

Facing Uncertainties

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

~ Gilda Radner

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



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

"Uncertainty will always be part of the taking charge process."

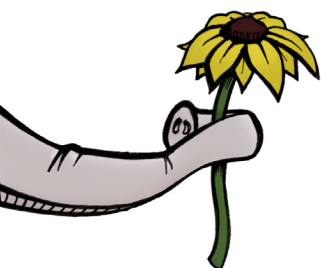
~ Harold S. Geneen

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

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

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

*"Once you choose hope, anything's possible."
~ Christopher Reeve*



Facing Uncertainties

Three Inevitable Questions

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

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

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



Will Life Ever be Normal Again?

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

But life does not go back to normal.

Instead, you learn to live a new normal.

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

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

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

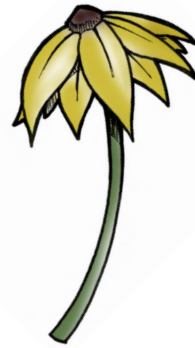
~ Alfred Adler

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

Will Your Cancer be Cured?

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

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



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

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

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

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

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

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

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

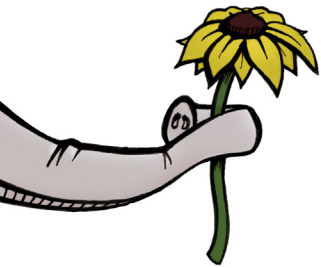
It is true, and can be said, that cancer research is going on all the time and new treatments are being developed, possibly while you are dealing with your cancer. And sometimes, cancer really does seem to miraculously go away. You can tell your child that you will hope for a new treatment or that your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

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

Will You Die?

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

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



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

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

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

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

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

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

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

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

Five Basic Steps to Facing Uncertainties Together

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

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

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

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

Keep in Mind

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



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

*Your uncertainties and those of your children
may be different.*

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

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

Children face tough stuff slowly and need time to adjust.

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

Some things will never be understood.

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

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

There is laughter amid sorrow and sorrow amid joy.

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

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

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

Facing Uncertainties

Infants to 2 Years

Developmental Factors

Trust, Mistrust and the Beginning of Independence

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

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

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



What to Say

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

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

What to Do

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



What to Watch for

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

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

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



Facing Uncertainties

3 to 5 Years

Developmental Factors

Independence, Sense of Self and Initiative

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

What to Say

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



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

What to Do

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



What to Watch for

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

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

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



Facing Uncertainties

6 to 9 Years

Developmental Factors

Industry and Competence

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

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

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



What to Say

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

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

What to Do

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



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

What to Watch for

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

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



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

Facing Uncertainties

10 to 13 Years

Developmental Factors

Curiosity about Sexuality, Reliance on Friends and Developing Independence.

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



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

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

What to Say

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

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

What to Do

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



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



What to Watch for

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

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

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

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

Facing Uncertainties

14 to 17 Years

Developmental Factors

Separation, Identity and Devotion to Friends and Causes

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

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

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

They are loyal to causes and to their friends.

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

What to Say

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



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

What to Do

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



What to Watch for

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

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

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

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

