Living with Lymphoma

If you have been newly diagnosed with lymphoma, this tip sheet may help you talk with your care team throughout your cancer journey.

ASK QUESTIONS

- It is completely normal to feel confused or lost after receiving information from your doctor. Once you allow yourself time to let the diagnosis become real for you, don’t be afraid to repeat your questions and ask for clarification. Some questions may include: “What type of lymphoma do I have?” “What can I expect over the next two months?” “What are my treatment options?”

- Having a friend or relative with you can help. That person can advocate for you, ask questions, and take notes that can be reviewed later.

KNOW YOUR TYPE OF BLOOD CANCER

- Lymphoma is a complicated disease that occurs when lymphocytes—white blood cells that help protect the body from infection and disease—begin behaving abnormally. Lymphoma is categorized into four stages:
  - **Stage I** (early disease): the cancer is found only in a single lymph node OR in one organ or area outside the lymph node
  - **Stage II** (locally advanced disease): the cancer is found in two or more lymph node regions on one side of the diaphragm
  - **Stage III** (advanced disease): the cancer involves lymph nodes both above and below the diaphragm
  - **Stage IV** (widespread disease): the cancer is found in several parts of one or more organs or tissues (in addition to the lymph nodes) OR it is in the liver, blood or bone marrow

Knowing the type of lymphoma and subtype can help your care team choose a treatment plan personalized to you. Lymphoma also has two main types—Hodgkin and Non-Hodgkin:

- **Hodgkin lymphoma** (HL) is a rare form of lymphoma with 6 subtypes.
Non-Hodgkin lymphoma (NHL) can be divided into two groups—indolent and aggressive. These are further split into more than 50 subtypes.

ESTABLISH YOUR HEALTH CARE TEAM

- When you are diagnosed with any type of lymphoma, remember that your doctor won’t be the only health care professional working with you.
- Keep a list of these professionals and their contact information (e.g., oncology nurses, social workers, etc.) and understand how and when each of them will be involved in your care.

VOICE YOUR CONCERNS

Patients have a variety of concerns at the time of their diagnosis, but your health care team may only address the most common concerns.

If you are worried about something specific, raise it with your health care team. Remember if you do not share your concerns, fears, or wishes with your team, they will have a difficult time tailoring information to your individual needs.

“When diagnosed with NHL, I told my physician about my daughter’s wedding. He worked with me to develop a treatment plan that accommodated this special day. Because of this initial line of communication we’ve developed a relationship that made all the difference in the world.”

– Jane, follicular Non-Hodgkin lymphoma patient

For more information and support, please visit www.CancerSupportCommunity.org/lymphoma.

THIS PROGRAM WAS MADE POSSIBLE WITH GENEROUS SUPPORT FROM:

MorphoSys    Bristol Myers Squibb    Incyte

Originally developed by the Cancer Support Community, with support from Teva Oncology, a team of health care professionals and lymphoma patients.

The Cancer Support Community provides this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.

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