

Understanding Hodgkin Lymphoma:

A Guide for Doctor Visits

What Is Hodgkin Lymphoma?

Hodgkin lymphoma is a type of blood cancer that affects the lymphatic system. This system helps your body fight infections and keeps fluids in balance. The disease starts in the lymph nodes and may spread if not treated.

What Tests Are Necessary for a Diagnosis?

Your doctor will diagnose Hodgkin lymphoma using tests such as:

- **Physical exam:** Checking for swollen lymph nodes.
- **Blood tests:** Looking for signs of cancer.
- **Imaging tests:** X-rays, CT scans, or PET scans to see if the cancer has spread.
- **Biopsy:** Taking a small sample of lymph node tissue to check for cancer cells.

Understanding Stages

There are four stages of Hodgkin lymphoma based on how far the cancer has spread. The higher the stage, the more advanced the cancer.

This guide is meant to help you take an active role in your health. Write down your thoughts, bring this with you to appointments, and don't be afraid to ask questions. Your doctor and care team are there to help!



Questions to Ask at Your First Doctor Visit:

Be prepared to ask questions and take notes. **Here are some helpful things to discuss:**

1. About My Diagnosis

- What type of Hodgkin lymphoma do I have?

- What stage is my cancer?

2. Treatment Options

- What are my treatment options?

- What are the possible side effects?

- How well does each treatment option work?

3. Preparing for Treatment

- How long will my treatment take?

- How often will I receive treatment?

- How will treatment be given?

- Where will I need to go to receive treatment? Will I need to stay overnight?

- What should I do if I have trouble with side effects?

- What is the goal for my treatment?



Assessing Symptoms

You may feel certain symptoms (e.g., tiredness, nausea, etc.), which may be a result of your Hodgkin lymphoma diagnosis, your treatment, or another disease, such as the flu or a cold. Consider listing the symptoms that are bothering you now, or that you are worried about experiencing in the future, and **discussing them with your care team:**

What if I feel _____?

What should I do?

I also feel like I am _____.

Do you have any advice for that?

I've been noticing I'm _____.

What should I do?

Sometimes _____ comes on.

Is that normal?



Balancing Treatment and Everyday Life

When talking about your treatment options with your care team, think about your personal goals. **Here are some things you may want to bring up:**

How will treatment impact my daily life?

Will I still be able to work and/or attend school?

Will I be able to do activities I enjoy?

What resources can I explore for my mental and emotional well-being?



Follow-up Questions for Your Doctor

Here are some important questions you may want to ask throughout your treatment:

What lifestyle changes may help me feel better?

Will treatment affect my ability to have children?

What resources can help with financial concerns?

Who should I contact with questions between visits?



Getting Support

Think about people in your life who can help—your spouse or partner, friends, etc.,—and consider making a list of things you need (such as childcare, meal prep, laundry) and who can help with each task.

Let your healthcare team know about any concerns you have and ask about resources for social, emotional, and practical support.



Managing Costs

Even with health insurance, treatment costs can be high, but many organizations are there to help.

Some Resources for Support:

- **Leukemia & Lymphoma Society:** www.lls.org | (800) 955-4572
- **American Cancer Society:** www.cancer.org | (800) 227-2345
- **Lymphoma Research Foundation:** www.lymphoma.org | (800) 500-9976
- **CancerCare:** www.cancercare.org | (800) 813-4673
- **Patient Advocate Foundation:** www.patientadvocate.org | (800) 532-5274
- **MyHealthCareFinances:** www.myhealthcarefinances.com



Emotional Support Resources

Living with cancer, or caring for someone living with cancer, isn't easy, **but many places offer support.**

Cancer Support Community (CSC):

CSC provides free programs and services.

Call (888) 793-9355 or visit www.CancerSupportCommunity.org.

- **Cancer Support Helpline®:** Licensed counselors are available Mon-Fri, 9 AM to 9 PM ET. Call (888) 793-9355.
- **Open to Options®:** CSC specialists can help you create a list of questions for your doctor. Call or visit the CSC website to book an appointment.
- **Local CSC and Gilda's Clubs:** With nearly 50 locations and over 120 satellite centers, you can find in-person support groups, workshops, and healthy lifestyle programs.
- **The Living Room (Online):** Join discussion boards and connect with others, including other teens and caregivers.
- **Cancer Experience Registry:** Share your experience to keep information up to date for cancer patients. Join at www.CancerExperienceRegistry.org.

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