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

Please visit the UHN Patient Education website for more health information: www.uhnpatienteducation.ca

© 2017 University Health Network. All rights reserved. This information is to be used for informational purposes only and is not intended as a substitute for professional medical advice, diagnosis or treatment. Please consult your health care provider for advice about a specific medical condition. A single copy of these materials may be reprinted for non-commercial personal use only.

Author: Dr. Catherine Maurice and Dr. Marcus Butler
Created: 04/2017
Form: D-8669
What is leptomeningeal disease?

Leptomeningeal disease occurs when your cancer has spread to the meninges. The meninges line the spinal cord and brain and help to support and protect them. 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:

- Melanoma
- Breast
- Lung
- 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. Different symptoms are caused by different things.
Symptoms of leptomeningeal disease can be divided into 3 possible causes:

Intercranial hypertension (pressure around the brain).
- Nausea
- Headaches
- Confusion
- Seizures (uncontrolled muscle spasms)
- Sleepiness
- Lethargy (extreme lack of energy)

Meningeal irritation/infiltration (irritation of the lining of the spinal cord and brain).
- Neck and/or back pain
- Headaches that start from the neck

Focal neurologic (problems with nerves in the spinal cord or brain. Symptoms will depend on the area of the brain affected).
- Seizures
- Trouble swallowing
- Loss of bladder and bowel control
- Hard time thinking
- Weakness
- Lack of coordination
- Vision or hearing problems
- Loss of balance
- Loss of sensation

What to do if you have symptoms of leptomeningeal disease?

Contact your oncologist, right away, if you have any of the symptoms listed above. It is vital to diagnose leptomeningeal disease early.
What are the diagnostic tests for leptomeningeal disease?

Diagnostic tests include:

- 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 leptomeningeal disease. A lumbar puncture is done by inserting a needle between two lumbar bones (vertebrae).

- MRI of brain and spinal cord. An MRI is a type of medical imaging used to see the inside of the body.

Diagnosing leptomeningeal disease is hard for your oncologist. A lumbar puncture does not always indicate leptomeningeal disease. Sometimes, the disease cannot be seen on your MRI. 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 3 to 6 months. Without treatment, survival is 4 to 6 weeks.

There is no standard treatment for leptomeningeal disease. This means that doctors have not decided on the best treatment options for this disease. Treatment will depend on the primary cancer, symptoms and functional status.

Functional status means your ability to do normal daily activities. Treatment will be customized to your exact needs. Talk to your doctor about the best options for you.
There are 5 possible treatment options. Treatment options may include 1 or more of the treatments listed.

1. **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.

2. **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.

3. **Surgery**

Usually, surgery is used in cancer treatment to remove cancer. For leptomeningeal disease, surgery can help doctors administer chemotherapy or control symptoms.

Surgery is used to place the ommaya reservoir mentioned in the chemotherapy section. It can also be used to treat blocks in the cerebral spinal fluid (CSF).
4. 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

5. 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

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.
Use the chart below to track your symptoms.

<table>
<thead>
<tr>
<th>Date</th>
<th>Time of day</th>
<th>How long</th>
<th>Symptom</th>
<th>Action taken</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The development of patient education resources is supported by the Princess Margaret Cancer Foundation.