit as far reaching. A cancer diagnosis creates its own array of personal losses, including the loss of energy, anonymity, hair or a part of one’s body. Sometimes the diagnosis can trigger 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 children, like you, will feel these losses. And when they multiply, as they can with cancer, they need to be expressed and addressed.

“Grief is itself a medicine”

~ William Cowpers



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

Find someone with whom you can share your loss and the feelings it creates. Naming your grief allows you and your children to better manage it. Anger, sadness and despondency are common. You may return to these feelings several times. During the process you will experience and express a host of difficult and painful emotions. Postponing or trying to stuff them will only prolong and intensify the feelings. They will simply resurface 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 children 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 experiencing 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 children can hope for together. Write your hopes on a list and keep adding to it over time.
- If grief leaves you feeling deeply depressed and it does not improve with time, talk to a good therapist.

“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

“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 accompany it. Like any resource list, it will never be complete. Explore what you find here, but do search beyond these pages and when you find something you like, please let us know.

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 simplistic and 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 under twelve years, many can be enjoyed by teens and adults as the truths span all ages.

Teen Books. The number of books written about cancer specifically for teens is limited. Yet, some teens will still enjoy reading the children’s books. Teens 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 teen.

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.

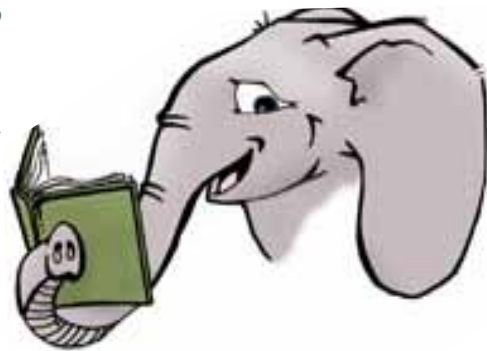
Storytelling. You and your children may enjoy writing or telling your own story. You may dream up a story using your children as the central characters. Telling stories helps us heal. Many of the authors listed here write from their own experiences, having lived the story they write about. The resulting 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 appropriate for your child and you.
- 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 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 interest wanes, 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

Someone I Really Love Has Cancer Pre-school – Early Elementary
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 Pre-school – Elementary
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** Pre-school – Elementary
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? Pre-school – Elementary
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** Pre-school – Elementary
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** Pre-school – Elementary
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 Pre-school – Elementary
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 Pre-school – Elementary
by *Marge Heegaard*

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

Promises Elementary Ages
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 Elementary Ages
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.

Becky and the Worry Cup: A Children's Book About a Parent's Cancer Elementary – Early Teens
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.

Can I Still Kiss You? Answering Your Children's Questions About Cancer Late Elementary – Early Teens
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 Late Elementary – Early Teens
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.

When Your Parent Has Cancer: A Guide for Teens 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 www.Cancer.gov or by calling 1-800-4-CANCER.

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

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

H is for Hair Fairy: An Alphabet of Encouragement and Insight for Kids and Kids at Heart with Cancer All Ages
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 All Ages
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 All Ages
by *Sheri Lichtenstein*

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

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

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

Our Family Has Cancer Too All Ages
by *Christine Clifford*

Pages of cartoons that illustrate the humorous and serious side of cancer in the family.

The Paper Chain All Ages
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 All Ages
by Jamie Reno

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? All Ages
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

Angel Kisses Elementary Ages
by Katie Dorn, Ginny Kelley and Amanda Garcia
A lyrical story that helps make religious sense of cancer.

Drawing Together to Learn About Feeling Elementary Ages
by Marge Heegard

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

Bridge to Terebithia All Ages
by Katherine Paterson and Donna Diamond

A story of friendship, imagination, love and loss written about two fifth-graders.

Fall of Freddie the Leaf All Ages
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: All Ages
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 All Ages
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

Finding Hope when Dreams Have Shattered Teens – Adults
by Ted Bowman

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

Kitchen Table Wisdom Teens – Adults
by Rachel Naomi Remen

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

Loss of Dreams Teens – Adults
by Ted Bowman

Dealing with non-death losses including dreams. A practical and poetically resourced book that provides perspective on a topic not often anticipated or discussed.

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.

When Bad Things Happen to Good People Teens – Adults
by Rabbi Harold Kushner

Thoughts about the "why" question and ways to respond to "bad things." A perspective on God, life and suffering.

Helping Children Grieve When Someone They Love Dies Adults
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.

Healing a Child's Grieving Heart: All Ages
100 Practical Ideas for Families, Friends & Caregivers
by *Alan D. Wolfelt*

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

Children's Books About Feelings

**Alexander and the Terrible, Horrible,
No Good, Very Bad Day** All Ages
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 All Ages
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 All Ages
by *Maurice Sendak*

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

The Grouchy Ladybug Elementary Ages
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. A very unique book that fosters discussion between parents and kids.

I Was So Mad Elementary Ages
by *Mercer Mayer*

A book for very young children about frustration and anger.

The Very Lonely Firefly Elementary Ages
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 discussion on what we feel like when we are feeling lonely.

There's a Nightmare in My Closet Elementary – Early Teens
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

Babar All Ages
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 All Ages
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 All Ages
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 All Ages
by *Mo Willems*

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

The Saggy Baggy Elephant All Ages
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 discusses 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 physicians 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 discusses 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

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 7-12 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 twenty years.

When a Parent is Very Sick

by Edna LeShan

This book discusses typical feelings and incidents encountered by a child 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 www.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 www.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 www.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 discussions with their children. It can be ordered from Fox Chase Cancer Center at 888-369-2427 or www.fccc.edu.

We Can Cope: When A Parent Has Cancer

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 discussing 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 800-848-3895 or www.wecancope.com.

Internet Web Sites

www.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..

www.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.

www.CancerCare.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: www.LungCancer.org.

www.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.

www.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.

www.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.



www.Livestrong.org

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