



- 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

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 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](#)⁴ 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)

- Ringing in the ears
- Trouble hearing words when background noise levels are high

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](#)⁸, 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

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.¹¹ 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:

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.

Hyperlinks

1. www.cancer.org/cancer/types/retinoblastoma.html
2. www.cancer.org/cancer/types/brain-spinal-cord-tumors-children.html
3. www.cancer.org/cancer/types/leukemia-in-children.html
4. www.cancer.org/cancer/types/pituitary-tumors.html
5. www.cancer.org/cancer/types/osteosarcoma.html
6. www.cancer.org/cancer/types/ewing-tumor.html
7. www.cancer.org/cancer/types/rhabdomyosarcoma.html
8. www.cancer.org/cancer/risk-prevention/tobacco/guide-quitting-smoking.html
9. www.cancer.org/cancer/managing-cancer/side-effects/fertility-and-sexual-side-effects/preserving-fertility-in-children-and-teens-with-cancer.html
10. www.cancer.org/cancer/survivorship/long-term-health-concerns/recurrence.html
11. www.survivorshipguidelines.org/
12. www.acco.org/
13. www.cbt.org/
14. www.childrenoncologygroup.org/
15. www.curesearch.org/
16. www.cancer.gov/
17. www.cancer.gov/cancertopics/types/childhoodcancers
18. www.canceradvocacy.org/

19. www.thenccs.org/
20. www.grouploop.org/
21. www.stupidcancer.org/
22. www.supersibs.org/

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.org¹²

- Website has sections just for children and teens with cancer and their siblings, as well as for adults. Provides information and parent support groups.

National Cancer Institute Toll-free number: 1-800-4-CANCER (1-800-422-6237)
Website: www.cancer.gov¹⁶

- 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/childhoodcancers¹⁷; 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.org¹⁸

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

Websites for teens and children

Beyond the Cure (part of the National Children’s Cancer Society for teens)
Website: www.thenccs.org¹⁹

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

Group Loop Toll-free number: 1-888-793-9355 Website: www.grouploop.org²⁰

- 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.org²¹

- 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.org²²

- 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.

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