# After Childhood Leukemia Treatment

Get information about how to live well after childhood leukemia treatment and make decisions about next steps.

**Living as a Childhood Leukemia Survivor**

For many people, cancer treatment often raises questions about next steps as a survivor.


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# Living as a Childhood Leukemia Survivor


- Follow-up exams and tests
- Keeping health insurance and copies of medical records
- Late and long-term effects of treatment
- Social and emotional issues during and after treatment


During treatment for childhood leukemia[1], the main concerns for most families are the daily aspects of getting through treatment and beating the leukemia. After treatment, the concerns tend to shift toward the long-term effects of the leukemia and its treatment, and concerns about the leukemia coming back.

It's certainly normal to want to put the leukemia 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 your child the best chance for recovery and long-term survival.

## Follow-up exams and tests

For several years after treatment, regular follow-up exams will be very important. The doctors will watch for possible signs of leukemia, as well as for short-term and long-term side effects of treatment[2].

Checkups typically include careful physical exams and lab tests[3], and sometimes might include imaging tests[4]. The schedule for these checkups will depend on the type and subtype of leukemia, the treatment given, and other factors. Checkups will usually be monthly during the first year, and then less often for at least 5 years after therapy. After that time, most children see their doctor at least yearly for a checkup.

For the most common types of leukemia in children (ALL[5] and AML[6]), if the leukemia does come back, it is most often while the child is still being treated or within a year or so after finishing treatment. It is unusual for ALL or AML to return if there are no signs of the disease within the next 2 years.

A benefit of follow-up care is that it gives you a chance to discuss questions and concerns that come up during and after your child's recovery. For example, almost any cancer treatment can have side effects. Some go away soon after treatment, but others can last a long time, or might not even show up until years later. It's important to report any new symptoms to the doctor right away, so that the cause can be found and treated, if needed.

### Ask the treatment team for a survivorship care plan

Talk with the treatment team about developing a survivorship care plan[7]. This plan might include:

- A summary of the diagnosis, tests done, and treatment given
- A suggested schedule for follow-up exams and tests
- A schedule for other tests that might be needed in the future, such as early detection (screening) tests for other types of cancer, or tests to look for long-term health effects from the leukemia or its treatment
- A list of possible late- or long-term side effects from treatment, including what to

watch for and when to contact the doctor

## Keeping health insurance and copies of medical records

As much as you might want to put the experience behind you once treatment is completed, it's also very important to keep good records of your (child's) medical care during this time. Gathering these details soon after treatment may be easier than trying to get them at some point in the future. This can be very helpful later on if you (or your child) change doctors. Learn more about this in Keeping Copies of Important Medical Records[8].

It's also very important to keep health insurance[9] coverage. Tests and doctor visits can cost a lot, and even though no one wants to think of the tumor coming back, this could happen.

## Late and long-term effects of treatment

Because of major advances in treatment, most children treated for leukemia now live into adulthood, so their health as they get older has become more of a concern in recent years.

Just as the treatment of childhood leukemia requires a very specialized approach, so does the care and follow-up after treatment. The earlier problems are recognized, the more likely it is they can be treated effectively.

Childhood leukemia survivors are at risk, to some degree, for several possible late effects of their treatment. This risk depends on a number of factors, such as the type and subtype of leukemia, the type and doses of treatments they received, and the age of the child at the time of treatment. It's important to discuss what these possible effects might be with your child's medical team so you know what to watch for and report to the doctor.

### Second cancers

Children who have been treated for leukemia are often at higher risk of developing other cancers later in life. One of the most serious possible side effects of acute lymphocytic leukemia (ALL) therapy is a small risk of getting acute myeloid leukemia (AML) later on.

This occurs in a small percentage of patients after getting certain chemotherapy drugs,

such as **epipodophyllotoxins** (etoposide, teniposide), **alkylating agents** (cyclophosphamide, chlorambucil), or **anthracyclines** (daunomycin, doxorubicin). Of course, the risk of getting these second cancers must be balanced against the obvious benefit of treating a life-threatening disease such as leukemia.

### Heart and lung problems

Certain chemotherapy drugs or radiation therapy to the chest can sometimes cause heart or lung problems later in life. The risks of heart disease and stroke are much higher among those treated for ALL as children, so careful follow-up is very important.

### Learning problems

Treatment that includes radiation therapy to the brain or some types of chemotherapy may affect learning ability in some children. Because of this, doctors try to limit treatments that could affect the brain (including radiation) as much as possible.

### Growth and development

Some cancer treatments may affect a child's growth, so they might end up a bit shorter as adults. This is especially true after stem cell transplants. This can be helped by treating survivors with growth hormone, if needed. Treatment might also affect the levels of other hormones in the body, which can increase the risk of health issues such as thyroid problems, obesity, and diabetes.

### Fertility issues

Cancer treatment may also affect sexual development and ability to have children later in life. Talk to your child's cancer care team about the risks of infertility with treatment, and ask if there are options for preserving fertility, such as sperm banking. For more information, see Preserving Fertility in Children and Teens With Cancer[10].

### Bone problems

Bone damage or osteoporosis (thinning of the bones) may result from the use of prednisone, dexamethasone, or other steroid drugs.

There may be other possible complications from chemotherapy or other treatments as well. Your child's doctor should carefully review any possible problems with you before your child starts treatment.

### Long-term follow-up guidelines

To help increase awareness of late effects and improve follow-up care for childhood cancer survivors throughout their lives, the Children's Oncology Group (COG) has developed long-term follow-up guidelines for survivors of childhood cancers. These guidelines can help you know what to watch for, what types of screening tests should be done, and how late effects can be treated.

It's very important to discuss possible long-term complications with your child's health care team, and to make sure there is a plan in place to watch for these problems and treat them, if needed. To learn more, ask your child's doctors about the COG survivor guidelines. You can also read them on the COG website: www.survivorshipguidelines.org[11]. The guidelines are written for health care professionals. Patient versions of some of the guidelines are available (as Health Links) on the site as well, but we urge you to discuss them with your doctor.

For more on the possible long-term effects of treatment, see Late Effects of Childhood Cancer Treatment[12].

## Social and emotional issues during and after treatment

Social and emotional issues may come up during and after treatment. Factors such as the child's age when diagnosed and the extent of treatment can play a role here.

Some children may have emotional or psychological issues that need to be addressed during and after treatment. Depending on their age, they may also have some problems with normal functioning and school work. These types of issues can often be helped with support and encouragement. Doctors and other members of the health care team can also often recommend special support programs and services to help children after treatment. For more information, see When Your Child's Treatment Ends[13].

Many experts recommend that school-aged patients attend school as much as possible. This can help them maintain a sense of daily routine and keep their friends informed about what is happening.

Friends can be a great source of support, but patients and parents should know that some people have misunderstandings and fears about cancer. Some cancer centers have school re-entry programs that can help in these situations. In these programs, health educators visit the school and tell students about the diagnosis, treatment, and changes that the cancer patient may go through. They also answer any questions from teachers and classmates. (For more information, see Returning to School After Cancer

Treatment[14].)

Parents and other family members can also be affected, both emotionally and in other ways. Some common family concerns during treatment include financial stresses, traveling to and staying near the cancer center, the need to take time off from work, and the need for home schooling. Social workers and other professionals at cancer centers can help families sort through these issues.

Centers that treat many patients with leukemia may have programs to introduce new patients and their families to others who have finished their treatment. This can give them an idea of what to expect during and after treatment, which can be very important.

Once treatment is finished, a number of emotional concerns can come up. Some of these might last a long time and can include:

- Dealing with physical changes that can result from the treatment
- Worries about the leukemia returning or new health problems developing
- Feelings of resentment for having had leukemia 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 leukemia, but for many childhood leukemia survivors, the experience can eventually be positive, helping to establish strong self-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, friends, other survivors, mental health professionals, and others, many people who have survived leukemia can thrive in spite of the challenges they've had to face.

## Hyperlinks

1. www.cancer.org/cancer/types/leukemia-in-children/treating.html
2. www.cancer.org/cancer/managing-cancer/side-effects.html
3. www.cancer.org/cancer/types/leukemia-in-children/detection-diagnosis-staging/how-diagnosed.html

4. www.cancer.org/cancer/types/leukemia-in-children/detection-diagnosis-staging/how-diagnosed.html
5. www.cancer.org/cancer/types/leukemia-in-children/treating/children-with-all.html
6. www.cancer.org/cancer/types/leukemia-in-children/treating/children-with-aml.html
7. www.cancer.org/cancer/survivorship/long-term-health-concerns/survivorship-care-plans.html
8. www.cancer.org/cancer/survivorship/long-term-health-concerns/keeping-copies-of-important-medical-records.html
9. www.cancer.org/cancer/financial-insurance-matters/understanding-health-insurance.html
10. www.cancer.org/cancer/managing-cancer/side-effects/fertility-and-sexual-side-effects/preserving-fertility-in-children-and-teens-with-cancer.html
11. www.survivorshipguidelines.org
12. www.cancer.org/cancer/survivorship/children-with-cancer/late-effects-of-cancer-treatment.html
13. www.cancer.org/cancer/survivorship/children-with-cancer/after-treatment.html
14. www.cancer.org/cancer/survivorship/children-with-cancer/after-treatment/returning-to-school.html

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Horton TM, Steuber CP. Overview of the outcome of acute lymphoblastic leukemia in children and adolescents. UpToDate. 2018. Accessed at www.uptodate.com/contents/overview-of-the-outcome-of-acute-lymphoblastic-leukemia-in-children-and-adolescents on December 29, 2018.Horton TM, Steuber CP. Overview of the treatment of acute lymphoblastic leukemia in children and adolescents. UpToDate. 2018. Accessed at www.uptodate.com/contents/overview-of-the-treatment-of-acute-lymphoblastic-leukemia-in-children-and-adolescents on December 29, 2018.Tarlock K, Cooper TM. Acute myeloid leukemia in children and adolescents.

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