After 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
- How Might Hodgkin Disease Affect Your Emotional Health?

Cancer Concerns After Treatment

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

- Second Cancers After Hodgkin Lymphoma
- If Treatment for Hodgkin Disease Is No Longer Working

Living As a Hodgkin Lymphoma Survivor

For many people with Hodgkin lymphoma, treatment can destroy 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 is called a recurrence.) This is very common if you’ve had cancer.

For some people, Hodgkin lymphoma 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
Hodgkin lymphoma that does not go away can be difficult and very stressful.

**Ask your doctor for a survivorship care plan**

Talk with your doctor about developing a survivorship care plan 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 for other types of cancer, or tests to look for long-term health effects from your cancer 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, as Hodgkin lymphoma 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](#)). Your doctor visits are a good time to ask questions and talk about any changes or problems you notice or concerns you have.

**Exams and tests**

During follow-up visits, the doctor will ask about symptoms, do physical exams, and may order blood tests or imaging tests such as CT scans or chest x-rays. Doctor visits and tests are usually recommended every few months for the first several years after treatment. Gradually, the length of time between visits can be increased, but even after 5 years they should be done at least yearly.

People whose Hodgkin lymphoma doesn’t go away completely with treatment will have a follow-up schedule that is based on their specific situation.

**Keeping health insurance and copies of your medical**
Even after treatment, it’s very important to keep health insurance. 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 about 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.

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 growing or 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, eating well, getting regular physical activity, 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 Hodgkin 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 Hodgkin lymphoma 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 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 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 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 Hodgkin lymphoma is treated, see Treating Classic Hodgkin Lymphoma, by Stage.

For more general information on dealing with a recurrence, see Understanding Recurrence.

**Could I get a second cancer after treatment?**

People who’ve had Hodgkin lymphoma can still get other cancers. In fact, Hodgkin lymphoma 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 Hodgkin 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 Coping With Cancer.

**References**


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 a cancer comes back after treatment it is called a recurrence. But some cancer survivors may develop another type of cancer later. This is called a second cancer.

People who have had Hodgkin lymphoma can get any type of second cancer, but research has found they have an increased risk of certain cancers, including:

- Leukemia and myelodysplastic syndrome (MDS)
- Non-Hodgkin lymphoma
- Breast cancer (in women)
- Lung cancer
- Thyroid cancer
- Cancer of the lip and tongue
- Salivary gland cancer
- Stomach cancer
- Colon cancer
- Liver cancer
- Bone cancer
- Soft tissue cancer
- Anal cancer
- Cancer of the uterus
- Cancer of the ureter (the tube that connects the kidney and the bladder)
- Melanoma of the skin
- Kaposi sarcoma

The increased risk of many of these cancers seems to be linked to treatment with radiation. 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 Hodgkin lymphoma has changed. Radiation is now given in lower doses, and often only to the areas directly affected by Hodgkin lymphoma. The risks with modern radiation treatment are likely to be lower, although long-term studies are needed to be sure.

Chemotherapy (chemo), especially with drugs called alkylating agents (such as mechlorethamine) has been linked with a higher risk of several types of cancer, including leukemias. Treatment with alkylating agents has become much less common, so these risks are probably not as high as they were in the past, but long-term follow-up studies are needed to be sure.

**Follow-up care after Hodgkin lymphoma treatment**

After completing treatment for Hodgkin lymphoma, 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 or by a new disease or 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 MRIs in addition to mammograms and clinical breast exams beginning at age 30 for these women.
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.org.

Survivors of Hodgkin lymphoma should also follow the American Cancer Society guidelines for the early detection of cancer, 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 lower your risk and stay as healthy as possible. For example, it’s important to stay away from tobacco 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, Hodgkin lymphoma survivors should also:

- Get to and stay at a healthy weight
- Be physically active
- Eat a healthy diet, with an emphasis on plant foods
- Limit alcohol to 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.

See Second Cancers in Adults for more information about causes of second cancers.

References


Late and Long-term Side Effects of Hodgkin Lymphoma Treatment

Each type of treatment for Hodgkin lymphoma has side effects that could last for months or longer, or that might not show up until long after treatment has ended. Some side effects, like loss of fertility (ability to have children), could 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 discuss what these possible effects might be with your medical team so you know what to watch for and report to the doctor.

Second cancers

One uncommon but very serious side effect of Hodgkin lymphoma treatment is developing a second type of cancer later on. People who have had Hodgkin lymphoma have a higher risk for several types of cancer. See Second Cancers After Hodgkin Lymphoma.

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 temporary 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 is started.

Likewise, women may stop having menstrual periods with chemotherapy. This may or may not return to normal. Radiation to the lower abdomen can cause infertility unless the ovaries are surgically moved outside the radiation field beforehand. Moving the ovaries does not affect cure rates because Hodgkin lymphoma almost never spreads to the ovaries.

To learn more about fertility issues, see Fertility and Women With Cancer and Fertility and Men With Cancer.

Infections

For unknown reasons, the immune systems of Hodgkin lymphoma patients often do not work normally. Treatments such as chemotherapy, radiation therapy, or removal of the spleen (splenectomy) can add to this problem. Splenectomy was once commonly done but is now rare for people with Hodgkin lymphoma. Patients who have their spleen removed should get vaccinated against certain bacteria.

All people who have had Hodgkin lymphoma should keep up with their flu shots. Keeping up with vaccinations and careful, prompt treatment of infections are very important.

Thyroid problems

Radiation therapy to the chest or neck to treat Hodgkin lymphoma might affect the thyroid gland, causing it to make less thyroid hormone. People with this condition, known as hypothyroidism, may need to take thyroid medicine daily. People who got radiation to the neck or upper chest should have their thyroid function checked with blood tests at least yearly.

Heart disease and strokes

People who have had radiation to the chest have a higher risk of heart disease and heart attacks. This has become less of a problem with more modern radiation techniques, but 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. Some chemo drugs such as doxorubicin (Adriamycin) can also cause heart damage. Your doctor might want to check your heart function for several years after your treatment.

Radiation to the neck increases the chance of stroke because it can damage the blood vessels in the neck that supply the brain. Smoking and high blood pressure also increase the risk of stroke. Once again, it’s important to avoid smoking. It’s also important to have regular check-ups with your doctor and to 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 such as 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 Hodgkin 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. 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 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 on the COG website: www.survivorshipguidelines.org. 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.

- References


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**How Might Hodgkin Disease Affect Your Emotional Health?**

During and after treatment, you may find yourself overcome with many different
emotions. This happens to a lot of people.

You may find yourself thinking about death and dying. Or maybe you’re more aware of the effect the cancer has on your family, friends, and career. You might take a new look at your relationships with those around you. Unexpected issues may also cause concern. For instance, you might be stressed by financial concerns resulting from your treatment. You might also see your health care team less often after treatment and have more time on your hands. These changes can make some people anxious.

Almost everyone who is going through or has been through cancer can benefit from getting some type of support. You need people you can turn to for strength and comfort. Support can come in many forms: family, friends, cancer support groups, church or spiritual groups, online support communities, or one-on-one counselors. What's best for you depends on your situation and personality. Some people feel safe in peer-support groups or education groups. Others would rather talk in an informal setting, such as church. Others may feel more at ease talking one-on-one with a trusted friend or counselor. Whatever your source of strength or comfort, make sure you have a place to go with your concerns.

The cancer journey can feel very lonely. It’s not necessary or good for you to try to deal with everything on your own. And your friends and family may feel shut out if you do not include them. Let them in, and let in anyone else who you feel may help. If you aren’t sure who can help, call us at 1-800-227-2345 and we can put you in touch with a group or resource that may work for you. You can also see Distress in People with Cancer or the Emotional Side Effects section of our website for more information.

- References


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If Treatment for Hodgkin Disease Is No Longer Working

If Hodgkin disease keeps growing or comes back after one kind of treatment, it’s often possible to try other treatment plans that might still cure it, or at least keep it under control enough to help you live longer and feel better. Clinical trials also might offer chances to try newer treatments that could be helpful.

But when a person has tried many different treatments and the lymphoma is no longer getting better, even newer treatments may no longer be helpful. If this happens, it’s important to weigh the possible limited benefits of trying a new treatment against the possible downsides, including treatment side effects. Everyone has their own way of looking at this.

This is likely to be the hardest part of your battle with cancer — when you have been through many treatments and nothing’s working anymore. Your doctor might offer you new options, but at some point you may need to consider that treatment is not likely to improve your health or change your outcome or survival.

If you want to continue to get treatment for as long as you can, you need to think about the odds of treatment having any benefit and how this compares to the possible risks and side effects. Your doctor can estimate how likely it is the cancer will respond to treatment you’re considering. For instance, the doctor may say that more treatment might have about a 1 in 100 chance of working. Some people are still tempted to try this. But it’s important to have realistic expectations if you do choose this plan.

**Palliative care**

No matter what you decide to do, it’s important that you feel as good as you can. Make sure you are asking for and getting treatment for any symptoms you might have, such as nausea or pain. This type of treatment is called *palliative care*.

Palliative care helps relieve symptoms, but it is not expected to cure the disease. It can be given along with cancer treatment, or can even be cancer treatment. The difference is its purpose — the main goal of palliative care is to improve the quality of your life, or help you feel as good as you can for as long as you can. Sometimes this means using drugs to help with symptoms like pain or nausea. Sometimes, though, the treatments used to control your symptoms are the same as those used to treat cancer. For instance, radiation or other treatments might be used to help relieve pain caused by a
large tumor. But this is not the same as treatment to try to cure the cancer.

**Hospice care**

At some point, you may benefit from hospice care. This is special care that treats the person rather than the disease; it focuses on quality rather than length of life. Most of the time, it is given at home. Your cancer may be causing problems that need to be managed, and hospice focuses on your comfort. You should know that while getting hospice care often means the end of treatments such as chemo and radiation, it doesn’t mean you can’t have treatment for the problems caused by the cancer or other health conditions. In hospice the focus of your care is on living life as fully as possible and feeling as well as you can at this difficult time. You can learn more in Hospice Care.

Staying hopeful is important, too. Your hope for a cure may not be as bright, but there is still hope for good times with family and friends — times that are filled with happiness and meaning. Pausing at this time in your cancer treatment gives you a chance to refocus on the most important things in your life. Now is the time to do some things you’ve always wanted to do and to stop doing the things you no longer want to do. Though the cancer may be beyond your control, there are still choices you can make.

**To learn more**

You can learn more about the changes that occur when treatment stops working, and about planning ahead for yourself and your family, in Advance Directives and Nearing the End of Life.

- **References**


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