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After Childhood Non-Hodgkin Lymphoma Treatment

Living as a Cancer Survivor

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

- [What Happens During and After Treatment for Non-Hodgkin Lymphoma in Children?](#)
- [Social, Emotional, and Other Issues in Treating Non-Hodgkin Lymphoma](#)

Cancer Concerns After Treatment

Childhood lymphoma survivors are at risk for possible late effects of their cancer 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.

- [Late and Long-Term Effects of Treatment for Non-Hodgkin Lymphoma in Children](#)
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What Happens During and After Treatment for Non-Hodgkin Lymphoma in Children?

During treatment for non-Hodgkin lymphoma (NHL), the main concerns for most families are the daily aspects of getting through treatment and beating the lymphoma. After treatment, the concerns tend to shift toward the long-term effects of the lymphoma and its treatment, and concerns about the lymphoma coming back (recurrence)..

It's certainly normal to want to put the lymphoma 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

It's very important for your child to go to regular follow-up exams with the cancer care team for many years after treatment. The doctors will continue to watch for possible signs of lymphoma, as well as for short-term and long-term side effects of treatment. Doctor visits will be more frequent at first, but the time between visits may be extended as time goes on.

Checkups after treatment typically include physical exams, lab tests, and sometimes [other tests](#)¹ such as PET or CT scans. If the lymphoma comes back, it is usually while the child is still getting treatment or just after. It is unusual for childhood lymphoma to return if there are no signs of the disease within a year or so after treatment.

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 might last for only a short time, but [others can last longer](#) or might not show up until months or even 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 your child's doctor for a survivorship care plan

Talk with your child's doctor about developing a survivorship care plan. This plan might include:

- A suggested schedule for follow-up exams and tests
- A schedule for other tests your child might need 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 lymphoma or its treatment
- A list of possible [late- or long-term side effects](#) from your child's treatment, including

- what to watch for and when to contact the doctor
- Diet and physical activity suggestions

Keeping records of health insurance and your child's medical care

As much as you might want to put the experience behind you once treatment is done, it's very important to keep good records of your child's medical care during this time. Eventually, your child will grow up, be on his or her own, and have new doctors. It's important for them to be able to give the new doctors the details of their cancer diagnosis and treatment. Gathering the details soon after treatment may be easier than trying to get them at some point in the future. There are certain pieces of information that your child's doctors should have, even into adulthood. These include:

- 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 that doctors prepare when patients are sent home.
- A list of the final doses of each chemotherapy drug or other drug your child received. (Certain drugs can have specific long-term side effects.)
- If radiation therapy was given, a summary of the type and dose of radiation and when and where it was given.

Ask your cancer care team where and how to get this information. Learn more in [Keeping Copies of Important Medical Records²](#).

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

Can we lower the risk of the lymphoma progressing or coming back?

If your child has (or has had) lymphoma, you probably want to know if there are things you can do that might lower the risk of the lymphoma growing or coming back, such as eating a certain type of diet or taking nutritional supplements. Unfortunately, it's not yet clear if there are things you can do that will help.

As your child gets older, adopting healthy behaviors such as [not smoking³](#), [eating well](#), [getting regular physical activity⁴](#), and staying at a healthy weight might help, but no one

knows for sure. However, we do know that these types of behaviors can have positive effects on your child's health that can extend beyond their risk of lymphoma or other cancers.

About dietary supplements

So far, no dietary supplements (including vitamins, minerals, and herbal products) have been shown to clearly help lower the risk of lymphoma progressing or coming back. This doesn't mean that no supplements can help, but it's important to know that none have been proven to do so.

Dietary supplements are not regulated like medicines in the United States – they do not have to be proven effective (or even safe) before being sold, although there are limits on what they're allowed to claim they can do. If you're thinking about having your child take any type of nutritional supplement, talk to your child's health care team. They can help you decide which ones can be used safely while avoiding those that might be harmful.

To learn more, see [Dietary Supplements: What Is Safe?](#)⁵

Hyperlinks

1. www.cancer.org/cancer/childhood-non-hodgkin-lymphoma/detection-diagnosis-staging/how-diagnosed.html
2. www.cancer.org/treatment/survivorship-during-and-after-treatment/be-healthy-after-treatment/keeping-copies-of-important-medical-records.html
3. www.cancer.org/healthy/stay-away-from-tobacco.html
4. www.cancer.org/healthy/eat-healthy-get-active.html
5. www.cancer.org/treatment/treatments-and-side-effects/complementary-and-alternative-medicine/dietary-supplements.html

Last Medical Review: June 20, 2017 Last Revised: August 7, 2017

Social, Emotional, and Other Issues in Treating Non-Hodgkin Lymphoma

Social and emotional issues may come up during and after your child's treatment. Factors such as the child's age when diagnosed and the extent of treatment may 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 functioning normally and with school work. These can often be overcome 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.

Many experts recommend that school-aged children 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 children and parents should know that some people have misunderstandings and fears about cancer. Some cancer centers have a school re-entry program that can help in these situations. In this program, health educators visit the school and tell students about the diagnosis, treatment, and changes that the child with cancer may go through. They can also answer any questions from teachers and classmates. (For more information, see [Children Diagnosed With Cancer: Returning to School¹](#).)

Centers that treat many children with lymphoma might have programs to introduce new patients to children or teens who have finished their treatment. This can give patients and their families an idea of what to expect during and after treatment, which is very important. Seeing another patient with lymphoma doing well after treatment is often helpful. Support groups also might be helpful.

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 possible loss of a job, taking care of other siblings, and the need for home schooling. Social workers and other professionals at cancer centers can help families sort through these issues.

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

- Dealing with physical changes that can result from the treatment
- Worrying about the lymphoma returning or new health problems developing
- Feeling resentment for having had lymphoma or having to go through treatment when others do not

- Having concerns about being treated differently or discriminated against (by friends, classmates, coworkers, employers, etc.)
- Having concerned about dating, marrying, and having a family later

For teens, another possible issue is having to rely more on their parents at a time when they are normally becoming more independent.

No one chooses to have lymphoma, but for many childhood lymphoma survivors, the experience eventually can 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 cancer can thrive in spite of the challenges they've had to face. If needed, doctors and other members of the health care team can often recommend special support programs and services to help children after cancer treatment.

You can learn more about some of these issues in [Children Diagnosed With Cancer: Dealing With Diagnosis](#)² and [When Your Child's Treatment Ends](#)³.

Hyperlinks

1. </content/cancer/en/treatment/children-and-cancer/when-your-child-has-cancer/returning-to-school.html>
2. </content/cancer/en/treatment/children-and-cancer/when-your-child-has-cancer/dealing-with-diagnosis.html>
3. </content/cancer/en/treatment/children-and-cancer/when-your-child-has-cancer/when-your-childs-treatment-ends.html>

Last Medical Review: March 7, 2014 Last Revised: January 27, 2016

Late and Long-Term Effects of Treatment for Non-Hodgkin Lymphoma in Children

Because of major advances in treatment, most children treated for lymphoma live into adulthood, so their health as they get older has come more into focus in recent years.

Just as the treatment of childhood lymphoma requires a very specialized approach, so does follow-up and monitoring for late effects of treatment. [Careful follow-up](#) after treatment is very important, as some side effects might not show up until many years after treatment. The earlier any problems are recognized, the more likely it is they can be treated effectively.

Childhood lymphoma survivors are at risk, to some degree, for several possible late effects of their cancer treatment. This risk depends on a number of factors, such as the type of lymphoma, the type and doses of treatments, and the child's age when getting 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.

Late effects of treatment can include:

- Heart or lung problems after getting certain chemotherapy drugs or getting radiation therapy to the chest
- Slowed or limited growth and development (especially after a stem cell transplant)
- Bone damage or thinning of bones (osteoporosis)
- Changes in sexual development and ability to have children (see below)
- Changes in intellectual function with learning difficulties
- Development of second cancers, such as leukemia, later in life. These are not common, but they can happen.

Cancer treatment might affect sexual development and the ability to have children later in life. Talk with your child's cancer care team about the risk of treatment affecting fertility, and ask if there are options for preserving fertility. For more information, see [Preserving Fertility in Children and Teens With Cancer](#)¹.

There may be other complications from treatment, as well. Your child's doctor should carefully go over any possible problems with you before your child starts treatment.

Along with physical side effects, survivors of childhood cancer may have [emotional or psychological issues](#). They also may have some problems functioning normally and with school work. These can often be addressed with Support and encouragement often help these issues. Doctors and other members of the health care team can often recommend special support programs and services to help children after cancer 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 may 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 download them for free at the COG website: www-survivorshipguidelines.org.² 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 a doctor.

For more about some of the possible long-term effects of treatment, see [Children Diagnosed With Cancer: Late Effects of Cancer Treatment](#)³.

Hyperlinks

1. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects/preserving-fertility-in-children-and-teens-with-cancer.html
2. <http://www-survivorshipguidelines.org/>
3. www.cancer.org/treatment/children-and-cancer/when-your-child-has-cancer/late-effects-of-cancer-treatment.html

Last Medical Review: June 20, 2017 Last Revised: August 7, 2017

Written by

The American Cancer Society medical and editorial content team
(www.cancer.org/cancer/acs-medical-content-and-news-staff.html)

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