



Primary Central Nervous System Lymphoma (PCNSL)

What is it?

Primary Central Nervous System Lymphoma (PCNSL) is a rare type of cancer (non-Hodgkin's lymphoma) that begins when lymphocytes, white blood cells that fight infections, grow out of control in the central nervous system (brain, eyes, spinal cord, or spinal fluid).

Are there risk factors?

- Immunosuppression (reduced immune system)
- Immunodeficiency disorder (HIV/AIDS)
- Autoimmune disease with prior immunosuppressive treatment
- Organ transplant with immunosuppressive treatment
- Over 60 years of age

What are the common signs and symptoms?

- Arm or leg weakness
- Coordination difficulties
- Personality changes
- Confusion and memory problems
- Loss of bladder control
- Difficulty speaking or swallowing
- Headaches
- Nausea or vomiting
- Blurry or double vision
- Seizures

Signs and symptoms may vary and are influenced by the location, size, and growth rate.

How is it diagnosed?

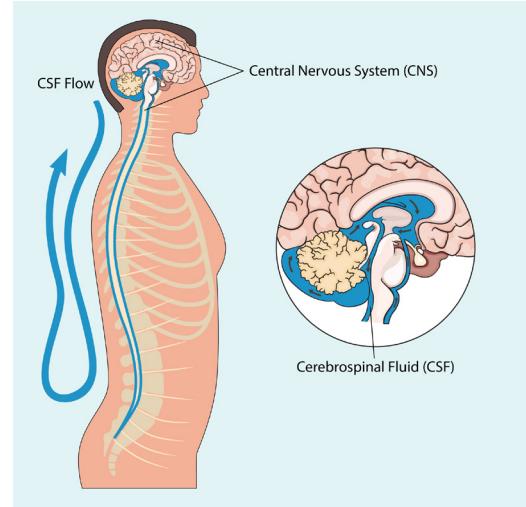
Your provider will order tests to check if your symptoms are caused by PCNSL, likely including:

- Imaging tests
 - Brain MRI
 - Spine MRI
- Stereotactic biopsy (removal of a small piece of tissue or fluid)

After a diagnosis has been confirmed, additional tests will be ordered to find out if it has spread to other parts of the Central Nervous System (CNS) or body:

- Eye exam
- Lumbar puncture (removal and testing of cerebrospinal fluid (CSF) from your spinal canal)
- PET/CT scan of body
- Ultrasound of the testes (male)

Other blood work to check for immune status may be needed (e.g., hepatitis, Epstein-Barr virus, HIV/AIDS)



What is the treatment?

Induction Therapy to wipe out as many of the lymphoma cells as possible

- High Dose Methotrexate Chemotherapy and Immunotherapy
- Clinical Trial

Consolidation Therapy to destroy any cells that remain and prevent them from coming back (considered if/ when induction therapy is completed and testing shows no signs of disease)

- High dose chemotherapy and stem cell transplant
- High dose chemotherapy alone
- Maintenance chemotherapy
- Whole brain radiation therapy
- Clinical trials

After treatment, you may need follow-ups with MRI imaging, eye exams and/or spinal fluid assessments (lumbar puncture) to monitor your status.

Can it be cured?

PCNSL is treatable but not curable. Your provider can discuss your unique case, and supportive care can help manage symptoms and quality of life.

Questions to ask your doctor

- Do you recommend getting a second opinion?
- What treatment options are available?
- What are the risks and benefits of treatment?
- How will treatment affect my daily activities?
- Would a clinical trial be right for me?
- How do you determine if treatment is effective? What follow-up tests are needed?
- What is my prognosis (outlook), both with and without treatment?
- What support services are available to me?

Resources



[Patient and Caregiver Mentor Support Program](#)

– pairs adult brain tumor patients, survivors, and caregivers with mentors who have been through a similar situation.



Connections – online support community where brain tumor patients, survivors, and caregivers come together to share experiences and support each other.



Support Group Locator – interactive tool to find virtual or in-person support groups.



[Primary CNS Lymphoma](#)

– ABTA webpage with an overview of diagnosis, incidence, and management of PCNSL.



[What to Know When Diagnosed with PCNSL](#)

– Expert-led video presentation on the diagnosis, treatment, and management of PCNSL.

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