



# Children Diagnosed With Cancer: Understanding the Health Care System

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 on how to cope with the cancer diagnosis, returning to school, and financial and insurance issues.

When a young person is diagnosed and treated for cancer, both the patient and the family enter the strange, complex, and often frightening world of modern medicine. Hospitals and medical centers can be big, confusing places with seemingly endless corridors and many buildings. Hospital rooms can be drab and scary. Professionals and staff members have questions to ask, tests to do, and information to share. But medical terms can sound like a foreign language. There are endless forms to fill out. Insurance or managed care providers are called often as families check coverage, try to get approval for tests and procedures, or question payment for care.

The schedules and routines of daily family life are changed to fit in the time-consuming treatment plan. Family members are separated as one parent returns to work, one cares for the sick child, and siblings go to school. Parents must give up some control of their sick child and place their trust in the strangers that make up the cancer care team.

But with time and experience, patients and families get to know the medical centers and other places where treatment is given. They learn the routes and figure out all the shortcuts from home to the hospital. They find the cafeteria and spots that offer needed privacy. They bring blankets and pictures from home to brighten rooms. They pack snacks and toys and books for clinic visits. They learn their way around miles of hallways. The staff members become real people and some key relationships start to form. Children with cancer and their parents adjust to this new world and often become experts in childhood cancer.

The discussion here assumes that you have already read our information, *Children Diagnosed With Cancer: Dealing With Diagnosis*. If not, you can read it on our Web site at [www.cancer.org](http://www.cancer.org). Or you can call us at 1-800-227-2345 to order a free copy.

## Getting started

Here are some tips to help patients and families begin to understand and cope with the health care system:

- Before you go, look at the hospital's Web site. Most have sites with a lot of information that can help you on your first visit.
- Ask for maps or a tour of the hospital.
- Have each person explain the part they will play in caring for your child.
- Find out exactly where treatment will be given.
- Make hospital rooms as homey as possible.
- Take things for your child to do during the time spent in the clinic.
- Find out what role the child's referring doctor or pediatrician will have during this time.
- Check on what your insurance or managed care company will require.
- Ask to have unfamiliar terms defined for you. Don't be afraid to ask questions.
- Read over the written materials you get from the cancer team or from your American Cancer Society.
- Ask team members to describe how the system works.
- Talk with other parents to see what helped them.

## What is comprehensive care?

With most illnesses of childhood or adolescence, parents can rely on their own knowledge and skills, or those of their doctor, for an accurate diagnosis and treatment. But cancer requires the help of a team of specialists trained to deal with different types of cancer and many types of treatment. Treatment may include surgery, radiation therapy, chemotherapy, bone marrow or stem cell transplant, and immunotherapy. Treating childhood cancer often means consulting with more medical specialists if any problems come up. Other specialists can also help patients and family members with the social, emotional, educational, and spiritual issues that are part of childhood cancer.

*Comprehensive care* is an approach that cares for the whole patient and all his or her needs, not just the medical and physical ones. Comprehensive care — using the services of many professionals working together — is the standard approach at all major medical

centers that treat young people with cancer. The key aspects of well-designed comprehensive care are:

- State-of-the-art medical diagnosis and treatment, including the chance to take part in clinical trials
- A team of professionals who are experts in treating childhood cancer
- A wide range of services for patients and families, including education, counseling, support groups, advocacy, and other special programs to improve the quality of life of patients and their families
- Resources to help meet basic needs, such as meals, lodging (a place to stay during treatment), and transportation
- Patient and family education programs with up-to-date materials (written, audio, DVD, or computer programs)
- School programs, including contact with classroom teachers, teachers who work with homebound students, and help with going back to the student's neighborhood school
- Organized efforts to help patients cope with treatment, tests, and procedures
- Advocacy programs to help with families' financial concerns about treatment and related costs
- Consultation with community health care professionals (those near the child's home)
- Patient-friendly and family-friendly facilities
- Studies that look at and evaluate the results of all treatments and services

## **What is a Comprehensive Cancer Center?**

The National Cancer Institute (NCI) identifies certain medical centers as Comprehensive Cancer Centers because they meet special requirements. These centers must:

- Take part in clinical trials (carefully controlled human studies of new treatments)
- Study cancer prevention and control in large groups of people
- Do basic laboratory research (studies on cells or animals)
- Offer cancer information services
- Have mental health and social services (psychosocial support services) available

The NCI also identifies certain hospitals as Cancer Centers. These centers must also meet certain NCI standards, although not quite as many as the Comprehensive Cancer Centers. Studies have shown that outcomes (such as survival rates) are better for children treated at hospitals such as these, which are staffed by childhood cancer specialists.

## Clinical trials for children with cancer

Most major centers in the United States that treat childhood cancer patients 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.

Treatment centers must follow strict guidelines to ensure that patients and families are fully informed about the potential value and risk of each clinical trial. After they have been given detailed information about the clinical trial, parents have the chance to ask questions. If they agree to have their child take part in the clinical trial, they must sign the consent form. This is called giving *informed consent*. Patients then are randomly assigned (*randomized*) by computer to get either the new treatment being studied or standard treatment. Families do not have to enroll their child in a clinical trial and can choose instead to get the standard treatment. (Standard treatment is defined as the best treatment we have so far.) You can get more information in *Clinical Trials: What You Need to Know*, which you can read on our Web site or get a free copy by calling us at 1-800-227-2345.

## Where are children and teens treated?

Most children with cancer are treated at large pediatric cancer centers. And most are in clinical trials sponsored by the NCI through the Children's Oncology Group. The NCI also supports Comprehensive Cancer Centers and Community Clinical Oncology Centers. Several medical facilities in the United States and abroad are members of COG and treat pediatric cancer patients. You can learn how to find a COG hospital near you in our document *Pediatric Cancer Centers*. You can read it on our Web site or call us for a copy.

When hospitalized, children and teens are treated in inpatient units in medical centers or community hospitals. Outpatient treatment (when the child is not in the hospital) may take place in hospital clinics, doctor's offices, or at home. When they are treated at home, patients usually get services from a home health agency. These services can include checking vital signs, giving chemotherapy or medicines by vein, and other types of care. Home care staff may also teach family members to give drugs, manage equipment, and handle certain health problems.

Local pediatricians or family practice doctors may be involved in giving chemotherapy, too. They may also take part in evaluating and treating symptoms, with guidance from the pediatric oncologist who is managing the child's cancer treatment. This helps avoid long stays in the hospital. Every effort is made to have children go to school and continue their normal activities as much as possible while they are being treated.

## How are children and teens treated?

Treatment depends on the type of cancer the child has, the stage of the cancer, the child's age, overall health, and other factors. Treatment may be chemotherapy, radiation, surgery, or some combination of these. The doctor and other members of the cancer team will explain the treatments they recommend and answer questions before treatment starts.

Keep in mind that the parent(s) or guardians must consent for the child's treatment, which is why they usually want to learn all they can about the child's cancer. If you would like to know more about the type of cancer your child has, and about the treatments used most often, please call us. Or, you may find information about the type of cancer the child has on our Web site at [www.cancer.org](http://www.cancer.org).

### Late effects

The survival rate for children with most cancers tends to be very good. But the treatments that allow these children to live can cause health problems that may not show up until months or even years after treatment. These are called *late effects*, and may include things like problems with learning, coordination, hearing, growth, and fertility. Treatment might affect organs like the heart, lung, eyes, muscles, or brain. Some of these effects can persist into adulthood or even throughout the child's entire life. Late effects vary by type of treatment, age at the time of treatment, and other factors. The parent or guardian can ask about late effects when planning the child's treatment with the doctor and the other members of the cancer team. You can also learn more about these effects in our document called *Childhood Cancer: Late Effects of Cancer Treatment*.

## Who are the members of the comprehensive health care team?

Experts from different disciplines (medicine, nursing, social work, and others) are part of the cancer care team available to help patients and families. They may be involved from the days before diagnosis through the months and years following the end of treatment.

They offer different services and programs. Team members work together to figure out what each patient and family needs in order to best cope with cancer and its treatment. They design and coordinate a personal plan for care. While in the hospital, patients and families will see some team members every day. Others will only come when help is needed with certain issues. During clinic visits the same or even more team members may be available. When patients are at home, team members generally stay in touch. They might offer help by phone or arrange community care.

Every treatment center is unique, so teams will have different members in different settings. Just before or just after diagnosis, parents are usually told about, or introduced to, all members of the cancer care team. All teams have doctors, nurses, and social workers. Teams may also include psychologists or psychiatrists, recreation therapists or child life workers, teachers, and chaplains. Most teams think of parents as team members

and want them to have an active role in caring for their child. The patients, both children and teens, also are part of the team if they are mature enough.

## Types of doctors who help care for children with cancer

**Pediatric oncologist:** a doctor who specializes in cancers of children. They generally are board-certified (have passed written national exams). They plan and direct cancer treatment. In teaching hospitals they serve as the doctor in charge. There might be more than one on the team, in which case they might rotate (switch places from one day to the next).

**Pediatric hematologist:** a doctor who specializes in diseases of the blood and blood-forming tissues of children

**Pediatric hematology or oncology fellow:** a pediatrician training to become hematologists or oncologists

**Pediatric resident:** doctors training to become pediatricians. They are in teaching hospitals, usually doing a rotation on the hematology or oncology service.

**Medical students:** although not yet doctors, third and fourth year medical students in teaching hospitals are assigned monthly rotations on the hematology or oncology services and help care for patients

**Radiologist:** a doctor with special training in diagnosing diseases by reading x-rays and other types of imaging studies, for example, CT scans and MRIs

**Pediatric surgeon:** a doctor who treats medical problems with surgery

**Thoracic surgeon:** a doctor who operates on the chest cavity

**Neurosurgeon:** a doctor who specializes in operations on the brain, spine, or other parts of the nervous system

**Neurologist:** a doctor who treats problems of the nervous system

**Ophthalmologist:** a medical doctor who specializes in eye diseases

**Orthopedic surgeon:** a surgeon who specializes in diseases and injuries of the bones

**Pathologist:** a doctor who specializes in diagnosing and classifying diseases by lab tests, such as looking at tissue and cells under a microscope. The pathologist decides whether a tumor is cancer, and, if it is, the exact cell type and grade.

**Psychiatrist:** a medical doctor who specializes in mental health and behavioral disorders. Psychiatrists prescribe medicines and can also provide counseling.

**Urologist:** a doctor who specializes in treating problems of the urinary tract in both sexes, and of the genital area in males

**Endocrinologist:** a doctor who specializes in diseases related to the glands of the endocrine system, such as the thyroid, pancreas, and adrenal glands

**Gynecologist:** a doctor who specializes in women's health and the female reproductive system

**Anesthesiologist:** a doctor who specializes in giving medicines or other agents that prevent or relieve pain, especially during surgery

Other doctors in the medical center and its clinics may play a part in caring for the child or teen with cancer, depending on the diagnosis, treatment plan, or symptoms that develop during the course of treatment. All work closely with the basic cancer care team to coordinate care.

## Other professionals who may help care for a child or teen with cancer

There are many professionals and specialists other than doctors who may work with your child or family. Here are just a few more you may meet as your child is treated.

**Radiation therapists:** people with special training to work the equipment that delivers radiation treatment

**Pharmacologists:** professionals trained in understanding the properties, dosing, and uses of drugs. They may consult with your cancer team about the uses, reactions, and interactions of drugs used to treat cancer and manage symptoms.

**Dietitians:** experts in the area of food, nutrition, and diet. A registered dietitian (RD) has at least a bachelor's degree and has passed a national exam

**Nurses:** like doctors, nurses have different roles and titles based on their education and training. Nurses help care for and treat children and teens with cancer. They play an important part in teaching the patient and family about cancer and its physical and emotional effects. They also help set up care for the patient in his or her home community when referrals are made to home health agencies.

Teams of nurses may include:

**Oncology Clinical Nurse Specialists (may also be called Advanced Practice Registered Nurses or APRNs in some states):** registered nurses with a master's degree in oncology nursing who specialize in the care of cancer patients. Oncology nurse specialists may prepare and give treatments, monitor patients, prescribe and provide supportive care, and teach and counsel patients and their families.

**Nurse practitioners (also called Advanced Practice Registered Nurses or APRNs):** registered nurses, usually with a master's or doctoral degree, who have passed a national certification exam. Certified nurse practitioners diagnose and manage illness and disease, usually working closely with a doctor. In nearly all states, they can prescribe medicines.

**Certified Pediatric Oncology Nurses (CPONs):** registered nurses who specialize in working with pediatric cancer patients, and who have passed an exam given by the Oncology Nursing Certification Corporation (ONCC).

**Registered nurses (RN):** nurses with associate or bachelor degrees who are licensed by their states to practice nursing. They give medicines (often including chemotherapy), start and monitor IV medicines, take vital signs, and provide other hospital and clinical care. They also provide patient and family education.

**Licensed practical nurses (LPN):** nurses who have completed training in a vocational school or community college program and have passed a state licensing exam. They do many skilled tasks for patients at the bedside or in clinics.

**Oncology social worker:** this person has a master's degree in social work and is an expert in coordinating and providing non-medical care to cancer patients. The oncology social worker provides counseling and assistance to people with cancer and their families. They can help you and your child talk with the cancer care team and they can speak up about issues that are important to you. They can also help with issues like financial problems, housing (when treatments must be given at a facility away from home), and finding child care.

**Pediatric psychologists:** psychologists generally have doctoral degrees and are licensed to practice after passing a written exam. Some psychologists specialize in oncology. They are also part of many comprehensive care teams. They help patients understand and talk about their cancer. They are skilled in helping young people use a variety of techniques to get through surgery, radiation treatment, chemotherapy, nausea, pain, IVs, shots (injections), procedures, scans, and other tests.

The psychologist also may work with patients, parents, and other team members to look at educational needs and help with school issues. They evaluate a child's mental and emotional state and provide counseling to children and teens to help them cope with their illness. They often refer patients to mental health providers and services in the family's home community. There usually is a fee associated with their professional services, but insurance may cover at least part of it.

**Recreational therapists or child life workers:** these team members encourage children and teens to take part in play activities designed to maintain and improve physical and mental health. Such activities also provide distraction and help relieve stress and anxiety during treatment, tests, and procedures. These experts also work closely with social workers, team psychologists, and psychiatrists. They generally have advanced college degrees.

**School teachers:** teachers often are part of comprehensive care teams and must have the same training, credentials, and state licenses as public school teachers. They bridge the gap between the hospital and school, and teach students based on plans outlined by the patients' teachers in their regular schools. They are usually available in both inpatient and outpatient settings.

**Chaplains or pastoral counselors:** these counselors help care for the spiritual needs of the patient and family and are available in most medical centers. They often coordinate their efforts with a family's pastor or spiritual caregiver. Along with a divinity degree and other advanced degrees, chaplains often have had special training in working with the ill and dying. Pastoral counselors have special training in counseling, as well as in divinity or theology. In teaching hospitals they may be involved in teaching and training.

## Talking with the health care team

Good communication among patients, families, and health care team members is very important. The intensity, complexity, and length of treatment and follow-up care require that everyone involved have confidence and trust in one another and be able to work well together.

Most of the time, children with cancer and their families develop a bond with the doctors, nurses, and other team members providing care. But sometimes, personalities and styles may clash, and all may not go smoothly. Fortunately, patients and parents usually find that there are certain team members with whom they can form helpful relationships and have good communication.

### Trust and confidence

Confidence comes with knowing that all team members are well trained and experienced in treating cancer in young people, and that the facility meets the highest standards. Information about the education and credentials of all team members should be readily available. The institution's status and reputation can be researched quickly. But trust in individuals will only come with time and the experience of sharing decisions and going through diagnosis and treatment.

### Two-way communication

Parents are the experts when it comes to their children. It is important for them to have that expertise recognized, just as it is important for professionals to have their knowledge and skills recognized. Parents can help team members learn how best to deal with their children. On the other hand, health professionals who have worked with many children who have cancer can often give parents new ideas to try when the old ones don't work. Good communication comes out of mutual respect for what each person brings to the joint effort to give the child with cancer the best possible care.

### Consent for the child's treatment

When a child or teen is being treated for cancer, the parent or guardian is asked to give consent for tests and treatments the doctor thinks are needed. The parents or guardians are in charge of looking out for the child's best interests. That is another reason it's important to understand what is happening and to be sure that the team knows your concerns.

Communication should be clear, direct, and honest. Team members need to be sure that they give complete information, and that they use words that patients and families can understand. In the same way, the patient and family members need to state their thoughts, opinions, and feelings clearly and ask their questions directly. They also need to feel certain that they are being heard. Because of the emotional impact of a cancer diagnosis, it is often necessary to repeat things and ask questions more than once. This is normal, and it is better to do this than have misunderstandings.

## Tips for good communication with the health care team

- Become a partner and actively take part in your child's care.
- Develop and expect an attitude of mutual respect and cooperation.
- Give accurate information about your child's and the family's health history.
- Keep a list of questions for doctors or other team members.
- Take notes when having important talks with your child's cancer team members.
- Ask for explanations of medical or technical terms you don't understand.
- Let team members know about your doubts or concerns about information given or about requests made of your child.
- Have reasonable expectations about how much time team members can spend with each patient and family.
- Let team members know what the family and patient prefer when there is more than one way to give care.
- Develop positive relationships with team members.
- Help children and teens develop trust in team members.
- Expect patient and family information to be kept private.
- Make sure parents have direct and equal access to doctors and other team members.
- Expect to have communication and other problems sometimes because of the many experts involved in caring for patients.
- Address confusion, frustrations, or disagreements directly with the team member involved.
- Get help from other team members only if your first efforts to resolve conflicts directly do not work.

# Using psychosocial support services

Childhood cancer affects all aspects of family life. For this reason, the care is focused not only on the child, but also the child's family and other parts of the child's life. Most centers have a broad range of services and programs to support children and family members through the entire cancer experience. This includes diagnosis through treatment and even the months and years after treatment. In many centers these services and programs are available to all.

Having a child with cancer is usually a new experience for all family members. It can be very stressful, so it is no surprise that families need education, support, and counseling to cope with it. All support services are optional, but parents are more likely to be satisfied with their child's overall care if they take advantage of what is available.

## Psychosocial help from the cancer team

Some of the common types of services available from psychosocial professionals on the team are:

**Advocacy (including financial advocacy):** helps children and families understand and manage the complex medical care system and identify and make use of programs, financial help, policies, and laws

**Education:** helps children and families learn about the normal social and emotional effects of a cancer diagnosis and treatment, about coping strategies, and about stress management and other helpful ways to get through this time

**Supportive counseling:** provides listening, empathy, and a way for children and family members to express the feelings that result from the stress of cancer

**Psychotherapeutic and behavioral interventions:** help children and family members manage anxiety, fear, anger, guilt, feelings of depression, and other emotions. Sometimes they can help with even physical problems, for instance, the nausea that can happen before treatment medicines are given (anticipatory nausea)

**Resource provision or referral:** helps families get meals, lodging, transportation, and/or emergency assistance

**Consultation:** provides children and families with community-based psychosocial professionals for illness-related services

## Programs in communities and medical centers

Many different types of programs are available for children and families. Some of these are provided in the hospital and others are found in the community. Team social workers, psychologists, and nurses usually can help you find them. Some kinds of programs offered are:

## **Support groups**

These may be for parents, siblings, or children with cancer. They may be only for certain groups of patients, such as teens or patients with a certain kind of cancer. Some are offered in hospitals and clinics, and others through organizations like the American Cancer Society, the Leukemia and Lymphoma Society, or the American Childhood Cancer Organization.

## **School programs**

Medical centers may have organized school programs, planned school re-entry programs, education programs for staff members at the child's or sibling's school, and contact with classroom teachers or teachers who teach homebound or hospitalized students. Some use volunteers for tutoring.

## **Patient-parent visitation programs**

Where available, these programs help parents meet other parents with common factors such as children's ages, diagnoses, or the area in which they live.

## **Buddy programs**

These programs use volunteers (sometimes university or medical students) to play with or befriend patients.

## **Summer camps**

Many medical centers, communities, or groups like the American Cancer Society, sponsor summer camps for children with cancer and sometimes siblings, too. The focus is on the fun aspects of the camping experience, rather than on having cancer.

## **Special events**

Medical centers often develop special programs to meet fundraising, recreational, or educational needs of children with cancer and their families, such as conferences on certain diagnoses, parent weekends, picnics, and survivors' days.

## **Wish fulfillment organizations**

Many agencies are set up to grant the wishes of seriously ill children, including cancer patients. Some accept parental referral, but most ask for referrals from a doctor or other team member.

## **Ronald McDonald Houses**

These houses originally were created to be a home away from home for children with cancer and their families. Now they often serve children with other serious illnesses, too. They give parents and children who are outpatients a place to get away and relax, offer another option besides staying in the hospital, and have low or no-cost housing for families during treatment. They also help provide parent-to-parent connections and support.

## **Follow-up care for the child after treatment**

Regular follow-up exams will be very important for many years after treatment of childhood cancer. The doctors who treated the child's cancer will watch for signs that the cancer has come back, as well as for short-term and long-term effects of treatment. These effects vary with each patient and with each type of treatment. Long-term effects may call for regular monitoring, and follow up each time a new medical problem shows up. Cancer treatment may not have caused the new medical problem, but may still play a role in the type of care the cancer survivor can get for the problem. Or, it may affect how the survivor responds to the problem or its treatment.

## **Getting and keeping medical records**

It is important to know what kind of treatment your child has and what impact this treatment might have as the child grows up. Ask the doctor to help you stay aware of what long-term effects might occur based on the treatments your child gets. And be sure your adult child knows the details of their childhood cancer and its treatment, so that this information can be given to new doctors.

As your child's cancer treatment winds down, you will need to get copies of treatment records. To start, contact the doctor who treated your child. If any treatment was given at a hospital or clinic, you will need to contact them, too. These records are usually destroyed at some point, and may not be available more than a few years after treatment. There are certain pieces of information that you and your child should have, and keep for the rest of your child's life:

- Copies of all pathology reports from biopsies and surgeries.
- If there was surgery, a copy of the operative report (or reports, if there was more than one surgery).
- If there were hospitalizations, copies of the discharge summaries doctors prepare when patients are discharged from the hospital.
- If the child had chemotherapy, a list of the total dose of each drug used. Certain drugs may have specific long-term side effects. If you can get a list of drugs from the pediatric oncologist, it can help any new doctors your child has should one of these effects surface.

- If radiation was given, a final summary of the dose and field.
- If your child had a hematopoietic cell transplant (HCT) or bone marrow transplant, you need to know the exact type of transplant and whether your child had chronic graft versus host disease, or any complications.
- Any problems or complications (serious enough to require hospitalization or other treatment) your child had during or shortly after cancer treatment.

Treatments that are used to beat cancer can cause delayed effects that may lead to problems later on. While these result from life-saving treatment, your child and your child's future doctors need to know about them. Researchers are looking for ways to reduce long-term effects, but right now, children who have been cured of cancer may have to deal with some of these effects for the rest of their lives. For more information, see our document called *Childhood Cancer: Late Effects of Cancer Treatment*.

## Long-term follow up for childhood cancer survivors

Along with watching your child to see if the cancer comes back, there are other special types of follow-up care. Because children and teens with cancer may face lifelong physical and emotional issues, there are guidelines for follow-up care that is designed to look for and help with them.

These special childhood cancer follow-up guidelines are fairly new, and facilities that use them may not be easy to find. But they can offer a unique perspective for parents and survivors of childhood cancer. You can learn more about the guidelines and download them for free at the CureSearch Web site: [www.survivorshipguidelines.org](http://www.survivorshipguidelines.org). The guidelines are written for health care professionals, so you might want to go over them with your child's doctor.

Some larger cancer treatment facilities have set up special follow-up clinics for childhood cancer survivors. They help the child, teen, or young adult adjust to their new lives after cancer, including school issues, emotional changes, and employment challenges. But they do not replace the child's cancer doctor's medical follow up during and after cancer treatment.

Follow-up clinics offer prevention and screening information. For example, girls who got radiation treatment to the upper chest should get extra breast cancer screening tests in adulthood. Some measures depend on which chemotherapy drugs were used; for instance, children who got the drug busulfan should have their eyes checked each year for cataracts. There are some special tests based on when the child was treated, both by age and year of treatment.

Follow-up clinics also offer help for those with certain types of complications. For instance, those who had stem cell transplants and chronic graft-versus-host disease need more frequent cancer checks. Some types of screening are only done the first 10 years after treatment, but others may be done for many years after that.

Some of the emotional impact of childhood cancer may show up years after the cancer is treated. Special childhood cancer follow-up clinics can often help the survivor deal with these effects as they arise over time. Even teens and young adults who completed cancer treatment long ago may benefit from this type of follow up.

## 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. Some can be read online at [www.cancer.org](http://www.cancer.org).

Children Diagnosed With Cancer: Dealing With Diagnosis (also available in Spanish)

Children Diagnosed With Cancer: Financial and Insurance Issues

Children Diagnosed With Cancer: Returning to School

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

Pediatric Cancer Centers

Cancer Information on the Internet

Childhood Cancer: Late Effects of Cancer Treatment

Clinical Trials: What You Need to Know

**Talking With Your Doctor** (also available in Spanish)

Health Professionals Associated With Cancer Care

Where to Turn: Patient and Family Support Program Overview (brochure for families, also available in Spanish)

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 the American Cancer Society. Call us to ask about costs or to place your order.

*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)

*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 has sub-sections just 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 to 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.

#### **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.

**National Dissemination Center for Children with Disabilities (NICHCY)**

Toll-free number: 1-800-695-0285 (also for TTY)

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

Provides information about disabilities and disability-related issues for families, educators, and other professionals; special focus on educational rights and school issues

**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.

**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; lets patients and caregivers keep loved ones informed.

**Hair Club for Kids**

Toll-free number: 1-800-269-7384 (If you reach voicemail, leave a message for a call back.)

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.

**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.

**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**

### **2bMe**

Web site: [www.2bme.org](http://www.2bme.org)

2bMe is part of Look Good...Feel Better for Teens. For those ages 13 through 17, it gives information on 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.

### **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; provides a safe, monitored online support group for teens with cancer.

### **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 (ages 15 to 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

*100 Questions & Answers About Your Child's Cancer*, by William L. Carroll and Jessica Reisman. 2004.

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

*Care for Children and Adolescents with Cancer: Questions and Answers*, National Cancer Institute. Available at [www.cancer.gov/cancertopics/factsheet/NCI/children-adolescents](http://www.cancer.gov/cancertopics/factsheet/NCI/children-adolescents) or call 1-800-422-6237.

*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.

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

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

*When Someone You Love is Being Treated for Cancer*, National Cancer Institute. Available at [www.cancer.gov/cancertopics/when-someone-you-love-is-treated](http://www.cancer.gov/cancertopics/when-someone-you-love-is-treated), or call 1-800-422-6237.

*Young People with Cancer: A Handbook for Parents*, National Cancer Institute, 2003. Available 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**

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 Ed.)*, 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.

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

*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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