



# Hodgkin Disease Overview

This overview is based on the more detailed information in our document *Hodgkin Disease*.

## What is cancer?

The body is made up of trillions of living cells. Normal body cells grow, divide into new cells, and die in an orderly way. During the early years of a person's life when they are still growing, normal cells divide faster. Once the person becomes an adult, most cells divide only to replace worn-out, damaged, or dying cells.

Cancer begins when cells in a part of the body start to grow out of control. There are many kinds of cancer, but they all start because of this out-of-control growth of abnormal cells.

Cancer cell growth is different from normal cell growth. Instead of dying, cancer cells keep on growing and form new cancer cells. In most cases the cancer cells form a tumor. Cancer cells can also grow into (invade) other tissues, something that normal cells can't do. Being able to grow out of control and invade other tissues are what makes a cell a cancer cell.

Sometimes cancer cells spread to other parts of the body. There they begin to grow and form new tumors. This process is called *metastasis*.

No matter where a cancer spreads, it is named (and treated) based on the place where it started. For instance, breast cancer that has spread to the liver is still breast cancer, not liver cancer. Likewise, prostate cancer that has spread to the bones is still prostate cancer, not bone cancer.

Different types of cancer can behave very differently. They grow at different rates and respond to different treatments. That is why people with cancer need treatment that is aimed at their own kind of cancer.

Not all tumors are cancerous. Tumors that aren't cancer are called *benign*. Benign tumors can cause problems – they can grow large and press on healthy organs and tissues. But

they can't grow into other tissues. Because of this, they also can't spread to other parts of the body (metastasize). These tumors are rarely life threatening.

## What is Hodgkin disease?

Hodgkin disease (Hodgkin lymphoma) is a type of lymphoma, a cancer that starts in white blood cells called *lymphocytes*. Lymphocytes are part of the immune system.

There are 2 kinds of lymphoma:

- Hodgkin disease (named after Dr. Thomas Hodgkin, who first described it)
- Non-Hodgkin lymphoma

These types of lymphomas differ in how they behave, spread, and respond to treatment, so it's important to tell them apart. Doctors can most often tell the difference between them by looking at the cancer cells under a microscope. Sometimes, lab tests might be needed to do this.

Both children and adults can get Hodgkin disease. This document covers treatment in both groups.

To learn about non-Hodgkin lymphoma, see our document *Non-Hodgkin Lymphoma*.

## The lymph system and lymphoid tissue

To understand Hodgkin disease, it helps to know about the body's lymph system. The lymph system is part of the immune system, which helps fight infections. The lymph system is made up of lymphoid tissue, lymph vessels, and a clear fluid called lymph.

Lymphoid tissue includes the lymph nodes and other organs that are part of the body's immune and blood-forming systems. Lymph nodes are bean-size collections of lymphoid tissue in many places throughout the body. Other parts of the lymph system include the spleen, the bone marrow (soft inner part of some bones), the tonsils, and the thymus. Lymphoid tissue can also be found in other organs, such as the stomach and intestines.

Lymphoid tissue is made up mainly of lymphocytes, which are special white blood cells that fight infection. There are 2 types of lymphocytes:

- B lymphocytes (or B cells)
- T lymphocytes (or T cells)

Almost all cases of Hodgkin disease start in B lymphocytes.

## Start and spread of Hodgkin disease

Lymphoid tissue is found in many parts of the body, so Hodgkin disease can start almost anywhere. Most often it starts in lymph nodes in the upper part of the body (in the chest, neck, or under the arms).

Hodgkin disease can spread through the lymph vessels in a stepwise fashion from lymph node to lymph node. Rarely, and late in the disease, the cancer can get into the blood vessels and then spread to almost any other place in the body.

## Types of Hodgkin disease

The main types of Hodgkin disease are:

- Classic Hodgkin disease (which has 4 subtypes), which accounts for about 95% of cases
- Nodular lymphocyte predominant Hodgkin disease (NLPHD), which makes up about 5% of cases

These types differ in the way the cancer cells look under a microscope. The types are important because they grow and spread in different ways. Often they are treated in different ways. You can ask your doctor about the exact type of Hodgkin disease you (or your loved one) has.

All types of Hodgkin disease are cancer because as they grow they can invade (grow into) nearby normal tissues and spread to other parts of the body.

## How many people get Hodgkin disease?

The American Cancer Society's estimates for Hodgkin disease in the United States for 2015 are:

- About 9,050 new cases of Hodgkin disease
- About 1,150 deaths from Hodgkin disease

Both children and adults can get Hodgkin disease, but it is most common in early adulthood (ages 15 to 40, especially in a person's 20s) and late adulthood (after age 55). About 10% to 15% of all cases are found in children and teens.

# What are the risk factors for Hodgkin disease?

We do not yet know exactly what causes Hodgkin disease, but we do know that certain risk factors are linked to the disease. A risk factor is something that affects a person's chance of getting a disease such as cancer. Different cancers have different risk factors. Some risk factors, like smoking, can be changed. Others, like a person's age or family history, can't be changed.

Scientists have found a few risk factors that may make a person more likely to get Hodgkin disease, although it's not always clear why these factors increase risk. But having a risk factor, or even several, doesn't mean that a person will get the disease. Likewise, having few or no risk factors doesn't mean a person won't get the disease.

**Epstein-Barr virus (EBV) infection/mononucleosis:** People who have had "mono" (infectious mononucleosis), caused by the Epstein-Barr virus, have a higher risk of Hodgkin disease. The overall risk is still very small. Many people are infected with EBV, but very few get Hodgkin disease.

**Age:** Hodgkin disease is most common in early adulthood (age 15 to 40, especially in a person's 20s) and in late adulthood (after age 55). But it can occur at any age.

**Gender:** Slightly more males than females get Hodgkin disease.

**Geography:** Hodgkin disease is most common in the United States, Canada, and northern Europe, and least common in Asian countries.

**Family history:** Brothers and sisters of young people with Hodgkin disease have a higher risk for this disease. The risk is very high for an identical twin of a person with Hodgkin disease. But still, a family link is not common – most people with Hodgkin disease do not have a family history of it.

**Socioeconomic status:** The risk of Hodgkin disease is greater in people with a higher income and educational background. The reason for this is not clear.

**HIV infection:** The risk of Hodgkin disease is higher in people who have HIV (the virus that causes AIDS).

## Can Hodgkin disease be prevented?

Few of the known risk factors for Hodgkin disease can be changed, so it is not possible to prevent most cases of the disease at this time.

One way to limit your risk would be to stay away from known risk factors for infection with HIV, the virus that causes AIDS (such as IV drug use and unsafe sex with many partners). You can read more about HIV in our document [HIV, AIDS, and Cancer](#).

## How is Hodgkin disease found?

At this time, there are no widely used screening tests for Hodgkin disease. (Screening is testing for cancer in people without any symptoms.) Still, in some cases Hodgkin disease can be found early.

Most people with Hodgkin disease see a doctor because they have felt a lump under the skin that hasn't gone away or they just don't feel well and go in for a checkup.

## Signs and symptoms of Hodgkin disease

You or your child can have Hodgkin disease and feel fine. But Hodgkin disease often causes symptoms.

### Lumps under the skin

You may notice a lump in the neck, under the arm, or in the groin. The lump may be a swollen lymph node. Usually it doesn't hurt, although it might after you drink alcohol. The lump might grow larger, or new lumps could show up near it (or even in other parts of the body).

Enlarged lymph nodes, especially in children, are more often caused by an infection or other illness – not cancer. Still, if you (or your child) have enlarged lymph nodes and no recent infection, it is best to have them checked by the doctor.

### General symptoms

Some people with Hodgkin disease have what are known as *B symptoms*:

- Fever (which can come and go over several days or weeks)
- Drenching night sweats
- Weight loss without trying

Other symptoms can include:

- Itching
- Feeling tired
- Poor appetite

Sometimes the only symptom is feeling tired all the time.

## **Cough, trouble breathing, chest pain**

If Hodgkin disease affects lymph nodes inside the chest, the swelling of these nodes can press on the windpipe. This can make you cough or even have trouble breathing, especially when lying down. Some people might feel pain behind the breast bone.

Having one or more of the symptoms above does not mean you have Hodgkin disease. In fact, many of these symptoms are more likely to be caused by other things such as an infection. Still, if you or your child has any of these symptoms, have them checked by a doctor so that the cause can be found and treated, if needed.

## **Medical history and physical exam**

If symptoms suggest that you or your child might have Hodgkin disease, the doctor will:

- Ask about the symptoms, your family history, and any other medical issues.
- Examine you (or your child), paying special attention to the lymph nodes (Because infections are the most common cause of enlarged lymph nodes, especially in children, the doctor will look for an infection.)
- Possibly order blood tests to look for signs of infection or other problems.
- Get a biopsy if it is thought that Hodgkin disease might be causing the symptoms.

## **Biopsies**

Swollen lymph nodes are more often caused by infections than by Hodgkin disease, so doctors often wait a few weeks to see if they stay swollen. Sometimes they give an antibiotic to see if it helps shrink the nodes. If not, a biopsy will be done.

In a biopsy, a lymph node (or a piece of one) is removed and looked at it under a microscope. This is the only way to know for sure if the swelling is caused by cancer. There are different kinds of biopsies. The doctor will choose the one best suited for you or your child. The goal is to get enough tissue to be sure of the diagnosis and, if it is Hodgkin disease, to tell what type it is.

## **Types of biopsies**

**Excisional or incisional biopsy:** This is the most common type of biopsy for a swollen lymph node. It is called an *excisional biopsy* when a cut is made through the skin to take out a whole lymph node. When only a small part of a larger tumor or node is taken out it is called an *incisional biopsy*.

If the swollen node is just under the skin, the biopsy is fairly simple and can sometimes be done just with numbing medicine (local anesthesia). But if the node is inside the chest or belly (abdomen), patients are given medicine to make them relaxed and sleepy, or general anesthesia (where they are in a deep sleep).

**Needle biopsies:** In another type of biopsy, called a *fine needle aspiration* (FNA), the doctor uses a very thin, hollow needle to take out a small amount of fluid and tiny bits of tissue from the tumor. For a *core needle biopsy*, the doctor uses a larger needle to remove a slightly larger piece of tissue.

A needle biopsy might not get enough of a sample to make a firm diagnosis. Most doctors don't use needle biopsies to diagnose Hodgkin disease. But they might use it in patients already known to have Hodgkin disease to see whether a swollen lymph node or organ in a different place also contains lymphoma.

**Bone marrow aspiration and biopsy:** These tests are not used to find Hodgkin disease. But in some cases they may be done after the disease is found to see if it is in the bone marrow. They are described in more detail in the section "Staging for Hodgkin disease."

## Lab tests of biopsy samples

All biopsy samples will be looked at under a microscope. A doctor checks how they look, as well as the size and shape of the cells in the sample. The doctor looks for special cells known as Reed-Sternberg cells, which are found in Hodgkin disease.

Looking at the tissue under the microscope can often tell whether you have Hodgkin disease and what type it is, but sometimes special stains and tests are used on the sample to get more information. Sometimes the first biopsy does not give a clear answer and more biopsies are needed.

## Staging for Hodgkin disease

Once Hodgkin disease is diagnosed, tests will be done to figure out the stage (extent) of the disease. The treatment and prognosis (outlook) for a person with Hodgkin disease depend somewhat on both the type and the stage of the disease. If you have any questions about the stage of your lymphoma or how it affects your treatment, be sure to ask your doctor.

Hodgkin disease most often starts in one set of lymph nodes. If it spreads, it is usually to a nearby set of lymph nodes. It can sometimes grow into nearby organs, too.

Staging is based on the results from:

- Your medical history (symptoms)
- The physical exam

- Biopsies
- Imaging tests, which often include a chest x-ray, CT scans, and a PET scan
- Blood tests
- Bone marrow aspiration and biopsy (sometimes but not always done)

## Imaging tests used to stage Hodgkin disease

Imaging tests use different methods to make pictures of the inside of the body. One or more of these tests may be used to help look for tumors or enlarged lymph nodes, to learn the extent of the Hodgkin disease, to find out how well treatment is working, or to see if the cancer has come back after treatment.

### **Chest x-ray**

Hodgkin disease often causes swelling of lymph nodes in the chest, which can often be seen on a plain chest x-ray.

### **Computed tomography (CT) scan**

The CT scan uses x-rays to make detailed pictures inside the body. This test gives your doctor a better look at lymph nodes in the chest, belly (abdomen), and pelvis, as well as other organs.

A CT scanner has been described as a large donut, with a narrow table that slides in the middle “hole.” You will need to lie still on the table while the scan is being done. CT scans take longer than regular x-rays, and you might feel a bit confined by the ring while the pictures are being taken. Doctors give some children medicine to help keep them calm or even asleep during the test.

Before the test, you or your child might be asked to drink a liquid or get an injection of a kind of dye to help better outline places in the body. Some people are allergic to the dye and get hives or a flushed feeling or—rarely—have more serious reactions like trouble breathing and low blood pressure. Be sure to tell the doctor if you or your child has any allergies has ever had a reaction to any contrast used for x-rays.

**CT-guided needle biopsy:** In some cases, a CT can be used to guide a biopsy needle into an area of concern. You lie on the CT scanning table while a doctor moves a biopsy needle through the skin and toward the area. A biopsy sample is then removed to be looked at in the lab.



## **Magnetic resonance imaging (MRI) scan**

This test is rarely used for Hodgkin disease, but if your doctor is concerned about spread to the spinal cord or brain, MRI is very useful for looking at these places.

MRI scans use radio waves and strong magnets instead of x-rays to make detailed pictures. A substance is often injected into a vein before the scan to better show details. It does not usually cause allergic reactions.

MRI scans take longer than CT scans – often up to an hour. You might have to lie inside a narrow tube, which can upset those who are afraid of enclosed spaces. Some children may need medicine to make them calm and sleepy. Newer, more open MRI machines might be another option.

## **Positron emission tomography (PET) scan**

For a PET scan, a small amount of radioactive sugar is injected into the blood. This sugar collects in the cancer cells. A special camera can then pick up the radioactivity and show the areas of cancer in the body.

PET scans can help tell whether a swollen lymph node contains Hodgkin disease. They are also used to tell how well treatment is working. In looking at people with Hodgkin disease, a machine that combines the PET scan with a CT scan (known as a *PET/CT scan*) is often used. These scans can help pinpoint the exact place of the lymphoma better than a CT alone.

## **Gallium scan**

During this test, a small dose of radioactive gallium is injected into a vein. It goes to lymph tissue. A few days later a special camera is used to find the gallium.

This test can find tumors that might be Hodgkin disease in lymph nodes and other organs. But it is not used as much now as in the past because most doctors do a PET scan instead.

## **Bone scan**

Hodgkin disease sometimes causes bone damage, which may be picked up on a bone scan. This test is not often done unless a person is having bone pain or has lab test results that suggest the Hodgkin disease may have reached the bones.

A radioactive substance is also used for bone scans. After it is injected, it travels to damaged areas of the bone. A special camera can then spot it.

## Other tests

### **Blood tests**

Blood tests aren't part of the formal staging system for Hodgkin disease, but they can help your doctor get a sense of how advanced the disease is and how well you might do with certain treatments.

Hodgkin disease cells do not show up in the blood, but a complete blood count (CBC) can sometimes show signs of the disease. This test measures the levels of different cells in the blood. A shortage of red blood cells (called anemia) can be a sign of more advanced Hodgkin disease. A high white blood cell count is another sign, although it can also be caused by infections.

Blood tests might also be done to check how well the liver and kidneys are working, to look for signs that that cancer may have reached the bones, and to look for signs of certain infections.

### **Bone marrow biopsy and aspiration**

If a person has Hodgkin disease, these tests are sometimes done to tell if the cancer is in the bone marrow. Often both are done at the same time from the back of the hip bone or, in some cases, from the breast bone (sternum), or other bones. A long thin needle is used to remove small bits of bone marrow. A piece of bone might also be removed with a thicker needle. The area is numbed first. But even with numbing, most people still feel some brief pain. The whole process takes only a few minutes. The samples are then checked for signs of Hodgkin disease.

Most children having these tests either get drugs to make them drowsy or have general anesthesia so they are asleep.

### **Tests of heart and lung function**

These tests are not used to help stage Hodgkin disease, but they may be done if certain chemo drugs that could affect the heart or the lungs are going to be used.

- Heart function may be checked with an echocardiogram (an ultrasound of the heart) or a MUGA scan.
- Lung function may be checked with pulmonary function tests, in which you breathe into a machine through a tube.

## Cotswold staging system

A staging system is a way for members of the cancer care team to describe the extent of a cancer's spread. The staging system for Hodgkin disease is known as the *Cotswold system*. It has 4 stages, labeled with the Roman numerals I, II, III, and IV. The higher the number, the more advanced the disease. If Hodgkin disease affects an organ outside of the lymph system, the letter E is added to the stage. If it affects the spleen, the letter S is added.

### **Bulky disease**

This term is used to describe tumors in the chest that are at least  $\frac{1}{3}$  as wide as the chest or tumors in other places that are at least 4 inches (10 centimeters) across. If bulky disease is present the letter X is added to the stage. Bulky disease may need more intense treatment.

### **A vs. B**

Each stage may also be assigned an A or B. The letter A is added if the person doesn't have certain symptoms that can be caused by Hodgkin disease. The letter B is added if they have any of these symptoms:

- Loss of more than 10% of body weight over the past 6 months (without dieting)
- Fever of 100.4°F or greater for an unknown reason
- Drenching night sweats

If a person has any of these B symptoms, more intense treatment is usually recommended.

### **Resistant or recurrent Hodgkin disease**

These terms are not part of the formal staging system, but doctors or nurses might use them sometimes to describe what is going on with the disease.

The terms *resistant* or *progressive* disease are used when the disease does not go away or keeps growing while you are first being treated.

*Recurrent* or *relapsed* disease means that Hodgkin disease went away at first with treatment, but now has come back. If Hodgkin disease returns, it may be in the same place where it started or in another part of the body. This could happen shortly after treatment or years later.

## **Other factors that can affect outlook**

Certain factors, if present, no matter what the stage, tend to make the outlook more serious, so the doctor might want to use more intense treatment. These include:

- Having B symptoms or bulky disease
- Being male
- Being older than 45
- Having a high white blood cell count
- Having a low red blood cell count
- Having a low blood lymphocyte count
- Having a low blood albumin level
- Having a high blood ESR level

## **How is Hodgkin disease treated?**

*This information represents the views of the doctors and nurses serving on the American Cancer Society's Cancer Information Database Editorial Board. These views are based on their interpretation of studies published in medical journals, as well as their own professional experience.*

*The treatment information in this document is not official policy of the Society and is not intended as medical advice to replace the expertise and judgment of your cancer care team. It is intended to help you and your family make informed decisions, together with your doctor.*

*Your doctor may have reasons for suggesting a treatment plan different from these general treatment options. Don't hesitate to ask him or her questions about your treatment options.*

## About treatment

After Hodgkin disease is found and staged, the cancer care team will discuss treatment options with you. Treatment for Hodgkin disease is based mainly on the stage of the disease. But other factors, including a person's age and health, and the type and location of the disease, can also affect treatment options. For almost all patients with Hodgkin disease, cure is the main goal.

The 2 main methods of treatment are chemotherapy (chemo) and radiation. Monoclonal antibodies and high-dose chemo with stem cell transplants may be used for certain patients, especially if other treatments haven't worked well. In most cases, except for biopsy and staging, surgery is rarely used to treat Hodgkin disease.

Based on your treatment options, you may have different types of doctors on your treatment team. These doctors might include:

- A hematologist: a doctor who treats disorders of the blood.
- A medical oncologist: a doctor who treats cancer with medicines.
- A radiation oncologist: a doctor who treats cancer with radiation.

Many other experts might be part of your treatment team as well, including physician assistants (PAs), nurse practitioners (NPs), nurses, nutrition specialists, social workers, and others. See [Health Professionals Associated With Cancer Care](#) for more on this.

It is important to discuss all of your treatment options, including their goals and possible side effects, with your doctors to help make the choice that best fits your needs. In choosing a treatment plan, think about your health and the type and stage of the Hodgkin disease. It's also very important to ask questions if you're not sure about something. You can find some good questions to ask in the section "What are some questions I can ask my doctor about Hodgkin disease?"

If time allows, it is often a good idea to seek a second opinion. A second opinion can give you more information and help you feel more certain about the treatment plan you choose. Your doctor should be willing to help you find a cancer doctor who can give you a second opinion.

## Chemotherapy for Hodgkin disease

Chemotherapy (chemo) is the use of drugs to kill cancer cells. For Hodgkin disease, the drugs usually are given into a vein or taken by mouth (as pills). Once the drugs enter the bloodstream, they spread throughout the body. Several chemo drugs are given at the same time to treat Hodgkin disease. If you'd like to learn more about a drug being used in your (or your child's) treatment, see our [Guide to Cancer Drugs](#).

Doctors give chemo in cycles. A round of treatment is followed by a rest period to give the body time to recover. Most of the time each chemo cycle lasts for several weeks. Most often, chemo is given in the doctor's office, clinic, or hospital outpatient department, but some may require a hospital stay.

## Side effects

Although the chemo kills cancer cells, the drugs also damage normal cells. This can lead to side effects. The exact side effects depend on the type and dose of drugs used and the length of time they are taken.

**Short-term side effects:** Some possible temporary side effects include:

- Hair loss
- Mouth sores
- Loss of appetite
- Nausea and vomiting
- Diarrhea
- Increased chance of infections (from low white blood cell counts)
- Easy bruising or bleeding (from low blood platelet counts)
- Feeling very tired (from low red blood cell counts)

These side effects are usually don't last long and go away after treatment ends. There are often ways to lessen these side effects. For example, drugs are usually given to help prevent or reduce nausea and vomiting. If you or your child has side effects, talk to your cancer care team. They can suggest steps to ease them.

[Infections](#) can be very serious in people getting chemo. If white blood cell counts are very low during treatment, you can help reduce the risk of infection by trying to limit your contact with germs. During this time, your doctor may tell you to:

- Wash your hands often.
- Avoid fresh, uncooked fruits and vegetables and other foods that might carry germs.
- Avoid fresh flowers and plants because they may carry mold.
- Make sure other people wash their hands before they come in contact with you.
- Avoid large crowds and people who are sick.

**Late or long-term side effects:** Some chemo drugs can have side effects that can last a long time or that happen long after treatment has ended. These can affect things like a person's heart, lungs, growth, and ability to have children. Some drugs also increase the risk of getting a second type of cancer, especially if a person gets radiation as well. It's important to discuss these possible side effects with the doctor before treatment begins. Long-term effects are discussed in more detail in the section "Moving on after treatment for Hodgkin disease."

To learn more about chemo, see the Chemotherapy section of our website, or our document [A Guide to Chemotherapy](#).

## Radiation therapy for Hodgkin disease

Radiation therapy uses high-energy x-rays to kill cancer cells. Radiation therapy for Hodgkin disease is given as a focused beam of radiation from a machine outside the body. This is called *external beam radiation*.

Most often, radiation treatments are given 5 days a week for several weeks. The treatment is much like getting an x-ray, but the radiation is stronger. Each treatment lasts only a few minutes, although the setup time – getting you or your child into place – usually takes longer. Radiation itself is painless, but some younger children may need to be sedated to make sure they don't move during the treatment.

Radiation therapy is most useful when Hodgkin disease is only in one part of the body. Chemo is often given first, followed by radiation to areas that showed cancer. Radiation can also be used by itself to treat some cases of nodular lymphocyte predominant Hodgkin disease. If radiation is used, only the involved areas are treated with radiation to try to limit side effects.

People who are getting a stem cell transplant may get radiation to the whole body (known as *total body irradiation*) along with high-dose chemo to try to kill lymphoma cells throughout the body. To learn more, see the section "High-dose chemotherapy and stem cell transplant for Hodgkin disease."

### Possible side effects

The side effects of radiation therapy depend on where the radiation is aimed.

**Short-term side effects:** Some possible temporary effects include:

- Skin changes like sunburn in the areas getting radiation
- Feeling tired
- Dry mouth

- Nausea
- Diarrhea

Radiation given to several areas, especially after chemo, can lower blood cell counts and increase the risk of infections.

**Long-term side effects:** Radiation treatment can also have long-term side effects. The most serious of these is a higher risk of another cancer in the part of the body that was treated with radiation.

Radiation to the chest or neck can damage the thyroid gland, which can lead to tiredness and weight gain. Treatment with thyroid hormone pills can help with this.

Radiation to the chest also increases the risk of heart and lung problems, while radiation to the neck may increase the risk of stroke many years later.

In children, another possible side effect is slow bone growth. This could lead to shortened height, or even bone deformities. Doctors use as little radiation as they can in children.

To reduce the risk of side effects, doctors carefully figure out the exact dose of radiation needed and aim the beam to hit the cancer and limit damage to nearby normal tissues.

For more on long-term side effects, see the section “Moving on after treatment for Hodgkin disease.”

To learn more about radiation therapy, see the [Radiation Therapy](#) section of our website or our document [Understanding Radiation Therapy: A Guide for Patients and Families](#).

## Monoclonal antibodies for Hodgkin disease

Antibodies are proteins made by the immune system to help fight infections. Man-made versions, called *monoclonal antibodies*, can be designed to attack a target, such as a substance on the surface of lymphocytes (the cells in which Hodgkin disease starts).

Some monoclonal antibodies are now being used to treat Hodgkin disease, including brentuximab vedotin (Adcetris<sup>®</sup>) and rituximab (Rituxan<sup>®</sup>). The drugs are given as an IV infusion, in the doctor’s office or clinic, usually once every few weeks.

Common side effects are usually mild but can include chills, fever, nausea, rashes, fatigue, and headaches. Rarely, more severe side effects occur.

## High-dose chemotherapy and stem cell transplant for Hodgkin disease

Standard doses of chemotherapy (chemo) drugs can damage cells that divide fast, such as those in the bone marrow (where new blood cells are made). Although even higher doses



of these drugs might work better to treat Hodgkin disease, they are not given because the severe damage to bone marrow cells would cause lethal shortages of blood cells, and other vital organs would likely be damaged, too.

But sometimes Hodgkin disease does not respond well to standard treatment, or the disease comes back after treatment. In these cases, a stem cell transplant (SCT) lets doctors use very high doses of chemo. After the chemo, the patient gets blood-forming stem cells to restore their bone marrow.

## **Types of transplants**

There are 2 kinds of transplants. They use different sources of blood-forming stem cells.

**Autologous stem cell transplant:** This is the more common type of transplant for Hodgkin disease. It uses stem cells from the patient's own blood or, less often, from the bone marrow. The stem cells are removed, frozen, and stored in the weeks before treatment. Then the patient is given very high doses of chemo (with or without radiation therapy) to kill the cancer. After the treatment, the stored stem cells are thawed and put back into the patient's bloodstream through a vein. Over time the stem cells return to the bone, replacing the marrow and making new blood cells.

If this type of transplant fails, an allogeneic transplant may be done.

**Allogeneic stem cell transplant:** In this type of transplant, the stem cells come from someone else. The donor's tissue type (also known as the HLA type) should match the patient's tissue type closely to help prevent the risk of problems with the transplant. Usually this donor is a brother or sister if they have the same tissue type as the patient. If there are no siblings with a good match, the cells may come from a matched, unrelated donor. Sometimes umbilical cord blood stem cells are used. These cells come from blood drained from the umbilical cord and placenta after a baby is born and the umbilical cord is cut.

Some patients (especially those who are older) may not be able to have a regular transplant using high doses of chemo because of the likely side effects. But some may be able to have what is called a "mini-transplant" (a *non-myeloablative transplant*; also called *reduced-intensity transplant*). For this type of transplant, lower doses of chemo and radiation are used so they do not destroy all the stem cells in the bone marrow. The patient is then given the donor stem cells. These cells enter the body and form a new immune system, which sees the cancer cells as foreign and attacks them. This attack is called a *graft-versus-lymphoma effect*. Doctors aren't yet sure how well these types of transplants work for patients with Hodgkin disease, but studies are now being done to find out.

## **The transplant process**

Patients may be in the SCT unit of the hospital or get treatment as an outpatient. If they are going to be treated in the hospital, they usually are admitted the day before the high-dose chemo is to begin. They will usually stay in the hospital until the stem cells have started to make new blood cells again, which often takes several weeks.

The patient is given very high doses of chemo to kill the cancer cells. The patient might also get total body radiation to kill any cancer cells that the chemo may not have killed. After treatment, the stored stem cells are given to the patient like a blood transfusion. The stem cells settle into the patient's bone marrow over the next several days and start to make new blood cells in the following weeks.

People who get a donor's stem cells are given drugs to keep this new immune system from attacking the body.

Patients having SCT have to be kept away from germs as much as possible until their white blood cell count returns to a safe level. They are kept in a special room in the hospital until part of the white blood cell count (known as the ANC) reaches a certain number. After they go home, they will be seen as an outpatient regularly for about 6 months.

## **Some things to keep in mind**

A stem cell transplant is a complex treatment that can cause life-threatening side effects. If the doctors think that a person might be helped by this treatment, it should be done at a hospital where the staff has experience with the procedure. Some transplant programs may not have experience in certain transplants, especially those from unrelated donors.

A stem cell transplant often requires a long hospital stay and can be very expensive. Because some insurance companies see it as an experimental treatment, they might not pay for it. Even if the transplant is covered by your insurance, your co-pays or other costs could easily amount to many thousands of dollars. It is important to find out what your insurance will cover and what you might have to pay before deciding to have a transplant.

## **Side effects of stem cell transplant**

Side effects from stem cell transplant can be divided into short- and long-term effects.

**Short-term or early side effects:** These are about the same as those caused by any other type of high-dose chemo, which can be severe. They can include:

- Low blood cell counts (with fatigue and increased risks of infection and bleeding)
- Nausea and vomiting

- Loss of appetite
- Mouth sores
- Diarrhea
- Hair loss

**Long-term or late side effects:** Some side effects can last for a long time, or may not happen until years after the transplant. These can include:

- Graft-versus-host disease, which occurs only in a donor (allogeneic) transplant (see below)
- Loss of fertility
- Damage to the thyroid gland
- Cataracts (damage to the eye that can affect vision)
- Damage to the lungs, causing shortness of breath
- Bone damage (if damage is severe, the patient might need to have part of the bone and joint replaced)
- Getting [another cancer](#) (such as leukemia) several years later

*Graft-versus-host disease* can be a major problem with a donor stem cell transplant. It happens when the new immune system from the donor starts to attack the patient's other tissues and organs.

Symptoms can include severe skin rashes with itching, mouth sores, nausea and severe diarrhea. The liver and lungs may also be damaged. The patient may also become tired and have aching muscles. If bad enough, the disease can be fatal. Drugs that weaken the immune system may be given to try to control it, although they can have their own side effects. On the plus side, the new immune system may kill any remaining lymphoma cells. Mild graft-versus-host disease can be a good thing.

To learn more about stem cell transplants, see our document *Stem Cell Transplant (Peripheral Blood, Bone Marrow, and Cord Blood Transplants)*.

## Treating Hodgkin disease in children

Treatment for Hodgkin disease in children is slightly different from the treatment used for adults. Children's bodies tend to withstand chemotherapy (chemo) better than adults. But because chemo can have some long-term side effects, children who survive cancer need careful attention for the rest of their lives.

## **Children with cancer are treated at special centers**

Children and teens with cancer and their families have special needs that are best met by children's cancer centers that work closely with the child's main doctor. These centers give you the advantage of being with a team of experts experienced in treating children. They know the special needs of children with cancer and their families. The team can include (besides doctors and nurses) psychologists, social workers, child life specialists, teachers, and others.

Most children with cancer in the United States are treated at a children's cancer center that is a member of the Children's Oncology Group (COG). These centers are linked to either a university or a children's hospital.

In these centers, doctors treating children with Hodgkin disease often use treatment plans that are part of clinical trials. The purpose of these studies is to find the best treatment that causes the fewest side effects.

Any time a child or teen has cancer, it affects every family member and nearly every aspect of the family's life. You can read more about coping with these changes in our document [\*Children Diagnosed With Cancer: Dealing With Diagnosis\*](#).

## **Treatment differences**

If the child is past puberty, the treatment is often the same as that given to adults. But if the child's body is still growing, then the doctor is more likely to use chemo instead of radiation because radiation can affect bone and muscle growth. The goal of treatment for children is to cure the cancer without causing long-term problems.

When treating children with Hodgkin disease, doctors often combine radiation in low doses with more intense chemo. The success of this approach has been very good, even for children with more advanced disease.

## **Hodgkin disease in pregnancy**

If a pregnant woman has Hodgkin disease, the woman and her doctors need to take into account the extent of the cancer, how quickly it is growing, how far along the pregnancy is, and what the woman wants to do.

If the cancer is found during the second half of the pregnancy and is not causing problems, a woman can often wait until the baby is born (sometimes by inducing labor a few weeks early) before starting treatment. This approach is safest for the baby.

If treatment needs to be given during pregnancy, one (or more) chemo drugs may be used, based on the situation. Treatment may be put off until later in the pregnancy (typically after the first trimester, when the baby's organs are fully formed), if possible.

Radiation is not often given because of concerns about the long-term effects on the unborn baby. But studies suggest that as long as very careful measures are taken to aim the radiation precisely and limit the doses used, pregnant women with Hodgkin disease in the lymph nodes in the neck, arm pit, or inside the chest may be able to have this treatment with little or no risk to the baby.

The need to avoid radiation also limits which imaging tests can be used. CT scans, PET scans, and x-rays all use radiation, so they are avoided if at all possible. MRI scans and ultrasound can often be used instead.

## Clinical trials for Hodgkin disease

You may have had to make a lot of decisions since you've been told you (or your child) has Hodgkin disease. One of the most important decisions you will make is deciding which treatment is best. You might have heard about clinical trials being done for Hodgkin disease. Or maybe someone on your health care team has mentioned a clinical trial to you.

Clinical trials are carefully controlled research studies that are done with patients who volunteer for them. They are done to learn more about promising new treatments or procedures.

Clinical trials are one way to get state-of-the-art cancer treatment. Sometimes they may be the only way to get some newer treatments. They are also the best way for doctors to learn better ways to treat cancer. Still, they are not right for everyone.

If you would like to learn more about clinical trials that might be right for you (or your child), start by asking your doctor if your clinic or hospital conducts clinical trials. You can also call our clinical trials matching service for a list of studies that meet your medical needs. You can reach this service at 1-800-303-5691 or on our website at [www.cancer.org/clinicaltrials](http://www.cancer.org/clinicaltrials). You can also get a list of current clinical trials by calling the National Cancer Institute (NCI) at 1-800-4-CANCER (1-800-422-6237) or by visiting the NCI clinical trials website at [www.cancer.gov/clinicaltrials](http://www.cancer.gov/clinicaltrials).

People have to meet certain requirements to take part in any clinical trial. But if you (or your child) qualify for a clinical trial, you still get to decide whether or not to enter (enroll in) it. Older children, who can understand more, usually must also agree to take part in the clinical trial before the parents' consent is accepted.

To learn more about clinical trials, see our document *Clinical Trials: What You Need to Know*.

# Complementary and alternative therapies for Hodgkin disease

You might hear about ways to treat Hodgkin disease or relieve symptoms that your doctor hasn't mentioned. Everyone from friends and family to social media groups and websites may offer ideas for what might help. These methods can include vitamins, herbs, and special diets, or other methods such as acupuncture or massage, to name a few.

## What are complementary and alternative therapies?

It can be confusing because not everyone uses these terms the same way, and they are used to refer to many different methods. We use *complementary* to refer to treatments that are used *along with* regular medical care. *Alternative* treatments are used *instead of* a doctor's medical treatment.

**Complementary methods:** Most complementary treatment methods are not offered as cures for cancer. Mainly, they are used to help a person feel better. Some examples of methods that are used along with regular treatment are meditation to reduce stress, acupuncture to help relieve pain, or peppermint tea to relieve nausea. Some complementary methods are known to help, while others have not been tested. Some have been proven not to be helpful, and a few are even harmful.

**Alternative treatments:** Alternative treatments may be offered as cancer cures. These treatments have not been proven safe and effective in clinical trials. Some of these methods may be harmful, or have life-threatening side effects. But the biggest danger in most cases is that you (or your child) might lose the chance to be helped by standard medical treatment. Delaying or interrupting medical treatments might give the cancer more time to grow and make it less likely that treatment will help.

## Finding out more

It is easy to see why people with cancer (or with children who have cancer) think about alternative methods. You want to do all you can to fight the cancer, and the idea of a treatment with few or no side effects sounds great. Sometimes medical treatments like chemotherapy can be hard to take, or they may no longer be working. But the truth is that most alternative methods have not been tested and proven to work in treating cancer.

As you think about your options, here are 3 important steps you can take:

- Look for “red flags” that suggest fraud. Does the method promise to cure all or most cancers? Are you told not to have regular medical treatments? Is the treatment a “secret” that requires you to visit certain providers or travel to another country?
- Talk to your doctor or nurse about any method you are thinking of using.

- Contact us at 1-800-227-2345 or read our document *Complementary and Alternative Methods and Cancer* to learn more. You can also find out about the specific methods you are looking at by calling us or visiting the Complementary and Alternative Medicine section of our website.

## **The choice is yours**

You always have a say in your (or your child's) treatment. If you want to use a non-standard treatment, learn all you can about the method and talk to your doctor about it. With good information and the support of your health care team, you may be able to safely use the methods that can help you while avoiding those that could be harmful.

## **What are some questions I can ask the doctor about Hodgkin disease?**

As you cope with Hodgkin disease and treatment, you need to have honest, open talks with your doctor. Feel free to ask any question, no matter how small it might seem. Here are some questions you might want to ask. Be sure to add your own questions as you think of them.

- What type of Hodgkin disease is it?
- What is the stage (extent) of the cancer? What does this mean?
- What tests need to be done before we can decide on treatment?
- Will I (we) need to see other doctors?
- How much experience do you have treating Hodgkin disease?
- Should we get a second opinion before starting treatment? Can you suggest someone?
- What are our treatment choices?
- What do you suggest and why?
- Does one type of treatment reduce the risk of Hodgkin disease coming back more than another?
- What short-term side effects might there be from the treatment? What can be done about these side effects?
- What are the possible long-term side effects?
- Will the treatment affect my (my child's) ability to have children? Can we do anything about this?

- How soon do we need to start treatment?
- What should I do to be ready (or get my child ready) for treatment?
- How long will treatment last? What will it be like? Where will it be done?
- How long will it take to recover from treatment?
- How will treatment affect my (or my child's) daily activities?
- What are the chances that the cancer will come back after treatment? What should we look out for?
- What would we do if the treatment doesn't work or if the lymphoma comes back?
- What type of follow-up will be needed after treatment?

Be sure to write your questions down so you remember to ask them during visits with your cancer care team. Also keep in mind that other health care experts, such as nurses and social workers, may be able to answer to some of your questions. You can find out more about speaking with your health care team in our document [Talking With Your Doctor](#).

## Moving on after treatment for Hodgkin disease

For many people with Hodgkin disease, treatment can cure the cancer. Completing treatment can be both stressful and exciting. You may be relieved to finish treatment, but find it hard not to worry about the cancer coming back. (When cancer comes back after treatment, it is called *recurrence*.) This is a very common concern in people who have had cancer.

It may take a while before your recovery begins to feel real and your fears are somewhat relieved. You can learn more about what to look for and how to learn to live with the chance of cancer coming back in *Living With Uncertainty: The Fear of Cancer Recurrence*.

For some people, Hodgkin disease might never go away completely. These people may get regular treatments with chemo, radiation, or other treatments to help keep it under control for as long as possible and to help relieve any symptoms. Learning to live with Hodgkin disease as more of a chronic disease can be hard and very stressful. It has its own type of uncertainty. Our document [When Cancer Doesn't Go Away](#) talks more about this.



## Follow-up care

After you (or your child) have completed treatment, your doctors will still want to watch you closely with frequent office visits. During these visits, your doctors will ask about symptoms, do physical exams, and may order blood tests or imaging tests (like CT scans or x-rays). Doctor visits and tests are usually needed every few months for the first several years after treatment. Over time, the time between visits can be increased, but even after 5 years they should be done at least once a year.

Follow-up is needed to watch for treatment side effects and to check for cancer that has come back or spread. This is the time for you to ask your health care team questions and discuss any concerns you might have.

Should the cancer come back, further treatment will depend on what treatments were used before, how long it's been since treatment, and a person's overall health. For more on dealing with a cancer recurrence, see our document *When Your Cancer Comes Back: Cancer Recurrence*.

It's also very important to keep your health insurance. While you hope the cancer won't come back, it could. If it does, you don't want to have to worry about paying for treatment.

## Watching for late and long-term side effects

Each type of treatment for Hodgkin disease has side effects that could last for months or longer, or that might not show up until long after treatment has ended.. Some can be permanent. Because so many people now live for a long time after their treatment, watching for these serious side effects is very important.

**Second cancers:** One of the most serious side effects of Hodgkin disease treatment is the chance of the person having a [second cancer](#). A small portion of people who get certain types of treatment for Hodgkin disease develop a type of leukemia called *AML* (acute myeloid leukemia). If this happens, it's usually in the first few years after treatment. It is seen more often in older people.

Although radiation treatment alone does not increase the risk for leukemia much, it can raise the risk of other cancers. Cancers of the muscle or bone, called *sarcomas*, can begin in the area that was treated with radiation. Digestive tract cancers such as colon cancer are also more likely.

Young women (under age 30) who get radiation to the chest have a much higher chance of getting breast cancer. These women should be careful about following the guidelines for finding breast cancer early. They should talk to their doctors about starting screening tests at an early age.

Both men and women treated with chest radiation have a higher chance of getting lung cancer, mesothelioma (a cancer of the lining of the lung), and thyroid cancer. Follow-up exams, blood tests, and chest scans may be helpful. The chance of getting lung cancer is much higher in smokers, so not smoking is really important for people who have had Hodgkin disease.

Another type of cancer, non-Hodgkin lymphoma, happens in a small number of patients with Hodgkin disease. It is thought that this risk is due mostly to the disease itself and not the treatment.

**Fertility problems:** A possible long-term effect of chemo and radiation treatment is having trouble getting pregnant or not being able to have children. Males can stop making sperm if they are treated with certain drugs. Sperm making might return but might not. If the patient is old enough and is scheduled to get drugs that affect fertility, sperm banking might be an option before chemo is started.

Likewise, women may stop having periods with chemotherapy. Radiation treatment near the ovaries can make a woman sterile unless the ovaries are moved outside of the radiation field with surgery.

To learn more about fertility issues from treatments, see our documents [\*Fertility and Women With Cancer\*](#) and [\*Fertility and Men With Cancer\*](#).

**Infections:** For unknown reasons, the immune system of people with Hodgkin disease does not work like it should. The treatment for Hodgkin disease can add to this problem. All people who have had Hodgkin disease should keep up with their vaccinations, including flu shots, and make sure that they get treatment for any infections promptly.

**Thyroid problems:** Radiation to the chest or neck to treat Hodgkin disease might affect the thyroid gland, and could keep it from making enough thyroid hormone. Patients may then need to take thyroid medicine. Thyroid function should be checked with blood tests at least once a year.

**Heart disease and strokes:** People who have had radiation to the chest have a higher rate of heart disease and heart attacks. With more modern treatment this has become less of a problem, but it's still important that survivors do what they can to help lower risk, such as not smoking, staying at a healthy weight, being active, and eating a healthy diet.

Some chemo drugs can also cause heart damage. Your doctor may advise you to have tests to check your heart function a few 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. Once again it is important to avoid smoking. It is also important to have regular check-ups with your doctor and to get treated for high blood pressure if needed.

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

## **Special concerns for children who have had Hodgkin disease**

Just as the treatment of childhood Hodgkin disease needs a very special approach, so does follow-up and watching 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.

Along with physical side effects (including those listed above), children who have had cancer may have emotional or psychological issues. They also may have some problems with normal things like activities and school work. There are often special support programs and services to help children after cancer 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 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 is 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](http://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 our document [\*Children Diagnosed With Cancer: Late Effects of Cancer Treatment\*](#).

## **Seeing a new doctor**

At some point after the cancer is found and treated, you (or your child) might go to a new doctor who doesn't know anything about your (child's) cancer history. It is important to be able to give the new doctor the exact details of the diagnosis and treatment. Gathering these details soon after treatment may be easier than trying to get them at some point in the future. Make sure you have this information handy (and always keep copies for yourself):

- The names and contact information of the doctors who treated the cancer

- A copy of the pathology reports from any biopsy or surgery
- If you had surgery, a copy of the operative report
- Copies of imaging tests (CT or MRI scans, etc.), which can usually be stored digitally (on a DVD, etc.)
- If you stayed in the hospital, a copy of the discharge summary that the doctor wrote when you were sent home
- If you had radiation treatment, a copy of the treatment summary
- If you had chemo or other drug treatments, a list of your drugs, drug doses, and when you took them

## Lifestyle changes after having Hodgkin disease

You can't change the fact that you have had cancer. What you can change is how you live the rest of your life — making choices to help you stay healthy and feel as well as you can. This can be a time to look at your life in new ways. Maybe you are thinking about how to improve your health over the long term. Some people even start during cancer treatment.

### **Make healthier choices**

For many people, finding out they have cancer helps them focus on their health in ways they may not have thought much about in the past. Are there things you could do that might make you healthier? Maybe you could try to [eat better or get more exercise](#). Maybe you could cut down on alcohol, or [give up tobacco](#). Even things like keeping your stress level under control might help. Now is a good time to think about making changes that can have positive effects for the rest of your life. You will feel better and you will probably also be healthier.

You can start by working on those things that worry you most. Get help with those that are harder for you. For instance, if you are thinking about [quitting smoking](#) and need help, call the American Cancer Society at 1-800-227-2345.

### **Eating better**

Eating right can be hard for anyone, but it can get even tougher during and after cancer treatment. Treatment may change your sense of taste. Nausea can be a problem. You may not feel like eating and lose weight when you don't want to. Or you may have gained weight that you can't seem to lose. All of these things can be very frustrating.

If treatment causes weight changes or eating or taste problems, do the best you can and keep in mind that most often these problems get better over time. You may find it helps

to eat small portions every 2 to 3 hours until you feel better. You may also want to ask your cancer team about seeing a dietitian, an expert in nutrition who can give you ideas on how to deal with these treatment side effects.

One of the best things you can do after cancer treatment is to start healthy eating habits. You may be surprised at the long-term benefits of some simple changes, like increasing the variety of healthy foods you eat. Getting to and staying at a healthy weight, eating a healthy diet, and limiting your alcohol intake may lower your risk for a number of types of cancer, as well as having many other health benefits.

To learn more, see our document [\*Nutrition and Physical Activity During and After Cancer Treatment: Answers to Common Questions\*](#).

## **Rest, fatigue and exercise**

Feeling very tired (fatigue) is a very common problem during and after cancer treatment. This is not a normal type of tiredness but a bone-weary exhaustion that often doesn't get better with rest. For some people, fatigue lasts a long time after treatment and can keep them from staying active. But exercise can in fact help reduce fatigue and the sense of depression that sometimes comes with feeling so tired.

If you were very ill or weren't able to do much during treatment, it's normal that your fitness, staying power, and muscle strength declined. You need to find a physical activity plan that fits your own needs. Talk with your health care team before starting. Get their input on your exercise plans. Then try to get an exercise buddy so that you're not doing it alone.

If you are very tired, though, you will need to balance activity with rest. Rest when you need to. To learn more about fatigue, please see our document *Fatigue in People With Cancer*.

Exercise can improve your physical and emotional health.

- It improves your heart fitness.
- Along with a good diet, it will help you get to and stay at a healthy weight.
- It makes your muscles stronger.
- It reduces fatigue.
- It can help lower anxiety and depression.
- It can make you feel happier.
- It helps you feel better about yourself.

Long term, we know that getting regular physical activity can help lower the risk of some cancers, as well as having other health benefits.

## **Can I lower my risk of Hodgkin disease progressing or coming back?**

Most people want to know if they can make certain lifestyle changes to reduce their risk of cancer growing or coming back. Unfortunately, for most cancers there isn't much solid evidence to guide people. This doesn't mean that nothing will help — it's just that for the most part this is something that hasn't been well studied. Most studies have looked at lifestyle changes as ways of preventing cancer in the first place, not slowing it down or keeping it from coming back.

At this time, not enough is known about Hodgkin disease to say for sure if there are things you can do that will be helpful. Healthy behaviors such as not smoking, eating well, and staying at a healthy weight may help, but no one knows for sure. But we do know that these types of changes can have positive effects on your health that can extend beyond your risk of Hodgkin disease or other cancers.

So far, no dietary supplements have been shown to clearly help lower the risk of Hodgkin disease growing or coming back. Again, this doesn't mean that none will help, but it's important to know that none have been proven to do so.

## **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. This can be hard for some people.

This is a good time to look for emotional and social support. You need people you can turn to. Support can come in many forms: family, friends, cancer support groups, religious or spiritual groups, online support communities, or private counselors.

The cancer journey can feel very lonely. You don't need to go it alone. Your friends and family may feel shut out if you decide not to include them. Let them in – and let in anyone else you feel may help. If you aren't sure who can help, call your American Cancer Society 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 read our document *Distress in People with Cancer* or see the Emotional Side Effects section of our website for more information.

## If treatment for Hodgkin disease is no longer working

If Hodgkin disease keeps growing or comes back after one kind of treatment, it is 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.

But when a person has had many different treatments and the cancer has not been cured, over time even newer treatments might no longer be helpful. At this time you may have to weigh the possible benefits of a new treatment against the downsides, like treatment side effects and clinic visits. Everyone has their own way of looking at this.

This is likely to be the hardest time in your battle with cancer – when you have tried everything within reason and the lymphoma is no longer getting better. Even newer treatments might not help. You will need to talk to your doctor about how likely it is that further treatment will improve your health or change your outlook for survival.

### **Palliative care**

No matter what you decide to do, it is important for you to feel as good as you can. Make sure you are asking for and getting treatment for pain, nausea, or any other problems you may have. This type of treatment is called *palliative care*. It helps relieve symptoms but is not meant to cure the cancer.

### **Hospice care**

At some point you may want to think about hospice care. This is special care that focuses on quality rather than length of life. Most of the time, it is given at home. Your cancer may be causing symptoms or problems that need to be treated. Hospice focuses on your comfort. You should know that having hospice care doesn't mean you can't have treatment for the problems caused by your cancer or other health issues. It just means that the purpose of your care is to help you live life as fully as possible and to feel as well as you can. You can learn more about this in our document *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 joy and meaning. Pausing at this time in your cancer treatment gives you a chance to focus 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.

You can learn more about the changes that occur when treatment stops working, and about planning ahead for yourself and your family, in our documents *Advance Directives* and [\*Nearing the End of Life\*](#). You can read them online or call us at 1-800-227-2345 to have free copies mailed to you.

# What's new in Hodgkin disease research?

Important research into Hodgkin disease is going on now in many places around the world. Scientists are getting closer to finding out what causes the disease and how to improve treatment.

## Imaging tests

In recent years, PET scans and combined PET/CT scans have been found to be very helpful in learning how far Hodgkin disease has spread, and in finding out how well treatment is working. PET/CT scans are now often used early in the course of treatment to help doctors decide how much treatment needs to be given.

## Tailoring treatment

As a rule, cure rates for Hodgkin disease are high, but there are often long-term side effects from treatment. A very active area of research is aimed at finding less toxic treatments that do not have serious, long-term side effects. This includes using newer drugs and forms of radiation therapy.

## Chemotherapy

New chemotherapy (chemo) drugs and drug combinations are being studied in patients with Hodgkin disease. Some drugs already used to treat other cancers have shown promise against Hodgkin disease. They have helped patients who have relapsed after other chemo treatments.

## Targeted therapy

Newer drugs that work in different ways from typical chemo drugs are now being studied. They are known as *targeted therapy* drugs. Some attack different parts of cancer cells, while others target some of the other cells in Hodgkin disease tumors.

## Monoclonal antibodies

Antibodies are proteins normally made by the immune system to help fight infections. Monoclonal antibodies (man-made versions of immune system proteins) have been made to target cancer cells. They may be used alone or given along with chemo. Some of these drugs are now being used in patients with Hodgkin disease, while others are being studied.



# More information about Hodgkin disease

## From your American Cancer Society

Here is more information you might find helpful. You also can order free copies of our documents from our toll-free number, 1-800-227-2345, or read them on our website, [www.cancer.org](http://www.cancer.org).

Hodgkin Disease Detailed Guide (also in Spanish)

### **Living With Cancer**

[After Diagnosis: A Guide for Patients and Families](#) (also in Spanish)

[Guide to Controlling Cancer Pain](#) (also in Spanish)

[Talking With Your Doctor](#) (also in Spanish)

[Distress in People With Cancer](#)

[Nutrition for the Person With Cancer During Treatment](#)

[Nutrition and Physical Activity During and After Cancer Treatment: Frequently Asked Questions](#)

[When Cancer Doesn't Go Away](#)

### **Understanding cancer treatment**

[A Guide to Chemotherapy](#) (also in Spanish)

[Understanding Radiation Therapy: A Guide for Patients and Families](#) (also in Spanish)

[Stem Cell Transplant \(Peripheral Blood, Bone Marrow, and Cord Blood Transplants\)](#) (also in Spanish)

Clinical Trials: What You Need to Know

### **Cancer treatment side effects**

[Caring for the Patient With Cancer at Home: A Guide for Patients and Families](#) (also in Spanish)

[Nausea and Vomiting](#)

[Anemia in People With Cancer](#)

[Fatigue in People With Cancer](#)

## **Family, communication, and caregiving**

[Talking With Friends and Relatives About Your Cancer](#) (also in Spanish)

[Helping Children When A Family Member Has Cancer: Dealing With Diagnosis](#) (also in Spanish)

[What It Takes to Be a Caregiver](#)

## **Other health information**

[Health Professionals Associated With Cancer Care](#)

[Nearing the End of Life](#)

[Hospice Care](#)

## **Insurance, employment, and financial issues**

[Working During Cancer Treatment](#)

[Health Insurance and Financial Assistance for the Cancer Patient](#) (also in Spanish)

[In Treatment: Financial Guidance for Cancer Survivors and Their Families](#) (also in Spanish)

Your American Cancer Society also has books that you might find helpful. Call us at 1-800-227-2345 or visit our bookstore online at [cancer.org/bookstore](http://cancer.org/bookstore) to find out about costs or to place an order.

## **National organizations and websites\***

Along with the American Cancer Society, other sources of information and support include:

### **Hodgkin disease**

#### **Leukemia & Lymphoma Society**

Toll-free number: 1-800-955-4572

Website: [www.lls.org](http://www.lls.org)

Offers information on Hodgkin disease and treatments, financial information, and financial assistance for people with certain cancers

### **Lymphoma Research Foundation**

Toll-free number: 1-800-500-9976

Website: [www.lymphoma.org](http://www.lymphoma.org)

Offers a helpline on lymphoma treatment, education materials, information on clinical trials, peer support, newsletters, and funding for research

### **National Cancer Institute**

Toll-free number: 1-800-4-CANCER (1-800-422-6237)

Website: [www.cancer.gov](http://www.cancer.gov)

Offers free, up-to-date information about cancer to patients, their families, and the general public; also helps people find clinical trials in their area

### **National Coalition for Cancer Survivorship**

Toll-free number: 1-888-650-9127

1-877-NCCS-YES (622-7937) for some publications and Cancer Survivor Toolbox<sup>®</sup> orders

Website: [www.canceradvocacy.org](http://www.canceradvocacy.org)

Has publications on many cancer-related topics; also offers the Cancer Survival Toolbox – a free program that teaches skills that can help people with cancer meet the challenges of their illness

## **Bone marrow and peripheral blood stem cell transplants**

### **Be the Match (formerly National Marrow Donor Program)**

Toll-free number: 1-800-MARROW-2 (1-800-627-7692)

Website: [www.bethematch.org](http://www.bethematch.org)

Provides a registry of volunteer bone marrow donors and cord blood units (the largest listing in the world), as well as a searchable listing of transplant centers that can be accessed directly at [www.marrow.org/access](http://www.marrow.org/access). Also supports patients throughout the transplant process, from diagnosis through survivorship; has free educational materials; and offers financial assistance to eligible underinsured patients.

### **National Bone Marrow Transplant Link (nbmtLINK)**

Toll-free number: 1-800-LINK-BMT (1-800-546-5268)

Website: [www.nbmtlink.org](http://www.nbmtlink.org)

Offers information and referrals to meet a wide range of needs; support via trained peer support volunteers who are transplant survivors, caregivers, and donors; phone support groups that link patients and families together to offer mutual support and coping strategies; and the nbmtLINK Online Resource Library – a searchable library giving access to the latest transplant information.

*\*Inclusion on this list does not imply endorsement by the American Cancer Society.*

No matter who you are, we can help. Contact us anytime, day or night, for information and support. Call us at **1-800-227-2345** or visit [www.cancer.org](http://www.cancer.org).

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For additional assistance please contact your American Cancer Society  
1-800-227-2345 or [www.cancer.org](http://www.cancer.org)