When a child has cancer, it’s a crisis for the whole family.
When a child or teen is diagnosed with cancer it’s a blow to the parents, siblings, and others who love them. The cancer creates a crisis in the life of each family member. Normal daily life is changed. Parents must be away from work. Siblings might need to be cared for by relatives or neighbors. The ill child (the patient) becomes the major focus of family time and attention.

Parents should be given detailed information about the diagnosis and treatment. They need to be told about the short- and long-term effects of treatment. They may have to think about things like the risk of heart or lung damage, second cancers, or fertility problems that their child may someday face. They will have to make tough decisions and must understand the treatment plan well enough to feel right about giving permission for tests and procedures. They have to sign treatment consent forms and make important decisions about what’s best for their child. This is a lot to ask.

To add to the stress, all of this happens in a very short time. In the first days and weeks after diagnosis, parents who have been through it describe feeling as if they are on an emotional roller coaster, or in a bad dream. Just about all parents going through this difficult time seem to have the same feelings. But what parents say or do to express these feelings differs. How they handle their emotions depends on their own life experiences, cultural differences, and their personal coping styles when faced with major stress.

**How do parents usually react to a child’s cancer diagnosis?**

All parents seem to feel shock, disbelief, fear, guilt, sadness, anxiety, and anger. In this situation, just about any feelings could be considered normal for parents and other family members.

**Shock**

No one is ever prepared to hear that their child has a life-threatening illness. At first, parents may be afraid their child is going to suffer and perhaps die. At the very least, they know their family will go through major changes and upheaval. Some have described feeling numb or as if they have been hit over the head. Parents also report feeling confused or being unable to hear, remember, or think clearly when the doctor explains their child’s diagnosis or treatment plan. This numbness is normal. It helps them slowly get used to the painful feelings. It gives parents time to absorb and face strong emotions and hard decisions.
What can help parents get through the shock?

- Knowing that this reaction is normal.
- Seeking comfort from one another or from other family members or friends.
- Talking with the team social worker or nurse about their feelings.
- Asking a family member or friend to go with them to doctor visits and take notes.
- Recording (with permission) or taking notes at important meetings, then going back over them with others.
- Reviewing information given to them by the treatment team.
- Asking staff to repeat information.
- Remembering that feelings of shock will pass with time.

Disbelief and denial

When parents are first told their child has cancer, it might seem unbelievable. Their child may not seem sick enough, or look sick enough, to have such a serious disease. They may question whether the lab could have made a mistake or if the test results really belong to another child. They might want to check on the reputation of the staff or medical center. They may wonder if the medical staff knows as much as they should, and may decide to get a second opinion (which is always a good idea).

The disbelief or denial that strikes at first can help buffer and delay painful feelings. It’s also a way for parents to gain time to adjust to the reality of their child’s diagnosis and do what it takes to be sure their child will get the best treatment. Some denial is normal and not a problem unless it keeps a child from getting timely treatment.

What can help parents get through the disbelief stage?

- Asking and getting answers to all your questions.
- Calling the American Cancer Society or other reliable sources for more information about diagnosis and treatment.
- Checking on the reputation of the medical center and qualifications of the treatment team.
- Asking for help in getting a second opinion.

Fear and anxiety
It’s normal to feel anxious and fearful when facing unfamiliar events and outcomes that can’t be controlled. And nearly everyone has a fear of cancer. A family’s only encounter with cancer may have been with an older family member (when it might have seemed a little easier to accept or understand). Or they might have heard stories about the problems other family members or friends had with certain treatments, or that having cancer is a death sentence.

Doctors cannot guarantee exactly how each person will respond to cancer treatment, and the fear of death is real. Trusting the knowledge and skill of others to protect the life of someone you love is frightening. Protecting a child is the normally a parent’s job. Now parents must trust others to take care of their child. That can be very hard to do.

Major changes in daily life are upsetting, too, and parents worry that they might not be up to all that will be asked of them. They could also be worried about their child getting through treatment and how it will affect their child’s body and self-esteem. Fear of intensive treatment, of an uncertain future, and of the unknown are all normal.

**What can help parents cope with fear?**

- Getting accurate information.
- Developing trust in treatment team members.
- Openly discussing fear and anxiety with cancer treatment team members.
- Using or learning strategies to reduce anxiety or tension.
- Listening to how other patients and parents have coped.
- Taking as much control as possible of everyday events and decisions.
- Accepting that some things cannot be controlled.
- Finding strength in religious beliefs or spiritual practices.

**Guilt**

Feelings of guilt often come up soon after parents accept that their child has cancer. Parents have the major task of protecting their child from danger. They may question what they might have done that caused their child to have this life-threatening disease. Could this be “payback” for past mistakes? The result of drug or alcohol abuse? Has their smoking caused the cancer? Mothers sometimes wonder if something they did or failed to do during pregnancy might have made a difference. Those with a family history of cancer might think that one parent or the other has “bad” genes. They may question the safety of where they live, their water supply, or wonder about toxins in the environment or in their home. They may wonder whether something related to their jobs might have caused the cancer.
Parents also voice guilt about not paying enough attention to their child’s symptoms. They worry that they didn’t get to the doctor quickly enough, or that they didn’t demand to have a specialist see their child when the symptoms didn’t go away. It’s normal to try to understand the causes of a problem, but the fact is that right now no one knows exactly what causes most cancers. Parents are not at fault for their child’s cancer. If parents feel guilty, they need to talk to someone on the cancer treatment team about their concerns. It’s important that they do not let guilty feelings distract them from the many tasks they must face when their child has cancer.

**What can help parents deal with guilt?**

- Talking with their child’s cancer treatment team about feelings of guilt.
- Getting answers to their questions about the causes of cancer.
- Making changes to create a healthier home environment if this is a concern.
- Talking with other parents of children with cancer.
- Accepting that they may never know what caused their child’s cancer.
- Realizing that finding a reason for something isn’t going to change the fact that it has happened.

**Sadness and depression**

Of course parents feel sad when their child is diagnosed with cancer. Every parent has hopes and dreams that their children’s lives will be healthy, happy, and carefree. Cancer and its treatment change that dream. Parents will grieve for the loss of some of those hopes. In grieving, they may feel hopeless about their child’s recovery. They’re also sad when they think about the hard days of treatment that lie ahead. The intensity of their feelings often matches their child’s outlook for recovery, but it also reflects their own temperament and personality. One parent may be more naturally optimistic, while another may react to any life problem with more fear of bad outcomes.

Parents may find it hard to eat or sleep at first. They may not have the energy they need for routine daily tasks or for facing all they need to do. Parents often report feeling overwhelmed. Unfortunately, parents cannot be spared these painful and unpleasant feelings and will have them again and again throughout their child’s illness.

But parents and families usually find a way to adjust to the changes in their lives. They usually find ways to maintain some quality of life for themselves, the rest of their family, and their sick child during this time.
What can help parents deal with sadness, depression, and grief?

- Finding ways to express their feelings, such as talking, writing, and/or letting themselves cry.
- Asking for support from each other, family, or friends.
- Using support from social workers, counselors, nurses, psychologists, and doctors.
- Seeking spiritual support, getting guidance from pastors, rabbis, or other clergy; using prayer, meditation, or other spiritual practices.
- Taking care of themselves: eating right, getting rest, and caring about how they look.
- Attending to their own needs, whether those needs are for medicines or other help with physical and/or mental health.

Anger

The fact that cancer is threatening the life of an innocent child often makes parents angry at the cruel and random injustice of life. When someone we love is attacked, even by illness, it’s easy to want to blame someone, or ask “Why me?” or “Why us?” This anger is sometimes directed at the doctors who found the cancer or who explained the treatment plan. Others rage at and question a world in which children become ill and suffer and die. Parents also feel upset, knowing the things their child will face, like tests and painful procedures.

The daily frustrations of dealing with a large and complex health care system, strange places, and many different care providers can also trigger anger. Parents may resent one another over past or current issues that now affect their child’s treatment. Anger also may be directed at family or friends who make thoughtless remarks or who are too busy to provide support. Allowing this stress to build up and explode into an angry outburst is not helpful for others or the child.

Parents are sometimes surprised and guilt-ridden to notice that they are angry with the sick child whose illness is causing so many problems or who’s not cooperating with the doctors and nurses. Some parents hide their anger or even deny that they feel that way, believing that such feelings are “not nice.” Others express their anger in explosive and hostile ways, taking it out on other people. Sometimes other children in the family become convenient targets for that anger. Since parents and the care providers must work together to help the child or teen deal with cancer and its treatment, it’s important to find healthy ways to express anger. It’s also important to find healthy ways to resolve valid complaints.
What can help parents deal with anger?

- Accepting that anger is a normal part of this process.
- Understanding the root of the anger in each situation.
- Expressing anger in a healthy way.
- Finding solutions when anger is justified.
- Discussing angry feelings with support staff or mental health care providers.
- Seeking physical release of tension (such as walking, exercising, or sports).
- Finding private space to vent feelings by shouting, screaming, or crying.
- Expressing feelings by keeping a journal.
- Talking with other parents who have dealt with feelings like this.
- Letting anger go, accepting that there may be no one to blame, and finding ways to use the energy to help themselves, their child, and their family.

Ways to improve coping

Most parents worry about whether they will be able to handle the emotions that come with their child’s cancer. But most parents have great strength when it comes to protecting and caring for their children. These strengths come through even when dealing with personal pain and distress.

Get help from the cancer team.

Develop trust in and get help from your team of cancer experts. Social workers, nurses, doctors, and others who are part of the health care team can help parents understand the range of emotions that are normal. Experts can also help you learn new skills, such as relaxation and stress management. Chaplains or child life specialists may be available to work with families of children with cancer. Help is available for you and your entire family, but you might have to ask for it.

Family members need to take time to care for themselves.

Parents and other adults who care for the child can often handle their feelings better if they take care of their own needs. It’s easy to neglect things like eating, sleeping, exercising, and taking breaks from providing care. But these things are especially important to help parents be able to care for the child. It also reassures the child that
some routines are being kept and that the adults are OK, despite the stress of the child’s illness.

When the parents and other important adults take care of themselves, it reminds the child that self-care routines are still important. Parents and other caregivers may need to be reminded to see their family doctors for their own personal health problems and concerns.

**Involve others and get their support.**

Grandparents, aunts, uncles, and other loved ones often have feelings much like those of parents and may struggle to manage many of the same emotions. They often cope better. It usually helps them when they get accurate information and are called on to give practical help. Team members can also help them discuss and handle their feelings in ways that support the parents and the child.

Sometimes, parents want to shield certain family members from the news of the diagnosis because of concern about its emotional impact. The health care team can help parents who must share bad news while being sensitive to the special issues of a family member. In general, secrets in a family tend to shut down communication rather than open it up. This tends to keep the family from working together as well as it could, at a time when it needs to pull together to cope.

Feelings often just appear whether we like it or not. But how we choose to express them is generally under our control. Reactions to a major life crisis, such as the diagnosis of cancer in a child or teen, are upsetting and painful, but natural. Most patients and family members express their feelings and manage them the best they can. Parents can help their child by showing that they are not ashamed or afraid to show what they feel. They can also help their children by encouraging them to express their emotions and try to keep focusing on moving forward.

**Get help from other sources.**

Families that can be flexible and can call on lots of support from friends and family tend to cope better. Families that might need extra help are those with problems in more than one area, such as family relationships, the marriage, and finances. Families with only one parent or caregiving adult may also have trouble balancing demands of the child’s illness with the needs of other family members. If this is your situation, talk with your cancer team’s social worker as soon as you can. The cancer team may be able to refer you to extra sources of help in your community or at the cancer center.
How can parents be sure their child gets the best treatment?

“Where can my child get the best available treatment?” is one of the first questions parents ask. Childhood cancer is still quite rare. Most pediatricians and family doctors will see only a handful of cases in all their years of practice. These doctors are often the first to suspect cancer based on the child’s symptoms. They’ll usually refer their patient to the nearest major medical center staffed with experts trained to diagnose and treat childhood cancers. Studies show that children being cared for by pediatric cancer specialists have better chances of surviving cancer.

Use childhood cancer centers.

Both the National Cancer Institute and the American Cancer Society recommend that children with cancer be treated at childhood cancer centers. These centers use a comprehensive team approach to care. Teams include doctors, nurses, social workers, psychologists, recreation therapists or child life workers, teachers, and chaplains. The whole team has experience in caring for young people with cancer and their families. Medical center teams work closely with primary care doctors and others in the child’s community to offer children the best quality of care.

In the United States, most major centers that treat childhood cancers are members of the Children’s Oncology Group (COG). This is a clinical trials group devoted to childhood and adolescent cancer research. It’s supported by the National Cancer Institute. Pediatric hematologists and oncologists in this group work together to design scientific studies called clinical trials to study which treatments work best for which cancers. These clinical trials compare standard treatments to newer, possibly better ones. State-of-the-art treatment is given according to a detailed plan (called a protocol). You can learn more by reading Pediatric Cancer Center Information on our website, which also tells you how to find a COG center near you.

More children survive childhood cancers today because so many parents and their children have taken part in clinical trials. More than 90% of children and teens with cancer in the US take part in clinical trials. Taking part in research studies (clinical trials) is always voluntary. All major childhood cancer centers also offer standard treatment, which is a plan based on the best known treatment for the child’s cancer type and stage. If you’d like to learn more about clinical trials, please read our document called Clinical Trials: What You Need to Know.
Local pediatricians or family doctors usually talk with parents about the possibilities of being diagnosed and treated nearby. They will then refer the child for treatment based on family preferences or the options offered by the family’s health insurance or managed care organization. Many times, families must travel some distance from home to get the care their child needs. But parents in these situations can ask what treatment is available at the nearest large hospital. Sometimes a local hospital or treatment center can work with a pediatric cancer center to follow the treatment plan designed at the pediatric center. Much of the treatment can then be given closer to home.

**Teens can benefit from childhood cancer centers, too.**

Sometimes older teens are sent to oncologists in their community who treat adult patients, rather than to major medical centers that treat children. But older teens may qualify for clinical trials used by pediatric (children’s) hematologists/oncologists. They also may be helped by the team approach to care used in the childhood cancer centers. Most children’s cancer centers treat patients up to the age of 20.

**What if parents want a second opinion?**

Cancer in a child usually needs to be dealt with quickly. Once a diagnosis is made and all the needed tests are done, treatment is started right away. Sometimes treatment planning is delayed because the doctors have trouble making an exact diagnosis. In this case, pediatric hematologists and oncologists often consult with their colleagues around the country to help make the diagnosis as quickly as possible.

If parents have doubts about their child’s diagnosis, or questions about the treatment plan, they have the right to get a second opinion. Most doctors understand and are comfortable with such requests, and will often help parents find specialists at another center. They can send tissue from biopsies or other test results that will help the doctors you are consulting. Parents should check with their insurer or managed care provider to see if their health plan will cover a second opinion.

Sometimes, parents have so much trouble believing their child’s diagnosis that they aren’t satisfied even with a second opinion. It’s important for them to remember that long delays may harm their child’s chances to respond well to treatment. Once a diagnosis is confirmed, treatment should be started as soon as possible.

**How do children with cancer and their**
siblings react to a cancer diagnosis?

Children and teenagers often respond to news of a cancer diagnosis with a range of emotions that reflect those of their parents. The child’s age, development, and personality also affect their responses.

Each child is different, but there are some common themes based on the age of the child. Keep in mind that the lists below are just some of the more common ways that children respond. There are many others. All responses call for patience and creative work with the cancer team to help the child through this time. Children with cancer and their siblings can benefit from the cancer team’s help. Be sure you get the help your family needs.

Infants and very young children with cancer might

- Fear being separated from parents
- Be afraid of and upset by painful medical procedures
- Yell, scream, throw tantrums, hit, or bite
- Refuse to cooperate, be negative and resist requests
- Withdraw, avoid interacting with others
- Cling to parents
- Be sad that their normal play and exploration are restricted
- Regress to behaviors such as thumb sucking or bed wetting
- Have nightmares

School-age children with cancer might

- Be upset by disruption of school
- Miss seeing classmates and friends
- Show anger and sadness over the loss of health, school, and normal life
- Feel guilty that they caused the cancer
- Worry that cancer is “catching”
- Look for more emotional and social support from family and friends

Teens with cancer might

- Be upset by the disruption of school and their activities with friends
• Feel their independence is threatened
• Show intense emotional responses
• Need support from friends, school contacts, and others who are important to them
• Focus on the meaning of life and the cancer’s effect on their identity
• Joke around about their cancer, detract from it, or try to “think positively”
• Take risks that could cause problems
• Rebel against parents, doctors, and treatments

**Siblings of children with cancer might**

• Feel shock, sadness, fear, and confusion over what to expect and what’s expected of them during the illness.
• Feel they somehow caused the cancer with angry thoughts or by wishing the child ill.
• Feel lonely, less valued, and jealous of the attention the sick child is getting.
• Resent the changes in their lives, and then feel guilty about that too.
• Have trouble with memory and concentration, which can cause school problems.
• Deny or minimize these responses because they don’t want to add to their parents’ distress.

Ways to help children cope with these and other problems are discussed in the section called “What helps kids with cancer and their brothers and sisters?”

**Fear and anxiety**

**The child with cancer**

Children with cancer are often as stunned as their parents by the sudden move from health to illness and the unwelcome tests and procedures needed to get a diagnosis. If the child needs to stay in the hospital, it may be a new, scary, and overwhelming experience. Fear and anxiety are the main emotions that both patients and siblings face after diagnosis.

It’s very frightening to be told your body isn’t working right, and that you have cancer. It’s normal for the child or teen to be afraid of new and often painful experiences. It’s hard to face being stuck with needles and having biopsies, bone marrow aspirations, lumbar punctures, scans, or other tests. Some kids are afraid they won’t be able to handle the treatment. It’s also upsetting to see your parents and relatives worried by all that’s happening. It’s disturbing to have to deal with a strange place and many new
people. It’s worrisome to think about what the treatment will do to your body, how you will look and feel, and how your friends will react. It can be terrifying to think you might die.

**siblings of the child with cancer**

Brothers and sisters have their own fears. Sometimes they’re afraid that they might get cancer, too. They may pick up on parents’ anxiety and not understand what’s going on – they may not be sure what cancer is but they know it’s bad. They may be afraid to visit the hospital or see their brother or sister sick or in pain. They worry that they don’t know the whole the truth about what’s happening. They are concerned when they see their parents distressed and fearful. They’re upset at being separated from mom or dad and being in the care of relatives or friends. They worry about going to school and maybe facing questions they can’t answer about their sick brother or sister. They’re afraid their sibling will die.

**anger and guilt**

**the child with cancer**

Anger and guilt are normal reactions. The child questions why this has happened to them. It’s not fair! They’re angry at all the things they have to do – be poked and prodded, swallow nasty-tasting liquids, take big pills, talk to strangers, lie in scary-looking machines, have their privacy invaded, and be kept in a hospital.

Feelings of guilt are also common. Children often worry that maybe they have cancer because they were bad in some way. Maybe something they did – telling lies, smoking, trying drugs, having sex, or even having bad thoughts – caused the cancer. They also may feel guilty that they caused this family crisis and may be concerned about their parents. They feel guilty for causing all this worry and trouble for the people who are important to them. This may be especially tough when parents are in conflict, divorced, or have other serious problems or stresses.

**siblings of the child with cancer**

Siblings might also be angry that this has happened to their brother or sister. They’re angry that life is disrupted for them and that things are never going to be the same. They’re angry that their parents may not seem to have time for them, or don’t seem to care how unhappy they are. They may be angry because their brother or sister is getting all the attention. They may feel angry with their sibling for being ill and causing
so much worry and trouble for everyone in the family.

They often feel guilty about their anger when their sibling is going through so much and their parents are so stressed. They may feel guilt about things they did or said to the child with cancer. Some might feel guilty just because they are healthy and their brother or sister is sick. They might also worry that something they thought or did might have caused the cancer. Rarely is a child is able to say these kinds of things to the parents, but some may act it out by rebelling or being the “bad child” – in contrast to the “good child” who has cancer.

**Sadness and feelings of depression**

**The child with cancer**

Feelings of sadness and depression are also common in children with cancer. They may realize that they won’t be able to do some of the things that are important to them, like dancing or sports, for a long time, if ever. They feel sad when they realize they are now different from their peers. They may feel depressed when they think about the months of treatment ahead and how it might interfere with their lives. They think about how the cancer and its treatment will change their body and feel depressed about how they’ll look and how their friends may see them. They might also feel hopeless, and be afraid that the treatment won’t work.

**Siblings of the child with cancer**

Siblings are also sad as they begin to realize that their brother or sister is really very sick and will need serious treatment. They feel sad as they witness their parents’ distress, too. Younger children miss the parent who usually provides most of the day-to-day care when that parent is unable to return home for days or weeks after the diagnosis. Teens understand the risk to their sibling’s life and may be depressed by a new awareness that life and health can be fragile. All young people are saddened by the changes in family life that often occur.

**Signs a child needs extra help**

Both patients and siblings express these normal feelings based on age, their nature, level of intelligence, maturity, and coping style. Most young people are still learning to name their feelings and talk about these feelings to others. They’re alert to the moods and expression of feelings of those around them, particularly their parents. They aren’t always able or willing to talk about their fear, anxiety, guilt, or sadness, but might show
their feelings through body language or behavior. Sometimes they look to parents and other key family members for cues about how to deal with their troubled feelings.

Although most children with cancer and their siblings seem able to cope, there are times when it might get to be too much. If a child in the family seems to be having trouble, it may mean a more serious problem than a normal, sad response to cancer. Extra help is needed if a child:

- Is unable to handle the feelings of sadness
- Feels sad all the time
- Cannot be comforted
- Admits to thinking of suicide or hurting himself or others
- Feels extra irritable
- Becomes very angry very quickly
- Has changing grades
- Withdraws or goes into isolation
- Acts very differently from the usual
- Has appetite changes (not counting those that are due to cancer treatment)
- Has low energy
- Shows less interest in activities
- Has trouble concentrating
- Cries a lot
- Has trouble sleeping

These are signs that should be discussed with the child’s doctor. You can talk with a mental health counselor or social worker at the cancer center who can evaluate the child and make sure that the child gets the kind of help he or she needs. Rarely, a child may need to see a psychiatrist for medicine or counseling.

What helps kids with cancer and their brothers and sisters?

Here are some ideas for helping children with cancer according to their age group. In the second part of each age group, there are ideas for helping siblings in that age group.

Infants and very young children (birth to age 3)
For the infant or very young child with cancer

- Soothe and comfort by being with your child, holding, touching, rocking, and singing or playing music.
- Cuddle and hug toddlers often.
- Stay with your baby or child during tests and procedures.
- Distract with toys and colorful things.
- Keep a favorite stuffed animal, blanket, or other special object near your child.
- Use a stuffed animal to let your baby know when a staff member or visitor entering the room isn’t going to do anything that causes pain. The stuffed animal can be a cue that this person is “safe,” to help the infant stay calm.
- Try to establish the crib as a safe, treatment-free place. Take your baby out of the crib for any treatment, test, etc., that may cause discomfort or pain.
- Limit the number of visitors.
- Have siblings visit as often as feels comfortable for the situation (based on the health and the need of each child to socialize).
- Create a cheerful hospital room with good lighting, art, and bright colors.
- Stick to your usual schedule as much as possible, including nap times and meals.
- Set aside time for play.
- Use video, phone, and other means so your child can see and hear parents in real time.
- Record lullabies, stories, or messages when a parent can’t be with the baby or child.
- Get ideas from a recreation therapist or child life worker on other ways to help.
- Talk with other parents of very young children with cancer to see what works for them.
- Talk with the team social worker or nurse about your own emotions in dealing with your child’s distress.

For infants or very young siblings of a child with cancer

- Keep your baby or child near parents, if possible.
- Get relatives or day care providers to help maintain your baby’s or child’s routine as much as possible.
- Have a parent or trusted adult who’s a consistent part of your child’s life spend time with them daily.
- Use video, phone, and other means so your child can see and hear parents in real
time.
- Record lullabies, stories, and messages when a parent can’t be at home.
- Remind toddlers often that mommy or daddy will be back soon.
- Cuddle and hug them often.
- Arrange visits to sick brother or sister.

**Toddlers or pre-schoolers (ages 3 to 5)**

**For the toddler or pre-school child with cancer**

- Give very simple explanations of what’s happening and repeat them often.
- Comfort your child when he or she is upset or scared.
- Check on your child’s understanding of what’s happening.
- Do not try to persuade your child using reason or logic.
- Offer choices when possible.
- Do not tolerate biting, hitting, kicking, or other aggressive behavior. Teach your child how to express feelings in healthy ways (things that don’t hurt the child or other people).
- Teach acceptable expressions of angry feelings such as talking, drawing, or pounding a pillow.
- Encourage doll play and other play to rehearse or repeat worrisome or painful experiences.
- Create opportunities for physical activities.
- Try to stick to a schedule for meals, naps, and play.
- Teach staff how to get your child’s cooperation.
- Talk with the child life expert or social worker about how to reward good behavior when your child cooperates with tests and procedures.
- Make use of experts on the cancer team to help you with your child or teach you useful strategies.
- Give simple explanations for a parent’s crying and sadness. For example, “I just feel a little sad and a little tired today. It makes me feel better to cry and get it all out of my system. Now I feel better.”
- Don’t forget to have fun; laugh together when possible.

**For toddler and pre-school siblings of a child with cancer**

- Give a simple explanation that brother or sister is sick and that the doctors are
helping.

- Offer comfort and reassurance about the parent’s absence.
- Arrange for reliable daily care, and keep usual routines.
- Keep caregivers informed about your family situation.
- Have a parent or trusted adult who’s a consistent part of the child’s life spend time with them daily, if possible.
- Have siblings nearby (for example, use a local Ronald McDonald House during hospitalization or treatment).
- Be alert to changes in behavior.
- Give simple explanations for a parent’s crying and sadness, as noted in the list above.
- Talk to your cancer care team about any concerns.
- Talk with the child life expert or social worker about ways to provide positive reinforcement for your child’s newfound independence and supportive role in the family.

**School-age children (ages 6 to 12)**

School-age children are especially sensitive to parental feedback during an illness.

**For the school-age child with cancer**

- Explain the diagnosis and treatment plan in words your child can understand.
- Include your child as much as possible in talks about diagnosis and treatment.
- Answer all questions honestly and in understandable language, including “Am I going to die?” (Discuss ways to answer these difficult questions with the cancer care team.)
- Listen for unasked questions, and pay attention when your child talks about fears and concerns.
- Offer repeated reassurance that the child did not cause the cancer.
- Encourage and help youngsters to identify and name feelings.
- Teach that sadness, anger, and guilt are normal feelings and that it’s OK to talk about them.
- Teach about feeling and managing anxiety.
- Relieve anxiety about missing school by sharing with your child’s teacher and classmates about what’s happening, and encourage your child to share as well.
- Console your child over missed sports events, parties, and other activities.
• Encourage expressing feelings, especially anger, and safe ways to do it.
• Use cancer team professionals to intervene or suggest strategies for parents to use.
• Allow your child to keep feelings private, if that’s preferred.
• Offer art activities (writing, drawing, painting, collage) that will encourage expression of personal thoughts and feelings Make sure there’s fun and pleasure in each day.
• Arrange for daily physical activity, if possible.
• Help your child stay in touch with siblings, friends, and classmates by using things like cards, phone calls, text messages, video games, social media, and e-mail.
• Make plans with team members and teachers to keep up with schoolwork, which can include classes on speakerphone or the computer, recordings of class discussion, and visits from classmates (if possible).
• Plan your child’s return to school when the cancer care team can estimate a date.
• Use humor to distract.
• Arrange for your child to meet other patients their age to see how they have dealt with cancer.

For school-age siblings of a child with cancer

• Let the sibling tour the clinic, meet the medical team, and ask questions if possible. Provide understandable information about diagnosis and treatment, and keep the sibling up to date on what’s happening. Find out if the cancer center has special group for siblings.
• Take your child to an educational or support program or a camp for siblings if available.
• Answer all questions honestly, including, “Will he (or she) die?” Get help from the social worker and cancer care team, if needed.
• Listen for unasked questions, especially about the their own health.
• Tell the sibling’s teachers, coaches, and other school staff about your family’s cancer situation.
• Offer repeated reassurance that the sibling did not cause the cancer.
• Arrange for your child to stay in school and do other usual activities as much as possible.
• Support having fun, despite brother or sister’s illness – make sure they don’t feel guilty about it.
• Arrange for good child care; if possible, let the sibling help choose where they go after school, and whose care they prefer when a parent can’t be there.
- Plan for daily contact with a parent or trusted adult who’s a consistent part of the child’s life.
- Teach about normal feelings, such as fear, anxiety, sadness, guilt, and anger.
- Encourage the sibling to share their feelings, taking the time to attend to emotional concerns as well as physical needs.
- Accept the sibling’s unwillingness to talk about feelings if they don’t want to talk to you, but be sure that the child is expressing feelings to another trusted adult.
- Explain that even though the parents have less time for the siblings during treatment, they are still loved and valued just as much as the sick child.
- Suggest siblings write or phone, and send drawings, pictures, text messages, email, or voice messages to the patient.
- Offer reassurance that the family will be OK.
- Explain that the parents’ distress, sadness, or crying is OK.
- Arrange for one family member or trusted friend to take a special interest in each sibling.

Teens (ages 13 to 18)

The teenage years are challenging as teens are learning to separate from their parents and be more independent. Illness forces some of the task of separation to be put on hold.

For the teen with cancer

- Offer comfort and empathy.
- Include your teen in all discussions about diagnosis and treatment planning.
- Encourage your teen to ask questions (parents should listen for unasked questions).
- Give information on normal emotional reactions to a cancer diagnosis.
- Repeat reassurances that they did not cause the cancer.
- Address spiritual concerns or questions such as “Why me?” (Or encourage others to address them.)
- Encourage your teen to share feelings with someone: parents, family, friends, the cancer team, or other staff.
- Be willing to tolerate some reluctance to share thoughts and feelings.
- Encourage your teen to keep a journal or log.
- Allow time for your teen to talk privately with team professionals.
• Offer assurance that all of you – the patient, parents, and other family members – will be able to manage this crisis and help each other through it.

• Address feelings of anger and frustration (even if they are unspoken).

• Use team professionals to teach new coping strategies.

• Encourage your teen to share news of their diagnosis with friends and classmates, and stay in touch with them.

• Arrange for visits of siblings and friends.

• Develop a plan with team members and teachers at school for keeping up with classes, as well as a plan to return to school and deal with any restrictions that might apply.

• Make sure there’s some fun and pleasure in each day.

• Use humor to deal with frustration.

• Help your child make contact with other teen patients, if desired.

• Take your child to a teen support group and stress the importance of learning from other teens (if available in your area).

• Look for a childhood cancer camp that your teen can attend.

**For teen siblings of a child with cancer**

• Arrange for the teen sibling to tour the clinic and ask questions of the cancer team if they wish.

• Keep the sibling up to date with what’s happening during treatment.

• Find out if the cancer center has a special group for siblings.

• Answer all questions honestly.

• Reassure that cancer is not contagious.

• Offer assurance that nothing they did or said caused the cancer.

• Tell your teen’s teachers, coaches, and other school staff about the family situation.

• Discuss spiritual concerns related to diagnosis.

• Encourage sharing of feelings and talk about what’s normal.

• Explain that even though parents have less time for the siblings during treatment, they are still loved and valued just as much as the sick child.

• Try to keep daily life at home as normal as possible.

• When possible, let the sibling help choose where to go after school and have a voice in who they prefer to care for them when a parent can’t be there.

• Provide assurance that the family will be able to handle the crisis.

• Encourage teens to keep up their usual involvement in school and other activities.

• Ask your teen to help out at home, but don’t expect your teen to take on all the caregiving, housekeeping, and other difficult tasks that need to be managed. Talk
with the cancer care team about your family situation and see if you can get other help.

• Ask a relative or trusted friend to take a special interest in each teen sibling.

Ask for help

Like parents, patients and their siblings will find that with the help and support of those who love them they’ll be able to handle this cancer crisis. Cancer care teams can refer you to skilled experts to help your family as needed, offering teaching, counseling, support, information, and other resources to make the task easier. Don’t hesitate to ask for help.

Keeping up with schoolwork during a child’s illness

Though it may not seem important in light of everything else going on, keeping up with schoolwork should be a priority. Whenever your child is able, he or she should continue learning, despite school absences. Good communication and preparation are key to a successful return to school when the time comes.

If your child is going to miss school for more than a few days, look into homebound or hospital teaching. The principal at your child’s school might be able to help you get tutoring while the child has to be at home. The home-based teacher will need to know about your child’s illness, treatment, medical appointments, and hospital stays.

Children’s hospitals may have education coordinators and teachers to help the child keep up if a long hospital stay is needed. The child may be able to transfer to the hospital’s school. For shorter hospital stays, especially if it’s in a different school district, you might want to get materials from the child’s school and see if hospital teachers can spend some time helping your child.

For many children, school is a safe place for learning, fun, and friendship that’s far from the world of cancer and treatments. School is the main part of almost every child’s daily life, and going back to school is a sign of normalcy. Having to go to school and learn is not only a sign that things are getting back to normal, it’s also a clear and reassuring message that there is a future.

Please see Children Diagnosed With Cancer: Returning to School, for more information
Will the child and family ever return to normal after a cancer diagnosis?

All human beings hope that things will get better and that tomorrow will be brighter, no matter what kind of struggles they face. Emily Dickinson wrote:

_Hope is the thing with feathers That perches in the soul And sings the tune without the words And never stops at all._

These words seem to capture how tightly we cling to hope. Young people and their families begin feeling hopeful about the future when they hear about available treatments and the great progress being made against childhood cancers. The diagnosis is still serious, and there are issues with treatment that can't be ignored, but there's reason for optimism. Today, about 4 of every 5 kids diagnosed with cancer are alive 5 years later. For some types of cancer, the statistics are even better. Many children live much longer than 5 years, and many are cured. (See _Cancer in Children_ or _Cancer in Adolescents_ for more on statistics and survival.)

Still, these numbers only apply to groups of patients, and can’t be used to make predictions for any one child. When cancer is diagnosed, each person has reason to believe that he or she will respond well to treatment and be cured. Most people believe that tomorrow will bring better times.

Hope, for some, is bolstered by faith that there’s a reason for what has happened to their child and family, even if they don’t understand what it is. And, in the end, they believe that they will find the strength they need to manage. Although it’s a struggle that can feel very uncertain at times, most families are able to find a “new normal” after a child’s cancer.

Here are some ideas for strengthening hope for patients and their family members:

- Seek facts about the diagnosis and treatment plan.
- Learn about progress in treatment methods.
- Give each family member a role in dealing with the illness. For instance, maybe someone keeps track of medical bills, organizes the cancer information you get, or keeps friends and family informed of what’s happening. Children may be in charge of things like making cards or “goodie” boxes, recording favorite TV shows, or
• Keep a healthy balance between optimism and reality.
• Find support in prayer, religious faith, or a spiritual outlook.
• Have confidence in your family’s ability to manage whatever must be faced.
• Share a sense of hope with one another.
• Develop trust in the skills of the doctors and other team members.
• Learn from the stories of others who have sustained hope in dealing with cancer.
• Find creative ways to bring joy or pleasure to each day.
• Learn to tolerate the ebb and flow of hope.
• Appreciate the beauty and wonder present in life each day.
• Accept that we only have the present moment in which to live.

To learn more

More information from your American Cancer Society

We have a lot more information for you. You can find it online at www.cancer.org. Or, you can call our toll-free number at 1-800-227-2345 to talk to one of our cancer information specialists.

National organizations and websites*

Along with the American Cancer Society, other sources of information and support include:

For adults

American Childhood Cancer Organization (ACCO) Toll-free number: 1-855-858-2226 Website: http://acco.org/

• Website offers support for families of children with cancer, including the child and siblings as well as parent support groups, insurance and legal advice, and long-term/follow-up information. Also has books for children, caregivers, and teachers.

CureSearch for Children’s Cancer Toll-free number: 1-800-458-6223 Website: www.curesearch.org

• Provides up-to-date information about childhood cancer from pediatric cancer
experts. Has sections on the website for patients, families, and friends to help guide them on how to support the child with cancer. Also has long-term follow-up guidelines for young cancer survivors at www.survivorshipguidelines.org. These guidelines provide recommendations for screening and management of late effects from pediatric cancer treatments.

**National Cancer Institute** Toll-free number: 1-800-4-CANCER (1-800-422-6237) TTY: 1-800-332-8615 Website: [www.cancer.gov](http://www.cancer.gov)

- Provides accurate, up-to-date information about cancer for patients and their families, including clinical trials information. Offers a special booklet for teen siblings of a child with cancer at: [www.cancer.gov/cancertopics/when-your-sibling-has-cancer](http://www.cancer.gov/cancertopics/when-your-sibling-has-cancer)

**Ronald McDonald House Charities (RMHC)** Telephone: 630-623-7048 Website: [www.rmhc.org](http://www.rmhc.org)

- Provides low-cost or no-cost temporary lodging for families of seriously ill children being treated away from home. Must be referred by medical staff or social workers from the child’s treatment center.

**Hair Club for Kids** Toll-free number: 1-800-269-7384 (If you reach voicemail, leave a message for a return call.) Website: [www.hairclub.com/hairclub-for-kids.php](http://www.hairclub.com/hairclub-for-kids.php)

- Offers free hair restoration services to children ages 6 through 17 who have hair loss due to cancer treatments. The hair system is a non-surgical hair replacement method that uses human or synthetic hair applied to a nylon mesh, which is put on the scalp using a medical grade adhesive tape. With this application method a child is able to swim and play sports, for instance, without removing the prosthesis.

**National Children’s Cancer Society, Inc. (NCCS)** Toll-free number: 1-800-5-FAMILY (1-800-532-6459) Website: [www.children-cancer.org](http://www.children-cancer.org)

- Services include an online support network for parents of children with cancer, educational materials, and financial assistance for treatment-related expenses.

**LIVESTRONG Fertility** Toll-free number: 1-855-220-7777 Website: [www.livestrong.org/we-can-help/fertility-services](http://www.livestrong.org/we-can-help/fertility-services)

- Offers information on having children in the future to cancer patients whose medical treatments cause the risk of infertility. Those who meet financial and other requirements may also qualify for discounted fertility services.

**CaringBridge** Telephone: 651-789-2300 Website: [www.caringbridge.org](http://www.caringbridge.org)
• Offers free, secure, personal websites that help you stay connected to family and friends during illness, treatment, and recovery; lets patients and caregivers keep loved ones informed.

**National Organization for Rare Disorders (NORD)** Toll-free number: 1-800-999-6673 Website: [www.rarediseases.org](http://www.rarediseases.org)

• A group of more than 2,000 non-profit voluntary health organizations serving adults and children with rare “orphan” disorders. NORD keeps data on resources and refers to organizations only (they do not refer people to healthcare providers or treatment facilities).

**For teens and children**

**Starlight Children’s Foundation** Toll-free number: 1-310-479-1212 Website: [www.starlight.org](http://www.starlight.org)

• Website has animated stories and interactive programs to teach kids and teens about chemo and procedures that may be done in the hospital; also provides a safe, monitored online support group for teens with cancer.

**2bMe** Website: [www.2bme.org](http://www.2bme.org)

• 2bMe is part of Look Good...Feel Better for Teens. For those aged 13 through 17, it gives both guys and girls information on a many appearance-related, social, and nutritional side effects of treatment.

**Group Loop** (a subsite of the Cancer Support Community for teens and their parents) Toll-free number: 1-888-793-9355 Website: [www.grouploop.org](http://www.grouploop.org)

• An online place for teens with cancer or teens who know someone with cancer to connect with other teens away from the pressures of classes, responsibilities, and treatment schedules. Group Loop has online support groups, chat rooms, information, and more.

**Cancer Really Sucks** Website: [www.cancerreallysucks.org](http://www.cancerreallysucks.org)

• An internet-only resource designed FOR teens BY teens who have loved ones facing cancer. Has answers and coping strategies to help deal with the emotions linked to a cancer diagnosis; “Q&A with a Cancer Survivor” online chats; and offers a monitored, safe format for teens to post stories about their situations and ask other teens questions.
Teens Living with Cancer Website: www.teenslivingwithcancer.org/

- An online-only resource dedicated to teens coping with a cancer diagnosis and treatment. It focuses on teen issues and provides resources to support teens, their families, and friends.

SuperSibs! powered by Alex’s Lemonade Stand Toll-free number: 1-866-333-1213
Website: www.supersibs.org

- Serves and supports 4- to 18-year-old brothers and sisters of children diagnosed with cancer so they may face the future with strength, courage, and hope. Alex’s Lemonade Stand is restarting SuperSibs in 2014 so there may be some delays with resuming support services.

*Inclusion on these lists does not imply endorsement by the American Cancer Society.*

No matter who you are, we can help. Contact us anytime, day or night, for information and support. Call us at 1-800-227-2345 or visit www.cancer.org.

References


Stewart JL, Pyke-Grimm KA, Kelly KP. Making the Right Decision for My Child With