Article Series Lymphoma

Being diagnosed with Hodgkin lymphoma

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If you or a loved one have just been diagnosed with Hodgkin lymphoma (HL), you may feel scared, anxious, overwhelmed—or a combination of all three. You may not be sure what to do next. Your healthcare team will help guide your next steps, but it’s important for you to be informed enough to feel like a partner in your treatment plan. Start by learning the basics and taking small steps to prepare for what’s ahead.

Learn the basics

What is Hodgkin lymphoma?

- Hodgkin lymphoma, also known as Hodgkin’s disease, is a type of cancer that starts in white blood cells called lymphocytes, which are part of the body’s immune system.
- Because you have lymph tissue in many parts of your body, HL can develop nearly anywhere.
- The most common symptom of HL is one or more enlarged lymph nodes in the neck, upper chest, armpit, abdomen, or groin.
- There are different types of HL. These different types can grow and spread differently and may be treated differently.
- **More than 80% of all patients diagnosed with HL can be cured with treatment.**

How common is Hodgkin lymphoma?

About 8,500-9,000 cases of HL are diagnosed each year in the United States. It is most common in early adulthood (20s) and later adulthood (after 55).

Find out which type of Hodgkin lymphoma you have

There are two main types of HL. The first, classic Hodgkin lymphoma (cHL) accounts for about 90% of all HL cases. The second type of HL is called nodular lymphocyte-predominant Hodgkin lymphoma. This is much rarer, accounting for only about 5% of HL cases.

Classic HL has 4 subtypes:

- **Nodular sclerosis Hodgkin lymphoma:** This is the most common type of Hodgkin disease in developed countries, accounting for about 7 out of 10 cases. It's most common in teens and young adults, but it can occur in people of any age.
- Mixed cellularity Hodgkin lymphoma or MCCHL: This is the second most common subtype, accounting for about 4 out 10 cases of HL. It's seen mostly in people with HIV infection. It's also found in children or the elderly.
- Lymphocyte-rich Hodgkin lymphoma: This subtype isn't common. It usually occurs in the upper half of the body and is rarely found in more than a few lymph nodes.
- Lymphocyte-depleted Hodgkin lymphoma: This is a rare subtype. It's seen mainly in older people and those with HIV infection.

Determine the Stage of HL

Staging refers to how much cancer is in the body. The stage of your disease will be one of the factors your doctor considers when developing a treatment plan. Imaging tests, such as a chest x-ray, PET and CT scans are used to help determine the stage of your lymphoma.

Stages of Hodgkin lymphoma

Stage 1

Only one lymph node or group of lymph nodes is affected in one place in your body

Stage 2

More than one group of lymph nodes is affected but they are all on the same side of your diaphragm

Stage 3

Lymph nodes both above and below the diaphragm are affected

Stage 4

Lymphoma has spread to other organs such as lungs, liver, or bone marrow

What you can do

Get to know your doctors

- Hematologists and oncologists are specialists who treat people with HL or other types of blood cancer.

Get a second opinion

- HL can be a difficult disease to diagnose, therefore you may want to get a second opinion by an experienced hematopathologist before you begin treatment. Seek treatment in a cancer center where doctors are experienced treating patients with lymphoma, or works in consultation with an HL specialist

Discuss all of your treatment options

This should be done after you have a clear picture of the stage and subtype of your cancer. As you develop a treatment plan with your doctor, be sure to discuss:

- The results you might possibly expect from treatment
- Potential side effects, including long-term and late effects
- If a different cancer center or hospital would be able to offer other treatment options

What else can you do?

Between diagnosis and treatment, you will have a lot of appointments and need to keep track of a lot of information. To make this easier you can:

- Obtain and keep records of your test results and the treatment you receive. There are ways to do this on your phone or computer, but if you have access to a printer, a binder can be handy.
- Take notes when you talk to your doctor.
- Bring a partner to your appointments.

Find a support group

This may be a point in your life where you need help. Connect with other people in your situation or find advocacy support. You do not have to go through this diagnosis alone.