

After A Primary Central Nervous System Lymphoma (PCNSL) Diagnosis: Questions To Ask Your Doctor

A diagnosis of Primary Central Nervous System Lymphoma (PCNSL) can be overwhelming. This fact sheet will discuss:

- How to prepare for your appointments
- How stem cell transplants work
- What questions will help you learn more about your diagnosis



The Importance of Communicating With Your Health Care Team

Your team of doctors, nurses and social workers are there to help. Here are some tips for your appointments.

- **Bring a list of questions.** This will help you remember important things to ask. Write down or record the responses so that you do not forget them.
- **Consider bringing a loved one with you.** A friend or a family member can help ask questions and provide emotional support.
- **Ask questions about costs.** Knowing how much your treatment and medications might cost can help you plan ahead and focus more attention on getting better.

If your doctors and nurses do not know every answer, they may be able to guide you to those who do.



Helping Understand PCNSL

While your doctor and health care team can help you understand your treatment options and other parts of care, it can help to know the basics of the diagnosis:

- **Primary.** In cancer, 'primary' cancer means this is where in the body the cancer began. A 'secondary' cancer means it has spread from elsewhere in the body.
- **Central Nervous System (CNS).** This is the brain, spinal cord and is what processes the body's senses and controls its functions.
- **Lymphoma.** This is a cancer of the body's lymphatic system, which is part of the body's immune system of fighting germs and infections.

PCNSL is a cancer that has formed within the central nervous system related to its immune responses.



Questions That You May Want to Ask Your Health Care Team

The following questions should help you learn key information about your diagnosis and situation.

“What stage is my PCNSL?”

PCNSL does not have the standard staging system of most cancers. Scans are instead used to see if the cancer has spread or whether it is contained within the central nervous system.

“What are my treatment options?”

Whether the cancer has spread into other parts of the body or stayed within the central nervous system will impact your doctor's recommendations for treatment. Options may include surgery, chemotherapy, radiology and more.

“Is there a clinical trial available to me?”

Clinical trials test new approaches based on known and effective treatments for cancer. Doctors often urge people to take part in clinical trials if they are available.

“Is surgery an option for me?”

If surgery is an option, your health care team can help you get ready. They should be able to explain what the surgery does, what recovery is like and what the effects may be.

“How can I cope with my emotions?”

In addition to loved ones, you can find help in places of worship, support groups and counseling. Activities such as meditation and relaxation exercises can also help.

CancerCare® Can Help

Founded in 1944, CancerCare is the leading national organization providing free support services and information to help people manage the emotional, practical and financial challenges of cancer. Our comprehensive services include resource navigation, counseling and support groups over the phone, online and in-person, educational workshops, publications and financial and co-payment assistance. All CancerCare services are provided by master's-prepared oncology social workers and world-leading cancer experts.

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