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After Childhood Non-Hodgkin Lymphoma Treatment

Get information about living well after non-Hodgkin lymphoma treatment and making decisions about next steps.

Living as a Cancer Survivor

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

- What Happens After Treatment for Non-Hodgkin Lymphoma in Children?
- Social, Emotional, and Other Issues in Treating Childhood 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

What Happens After Treatment for Non-Hodgkin Lymphoma in Children?

- Follow-up exams and tests
- Ask your child's doctor for a survivorship care plan
- Keeping health insurance and records of your child's medical care
- Can we lower the risk of the lymphoma progressing or coming back?

During treatment for childhood non-Hodgkin lymphoma (NHL), most families are mainly concerned with 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, as well as the possibility of the lymphoma coming back (recurring).

It's certainly understandable for you to want to put 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 and tests

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 get longer as time goes on.

Checkups after treatment typically include physical exams, lab tests, and sometimes other tests¹ such as CT, MRI, or PET scans. If the lymphoma does come 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 <u>survivorship care plan</u>². 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 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 health insurance and records of 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 their 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.

Ask your cancer care team where and how to get this information. Learn more in Keeping Copies of Important Medical Records³.

It's also important to keep health insurance⁴ 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 having them eat a certain type of diet or take 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 <u>not smoking</u>⁵, <u>eating well</u>, <u>getting regular physical activity</u>⁶, 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 <u>Dietary Supplements: What Is Safe?</u>

Hyperlinks

- 1. <u>www.cancer.org/cancer/types/childhood-non-hodgkin-lymphoma/detection-diagnosis-staging/how-diagnosed.html</u>
- 2. <u>www.cancer.org/cancer/survivorship/long-term-health-concerns/survivorship-care-plans.html</u>
- 3. <u>www.cancer.org/cancer/survivorship/long-term-health-concerns/keeping-copies-of-important-medical-records.html</u>
- 4. <u>www.cancer.org/cancer/financial-insurance-matters/understanding-health-insurance.html</u>
- 5. <u>www.cancer.org/cancer/risk-prevention/tobacco.html</u>
- 6. www.cancer.org/cancer/risk-prevention/diet-physical-activity.html
- 7. <u>www.cancer.org/cancer/managing-cancer/treatment-types/complementary-and-integrative-medicine/dietary-supplements.html</u>

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Gross TG, Kamdar KY, Bollard CM. Chapter 19: Malignant Non-Hodgkin Lymphomas in Children. In: Blaney SM, Adamson PC, Helman LJ, eds. *Pizzo and Poplack's Principles and Practice of Pediatric Oncology*. 8th ed. Philadelphia Pa: Lippincott Williams & Wilkins; 2021.

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Termuhlen AM, Gross TG. Overview of non-Hodgkin lymphoma in children and adolescents. UpToDate. 2021. Accessed at https://www.uptodate.com/contents/overview-of-non-hodgkin-lymphoma-in-children-and-adolescents on June 14, 2021.

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

- Concerns after treatment is finished
- Returning to school

Some children and teens may have emotional or psychological issues that need to be addressed during and after treatment. Factors such as the <u>child's age when diagnosed</u>¹ and the extent of treatment play a role here.

cancer centers can help families sort through these issues.

Centers that treat many children and teens with lymphoma might have programs to introduce new patients to others 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.

Concerns after treatment is finished

During treatment, children and their families tend to focus on the daily aspects of getting through it⁴ 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 concerns 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.

Returning to school

Many experts recommend that school-aged <u>children attend school</u>⁵ as much as possible. This can help them maintain a daily routine and keep their friends informed about what is happening. But they might also have some problems functioning normally and with school work. These issues can often be overcome with support and encouragement. Doctors and other members of the health care team can often recommend special support programs and services to help children and teens after treatment.

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.

You can learn more about some of these issues in <u>When Your Child Has Cancer</u>⁶, <u>When Your Child Is Going Through Cancer Treatment</u>⁷, and <u>When Your Child's Treatment Ends</u>⁸.

Hyperlinks

- 1. <u>www.cancer.org/cancer/survivorship/children-with-cancer/after-diagnosis/helping-your-child.html</u>
- 2. <u>www.cancer.org/cancer/managing-cancer/side-effects/emotional-mood-changes/anxiety.html</u>
- 3. <u>www.cancer.org/cancer/managing-cancer/side-effects/emotional-mood-changes/depression.html</u>
- 4. <u>www.cancer.org/cancer/survivorship/children-with-cancer/after-treatment/getting-back-to-normal.html</u>
- 5. <u>www.cancer.org/cancer/survivorship/children-with-cancer/after-treatment/returning-to-school.html</u>
- 6. www.cancer.org/cancer/survivorship/children-with-cancer.html
- 7. www.cancer.org/cancer/survivorship/children-with-cancer/during-treatment.html
- 8. www.cancer.org/cancer/survivorship/children-with-cancer/after-treatment.html

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

• Long-term follow-up guidelines

Because of major advances in treatment, most children treated for non-Hodgkin lymphoma (NHL) now live well into adulthood, so there are more concerns about their health as they get older.

Just as the treatment of childhood lymphoma requires a very specialized approach, so does follow-up and monitoring for late effects of treatment.

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

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 help increase awareness of late effects and improve follow-up care for childhood cancer survivors throughout their lives, the Children's Oncology Group (COG, the major group of doctors who treat childhood cancer in the US) has developed long-term follow-up guidelines for survivors of childhood cancers. These guidelines are used to help create a child's <u>survivorship care plan</u>⁵. They can also can help you know what to watch for, what types of screening tests should be done, and how late effects may be treated.

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.6 The guidelines are written for health care professionals but patient versions of some of the guidelines are available (as "Health Links") on the site as well.

For more about some of the possible long-term effects of treatment, see <u>Late Effects of Childhood Cancer Treatment.</u>⁷

Hyperlinks

- 1. www.cancer.org/cancer/types/childhood-non-hodgkin-lymphoma/about.html
- 2. www.cancer.org/cancer/types/childhood-non-hodgkin-lymphoma/treating.html
- 3. www.cancer.org/cancer/types/leukemia.html
- 4. <u>www.cancer.org/cancer/managing-cancer/side-effects/fertility-and-sexual-side-effects/preserving-fertility-in-children-and-teens-with-cancer.html</u>
- 5. <u>www.cancer.org/cancer/survivorship/long-term-health-concerns/survivorship-care-plans.html</u>
- 6. www.survivorshipguidelines.org/
- 7. <u>www.cancer.org/cancer/survivorship/children-with-cancer/late-effects-of-cancer-treatment.html</u>

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Gross TG, Kamdar KY, Bollard CM. Chapter 19: Malignant Non-Hodgkin Lymphomas in Children. In: Blaney SM, Adamson PC, Helman LJ, eds. *Pizzo and Poplack's Principles and Practice of Pediatric Oncology*. 8th ed. Philadelphia Pa: Lippincott Williams & Wilkins; 2021.

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