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After Hodgkin Disease Treatment

Living as a Cancer Survivor

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

- [Living As a Hodgkin Lymphoma Survivor](#)
- [Late and Long-term Side Effects of Hodgkin Lymphoma Treatment](#)

Cancer Concerns After Treatment

Treatment may destroy the cancer, but it's very common to have questions about cancer coming back or treatment no longer working.

- [Second Cancers After Hodgkin Lymphoma](#)

Living As a Hodgkin Lymphoma Survivor

For many people with Hodgkin lymphoma (HL), treatment can cure the lymphoma. Completing treatment can be both stressful and exciting. You may be relieved to finish treatment, but find it hard not to worry about the lymphoma coming back. (When cancer comes back after treatment, it's called a recurrence .) This is a very common concern if you've had cancer.

For some people, HL may never go away completely. These people may get regular treatments with chemotherapy, radiation therapy, or other therapies to help control it for as long as possible and to help relieve symptoms. Learning to [live with HL that doesn't go away](#)¹ can be difficult and very stressful.

Ask your doctor for a survivorship care plan

Talk with your doctor about developing a [survivorship care plan](#)² for you. This plan might include:

- A suggested schedule for follow-up exams and tests
- A schedule for other tests you might need in the future, such as [early detection \(screening\) tests](#)³ for other types of cancer, or tests to look for long-term health effects from the HL or its treatment
- A list of possible late- or long-term side effects from your treatment, including what to watch for and when you should contact your doctor
- Diet and physical activity suggestions

Follow-up after Hodgkin Lymphoma

Even if you've completed treatment, your doctors will still want to watch you closely. It's very important to go to all your follow-up appointments because HL can sometimes come back even many years after treatment.

Some treatment side effects might last a long time or might not even show up until years after you have finished treatment (see [Late and Long-term Side Effects of Hodgkin Lymphoma Treatment](#)). These doctor visits are a good time to ask questions and talk about any changes or problems you notice or concerns you have.

Many people with Hodgkin lymphoma are cured, but the treatments used can lead to health problems in the future. See your doctor regularly, get the recommended cancer screening tests, and tell your health care team about any changes you notice in how you feel.

Exams and tests

During follow-up visits, the doctor will ask about symptoms, do physical exams, and may do blood tests or [imaging tests](#)⁴ such as PET or CT scans . Doctor visits are usually recommended every 3 to 6 months for the first several years after treatment. Over time, the length of time between visits can be increased, but even after 5 years you should see your oncologist at least once a year.

People whose HL doesn't go away with treatment will have a follow-up schedule that's based on their specific situation.

Keeping health insurance and copies of your medical records

Even after treatment, it's very important to keep [health insurance](#)⁵. Tests and doctor visits cost a lot, and even though no one wants to think of their cancer coming back, this could happen.

At some point after your treatment, you might find yourself seeing a new doctor who doesn't know your medical history. It's important to keep copies of your medical records to give your new doctor the details of your diagnosis and treatment. Learn more in [Keeping Copies of Important Medical Records](#)⁶.

Can I lower my risk of Hodgkin lymphoma progressing or coming back?

If you have (or have had) Hodgkin lymphoma, you probably want to know if there are things you can do that might lower your risk of the lymphoma coming back, such as exercising, 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.

Adopting healthy behaviors such as [not smoking](#)⁷, [eating well, getting regular physical activity](#),⁸ and staying at a healthy weight might help, but no one knows for sure. However, we do know that these types of changes can have positive effects on your health that can extend beyond your risk of HL 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 HL progressing or coming back. This doesn't mean that no supplements will 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 don't 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 taking any type of nutritional supplement, talk to your health care team. They can help you decide which ones you can use safely while avoiding those that might be harmful.

If Hodgkin lymphoma comes back

If Hodgkin lymphoma does come back (recurs) at some point, your treatment options will depend on where the lymphoma is, what treatments you've had before, how long it's been since treatment, and your current health and preferences. For more on how recurrent HL is treated, see [Treating Classic Hodgkin Lymphoma, by Stage](#)⁹.

For more general information, see [Understanding Recurrence](#)¹⁰.

Could I get a second cancer after treatment?

People who've had Hodgkin lymphoma can still get other cancers. In fact, HL survivors are at higher risk for getting some other types of cancer. Learn more in [Second Cancers After Hodgkin Lymphoma](#).

Getting emotional support

Some amount of feeling depressed, anxious, or worried is normal when lymphoma is a part of your life. Some people are affected more than others. But everyone can benefit from help and support from other people, whether friends and family, religious groups, support groups, professional counselors, or others. Learn more in [Life After Cancer](#)¹¹.

Hyperlinks

1. www.cancer.org/treatment/survivorship-during-and-after-treatment/when-cancer-doesnt-go-away.html
2. www.cancer.org/treatment/survivorship-during-and-after-treatment/survivorship-care-plans.html
3. www.cancer.org/healthy/find-cancer-early/cancer-screening-guidelines/american-cancer-society-guidelines-for-the-early-detection-of-cancer.html
4. www.cancer.org/treatment/understanding-your-diagnosis/tests/imaging-radiology-tests-for-cancer.html
5. www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-

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6. www.cancer.org/treatment/survivorship-during-and-after-treatment/be-healthy-after-treatment/keeping-copies-of-important-medical-records.html
7. www.cancer.org/healthy/stay-away-from-tobacco.html
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9. www.cancer.org/cancer/hodgkin-lymphoma/treating/by-stage.html
10. www.cancer.org/treatment/survivorship-during-and-after-treatment/understanding-recurrence.html
11. www.cancer.org/treatment/survivorship-during-and-after-treatment/be-healthy-after-treatment/life-after-cancer.html

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Second Cancers After Hodgkin Lymphoma

Cancer survivors can be affected by a number of health problems, but often a major concern is facing cancer again. If the same kind of cancer comes back after treatment it's called a recurrence. But some cancer survivors might develop another type of cancer later (usually more than 10 years after treatment). This is called a **second cancer**.

People who have had Hodgkin lymphoma (HL) can get any type of second cancer, but research has found they have an increased risk of certain cancers. These tend to be linked to the treatments used for HL. Chemo is linked to blood cancers, and radiation therapy is linked to cancers in the organs in the area that was treated. The cancers include:

- [Leukemia](#)¹
- [Myelodysplastic syndrome \(MDS\)](#)²
- [Non-Hodgkin lymphoma](#)³
- [Breast cancer](#)⁴ (in women)
- [Lung cancer](#)⁵
- [Thyroid cancer](#)⁶
- [Cancer of the lip and tongue](#)⁷
- [Salivary gland cancer](#)⁸
- [Stomach cancer](#)⁹
- [Colon cancer](#)¹⁰
- [Liver cancer](#)¹¹
- [Pancreas cancer](#)¹²
- [Bone cancer](#)¹³
- [Soft tissue cancer](#)¹⁴
- [Anal cancer](#)¹⁵

- [Cancer of the uterus](#)¹⁶
- Cancer of the ureter (the tube that connects the kidney and the bladder)
- [Melanoma of the skin](#)¹⁷
- [Kaposi sarcoma](#)¹⁸

The increased risk of many of these cancers are linked to treatment with [radiation](#)¹⁹. For example:

- Women who have had chest radiation (especially before age 30) have been found to have a higher risk of breast cancer.
- Radiation to the neck has been linked to a higher risk of thyroid cancer.
- Radiation to the chest has been linked to a higher risk of lung cancer.

But over time, the use of radiation to treat HL has changed a lot. Radiation is now given in lower doses, and often only to the areas directly affected by the lymphoma. The risks with modern radiation treatment are likely to be lower, still long-term studies are needed to be sure.

[Chemotherapy](#)²⁰ (chemo), especially with drugs called alkylating agents (such as dacarbazine and cyclophosphamide) has been linked with a higher risk of several types of cancer, including leukemias. Today, alkylating agents are used less often and at much lower doses, so these risks are probably not as high as they were in the past, but, again, long-term follow-up studies are needed to be sure.

Follow-up care after Hodgkin lymphoma treatment

After completing treatment for HL, you should still see your doctor regularly and may have tests to look for signs that the cancer has come back. Let them know about any new symptoms or problems, because they could be caused by the lymphoma coming back, by a new disease, or by second cancer.

Women who were treated with radiation therapy to the chest (such as mantle field radiation therapy) before age 30 have an increased risk of breast cancer. The American Cancer Society recommends yearly [breast cancer screening](#)²¹ with breast MRIs along with mammograms and clinical breast exams beginning at age 30 for these women. Some experts recommend that screening start 8 to 10 years after treatment or at age 40 (whichever is earlier).

The Children's Oncology Group has guidelines for the follow-up of patients treated for cancer as a child, teen, or young adult, including screening for second cancers. These

can be found at www.survivorshipguidelines.org²².

Survivors of HL should also follow [the American Cancer Society guidelines for the early detection of cancer](#)²³, such as those for colorectal and lung cancer. Most experts don't recommend any other testing to look for second cancers unless you have symptoms.

Can I lower my risk of getting a second cancer?

There are steps you can take to help lower your risk and stay as healthy as possible. For example, it's important to [stay away from tobacco](#)²⁴ products. Smoking increases the risk of many cancers, including some of the second cancers seen in people who have had Hodgkin lymphoma.

To help maintain good health, HL survivors should also:

- Get to and stay at a [healthy weight](#)²⁵
- Keep [physically active](#)²⁶ and limit the time you spend sitting or lying down
- Follow a healthy [eating pattern](#)²⁷ that includes plenty of fruits, vegetables, and whole grains, and limits or avoids red and processed meats, sugary drinks, and highly processed foods
- Not drink [alcohol](#)²⁸. If you do drink, have no more than 1 drink per day for women or 2 per day for men

These steps may also lower the risk of other health problems, including heart disease.

See [Second Cancers in Adults](#)²⁹ for more information.

Hyperlinks

1. www.cancer.org/cancer/leukemia.html
2. www.cancer.org/cancer/myelodysplastic-syndrome.html
3. www.cancer.org/cancer/non-hodgkin-lymphoma.html
4. www.cancer.org/cancer/breast-cancer.html
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Late and Long-term Side Effects of Hodgkin Lymphoma Treatment

Each type of treatment for Hodgkin lymphoma (HL) has side effects that could last for months or longer. And there are some that might not show up until long after treatment has ended. Some side effects, like loss of fertility (ability to have children), heart damage, and low thyroid hormones, can be permanent.

Because so many people are now living for a long time after their treatment, watching for these late and long-lasting side effects is very important. Be sure to talk to your treatment team about what these possible effects might be so you know what to watch for and report to the doctor.

Second cancers

One uncommon but very serious side effect of HL treatment is developing a second type of cancer later on. People who've had HL have a higher risk for many types of cancer. See [Second Cancers After Hodgkin Lymphoma](#) for more on this.

Fertility issues

A possible long-term effect of chemotherapy and radiation therapy, especially in younger patients, is reduced or lost fertility. For example, some chemo drugs can affect a male's ability to make sperm, which might be short-term or permanent. If the patient is old enough and is going to get chemo drugs that can affect fertility, sperm banking should be considered before chemo starts.

Likewise, women may stop having menstrual periods with chemotherapy. This may or may go back to normal; some women go into early menopause after treatment. Radiation to the lower abdomen (belly) can cause infertility unless the ovaries are surgically moved outside the radiation field beforehand. Moving the ovaries does not affect cure rates because HL almost never spreads to the ovaries.

To learn more, see [Fertility and Women With Cancer](#)¹ and [Fertility and Men With Cancer](#)².

Infections

For unknown reasons, the immune systems of people with HL often do not work the way they should. Treatments such as chemo, radiation, or removal of the spleen (splenectomy) can add to this problem. (Splenectomy was once commonly done, but is now rarely needed.) Patients who have their spleen removed should get vaccinated against certain bacteria.

All people who have had HL should keep up with their flu shots. Getting [vaccinations](#)³ and treating [infections](#)⁴ right away are very important.

Thyroid problems

Radiation to the chest or neck to treat HL can affect the thyroid gland, causing it to make less thyroid hormone. People with this condition, known as **hypothyroidism**, may need to take thyroid medicine every day for the rest of their lives. Anyone who got radiation to the neck or upper chest should have their thyroid function checked with blood tests at least once a year.

Heart disease and stroke

People who have had radiation to the chest have a higher risk of heart disease and heart attacks. Though this has become less of a problem with more modern radiation techniques. Some chemo drugs such as doxorubicin (Adriamycin[®]) can also cause heart damage. And sometimes the damage isn't seen until more than 10 years after treatment. Your doctor might want to check your heart function for many years after treatment.

Radiation to the neck increases the chance of stroke because it can damage the blood vessels in the neck that supply the brain. Ultrasound may be used to check the health of the blood vessels in your neck.

Smoking, high cholesterol, and high blood pressure (hypertension) also increase the risk of heart disease and stroke. It's important to do what you can to help lower your risk, such as not smoking, staying at a healthy weight, being active, and eating a healthy diet. It's also important to have regular check-ups with your doctor and get treated if you have high blood pressure.

Lung damage

The chemo drug bleomycin can damage the lungs, as can radiation therapy to the chest. This can lead to problems like shortness of breath, which might not show up until years after treatment. Smoking can also seriously damage the lungs, so it's important that people who have had these treatments do not smoke.

Special concerns in childhood Hodgkin lymphoma survivors

Just as the treatment of childhood HL requires a very specialized approach in children, so does follow-up and monitoring for relapse (HL coming back) and late effects of treatment. Careful follow-up after treatment is very important and it should be done for the rest of the child's life. The earlier problems are found, the more likely it is they can be treated effectively.

Along with physical side effects (including those listed above), survivors of childhood lymphoma may have emotional or psychological issues. They also may have some problems with normal functioning and school work. These can often be addressed 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.

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 health screening should be done, and how late effects may be treated.

It's very important to discuss possible long-term problems with your child's health care team, and to make sure there's 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 on the COG website: www.survivorshipguidelines.org.⁵ 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](#)⁶.

Hyperlinks

1. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects/fertility-and-women-with-cancer.html
2. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects/fertility-and-men-with-cancer.html
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5. <http://www.survivorshipguidelines.org/>
6. www.cancer.org/treatment/children-and-cancer/when-your-child-has-cancer/late-effects-of-cancer-treatment.html

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