



## Children Diagnosed With Cancer: Dealing With Diagnosis

When a child is diagnosed with cancer, families and parents will need to know about and cope with many problems. This document, which offers ideas for coping and moving forward, is one in a series of documents for parents and loved ones of a child with cancer. The other documents have information about returning to school, understanding the health care system, and financial and insurance issues..

A note about families and parents: There are many kinds of families today. Single-parent families and blended families are common. There also may be trusted adults other than parents who are involved in the daily lives of children. These adults are often very important to children, serving in parent and caregiver roles. A trusted adult who is involved in the daily life of the child with cancer (or the child's siblings) may be greatly affected by the child's cancer, too, and may be key to the family's coping with it. When we use the word parent, it may also refer to one of these caregivers.

### **When a child has cancer, it's a crisis for the whole family.**

A diagnosis of cancer in a child or teenager is a devastating blow to the parents, siblings, and others who love the child. Cancer creates an instant crisis in the lives of the whole family. Normal daily life stops. Parents must be away from work so they can be with their child. 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, and all other concerns are put on hold. Parents should be given detailed information about the diagnosis and treatment. They must understand enough about the treatment plan to feel OK giving permission for tests and procedures. They have to sign consent forms for treatments and make important decisions about their child's care. This is a lot to ask of them.

To add to the stress, all of this happens in a very short time. In the first days and weeks after the 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 actually say or do to express these feelings differs. How they handle their emotions is colored by 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, depending on their knowledge or personal experience with cancer, they 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. They often describe 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 helps them slowly get used to the painful feelings. It gives parents time to absorb and face these emotions and hard decisions.

### **What can help parents get through the shock?**

- Knowing that this is a normal reaction.
- 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, of course) or taking notes at important meetings, then going back over them with others.
- 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.

If a diagnosis is hard to make, they may wonder if the medical staff knows as much as they should. They may decide to get a second opinion (always a good idea). The disbelief or denial that strikes at first can help buffer and delay painful feelings. It is 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 gets in the way of timely treatment.

### **What can help parents get through the disbelief stage?**

- Getting answers to all your questions to resolve your doubts.
- 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 is normal to feel anxious and fearful when facing unfamiliar events and outcomes that we can't control. 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). There may be stories about the problems other family members or friends had with chemotherapy or radiation treatments, or beliefs that having cancer is a death sentence. If a child is diagnosed in a major medical center, parents may believe rumors they have heard that doctors in big hospitals "experiment" on patients.

Since doctors cannot guarantee exactly how each person will respond to cancer treatment, fear of the death of a child or teen is real. Trusting the knowledge and skill of others to protect the life of someone you love is frightening. Protecting the child is the normally the parent's job. Now parents must trust others to take care of their child. That's hard to do. Also, facing major changes in daily life is upsetting, 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 the treatment 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 and getting help from 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 really does have 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 cancer in their families 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. Although it is normal to try to understand the causes of a problem, 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 is 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 whose children have diagnoses like their child’s
- Accepting that there may never be an answer to the question of 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 are 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 by their child's diagnosis. 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 work to 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 or crying.
- 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 is 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, including the diagnostic 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.

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 is 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 is important to find healthy ways to express anger at the unfairness of it all. It is 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 effectively.
- Finding solutions when anger is justified.
- Discussing angry feelings with support staff or mental health care providers.
- Seeking physical release of tension (walking, exercising, or sports).
- Finding private space to vent feelings by shouting, screaming, or crying.
- Expressing feelings by keeping a journal or writing a letter (to keep, not to send).
- 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 their ability to handle the emotions that come with their child's cancer. But most parents have great strengths when it comes to protecting and caring for their children. These strengths come through even during personal pain.

### **Get help from the cancer team.**

Develop trust in and get help from your team of 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. Sometimes chaplains or child life specialists work with families of children with cancer.

## **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 caring for the child. 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 serves as a model to help remind 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.

## **Express feelings in ways that don't frighten the child.**

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. 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. Sometimes, parents try 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 teenager, 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 controlling when and how they express their emotions and focusing on moving forward.

## **Get help from other sources.**

Families that are flexible and can call on lots of support from their extended family, church, workplace, or community, tend to cope better. Open and clear communication is also helpful. So is an ability to reorganize and balance the demands of the child's illness with the rest of the family's needs.

Families that may 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 will get the best available 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 usually will 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 such specialists have better chances of surviving their cancers.

### 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 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. Medical center teams work closely with 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 or COG. This is a clinical trials group devoted only to childhood and adolescent cancer research. It is supported by the National Cancer Institute. Pediatric hematologists and oncologists in this group work together to design scientific studies called *clinical trials* that allow them to study which treatments work best for which cancers. These clinical trials compare standard treatments to newer ones. State-of-the-art treatment is then given according to a detailed plan (called a *protocol*). A few institutions design their own research trials for treatment.

The biggest reason that more children are now surviving childhood cancers is because so many parents and their children volunteer for research studies. Well over half of the children younger than age 15 with cancer enter a clinical trial. For teens 15 and older, only 1 in 10 take part in research. This means that the rate of learning about new treatments for older teens happens more slowly. 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 more information on clinical trials, you can read more in 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 insurers or managed care organizations. Families often must travel some distance from home to get the care their child needs.

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

Sometimes older teenagers are referred to oncologists in their community who mainly treat adult patients, rather than to major medical centers that treat children. But older teens may qualify for clinical trials used by pediatric hematologists/oncologists. They also may be helped by the team approach to care used in the childhood cancer centers. 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 come up with a treatment plan designed at the major center. The plan can then be put into effect closer to home.

## 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 required tests are done, treatment is started right away. Sometimes treatment planning is delayed because the doctors are having trouble making a precise 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 covers extra testing and consultation.

Sometimes, parents have so much trouble believing their child's diagnosis that they are not satisfied even with a second opinion. It is important for them to remember that long delays may harm their child's chances for a good response 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 the diagnosis of cancer?

Children and teenagers often respond to news of a cancer diagnosis with a range of emotions that reflect those of their parents. Their feelings vary with what each child goes through as a result of the diagnosis. Patients may become ill very quickly, have a lot of pain, or have many diagnostic tests. Some may need to travel far from home to see the doctors. Others may have to wait days or weeks to learn what is actually wrong with them. Some may miss school for a long time, or have to give up sports or other activities. Brothers and sisters may face sudden long separations from parents and each other. The family's usual life and daily routines are changed.

The child's age, development, and personality also affect their responses. For example, a toddler with cancer may fear being away from parents for scans and tests. School-age children may understand what's going on, but feel angry and sad over what they've lost.

Some teens may notice how the cancer affects their identity or sense of self. Others may be angry and rebel during diagnosis and treatment.

Each child is different, though there are a few 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 it.

### **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, refuse to cooperate, or withdraw
- Cling to parents
- Become aggressive
- Be angry or sad that their normal play and exploration are restricted

### **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
- 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, distract from it, or try to "think positively"
- Take risks that could cause problems
- Rebel against parents, doctors, and treatments

## Siblings of children with cancer have their own burdens.

Siblings may feel shock, sadness, fear, and confusion over what to expect and what is expected of them during the illness. It is common for them to feel they somehow caused the cancer with angry thoughts or by wishing the child ill. While their brother or sister is in treatment, they often feel lonely, less valued, and jealous of the attention the sick child is getting. They may resent the changes in their lives, and then feel guilty about that as well. Siblings may have trouble with memory and concentration, which can cause school problems. Sometimes they deny or minimize these responses because they don't want to add to their parents' distress. Ways to help the child cope with these and other problems are discussed in the section "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 go into the hospital, it may be a new experience. It could be scary and overwhelming. Fear and anxiety are the main emotions that both patients and siblings face after diagnosis.

It is very frightening to be told your body isn't working right, and that you have cancer. It is normal for the child or teen to be afraid of new and often painful experiences. It is hard to face being stuck with needles and having biopsies, bone marrow aspirations, lumbar punctures, scans, or other tests. Some kids fear they will not be able to handle the treatment. It is also upsetting to see your parents and relatives worried by all that is happening. It is disturbing to have to deal with a strange place and many new people. It is 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 that you might die.

### **Siblings of the child with cancer**

Brothers and sisters have their own fears. Sometimes they are afraid that they also might get cancer. 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 cannot 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 is not fair! They are 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 are angry that life is disrupted for them and that things are never going to be the same. They are 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 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. It is rare that the 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 will not be able to do some things that are important to them, such as 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 facing them and how it might interfere with their life. They think about the changes in their body that will result from cancer and its treatment, and feel depressed about how they will look and how their friends may see them. They might also feel hopeless, and be afraid that the treatment will not 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 are alert to the moods and expression of feelings of those around them, particularly parents. They are not always able or willing to talk about their fear, anxiety, guilt, or sadness, but may 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 (only counting those that are not 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 will want to 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)**

#### **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 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 the 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 area. 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 cannot be with 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.

### **Infants or very young siblings of a child with cancer**

- Keep your baby or child near the parents, if possible.
- Get relatives, nanny, or day care providers to help maintain baby's or child's routine as much as possible.
- Have a parent or trusted adult who is a consistent part of your child's life spend time with the baby or child 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 cannot be at home.
- Remind toddlers often that mommy or daddy will be back soon.
- Cuddle and hug them often.
- Arrange visits to ill brother or sister.

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

#### **The toddler or pre-school child with cancer**

- Give very simple explanations of what is happening and repeat them often.
- Comfort your child when he or she is upset or scared.
- Check on your child's understanding of what is 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 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.
- Discourage whining and tantrums.
- Create opportunities for physical activities.
- Try to stick to a schedule for meals, naps, and play.
- Teach staff about what works 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 humor; laugh together when possible.

### **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 family situation.
- Have a parent or trusted adult who is a consistent part of the child's life spend time with your child 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.
- Consult with cancer team professionals 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 the time of illness.

### **The school-age child with cancer**

- Explain 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?" (Talk with the cancer care team about ways to answer these difficult questions.)
- 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 keeping as many connections to your child's teacher and classmates as possible.
- Console your child over missed sports events 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 is preferred.
- Suggest personal recording of thoughts and feelings through writing or drawing.
- Make sure there is 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 cards, phone calls, text messages, e-mail, and other methods.

- 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 to see how they have dealt with cancer.

### **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.
- 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 sibling's personal 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 the sibling's 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 to 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 is 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.
- Explain that even though the parents have less time for the siblings during the treatment period, 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.

## Adolescents (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.

### **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.
- Provide repeated reassurance that they did not cause their 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 private time for your teen to talk with team professionals.
- Offer assurance that the patient, parents, and family members will be able to manage the crisis.
- 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 any restrictions that might apply.

- Make sure there is some fun and pleasure in each day.
- Use humor to deal with frustration.
- Help your teen make contact with other adolescent patients, if desired.

### **Teen aged 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 sibling'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 is normal.
- Explain that even though parents have less time for the siblings during the treatment period, 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.
- Don't expect your teen to take on caregiving and other difficult tasks. 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 will 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.

## 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. When 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 and treatment, medical appointments, and hospital stays.

Children's hospitals have education coordinators and teachers to help the child keep up if a long hospital stay is required. The child will actually be transferred to the hospital's school. For shorter hospital stays, especially if it is 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 is 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 on this important part of your child's life. You can read it on our Web site, [www.cancer.org](http://www.cancer.org), or call us at 1-800-227-2345 for a free copy.

## Will the child and family return to normal after a cancer diagnosis?

The hope that things will get better and that tomorrow will be brighter lives in all human beings, 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 that is being made against childhood cancers. The diagnosis is still serious, and there are issues with treatment that cannot be ignored, but there is reason for optimism. More than 75% of children and teens are cured of cancer. For some types of cancer, the statistics are even better. But these numbers only apply to groups of patients,

and can't be used to make predictions for any one child. When the 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 is 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 is 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.)
- Keep a healthy balance between optimism and reality.
- Find support in prayer, religious faith, or a spiritual outlook.
- Have confidence in the 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 selected some related information that may also be helpful to you. These materials may be ordered from our toll-free number, 1-800-227-2345, and most can be read on our Web site.

After Diagnosis: A Guide for Patients and Families (also available in Spanish)

Children Diagnosed With Cancer: Understanding the Health Care System (also available in Spanish)

Cancer Information on the Internet

Pediatric Cancer Centers

Children Diagnosed With Cancer: Financial and Insurance Issues

Children Diagnosed With Cancer: Returning to School

Childhood Cancer: Late Effects of Cancer Treatment

When Your Child's Treatment Ends: A Guide for Families (booklet for families)

Surgery (also available in Spanish)

Understanding Chemotherapy: A Guide for Patients and Families (also available in Spanish)

Understanding Radiation Therapy (also available in Spanish)

Anxiety, Fear, and Depression (also available in Spanish)

What Happened to You, Happened to Me (booklet for kids and teens with cancer)

When Your Brother or Sister Has Cancer (booklet for siblings aged 11-14 of a child with cancer)

We also have **detailed information available about most types of childhood cancer**. Call us or check our Web site.

## **Books from your American Cancer Society**

The following books are available from your American Cancer Society. Call us to ask about costs or to place your order.

*Angels & Monsters: A Child's Eye View of Cancer* (for adults and teens)

*Jacob Has Cancer: His Friends Want to Help* (coloring book for an elementary school child whose friend has cancer)

*Imagine What's Possible: Use the Power of Your Mind to Take Control of Your Life During Cancer* (for children with cancer in grades 4 through 6)

*Because...Someone I Love Has Cancer: A Kids' Activity Book* (best for children ages 5 to 10)

*Caregiving: A Step-By-Step Resource for Caring for the Person With Cancer at Home* (for adults taking care of someone with cancer at home)

## National organizations and Web sites\*

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

### **Web sites for adults**

#### **American Childhood Cancer Organization (ACCO)**

Toll-free number: 1-800-366-2223

Web site: <http://acco.org/>

Web site offers support for children and teens with cancer and their siblings, as well as support for adults dealing with children with cancer and parent support groups. Note that some of the books for children listed below are available from this group.

#### **CureSearch (National Childhood Cancer Foundation and Children's Oncology Group)**

Toll-free number: 1-800-458-6223

Web site: [www.curesearch.org](http://www.curesearch.org)

Provides up-to-date information about childhood cancer from pediatric cancer experts. Has sections on the Web site for patients, families, and friends to help guide them on how to support the child with cancer.

#### **National Cancer Institute**

Toll-free number: 1-800-4-CANCER (1-800-422-6237)

TTY: 1-800-332-8615

Web site: [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

Web site: [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.)

Web site: [www.hairclub.com/hc\\_for\\_kids.php](http://www.hairclub.com/hc_for_kids.php)

Offers free hair restoration services to children ages 6 through 17 who have hair loss due to cancer treatments.

**The National Children's Cancer Society, Inc.**

Toll-free number: 1-800-5-FAMILY (1-800-532-6459)

Web site: [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.

**Fertile hope**

Toll-free number: 1-866-965-7205

Web site: [www.fertilehope.org](http://www.fertilehope.org)

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

Web site: [www.caringbridge.org](http://www.caringbridge.org)

Offers free, personal Web sites that help you stay connected to family and friends during illness, treatment, and recovery. It lets patients and caregivers keep loved ones informed.

**Cancer.net**

Web site: [www.cancer.net/patient/Coping](http://www.cancer.net/patient/Coping)

Cancer information from the American Society of Clinical Oncology. Online, choose "Age-specific information," then either "teens" or "children" to find more about coping with cancer in children or adolescents.

**National Organization for Rare Disorders**

Toll-free number: 1-800-999-6673

TDDY number: 203-797-9590

Web site: [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).

**Web sites for teens and children****Starlight Children's Foundation**

Toll-free number: 1-800-315-2580

Web site: [www.starlight.org](http://www.starlight.org)

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

**2bMe**

Web site: [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 information on a many appearance-related, social, and nutritional side effects of treatment.

**Beyond the Cure** (part of the National Children's Cancer Society for teens)

Web site: [www.beyondthecure.org](http://www.beyondthecure.org)

Support and education for survivors of childhood cancer and their families

**Group Loop** (a subsite of the Wellness Community just for teens)

Toll-free number: 1-888-793-9355

Web site: [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 Kids**

Web site: [www.cancerkids.com](http://www.cancerkids.com)

An online-only resource designed to help kids, from ages 5 to 11, learn about cancer in a fun and interactive manner.

**Cancer Really Sucks**

Web site: [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" offers a monitored, safe format for teens to post stories about their situations and ask other teens questions.

**Teens Living with Cancer**

Web site: [www.teenslivingwithcancer.org/](http://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.

**I'm too young for this**

Web site: <http://i2y.com>

Social networking organization for young adult cancer survivors and care providers that offers support to help improve quality of life for young adults (older teens and adults up to age 39) affected by cancer.

## **SuperSibs!**

Toll-free number: 1-888-417-4704

Web site: [www.supersibs.org](http://www.supersibs.org)

Supports, honors, and recognizes 4- to 18-year-old brothers and sisters of children diagnosed with cancer so they may face the future with strength, courage, and hope.

## **Other publications\***

### **Books for adults**

*Cancer & Self-Help: Bridging the Troubled Waters of Childhood Illness*, by Mark A. Chester and Barbara K. Chesney. University of Wisconsin Press, 1995.

*Childhood Brain and Spinal Cord Tumors: A Guide for Families, Friends, and Caregivers*, by Tania Shiminski-Maher, Patsy McGuire Cullen, and Maria Sansalone. O'Reilly and Associates, 2001.

*Childhood Cancer: A Parent's Guide to Solid Tumor Cancers*, by Honna Janes-Hodder and Nancy Keene. O'Reilly and Associates, 1999.

*Childhood Cancer Survivors: A Practical Guide to Your Future*, by Nancy Keene, Wendy Hobbie, and Kathy Ruccione. O'Reilly and Associates, 2000.

*Children with Cancer: A Comprehensive Reference Guide for Parents (Revised and updated edition)*, by Jeanne Munn Bracken. Oxford University Press, 2010.

*Educating The Child With Cancer: A Guide for Parents and Teachers*, edited by Nancy Keene. American Childhood Cancer Organization, 2003. Can be ordered from <http://acco.org/>.

*Living with Childhood Cancer: A Practical Guide to Help Families Cope*, by Leigh A. Woznick and Carol D. Goodheart. American Psychological Association, 2002.

*When Bad Things Happen to Good People*, by Harold Kushner. First Anchor, 2004.

*Young People with Cancer: A Handbook for Parents*. National Cancer Institute, 2003. Available online at [www.cancer.gov/cancertopics/youngpeople](http://www.cancer.gov/cancertopics/youngpeople) or call 1-800-422-6237.

*Your Child in the Hospital: A Practical Guide for Parents, 2nd Ed.*, by Nancy Keene and Rachel Prentice. O'Reilly Media, 1999. (Also available in Spanish.)

### **Books for children and teens**

Although these books are intended for children, younger kids are helped more when an adult reads with and helps the child reflect about what different parts of the book mean to the child.

*Chemo, Crazyness and Comfort: My Book about Childhood Cancer*, by Nancy Keene. American Childhood Cancer Organization, 2002. Can be ordered from <http://acco.org/>. For ages 6 to 12.

*Childhood Cancer Survivors: A Practical Guide to Your Future* (2nd Edition), by Kathy Ruccione, Nancy Keene, and Wendy Hobbie. 2006. For older teens.

*Going to the Hospital*, by Fred Rogers. Paperstar Book, 1997. For ages 4 to 8.

*Little Tree: A Story for Children with Serious Medical Problems*, by Joyce C. Mills. Magination Press, 2003. For ages 4 to 8. May be hard to find new copies; check at the cancer center library, other libraries, or look for used copies.

*My Book for Kids with Cansur [sic]: A Child's Autobiography of Hope*, by Jason Gaes. Viking Penguin, 1998. For ages 4 to 8.

*Shelter from the Storm: Caring for a Child with a Life-Threatening Condition*, by Joanne Hilden, MD. Perseus, 2002.

*The Amazing Hannah, Look at Everything I Can Do!* by Amy Klett and Dave Klett. American Childhood Cancer Organization, 2002. (Also available in Spanish.) Can be ordered from <http://acco.org/>. For ages 1 to 5.

*What About Me? When Brothers and Sisters Get Sick*, by Allan Peterkin and Frances Middendorf. Magination Press, 1992. For brothers and sisters of a child with cancer. For ages 4 to 8.

*When Someone Has a Very Serious Illness: Children can learn to cope with loss and change*, by Marge Heegaard. Woodland Press, 1991. For ages 6 to 12.

*Why, Charlie Brown, Why? A Story About What Happens When a Friend is Very Ill*, by Charles M. Schultz. Ballantine Publishing Group, 1990. For ages 6 to 12.

*\*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](http://www.cancer.org).

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