

# Learn About Leptomeningeal Disease

## Information for patients and caregivers

Read this resource to learn:

- what is leptomeningeal disease
- what are the symptoms of leptomeningeal disease
- what to do if you have symptoms
- what are the diagnostic tests for leptomeningeal disease
- what to expect with leptomeningeal disease
- what are the common emotional responses to leptomeningeal disease



## **What is leptomeningeal disease?**

Leptomeningeal disease occurs when your cancer has spread to the meninges. The meninges line the spinal cord and brain. There are many names for leptomeningeal disease, which include:

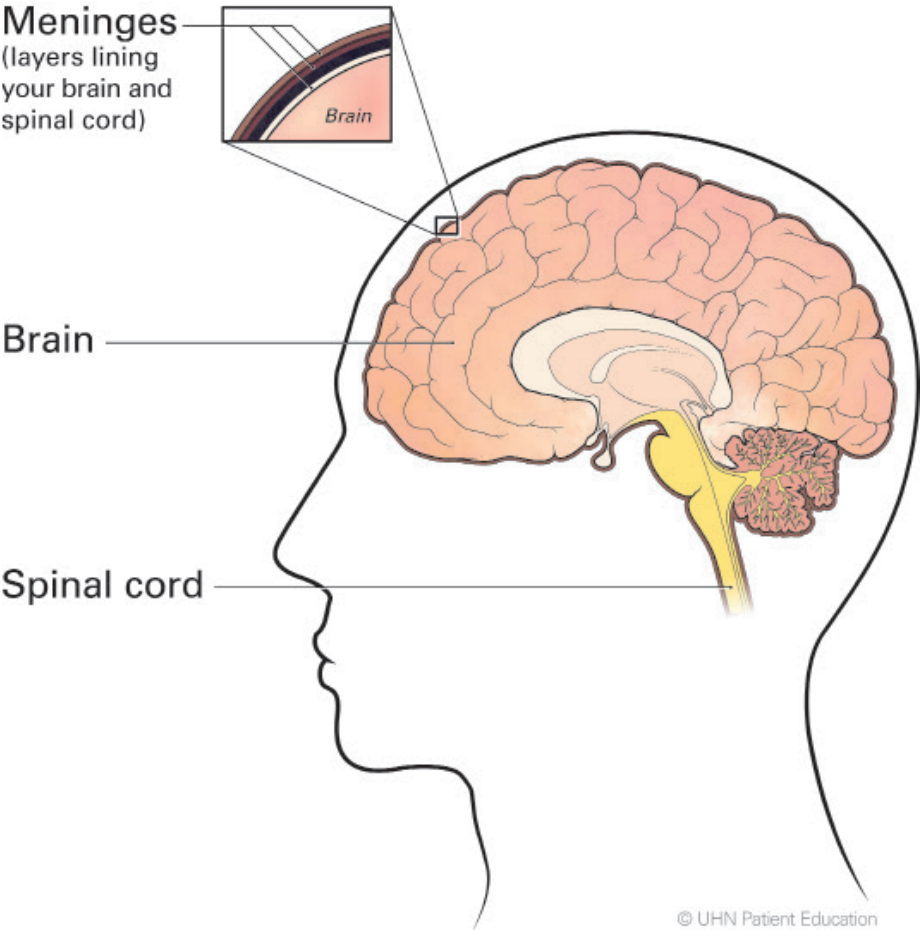
- Carcinoma meningitis
- Leptomeningeal carcinomatosis
- Leptomeningeal metastases
- Meningeal carcinomatosis
- Meningeal metastases
- Neoplastic meningitis

Leptomeningeal disease is a form of metastatic cancer. Metastatic means your primary cancer has spread.

The most common primary cancers that lead to leptomeningeal disease are:

- Lung
- Melanoma
- Breast
- Stomach
- Bowel
- Leukemia
- Lymphoma

Leptomeningeal disease occurs in 1 out of 20 people (5%) who have cancer. This disease is becoming more common because cancer treatments allow patients to live longer.



## **What are the symptoms of leptomeningeal disease?**

Leptomeningeal disease means the primary cancer has spread to the meninges. You may have many different types of symptoms. You may have only one symptom or many. This is because the meninges line your spinal cord and brain.

Symptoms of leptomeningeal disease can be divided into 2 possible causes:

### 1. Intracranial hypertension (pressure around the brain).

- Nausea
- Headaches
- Confusion
- Seizures (uncontrolled muscle spasms)
- Sleepiness
- Lethargy (extreme lack of energy)

### 2. Meningeal infiltration (irritation of the lining of the spinal cord and brain).

- Neck and/or back pain
- Headaches that start from the neck

## **What to do if you have symptoms of leptomenigeal disease?**

Contact your oncologist, right away, if you have any of the symptoms listed above.

## **What are the diagnostic tests for leptomenigeal disease?**

Diagnostic tests include:

- MRI of brain and spinal cord. An MRI is a type of medical imaging used to see the inside of the body.
- Lumbar puncture. If the MRI does not show leptomenigeal disease, your doctor may want to do a lumbar puncture. A lumbar puncture takes a sample of the fluid around the spinal cord and brain. This fluid is called cerebral spinal fluid (CSF). Your CSF will be sent to a lab to test for leptomenigeal disease. A lumbar puncture is done by inserting a needle between two lumbar bones (vertebrae).

These tests may need to be done many times before a diagnosis is found.

## **What to expect with leptomeningeal disease?**

This disease has a very low survival rate. With treatment, survival is about 3 to 6 months. Without treatment, survival is 4 to 6 weeks.

The most common treatment for leptomeningeal disease is radiation therapy. Treatment will depend on your primary cancer, symptoms and functional status.

Functional status means your ability to do normal daily activities.

**Talk to your doctor about the best options for you.**

There are 4 possible treatment options. Treatment options may include 1 or more of the treatments listed.

### **1. Radiation Therapy**

Radiation therapy is the use of high energy x-rays to damage cancer cells. It is used to control symptoms and slow the spread of the cancer. Treatment areas can include the brain, the spinal cord or both.

### **2. Chemotherapy**

Chemotherapy is the use of drugs to treat cancer. Chemotherapy for leptomeningeal disease can be given in many ways.

Your doctor will decide the best way to get chemotherapy treatment.

Chemotherapy can be given by:

- Intravenous (IV) line: An Intravenous (IV) line uses a needle to put chemotherapy directly into the veins.
- Lumbar puncture: Chemotherapy is put into the fluid around your spinal cord and brain. This fluid is called cerebral spinal fluid (CSF). This is done through a lumbar puncture. A lumbar puncture is done by inserting a needle between two lumbar bones (vertebrae).
- Pill form: Chemotherapy is given in pill form and is taken orally (by mouth).

- Ommaya reservoir: An ommaya reservoir is a chemotherapy device placed in the skull. You will need surgery to have your ommaya reservoir placed. This reservoir gives chemotherapy directly to the fluid around the brain and spinal cord.

### **3. Biological Therapy/ Immunotherapy**

Biological therapy stimulates the body to fight cancer. Similar to chemotherapy, this treatment can be given in many ways. The way biological therapy is given depends on the type of cancer you have. Biological therapy can be given by:

- intravenous (IV) line
- a lumbar puncture
- pill form

### **4. Supportive Therapy**

Supportive therapy is the use of medicines to help control the symptoms. Many different medicines can be used to help control many different symptoms.

Medicines include:

- Analgesics to treat pain
- Anticonvulsants to treat seizures
- Antidepressants to treat mood changes
- Anxiolytics to treat anxiety
- Corticosteroids to treat symptoms from swelling
- Antiemetics to treat nausea

Talk to your doctor about supportive therapy treatments for your disease.

## **What are the common emotional responses to leptomeningeal disease?**

Finding out you have leptomeningeal disease can cause many emotions. It is okay to feel what you feel. You may feel stress, anxiety, and sadness. Ask your doctor about other health care team members that can help you.

You can also contact a Social Worker or Spiritual Care Professional for support. Below is the contact information for Social Work in the Psychosocial Oncology Department and Spiritual Care.

### [Psychosocial Oncology Clinic](#)

Princess Margaret Cancer Centre – 16th floor

Phone: 416 946 4525

Website: [https://www.uhn.ca/PrincessMargaret/Clinics/Psychosocial\\_Oncology](https://www.uhn.ca/PrincessMargaret/Clinics/Psychosocial_Oncology)

Spiritual Care Professional

Page us at: 416 719 1234 between 8:30 am – 11:00 pm.

For more information, contact the [Patient & Family Library](#)

[Princess Margaret Cancer Centre](#) – 1st floor

Phone: 416 946 4501, ext. 5383.

Website: [https://www.uhn.ca/PrincessMargaret/PatientsFamilies/Specialized\\_Program\\_Services/Pages/princess\\_margaret\\_patient\\_family\\_library.aspx](https://www.uhn.ca/PrincessMargaret/PatientsFamilies/Specialized_Program_Services/Pages/princess_margaret_patient_family_library.aspx)



Use the chart below to track your symptoms.

<b>Date</b>	<b>Time of day</b>	<b>How long</b>	<b>Symptom</b>	<b>Action taken</b>

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