## **Breaking the News Preparing Yourself**

"We are always communicating, even when we do not speak." ~ Virginia Satir

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

### Setting the Stage

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

#### "Pace yourself. An elephant can be swallowed only one bite at a time." ~ Anonymous

Pay attention to your child's attention span. Children have varying attention spans, and so do you. There will be times that are better than others to talk to your child about



what cancer means to your family. Use the metaphor of the elephant if it helps. Don't worry if your child tunes out after just a few minutes. Ask what he or she is feeling as you talk.

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

### **Talking About Cancer**

- Share your feelings, but focus on your child's feelings more than your own.
- Put two of the most common fears of children at ease: Say, "You cannot catch cancer and you did nothing to cause it."
- Use the real name of your cancer.
- Ask your child what he or she already knows about cancer. Don't be afraid of talking over his or her head. Give your child credit. He or she understands more than you realize.



- Tell your child your best understanding of what will happen and when. Children need to have anchors, even dates and times, if possible. Making a calendar with medical appointments listed can be helpful.
- Children want life to be predictable. Let your child know some things may change and how that might look. Reassure your child that he or she will always be cared for. Explain that things that will not change in his or her life.
- Encourage questions, but realize you may not always know all the answers. You can say, "I don't know but I will find out." Follow your child's lead as to how much he or she wants to know.

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

### Keep in Mind

*Every child is unique.* 

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

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

Children absorb as they are able.

*Honesty is better than secrets.* 

*Providing structure and predictability is important.* 

Look through the eyes of your child.

*Be curious about your child's experience.* 

Mistakes made with love are easier to correct.

Simplify, simplify, simplify.

Not all children will have questions.

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



## **Breaking the News** Infants to 2 Years

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

### **Developmental Factors**

#### Trust, Mistrust and the Beginning of Independence

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

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

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



### What to Say

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

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

### What to Do

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



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

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

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

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



### **Breaking the News**

3 to 5 Years

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

### **Developmental Factors**

#### Independence and Sense of Self and Initiative

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

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

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

### What to Say

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

### What to Do

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



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

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

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

### **Breaking the News**

6 to 9 Years

"Tell me I'm clever. Tell me I'm kind. Tell me I'm talented. Tell me I'm cute. Tell me I'm sensitive, graceful and wise. Tell me I'm perfect – but tell me the truth." ~ Shel Silverstein

### **Developmental Factors**

#### **Industry and Competence**

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

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

feel good about themselves.

This is also a social stage when children can have low self-esteem, especially if they feel different about



themselves or the changes in their family. The neighborhood and school are becoming important, and family is a little less the authority.

### What to Say

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

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

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

### What to Do

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



- Look at pictures of the human body and point out where the cancer is. See the *Ideas and Resources* section.
- Take time to snuggle and look at pictures together. Don't worry if your child's need for attachment is stronger now or if your child is afraid to get close. Talking about the feelings often allows the real needs to surface.

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

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

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

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





### **Breaking the News**

### 10 to 13 Years

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

#### **Developmental Factors**

# Curiosity about Sexuality, Reliance on Friends and Developing Independence

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

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

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

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



### What to Say

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

### What to Do

- Try to keep home and school routines as normal as possible.
- It may be helpful to post a weekly schedule for your child to check that includes everyone's activities, tells who the daily go-to person will be at home and who will be providing carpooling or other supports.
- Make after-school schedules as simple as possible. Talk with your child about which activity is his or her favorite and which may be put on hold for awhile, if needed. It is better for your child to be present to one favorite activity regularly than to irregularly attend several.
- Hug your child when he or she needs it and when your child does not.
- Enjoy some fun, quality together time.
  Play a game or watch a movie together.
- Talk openly about both of your fears.
- Look over old pictures and point out stories of your child's strengths and good times.
- Read about cancer together or give your child an assignment to find out something specific about your cancer.



- Invite your child to come to an appointment with you and talk about it afterward.
- Draw, paint or write together or separately about the cancer and how it affects your family. Compare notes and drawings.
- Try to understand some of the fantasy books or games that interest your child – or at least parts of them. Let your child teach you or explain what he or she likes about the book or game.
- Continue to be involved, or have your partner or a friend be involved in what is going on with your child. Talk to school counselors and teachers about his or her work. If it is OK with your child, share about what is going on at home.

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

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

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

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

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



### **Breaking the News**

14 to 17 Years

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

### **Developmental Factors**

#### Separation, Identity and Devotion to Friends and Causes

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

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

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

They are loyal to causes and their friends.

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

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

friends and other activities. Let your child know that you understand it is hard to live face-to-face with cancer.

and go to health care appointments with you, if that feels comfortable.

What to Say

Use words that accurately describe what is going on with you. Talk openly and don't keep important information from your child. He or she is capable of understanding much more than you might think.

Explain the cancer clearly. Let your child read about it

Ask your child to tell you what scares him or her about the cancer, if able to. Fear of death is often a large part of your child's concern.

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



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

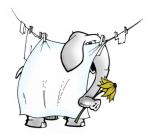
Some adolescents may "disappear," finding comfort in

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

### What to Do

- Provide consistent structure, limits and expectations for your child. Tell your child to continue to do his or her chores and homework as well as other responsibilities. Choose your battles carefully, and make sure they are worth it.
- Connect your child to recommended Internet sites. Help your him or her find online cancer chat rooms and encourage your child to talk with other teens facing the same issues. See the *Ideas and Resources* section. Let your child become educated about your cancer.
- Watch a movie or play a video game together, especially if you don't have as much energy as usual. Lighthearted "chill" time is a great way to spend quality time together.
- Encourage activities that your child might do at home with friends.

 Be aware of your child's role with younger siblings. Your child will need permission to have his or her activities without feeling he or she is being selfish. At the same time, finding ways he or she can provide emotional support to younger siblings is a powerful lesson about love and responsibility within a



family. Be aware that adolescents who feel the need to move into parenting roles may also over-parent their siblings.

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



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

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

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

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

