Late Effects of Childhood Cancer Treatment

- Will my child be at risk for late effects after cancer treatment?
- Late effects of childhood cancer treatment on different areas of the body
- Late effects of cancer treatment on children’s growth and sexual development
- Living as a childhood cancer survivor

Today, because of advances in treatment, more than 80% of children treated for cancer survive at least 5 years. But the treatments that help these children survive their cancer can also cause health problems later on.

Most treatment side effects appear during or just after treatment and go away a short time later. But some problems might not go away or might not show up until months or years after treatment. These problems are called late effects. Because more children with cancer now survive into adulthood, their long-term health and these late effects have become a focus of care and research.

Careful follow-up after cancer treatment helps doctors find and treat any late effects as early as possible. The follow-up schedule depends on many things, including the type of cancer the child had, the treatments used, the risk of late effects from those treatments, and other factors such as the patient’s age, amount of chemotherapy or radiation given, and how long it has been since treatment was completed.

Will my child be at risk for late effects after cancer treatment?

Each child getting cancer treatment is unique. The treatments used vary from child to child and from one type of cancer to another. Other things that can affect a child’s risk include:
• The type of cancer
• Where the cancer was in the body
• How old the child was when treated
• The child’s overall health before the cancer
• The child’s genetic make-up (inherited risk for certain health problems)

Late effects are caused by the damage that cancer treatment does to healthy cells in the body. Most late effects are caused by chemotherapy or radiation. Major surgery can also lead to late effects.

Chemotherapy

Chemotherapy (chemo) is the use of drugs to kill cancer cells. But chemo drugs can damage normal cells, too, which can cause short-term and long-term side effects.

Chemotherapy damage to quickly dividing cells can cause side effects such as low blood cell counts, nausea, diarrhea, or hair loss during treatment. These short-term side effects usually go away over time after treatment is over.

Late effects, on the other hand, may happen many years later. A child’s whole body is growing. This means that many different kinds of healthy, normal cells are dividing faster than they would be in an adult. Some types of chemo drugs can damage these cells and keep them from growing and developing the way they should.

Radiation therapy

Radiation treatment uses high-energy rays (such as x-rays) to kill cancer cells and shrink tumors. The radiation may come from outside the body (external radiation) or from radioactive materials placed into or right next to the tumor (internal or implant radiation). Radiation is sometimes used along with other treatments, such as before or after surgery, or along with chemo. For some, it may be the main treatment.

As with chemo, radiation therapy can affect normal cells as well as cancer cells. Some organs and parts of the body are more likely to be affected by radiation than others. Younger children’s bodies tend to be more sensitive to the effects of radiation. Some children are at greater risk for side effects. For example, children with the hereditary form of retinoblastoma (an eye cancer) are more sensitive to the effects of radiation.

Surgery
Surgery is an important part of treatment for many cancers. As with other types of treatment, the possible long-term effects of surgery depend on a number of different factors.

In some cases, surgery may be fairly minor and may leave nothing more than a scar. In other situations it may need to be more extensive and require removing part or all of an organ, or even a limb. Doctors do their best to limit the effects of surgery by striking a balance between removing all of the cancer and taking out as little healthy body tissue as possible.

Younger children, whose bodies are still actively growing, may be more affected by some operations than older children who are already at or near their full body size.

**Late effects of childhood cancer treatment on different areas of the body**

Just as the treatment of childhood cancer requires a very specialized approach, so does aftercare and watching for late effects. Late effects can involve more than one part of the body (or more than one organ system) and can range from mild to severe.

Below are some of the more common possible late effects of cancer treatment. This is by no means a complete list, as other late effects can occur as well. If your child is being treated for cancer or if you were treated as a child, it’s important to speak with the health care team to learn more about the possible late effects based on your specific situation.

**Brain**

Some treatments used for [tumors in the brain](https://www.cancer.org/cancer/tumor-types-2/a-childs-tumor-their-treatment.html) or to try to prevent cancer from spreading there can cause late effects. Children with brain tumors or with [acute lymphocytic (lymphoblastic) leukemia (ALL)](https://www.cancer.org/cancer/acute-lymphoblastic-leukemia-ALL/lymphoblastic-leukemia-therapy.html) are most likely to have late effects in the brain, but children with other cancers may be affected as well. Treatments that can affect the brain include surgery, radiation therapy, and chemotherapy.

Normal brain cells grow quickly in the first few years of life, making them very sensitive to radiation. Doctors try to avoid using radiation therapy to the head or to postpone it in children younger than 3 years old to limit damage that might affect brain development. But even in older children, radiation may cause problems such as learning disabilities. Doctors try to use as little radiation as possible, but this needs to be balanced with the risk of the cancer growing or returning, as radiation therapy may be lifesaving in some cases.
Some types of chemotherapy, given either into a vein (intravenous, or IV chemo) or directly into the spinal column (called intrathecal chemo or “spinal tap chemo”), can also cause learning disabilities in children. This is more likely if higher doses of certain chemo drugs are used, and if the child is younger at the time of treatment. Learning disabilities are more common in children who get both chemo and radiation to the brain.

Learning problems, often called *cognitive impairments*, usually show up within a few years of treatment. They may be seen as:

- Lower IQ scores, which can vary depending on the intensity of the treatment
- Lower academic achievement test scores
- Problems with memory and attention
- Poor hand-eye coordination
- Slowed development over time
- Behavior problems

Non-verbal skills like math are more likely to be affected than language skills like reading or spelling, but nearly any area of brain development can be affected.

Other late effects that may show up, depending on the type of treatment used, include things like seizures and frequent headaches.

Treatments that affect the brain can also lead to other effects in the body. For example, radiation therapy can sometimes affect the pituitary gland, which is at the base of the brain and helps control the levels of many hormones in the body.

Symptoms of pituitary problems can include fatigue, listlessness, poor appetite, cold intolerance, and constipation, which may point to low levels of certain hormones. Other problems can include delayed growth and/or sexual maturation, which are described below in Treatment effects on growth and development.

**Eyes**

Cancer treatment can affect vision in a number of ways. Vision problems after treatment are most common with retinoblastomas, which are childhood cancers that start in the light-sensitive area of the eye (retina). In many cases, the vision in the eye has already been destroyed by the tumor at the time of diagnosis. Surgery may be needed to remove the affected eye. If this is done, a prosthetic (artificial) eye is put in to take the place of the eyeball.

Radiation therapy to the eye can sometimes damage inner parts of the eye, which can
lead to vision problems. Radiation in the area of the eye can also sometimes cause cataracts (clouding of the lens of the eye) over time. Radiation treatment to the bones near the eye may also slow bone growth, which can change the shape of the child’s face as it grows.

Pituitary gland tumors or their treatment might also affect vision. This gland is very close to the optic nerves, which connect the eyes to the brain. Surgery or radiation in the area might also affect these nerves, which could lead to vision problems.

Certain chemo drugs can be toxic to the eye and may lead to problems like blurred vision, double vision, and glaucoma. Many times, these effects go away over time.

Children who have had a stem cell transplant may be at higher risk for some eye problems if they develop chronic graft-versus-host-disease. This is a condition in which the new immune system attacks cells in the eye (as well as other cells in the body).

Other late effects on the eye may include:

- Dry eyes
- Watery eyes
- Eye irritation (feels like something is in the eye)
- Discolored sclera (white part of the eye)
- Poor vision
- Light sensitivity
- Poor night vision
- Tumors on the eyelid
- Drooping eyelid

If cancer treatment might affect eyesight, your child’s vision will be checked during treatment so that, if possible, the treatment plan can be changed if there are signs of vision loss. After treatment, eye exams will be done regularly to help find problems. Over time, treatments such as cataract removal or eyeglasses may be needed.

**Ears**

Certain chemo drugs and antibiotics may cause hearing loss (especially high-pitched sounds). Radiation given to the brain or ear can also lead to hearing loss, as can surgery in these areas. This risk may be higher in children who are young at the time of treatment. Other late effects of treatment in this area may include:
• Ringing in the ears
• Trouble hearing words when background noise levels are high
• Dizziness (if treatment affects the inner ear)
• Hard, crusty earwax

If your child is getting treatment that might affect hearing, the cancer care team will likely check your child’s hearing during treatment. This may allow for early changes in treatment if hearing loss becomes a concern.

After treatment, regular hearing tests can help find any problems. It is important to find and address any hearing issues as soon as possible. Younger children with hearing loss may have problems with language development. Older children may have problems in school or in social situations. Some children might need hearing aids or need to use other resources to help them communicate effectively.

**Thyroid**

The thyroid gland is an important part of the endocrine system. Hormones from the thyroid affect growth and development in children, as well as help regulate the body’s metabolism.

Thyroid function can be affected by radiation therapy or surgery in the head and neck area, or by total body irradiation, which is sometimes used as part of a stem cell transplant. Some treatments damage the thyroid directly, or they can damage the pituitary, which in turn affects thyroid function.

Low thyroid function (hypothyroidism) occurs when the thyroid no longer makes enough thyroid hormone. It can cause extreme tiredness, dry skin, unexplained weight gain, constipation, slowed bone growth, poor memory, depression, and thinning hair. Thyroid hormone replacement pills can be given daily to correct this, if needed.

An overactive thyroid (hyperthyroidism) is less likely, but it can happen. Signs of this can include nervousness, weight loss, trouble sleeping, diarrhea, and an enlarged thyroid gland (goiter). If treatment is needed, surgery or radiation may be used on the thyroid gland to lower thyroid hormone levels.

Regular thyroid blood tests can help detect these problems early, often before symptoms appear. Testing is often needed for many years after radiation treatment, as sometimes problems may not show up until a decade or more later.
Muscles and bones

Radiation treatment can have serious effects on the proper growth of bone and muscle in young people, slowing the growth of any area exposed to it. Bones, soft tissue, muscle, and blood vessels are very sensitive to radiation during times of rapid growth. Young children and children going through a growth spurt at puberty are at especially high risk for effects on growth.

Along with stunted bone growth, other late effects related to bone and muscle problems can include:

- Unequal growth (the treated side of the body doesn’t grow the same way as the untreated side)
- Bone pain
- Joint stiffness
- Changes in the way the child walks
- Weak bones that can break easily
- Decreased calcium in the bones
- Increased risk of having a bone tumor develop in the area of radiation treatment

Some medicines used to treat certain kinds of cancers can also affect the bones. For example, drugs called corticosteroids (such as prednisone and dexamethasone) are often part of the chemotherapy used to treat some cancers such as leukemia or lymphoma. These drugs can sometimes cause osteonecrosis (also called avascular necrosis, or AVN), in which the blood vessels feeding the bones are damaged. This can cause parts of bones to weaken or die, which in turn can cause pain (especially at bone joints) or even breaks in the bone. Osteonecrosis can affect any bone, but most often it affects parts of bones around the hips or knees. High-dose chemotherapy as part of a stem cell transplant can also cause osteonecrosis.

Surgery for some types of childhood cancers can have obvious effects on muscle and bone growth in certain parts of the body. This is most likely with cancers that start in bones (such as osteosarcomas or Ewing tumors) or muscles (such as rhabdomyosarcomas).

Some problems in bone growth can be caused by damage to the endocrine system. (see the section “Treatment effects on growth and development.”)

Heart/cardiovascular system
Heart disease can be a serious late effect of certain cancer treatments. The actual damage to the heart may occur during treatment, but the effects may not show up until many years, or even decades later.

A class of chemo drugs called anthracyclines, which are used to treat many childhood cancers, can damage the heart muscle or affect its rhythm. The amount of damage is related to the total dose of the drug given and the child’s age at the time of treatment. Doctors try to limit the doses of these drugs as much as possible while still giving high enough doses to treat the cancer effectively. Studies are now being done to see if certain drugs shown to help protect the heart in adults getting anthracyclines can also help children.

Radiation therapy to the chest or spine, or when given to the whole body (total body irradiation), can also damage the heart muscle or cause problems with its rhythm. Radiation can also damage the heart valves or the blood vessels (coronary arteries) that supply the heart muscle with oxygen. The total dose and type of radiation and the age of the child at the time of treatment affect this risk.

Most people who get these treatments do not develop major heart problems. This is especially true in children being treated today, as modern approaches have reduced treatment doses and lowered the risk. Problems are more likely in children who receive more intensive treatment, but doctors can’t always predict who will or won’t have problems. When these treatments do affect the heart, the damage does not usually show up right away, but it can raise the risk of heart problems later in life.

Careful monitoring for heart problems is very important in the years after treatment because often there are no symptoms. Special tests, such as an EKG or an echocardiogram (an ultrasound of the heart), can help show hidden problems. With routine physical exams and testing, heart problems can often be found early and treated, if necessary.

Heart disease is one of the leading killers among all Americans, so doing things to help keep the heart healthy — like not smoking, staying at a healthy weight, eating well, and getting regular physical activity — is important for everyone. But it’s especially important in people treated for childhood cancers. Talk with your cancer treatment doctor about any limits on exercise, now and in the future, and what kinds of activity will be best. This will help you plan exercise programs or increase your current level of activity. Some childhood cancer treatment centers have special programs to get children back into physical activity. If your center doesn’t have such a program, ask for a referral to a physical therapist who can work with the child.

Lungs
Certain cancer treatments can affect the lungs.

Lung problems can occur in children who have had radiation therapy to the chest or total body irradiation. The risk of problems depends on the dose of radiation, how much of the lungs get radiation, and the age of the patient. The use of certain chemo drugs at the time of radiation may increase the risk. Possible late effects include:

- Decreased lung volume (lungs can’t hold as much air)
- Shortness of breath, which might be worse with exercise
- Constant cough
- Lung tissue that becomes scarred and thickened (called pulmonary fibrosis), which limits how much the lungs can expand
- Inflamed lung tissue (called pneumonitis), which can cause trouble breathing
- Increased risk of lung infections
- Increased risk for lung cancer later in life

Certain chemo drugs, such as bleomycin, can also cause lung problems, especially fibrosis and pneumonitis. The risk of problems increases with higher drug doses.

Some people who get these treatments may have no noticeable symptoms, but for others, problems may start as soon as within the first few years after treatment.

People who have received these treatments need careful follow-up with a doctor, especially during the first few years after treatment. Special tests such as chest x-rays or pulmonary function tests may be done regularly in those at high risk for problems. For some, seeing a pulmonologist (lung doctor) may be helpful.

Keeping the lungs healthy is important for everyone, but it’s especially important in people who had treatments for childhood cancers. The best way to help keep the lungs healthy is to avoid smoking or being around tobacco smoke. If you do smoke and want help quitting, call the American Cancer Society at 1-800-227-2345.

**Teeth**

Chemotherapy or radiation therapy in an area that involves the teeth and jaw can lead to late effects, mostly in children who are treated before age 5. But older children may have problems too. Late effects of these treatments can include:

- Small teeth
- Missing teeth or delayed tooth development
- Abnormal tooth enamel (teeth may be discolored or not have a normal shape)
- Increased risk of cavities
- Teeth that are too sensitive to hot or cold
- Gum disease
- Short tooth roots (which can lead to early loss of teeth)

Radiation in the area around the mouth can also affect the salivary glands, which can lead to decreased saliva and dry mouth. This can cause tooth decay and gum disease.

Regular dental exams are important to find problems early and reduce the risk of infection, decay, and tooth loss.

**Late effects of cancer treatment on children’s growth and sexual development**

**Growth**

Slowed growth is a common problem during childhood cancer treatment.

Chemotherapy can contribute to a slow-down in growth. When chemo is given alone, without radiation, the change in growth rate is most often short-term. Over time many children catch up to a normal growth pattern after treatment. But certain chemo drugs, when given in high enough doses, have more lasting effects. And some of the long-term effects of intensive chemotherapy are still unclear.

Many of the late effects on growth and development are linked to radiation therapy. Radiation has a direct effect on the growth of bones in the area being treated (see Muscles and bones).

Radiation (and sometimes surgery) in the head and neck area can sometimes damage the pituitary gland, which is the main gland of the endocrine system. This can sometimes affect overall growth and development.

The endocrine system is a group of glands that help control many important body functions, including growth, metabolism, puberty, and responses to stress. Endocrine glands include the pituitary, thyroid, adrenals, testicles (in boys), and ovaries (in girls). These glands work by releasing hormones into the bloodstream, which can then affect cells throughout the body. For example, the pituitary releases growth hormone, which stimulates body growth in children. Hormones from the ovaries and testicles affect sexual maturation and fertility.
Hormone changes that result from damage to endocrine glands such as the pituitary can slow the child’s growth, and may affect bones, height, and sexual development at puberty. Again, very young children are most likely to be affected. The slowing of growth is usually seen within 5 years of treatment.

If the pituitary gland is damaged, treatment with growth hormone can often reverse some of the effects on growth. But growth hormone treatment has its own risks. The choice to use growth hormone should be made with your child’s doctor, and you should fully discuss its possible side effects.

It’s important for parents to discuss the possible long-term effects of cancer treatment on sexual development and fertility with your child’s health care team before starting treatment. There may be options for limiting or preventing some of these effects.

**Male sexual development**

In males, the testicles have 2 main functions. They make male hormones (such as testosterone), which influence sexual development and help the body maintain bone and muscle strength. The testicles also make sperm, which are needed to father children.

Both radiation therapy and chemo can reduce sperm production and might also affect sexual development. In general, the cells in the testicles that make sperm are more likely to be damaged by cancer treatments than are the cells that make hormones. The effects may be short- or long-term, depending on the intensity of the treatment.

Radiation therapy aimed at the testicles can affect the cells that make sperm. It might also damage the cells that make hormones if given at higher doses. Radiation aimed at the abdomen (belly) or pelvis might also have this effect. Sometimes the testicles may be shielded or moved out of the radiation field during treatment to try to prevent this.

Sex hormone levels in the body are also influenced by the pituitary gland, so radiation therapy to the head area can affect sexual development and sperm production as well.

High doses of certain chemo drugs are more likely to affect the cells that make sperm, but very high doses can also affect the cells that make hormones.

Treatments that affect sperm production can alter the patient’s ability to father children. For some, this may be only temporary, but for others it may be long lasting or even permanent. It’s important to think about this before starting cancer treatment in the older child. For boys who have gone through puberty, sperm banking (collecting and freezing sperm samples) may be an option that can allow them to father children later in life. The
risks of effects on fertility are less in boys who are treated before puberty.

Treatments that affect testosterone levels can cause problems such as failure to complete puberty, early or delayed puberty, and impotence (being unable to get and keep an erection). If needed, doctors can prescribe testosterone in the form of injections, patches, or gels applied to the skin to help maintain normal testosterone levels.

**Female sexual development**

In females, organs important for sexual development and pregnancy include the ovaries and the uterus (womb). These organs can be affected by cancer treatments.

The ovaries can be affected by both chemotherapy and radiation therapy. The risk of problems depends mainly on the intensity of treatment and the girl's age and stage of puberty when they are treated. Girls who have not yet been through puberty are less likely to be affected.

Radiation treatment to the abdomen or pelvis can damage the ovaries, so protecting the ovaries is a major concern when treating the nearby areas with radiation. Radiation to the head can also affect the pituitary gland, which in turn can interfere with the hormones needed for the ovaries to work as they should.

High doses of certain chemo drugs can damage the ovaries. In girls who are already menstruating, this can make menstrual periods irregular or stop, which may be temporary or more long lasting. Some chemo drugs (and lower doses of chemo) are less likely to cause problems.

Girls who get treatments that affect the ovaries are at risk for early or delayed puberty and start of menstruation, irregular menstrual periods, early menopause, reduced fertility, and other health problems. Doctors may recommend hormone replacement therapy to help with some of these issues if they remain after cancer treatment.

The uterus can be affected, too, especially if radiation is given to the abdomen. Late effects can include a uterus that is smaller than normal or which may not stretch during pregnancy as it should. This can increase the risk of miscarriage, low birth-weight babies, and premature birth.

**Fertility**

Childhood cancer survivors may be concerned about their ability to have children. Most
childhood cancer survivors can go on to have healthy children, though there may be some risks.

Some men who were treated for cancer as children may have decreased fertility due to low sperm counts or other problems. In women, some of the problems that could affect fertility include irregular menstrual periods, early menopause, and changes in the uterus. The causes of some of these problems are discussed above. Problems can vary greatly from person to person, so careful monitoring for any problems both during and after treatment is important.

For some who are treated for cancer as children, there may be ways to help preserve fertility or increase the chances of having their own children later in life. As mentioned above, sperm banking before treatment may be an option for some older boys. Some women who want to have children may be encouraged to try and get pregnant early in their childbearing years to improve the chances of success. Researchers are also studying newer ways of preserving or restoring fertility in people treated for childhood cancers.

Most studies have not found an increased risk of congenital (inborn) health problems in the children of cancer survivors. But this is an area of active study, as some of the treatments given today may use different drugs or doses not yet proven safe to future offspring.

Living as a childhood cancer survivor

After treatment, the main concerns for most families are the immediate and long-term effects of the cancer and its treatment, and concerns about possible cancer recurrence.

It is certainly normal to want to put the cancer and its treatment behind you and to get back to a life that doesn’t revolve around cancer. But it’s important to realize that follow-up care is a central part of this process that offers the best chance for recovery and long-term survival.

For many years after treatment of childhood cancer, regular follow-up exams will be very important. Doctors will watch for signs that the cancer might have 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.

For the rest of the childhood cancer survivor’s life, doctors should watch for things like pain, tiredness, and anxiety, as well as other possible signs of late effects. Physical and emotional effects may linger.
For parents, it’s important to know what kind of treatment your child had and what impact this treatment might have on his life as he grows up. Ask your child’s doctor to help you stay aware of what long-term effects might occur based on the treatments your child had.

And be sure your adult child knows the details of their childhood cancer so they can share that information with their doctors. Gathering these details soon after treatment will be easier than trying to get them at some point in the future. If you don’t have a copy of this information, contact the doctor who treated your child. If treatment was given at a hospital or clinic, you may need to contact them, too. These records are usually destroyed at some point, so they may not be available more than a few years after treatment.

There are certain pieces of information that you and your child should have, even into adulthood, including:

- A copy of the pathology reports from any biopsies or surgeries.
- If your child had surgery, a copy of the operative report(s).
- If your child stayed in the hospital, copies of the discharge summaries doctors prepare when patients are sent home.
- If your child had chemotherapy or other drug treatments, a list of the total doses of each drug.
- If your child had radiation therapy, a final summary of the dose and field.
- Copies of imaging tests (CT or MRI scans, etc.), which can usually be stored digitally (on a DVD or another electronic medium).
- The names and contact information of the doctors who treated your child’s cancer.

While late effects are a major concern for all childhood cancer survivors, it’s important to keep in mind that they are the result of life-saving treatment. Researchers continue to search for ways to reduce long-term effects. But for now, the gift of life may involve having to cope with some of the late effects of cancer treatment.

The Children’s Oncology Group (COG) is the world’s largest group of doctors and other health professionals devoted to treating cancer in children and teens. To increase awareness of late effects and improve follow-up care of childhood cancer survivors throughout their lives, the COG has developed long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. These guidelines can help you know what to watch for, what type of screening should be done, and how late effects can be treated.
To learn more, ask your doctors about the COG survivor guidelines. You can also find them online at [www.survivorshipguidelines.org](http://www.survivorshipguidelines.org). The guidelines are written for health care professionals. Patient versions of some of the guidelines are also available (as “Health Links”).

**Second cancers in children treated for cancer**

Some childhood cancer survivors have a small increase in risk of developing a second cancer during their lifetime. This risk is not the same for all survivors. Many factors affect risk, such as the type of the first cancer, the type of treatments given, the child’s age at the time of treatment, and the child’s genetic make-up. For example, survivors who had radiation treatment tend to have a higher risk of second cancers in the areas that were treated.

As childhood cancer survivors live longer into adulthood, they are also at risk of developing other cancers usually seen in adults, such as prostate, breast, or colon cancer. As these children grow up and age, things like genetics, body weight, diet, activity level, overall health, exposure to viruses, and environmental exposures all play a part in their cancer risk.

For parents, it’s very important to keep detailed records of the cancer treatments that were used during childhood (see specifics in the section “Follow-up is key”). Sharing this information with doctors who care for the child later in life can help them decide what tests they might need to help find certain cancers early, when treatment is most likely to be effective.

**Emotional issues in children treated for cancer**

Emotional issues may come up, too, and can affect all ages. As with other late effects, factors such as the child’s age at diagnosis and the extent of treatment may play a role here.

During treatment, families tend to focus on the daily aspects of getting through it and beating the cancer. But once treatment is finished, a number of emotional concerns may arise. Some of these might last a long time. They can include things like:

- Dealing with physical changes that can result from the cancer or its treatment
- Worries about the cancer returning or new health problems developing
- Feelings of resentment for having had cancer or having to go through treatment when others do not
- Concerns about being treated differently or discriminated against (by friends,
classmates, coworkers, employers, etc.)
  • Concerns about dating, marrying, and having a family later in life

No one chooses to have cancer, but many childhood cancer survivors find the experience meaningful over the long term, allowing for clearer setting of priorities and helping to establish strong personal values. Other survivors may have a harder time recovering, adjusting to life after cancer, and moving on. It’s normal to have some anxiety or other emotional reactions after treatment, but feeling overly worried, depressed, or angry can affect many aspects of a young person’s growth. It can get in the way of relationships, school, work, and other aspects of life.

With support from family, other survivors, mental health professionals, and others, many people who have survived cancer can thrive in spite of the challenges they’ve had to face.

**Additional resources**

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

**American Childhood Cancer Organization (formerly Candlelighters)** Toll-free number: 1-855-858-2226 Website: [www.acco.org](http://www.acco.org)
  • Website has sections just for children and teens with cancer and their siblings, as well as for adults. Provides information and parent support groups.

**Children’s Brain Tumor Foundation** Toll-free number: 1-866-228-HOPE (1-866-228-4673) Website: [www.cbtf.org](http://www.cbtf.org)
  • Offers a support line, as well as web-based and printed information for parents and children with cancer.

**Children’s Oncology Group (COG)** Website: [www.childrensoncologygroup.org](http://www.childrensoncologygroup.org)
  • Provides key information from the world’s largest organization devoted to childhood cancer research to help support children and their families from the time of diagnosis, through treatment, and beyond. Also has a searchable database to find the COG center closest to you.
CureSearch for Children’s Cancer Toll-free number: 1-800-458-6223 Website: www.curesearch.org

- Provides medical information about childhood cancer from pediatric cancer experts, including late effects. Has sections on the website 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) Website: www.cancer.gov

- Provides accurate, up-to-date information about cancer to patients and their families, including clinical trials information for patients. Has a childhood cancer section at: www.cancer.gov/cancertopics/types/childhoodcancers; late effects information at: www.cancer.gov/cancertopics/pdq/treatment/lateeffects/Patient

National Coalition for Cancer Survivorship Toll-free number: 1-877-NCCS-YES (1-877-622-7937) to order the Cancer Survival Toolbox® or other publications. Toll-free number: 1-888-650-9127 Website: www.canceradvocacy.org

- Provides publications on many topics, including employment and health insurance as it relates to cancer. Materials are also offered in Spanish.

Fertile Hope Toll-free number: 1-888-994-4673 Website: www.fertilehope.org

- Provides information on having children in the future to cancer patients whose medical treatments cause the risk of infertility.

Websites for teens and children

Beyond the Cure (part of the National Children’s Cancer Society for teens) Website: www.thenccs.org

- Online support and education for survivors of childhood cancer and their families.

Group Loop Toll-free number: 1-888-793-9355 Website: www.grouploop.org
• An online resource for teens with cancer and their parents – a way to connect with other teens. Group Loop includes online support groups, chat rooms, educational resources, and more.

**Stupid Cancer** Website: [www.stupidcancer.org](http://www.stupidcancer.org)

• A social networking organization for young adult cancer survivors (ages 15 to 40 years old) and their caregivers that offers support to help improve quality of life for young adults affected by cancer.

**SuperSibs! powered by Alex’s Lemonade Stand** Toll-free number: 1-866-333-1213
Website: [www.supersibs.org](http://www.supersibs.org)

• Supports, honors, and recognizes brothers and sisters of children diagnosed with cancer so they may face the future with strength, courage, and hope. Alex’s Lemonade Stand is restarting SuperSibs in 2014 so there may be some delays with resuming support services.

*Inclusion on this list does not imply endorsement by the American Cancer Society.*

**References**


Written by


Our team is made up of doctors and oncology certified nurses with deep knowledge of cancer care as well as journalists, editors, and translators with extensive experience in medical writing.

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