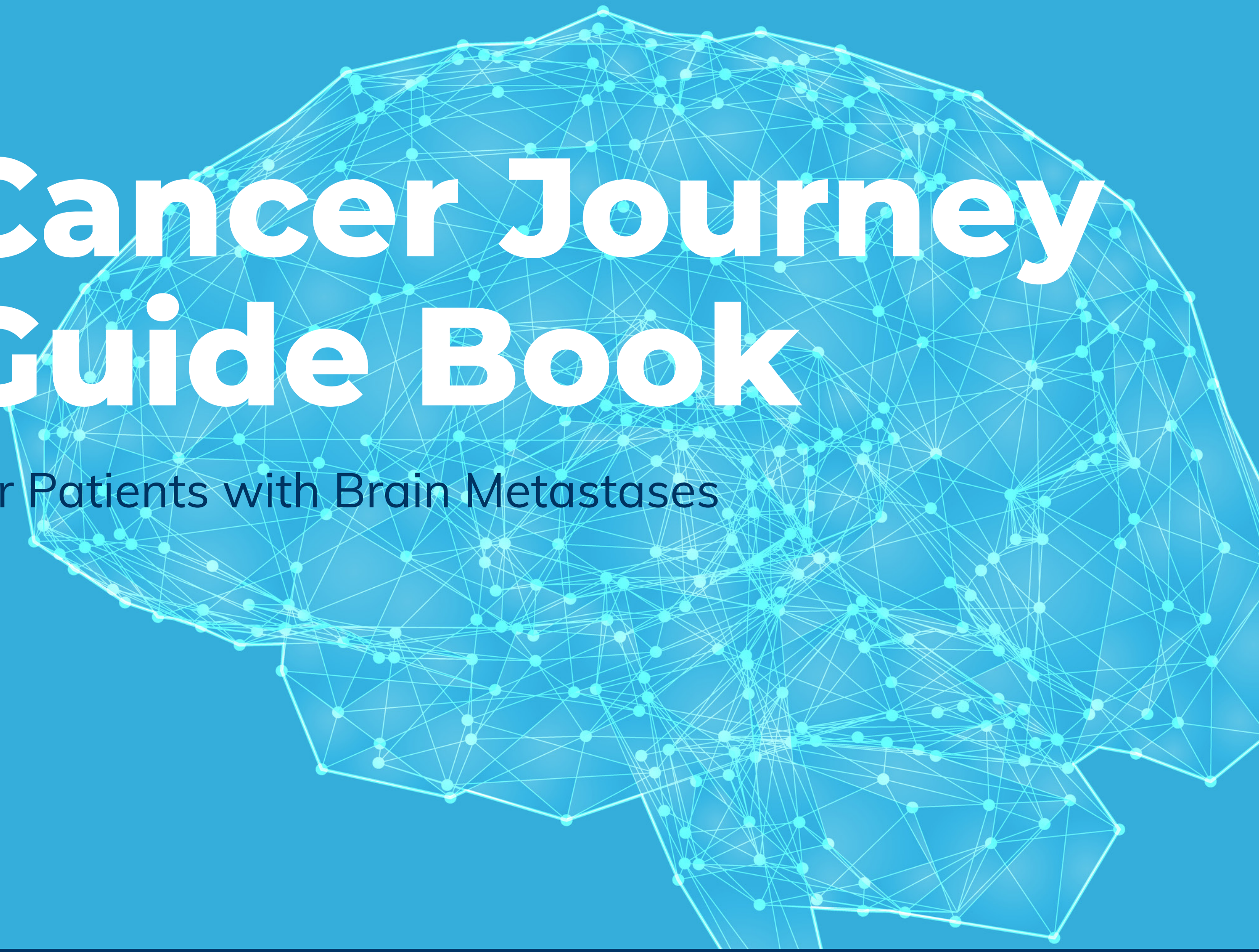


Cancer Journey Guide Book

For Patients with Brain Metastases

This Guide Book is meant to help you:

- Find resources and information at Princess Margaret Cancer Centre and in your community
- Understand your treatment
- Help you speak with your Brain Metastases Clinic care team

UHN Princess Margaret Cancer Centre

Cancer Education
Princess Margaret

The Cancer Journey Resources for Patients with Brain Metastases

At the Princess Margaret Cancer Centre, we know that finding out you have brain metastases can make you feel overwhelmed, afraid, numb or anxious.

You will get a lot of information from your Brain Metastases Clinic care team about:

- Your brain metastases
- Treatment options
- Side effects
- Supports at Princess Margaret Brain Metastases Clinic and the community that you can access

You will get all of this information while coping with the news that you have brain metastases. Given this, it may be hard to keep track of all of the information you get at once.

Finding out you have brain metastases is the first step in treating it. Brain metastases is often treated with many treatments that can take many months and even years.

Coping with brain metastases can be a complex and long journey. There may be difficult periods along the way. For this reason, the Princess Margaret Brain Metastases Clinic staff, and cancer patients and survivors made two resources to help you on this journey:

The Cancer Journey Planner for Patients with Brain Metastases

The Planner was made to help you organize your health information and keep a record of your brain metastases journey. In the Planner you will find:

- Lists of questions you may want to ask your Brain Metastases Clinic care team
- Trackers and calendars to help you keep information about your cancer journey organized in one place

Bring the Planner with you to your appointments. You (or a family member or friend) can take notes to help you recall information.

The Cancer Journey Guide Book for Patients with Brain Metastases

The Guide Book was made to help you find:

- Information about brain metastases
- Practical information to help guide you through your cancer journey
- Tips on how to manage side effects of brain metastases

You can also get the brain metastases resources from the Patient & Family Library or online at www.brainmetsclinic.theprincessmargaret.ca

Table of Contents

Just Diagnosed

When you are first diagnosed (told you have brain metastases), you may have a lot of questions. You may also feel overwhelmed by the amount of information you are getting.

This section has tips to help you:

- Understand what brain metastases are
- Talk with your Brain Metastases Clinic care team
- Prepare for your appointments

Your Brain Metastases Clinic Care Team

The Brain Metastases Clinic has a team approach. This means that you may speak with different cancer care professionals each time you visit the clinic. Each of the cancer care professionals will know about your medical history.

Information in this section will tell you about the team members involved in your care.

Specialized Oncology Nurse

A nurse cares for people who are sick. The specialized oncology nurse will help to plan and manage your care. They can also show you resources that may be helpful for you. If you have questions or new symptoms, call your nurse.

Radiation Oncologist

A radiation oncologist is a doctor that uses radiation to treat cancer. If you are having radiation (whole brain radiation or radiosurgery), this doctor will plan your treatment.

Radiation Therapist

A radiation therapist gives radiation treatment. You will see a radiation therapist at each of your radiation appointments. You will be able to ask them questions before, during, and after your treatments.

Neurosurgeon

A neurosurgeon is a doctor who performs surgery on the brain and spine. You may see a neurosurgeon if you are having surgery on your brain or spine. Speak to this doctor if you have questions about surgery.

Medical Oncologist

A medical oncologist is a doctor who gives chemotherapy and other medicines to treat cancer. You will likely see a medical oncologist to treat your primary cancer. Your primary cancer is the cancer that the brain metastases came from. Medical oncologists are not part of the Brian Metastases Clinic but are in contact with your Brain Metastases Clinic care team to manage your care.

Residents and Fellows

Residents and fellows are doctors in training. All residents and fellows have finished medical school and have medical degrees. They help senior doctors at the hospital to look after patients.

Contact the Brain Metastases Clinic Team

Brain Metastases Clinic Coordinator

Phone: 416 946 2130

Email: brainmetsclinic@rmp.uhn.on.ca

Hours: Monday to Friday, 9am to 5pm

After Hours

Phone: 416 946 2000 (ask for the On-Call Radiation Oncologist)

Website: www.brainmetsclinic.theprincessmargaret.ca

About Brain Metastases

What are brain metastases?

A brain metastasis is a tumour that has spread to the brain from another place in your body. When there is one tumour in the brain, it is called a brain metastasis. When there is more than one tumour, it is called brain metastases. For example, if you have lung cancer, cancer cells that spread to the brain from the lung(s) are called brain metastases. Metastases are different from cancers that start in the brain. Cancer that starts in the brain is called a “primary brain cancer”.

Each part of the brain controls a unique function, action or feeling. Brain metastases can affect any part of the brain. The number, size, and location of your brain metastases can change what you feel. Many people feel nothing from their brain metastases.

For some patients, brain metastases are how they first find out they have cancer in other parts of their body.

Many types of cancer can spread to the brain. The most common cancers that spread to the brain are:

- Lung
- Breast
- Melanoma (skin)
- Kidney
- Colon

How many brain metastases do I have?

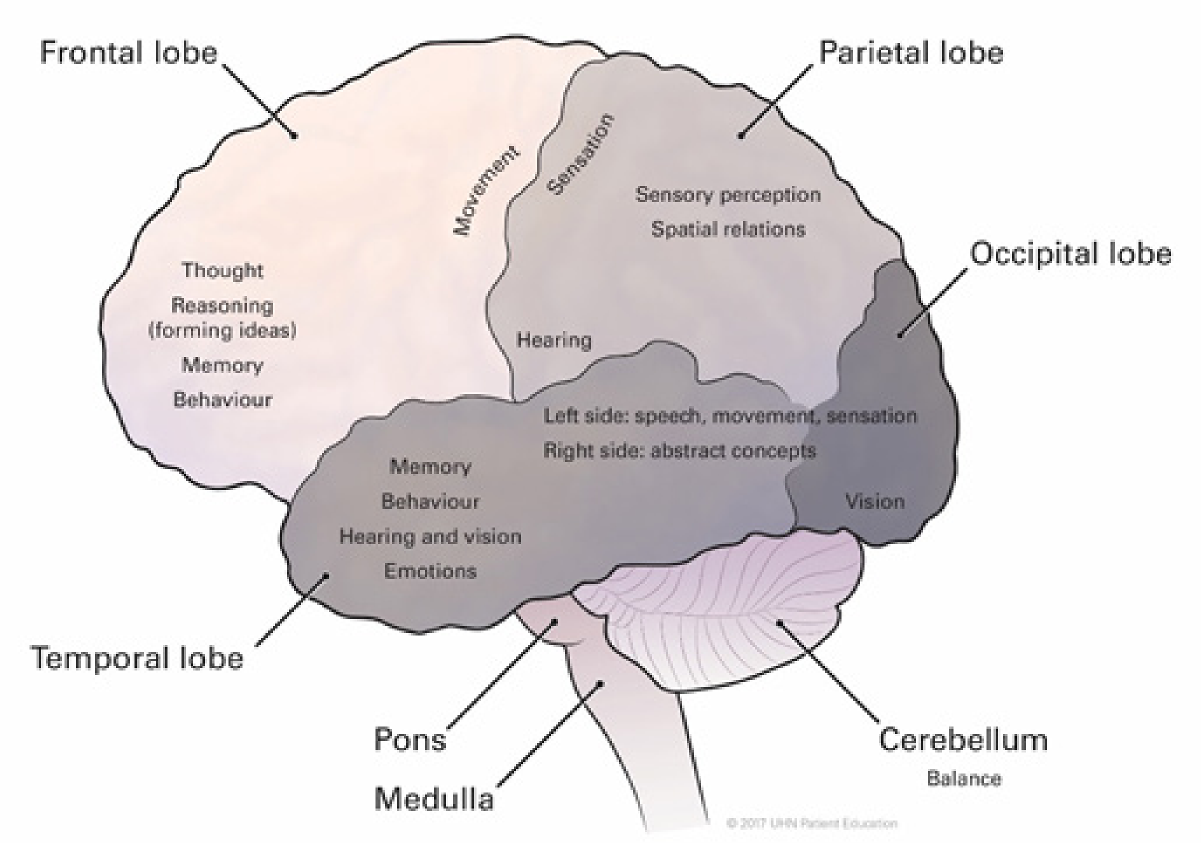
You can have many brain metastases in different parts of the brain, one large metastasis in one part of the brain, or both. The number and size of your brain metastases may affect your treatment. Your treatment is planned just for you. Knowing how many metastases you have, their size, and location, can help your Brain Metastases Clinic care team decide your treatment options.

Where are my brain metastases?

Knowing where your brain metastases are can help explain your symptoms. Symptoms of brain metastases are affected by the location of the metastases in the brain.

Understand the parts of your brain

When we think about the brain, it is helpful to know what each part of the brain does. The brain has two halves (left and right). Each half has four major "lobes". A lobe is an area in the brain that carries out a certain function. Each part of the brain connects to and talks to other parts. Brain metastases can affect how well this process occurs.



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Location	Function
Frontal lobe	Thinking, memory, paying attention, behaviour, reasoning (forming ideas), movement, language (speaking)
Parietal lobe	Sensory (feeling when something touches you), spatial sense (knowing where your body parts are in space)
Temporal lobe	Memory, behaviour, emotions, hearing, language (understanding)
Left side	Speech, movement, sensation
Right side	Abstract concepts
Occipital lobe	Vision
Pons, Medulla	Basic body functions like breathing, consciousness (being asleep/awake)
Cerebellum	Balance, coordination (making movements smooth)

You can have exact “focal” symptoms, for example, not being able to move your right arm or leg. You can also have less clear “generalized” symptoms, for example, not acting like yourself. The symptoms you have depend in part on where and how large your metastases are.

Get Information

How Much Do I Need to Know?

How much information should I get from my Brain Metastases Clinic care team?

This is a hard question and the answer very much depends on you.

There is no perfect amount of information for every person. Each person wants to learn a different amount about their cancer and treatment.

Some people like to know all of the details. Other people prefer much less. In most cases, the amount of information you want will change over time. You might not want to know much to start with, but later on, you might want to know more.

Bring a family member or friend with you to your appointments. A family member or friend can help you recall or write down information that you get. It can be hard to absorb all of the information on your own.

Although the Brain Metastases Clinic can be very busy, your care team is here to support you. To get the details that you need:

- ✓ Ask for the information that you most want to know right now.
- ✓ Know that you will have many chances to get more information. You do not have to get all the information at once.

For a good general picture of your cancer and treatment, the most important details may be:

- Your type of cancer (what your cancer cells look like under a microscope)
- The extent of your brain metastases (how large the tumours are and how many there are)
- What treatment your Brain Metastases Clinic care team recommends for you (for example, radiation or surgery)

You can write down these details in the **"My Diagnosis"** (page 16) section of your Cancer Journey Planner.

Talk With Your Brain Metastases Clinic Care Team

Your Brain Metastases Clinic care team uses the information they have about your cancer and the information you give them to inform your treatment plan. You may only meet some members of your care team one or two times (for example, in the radiation planning area or for a diagnostic test such as an MRI or CT scan). Or, you may end up knowing members of your care team for years after treatment ends (for example, your radiation oncologist, neurosurgeon, or Specialized Oncology Nurse). How well you are able to talk with your Brain Metastases Clinic care team is key to getting the care that is best for you.

Before being diagnosed with cancer and brain metastases, many people do not know much about available treatments. Many people also do not know much about the types of health care providers who work in cancer centres and what supports are available to them. This is normal.

As a patient, you may need to know about:

- The details of your brain metastases
- Your treatment options
- Support resources available to you (for example, a social worker)

Your Brain Metastases Clinic care team also needs to learn about you to best treat your cancer. Your Brain Metastases Clinic care team needs to know:

- Your medical history
- How you are feeling
- Your support needs

Remember that you and your cancer care team will always come back to the goal. This goal is to treat your cancer and help you get through treatment.

Calling Princess Margaret Cancer Centre

- ✓ For emergencies, go to your local emergency department or to the Emergency at the Toronto General Hospital. Be sure to tell the emergency staff that your cancer is being treated at Princess Margaret Cancer Centre. Note, Princess Margaret Cancer Centre does not have an emergency department.
- ✓ If you have a care or concern about how you are feeling, call the site telephone line to talk to the Specialized Oncology Nurse. Leave your OHIP number (found on your health card), name, daytime phone number, and your concern on the answering machine. The answering machine is available Monday to Friday, from 9 am to 4 pm. You will be given the number for the site telephone line on your first visit.
- ✓ If you have urgent medical concerns on weekends, holidays or after 4 pm:
    - Call the after-hours CAREpath™ line at 1 877 681 3057. A specialized oncology nurse will answer your call. If the nurse is not available at the time of your call, a nurse will return your call within 15-20 minutes.
    - Call the Radiation Oncologist or Neurosurgeon on-call at 416 946 2000.
- ✓ Call the Brain Metastases clinic if you need to change or cancel your appointment:
    - Brain Metastases Clinic: 416 946 2130
- ✓ Contact your Brain Metastases Clinic care team doctor at their office if you need:
    - Any forms or letters filled
    - Access to your medical records or information sent to your primary care provider (family doctor or nurse practitioner)

Coming in for a Clinic Visit

When you come in for a clinic visit, bring:

☐ Your OHIP card

☐ The contact information of your pharmacist and primary care provider (family doctor or nurse practitioner)

☐ A complete list of all your medicines. This includes over-the-counter drugs, herbals, minerals, vitamins, and eye, ear, and nose drops.

☐ All of your current medicines in their original bottles. This includes over-the-counter drugs, herbals, minerals, vitamins, and eye, ear, and nose drops.

☐ A list of questions you have about your treatment plan and care

☐ A family member or friend to take notes and help you remember what was said in your appointments. You can also bring a family member or friend to keep you company.

☐ A snack or drink and something to read if you have to wait (for example, a book or magazine)

☐ Your Cancer Journey Planner For Patients with Brain Metastases. You can write down important information in your Planner and take notes at appointments.

myUHN Patient Portal

myUHN is a secure website for patients of University Health Network (UHN). UHN is a health care and research organization made up of four health care centres. These centres are: Princess Margaret Cancer Centre, Toronto General Hospital, Toronto Western Hospital, and the Toronto Rehabilitation Institute.

The myUHN website lets you see your appointments and results from all UHN hospitals and clinics as soon as they are ready. With myUHN, you can access your personal health record anywhere, anytime on a computer, smartphone or tablet. Ask for a registration code when you check in for your next appointment or call myUHN Support at 416 340 3777.

What will I see in myUHN Patient Portal?

With myUHN, you can:

- ✓ See your UHN appointments and receive appointment reminders
- ✓ See your UHN lab results dating back to 2008
- ✓ See your UHN reports, such as pathology and imaging reports, and clinic notes dating back to May 1, 2015
- ✓ Find links to education resources, medical dictionaries and other helpful websites
- ✓ Share your health information with others

Contact the myUHN Patient Portal Team

For questions about sign in, registration, registration codes or using myUHN:

Phone: 416 340 3777

Email: myUHN@uhn.ca

Hours: Monday to Friday, 9 am to 5 pm

During Treatment

In this section you can find information to help you when you are going through treatment.

This section has tips to help you:

- Understand common brain metastases treatments
- Understand your medicines
- Care for yourself
- Cope when you are waiting for test results

Common Brain Metastases Treatments

How are Brain Metastases Treated?

The treatment that you get is planned just for you. Your health care team will look at many factors and discuss them with you before choosing the best treatment for you. These factors include:

- Your primary cancer (place in the body where the brain metastases have spread from)
- The number of brain metastases you have
- The treatments you already had
- Your overall health
- The size of your brain metastases
- The location of your brain metastases
- Your symptoms
- How well you can do daily activities (for example, getting dressed, cooking, going to work)
- How well your cancer is managed in the rest of your body
- Your personal choices

There are three main treatments for brain metastases:

1. Surgery
2. Radiosurgery (Gamma Knife®)
3. Whole Brain Radiation

Your Brain Metastases Clinic care team might suggest more than one of these treatments for you. You may also have other types of treatment to treat your primary cancer, or side effects that you have. Ask your doctor about any concerns you have about the treatments, and why they suggest one treatment option over another.

Surgery

What is surgery?

Surgery for brain metastases is a type of treatment in which an area of the head is cut open to remove a brain metastasis.

Brain metastasis surgery can be used to:

- ✓ Diagnose cancer
- ✓ Treat the brain metastasis

Diagnosing cancer

In some cases, surgery may be the only way to find out if someone has cancer and the kind of cancer. During surgery, the surgeon removes a small piece of tissue called a sample. The sample is sent to the lab where it is tested to find out if the sample contains cancer and what type of cancer it is.

Treating cancer

Surgery may be an option for you if you have one large tumour. You may also have surgery if you have many tumours, but one or more is large enough to make you feel better if it is removed. Surgery can be an option before or after radiation treatment.

Surgery may be your main treatment if:

- ✓ A brain metastasis is pressing on other parts of the brain and causing symptoms
- ✓ The tumour is in a spot that is safe to reach through surgery

How is surgery done?

Surgery might be an important part of your treatment plan. This type of treatment is performed by a neurosurgeon.

Surgery is often done under anesthetic. An anesthetic is medicine to help you relax and sleep through surgery. In some cases, you might be given a lighter sedation. If you have a lighter sedation, you will be awake but relaxed.

Your surgery may last several hours. The length of your surgery will depend on how many tumours you have and where they are.

The goal of your surgery will depend on details about your health and your cancer. Ask your neurosurgeon what the goal of your treatment is.

What side effects might I have?

The side effects and risks you may have from surgery depend on:

- The type of surgery
- Your overall health

Most side effects will go away after surgery, but some may be long term or permanent.

Possible side effects of surgery include:

- Pain
- Nausea (feeling like you might throw up)
- Vomiting (throwing up)
- Bruising or bleeding
- Swelling
- Fatigue
- Scarring
- Loss of movement or feeling

It takes time to recover from surgery. You may feel tired or weak after having surgery. Before your surgery, your Brain Metastases Clinic care team will talk to you about how to deal with pain, and they may give you a prescription (medicine ordered by a doctor) for medicines to take afterwards. Write down your side effects in the Side Effects Tracker (page 63) in your Planner. Tell your Brain Metastases Clinic care team if you have any side effects you think may be from surgery. Your Brain Metastases Clinic care team can help improve many side effects with treatment.

Radiosurgery (Gamma Knife®)

What is radiosurgery?

Radiosurgery is done with a machine called a Gamma Knife®. The Gamma Knife® machine sends high-energy x-rays to a very focused part of your brain. The x-rays kill the cancer cells, making the tumours smaller. This treatment happens while you are awake. You usually have one round of treatment, which can last 45 minutes to many hours.

When is radiosurgery used?

This type of treatment is used if:

- You have only a few metastases
- The metastases are small (usually less than 3cm)

Radiosurgery can be used after a previous radiation treatment if new metastases grow.

Radiosurgery can be used after surgery:

- To treat the brain around the tumour that was taken out
- To treat any tumours that were not taken out

How is radiosurgery done?

Some radiosurgery treatments use a frame and other treatments use a mask. Ask your doctor if you will have treatment with the frame or treatment with the mask.

Frame

The morning of your treatment, your neurosurgeon and radiation therapist will attach a frame to your head. The frame is placed with pins that will be adjusted to make sure the frame fits you. You will be given a local anesthetic where the pins are placed. The anesthetic will numb the area where the frame is placed. You may feel a bit of pressure where the pins are tightened. This pressure will go away after about 5 to 10 minutes.

The frame will stay on your head until you have finished treatment. This is to keep you in a stable position during imaging and treatment. If you have a headache after the frame is removed, take an over the counter pain killer such as Ibuprofen (Advil). Watch this video to know what to expect when having Gamma Knife Radiosurgery with the frame:

https://tinyurl.com/GKframe

Mask

If you have treatment with a mask, a custom, plastic mask will be made that fits over your head. This mask will hold your head in place during your treatment. The mask will be made a day or two before you have treatment. Watch this video to know what to expect when having Gamma Knife Radiosurgery with a mask:

https://tinyurl.com/GKmask

Whole Brain Radiation

What is whole brain radiation?

Whole brain radiation treatment sends x-rays to the whole brain. Whole brain radiation treats brain metastases by shrinking them. The x-rays kill the cancer cells, making the tumours smaller. This also stops new metastases from growing in healthy areas in the brain.

When is whole brain radiation used?

Whole brain radiation can be used if:

- Your tumour is not in a safe spot for surgery
- Your tumours are too big for radiosurgery
- You have many smaller metastases

It can also be used after radiosurgery to:

- Decrease the chance of new brain metastases from growing in the future

- Treat tumours that grow back
- Treat new brain metastases that grow in the future

Whole brain radiation can be used after surgery to stop new brain metastases from growing in the future.

How is whole brain radiation done?

This treatment is done while you are awake. A mask made just for you will keep your head still during planning and treatment. You will have treatment every day for about 15 to 20 minutes each day. The number of treatments you need, and how long your treatment will last, will depend on your treatment plan.

What side effects might I have?

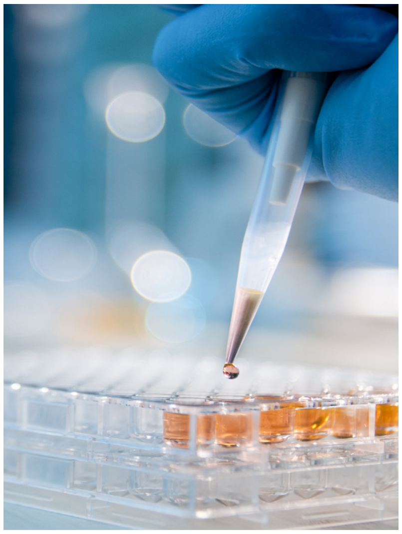
Side effects you may have include:

- Fatigue (feeling of tiredness that does not go away with rest or sleep)
- Headaches
- Nausea (feeling of having to throw up)
- Feeling like your ears are plugged
- Complete hair loss on your head. That often starts during radiation treatment. Your hair may grow back 2 to 3 months after radiation treatment is done
- Changes to your scalp (skin). Your scalp may look more red or darker than normal. It may feel warm, dry and itchy

Clinical Trials

What are clinical trials?

Clinical trials are research studies that involve people. Clinical trials look for new ways to prevent, detect or treat cancer. Clinical trials may also explore ways to improve quality of life for cancer patients. Every treatment used today is the result of past clinical trials.



How can I find a clinical trial that's right for me?

Princess Margaret Cancer Centre is a research hospital, so you may be asked if you would like to join a clinical trial or research study. You can also ask your doctor if there are any clinical trials you could be involved in. Being in a clinical trial or research study is always your choice.

There are many clinical trials taking place at Princess Margaret Cancer Centre. Each clinical trial is designed to include patients with specific traits. "Inclusion criteria" are the traits patients must have to join a clinical trial. "Exclusion criteria" are traits that prevent patients from joining a clinical trial. Inclusion and exclusion criteria:

- Help to keep patients safe
- Help the researchers find the answer they are looking for

There are many websites that list current clinical trials. If you find a clinical trial you want to join, tell your doctor. Your doctor can help you know if the clinical trial could be a good fit for you.

Find a Clinical Trial

- **At Princess Margaret Cancer Centre:** https://www.uhn.ca/PrincessMargaret/Research/Cancer_Clinical_Research/Pages/clinical_trials.aspx
- **In Canada:** www.canadiancancertrials.ca

For more information about clinical trials, and what to consider when you join, visit: https://bit.ly/2HIy94A

Chemotherapy

What is chemotherapy?

Chemotherapy is a systemic therapy and is a common type of cancer treatment. You may hear chemotherapy referred to as “chemo”.

Chemotherapy uses different kinds of medicines to kill cancer cells. Chemotherapy does not often work to treat brain metastases. But some types of chemotherapy, such as targeted therapies, may work in treating brain metastases.

Chemotherapy can be used to:

- ✓ Kill cancer cells
- ✓ Slow the growth of cancer
- ✓ Keep cancer from spreading
- ✓ Help manage cancer symptoms, like pain
- ✓ Cure cancer

The goal of your chemotherapy treatment will depend on details about your health and your cancer. Ask your medical oncologist (a doctor who gives chemotherapy and other medicines to treat cancer) what the goal of your treatment is.

How does chemotherapy work?

Chemotherapy kills cells that multiply or grow quickly, like cancer cells. Unlike radiation therapy and surgery, which can target specific areas, chemotherapy works throughout the whole body. That is why chemotherapy is called a systemic therapy. Chemotherapy travels through your blood to reach cells over your entire body, or system.

Understanding My Prescription Medicine

It is important to keep your Brain Metastases Clinic care team informed about any medicines you are taking. Ask questions about how different medicines can interact with one another. Use the practical tips below to better understand your medicines.

Tips for Understanding Your Medicines

✓ Be ready with questions. Write down as many questions as you can before seeing your Brain Metastases Clinic care team. Be sure to have all your questions about your medicines answered during your appointments. Questions to ask about your medicines include:

- Have any medicines been added, stopped or changed, and why?
- What medicine do I need to continue and why?
- How do I take my medicine and for how long?
- What side effects should I watch out for?
- How will I know if my medicine is working?

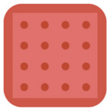
✓ Use the tables in the **"My Medicines"** section (page 41) of the Planner to list your prescription and non-prescription medicines. Include:

☐ Prescription medicines (medicines ordered by a doctor)

☐ Over-the-counter medicines (medicines you can buy in a pharmacy or drug store without a prescription)

☐ Vitamins, minerals and herbals

☐ Eye, ear and nose drops



☐ Patches

☐ Inhalers

☐ Sprays

☐ Cannabis

Tell your doctors, nurses and pharmacists about any medicines you take and if you have any allergies.

- ✓ Update your doctors, nurses and pharmacists about any changes to medicines you take. This includes telling them if you have stopped taking a medicine and why. Tell them how and when you are taking your medicines.
- ✓ If you get your medicines from your local pharmacy, give your Brain Metastases Clinic care team the pharmacy's contact information.

Common Medicines

You may be given medicines during your treatment. These medicines do not make your tumour go away. They will help with the symptoms and side effects that the metastases and treatments may cause.

Anti-Seizure Medicines

You may have seizures because of your tumour. Not all seizures are the same. Seizures can feel like muscle spasms you cannot control. You may briefly black out and have other symptoms. It can be very scary to have a seizure or to watch someone having a seizure. Seizures are usually not life threatening. If you have a seizure, seek medical attention right away so that you can begin anti-seizure medicines. Anti-seizure medicines may decrease the chance of having another seizure.

Common medicines used to help manage seizures include:

- Dilantin (also called “phenytoin”)
- Keppra (also called “Levitiracem”)
- Valproic acid
- Clobazam
- Vimpat (also called “lacosamide”)

Some common side effects of anti-seizure medicines include:

- Dizziness (feeling light-headed, weak or not steady)
- Feeling that thinking is “foggy”, or that you cannot think clearly
- Fatigue (feeling of tiredness that does not go away with rest or sleep)
- Lack of coordination (problems with balance and movement)
- Blurred vision

Talk to your doctor about the side effects specific for your medicine. You may need to have blood tests done to make sure you are on the right dose.

Anti-Nausea Medicines

Nausea (the feeling of having to throw up) is a common side effect of brain metastases, and cancer treatment. Anti-nausea medicines are used to treat nausea.

Common medicines used to help manage nausea include:

- Gravol (also called “dimenhydrinate”)
- Ondansetron
- Decadron (also called “dexamethasone”)

Your doctor may prescribe you other medicines to treat nausea.

Some common side effects of anti-nausea drugs include:

- Dizziness (feeling light-headed, weak or not steady)
- Fatigue (feeling of tiredness that does not go away with rest or sleep)
- Blurred vision
- Dry mouth
- Constipation (not being able to poo)

Talk to your doctors and nurses about any concerns or questions you have.

Dexamethasone

Dexamethasone (also known as “Decadron”) is a type of medicine known as a steroid. When a tumor grows in your brain, your brain can swell (gets bigger). Steroids reduce swelling (inflammation) in the body.

Swelling can happen after surgery or radiation treatments. Swelling in the brain can make your symptoms worse.

Early side effects of dexamethasone include:

- **Trouble sleeping.** Talk to your cancer care team about taking dexamethasone at a different time (for example, earlier in the day) to help you sleep

- **Mood changes**. You can feel easily bothered, irritated, or mad.
- **Increased appetite.** You want to eat more
- **Weight gain**. This is due to more water in your body, and wanting to eat more. Weight gain is often seen more in the face and stomach
- **Increase in blood sugars.** If you have diabetes, this will affect your sugar levels. Tell your doctor if you have diabetes
- **Trouble fighting infections**. Infections happen when germs cause problems in the body. You might get more infections. Infections caused by fungi, such as candida or ‘thrush’, are most common

Some side effects of dexamethasone may last longer. These include:

- **Muscle loss.** This happens mainly to the muscles at the top of your legs and arms. This can make it hard to get up from a chair or walk up stairs
- **Thinning skin.** This can make you bruise more easily.
- **Acne-type rash**
- **Bone thinning**

Caring for Myself

As well as the physical effects of cancer and treatment, there are also emotional and practical effects. When you are first diagnosed with cancer, there tends to be a focus on the medical side of the illness. But a cancer diagnosis also affects other parts of your life. This can include your family, finances, friendships, household tasks, and being able to sleep.

Many cancer survivors who have finished treatment have said that it is important to notice all of these areas throughout your cancer journey. You need to take care of yourself, and ask for extra support as you need it. Adjust your commitments to account for the time and energy it takes to go through treatment. There is nothing wrong in asking for help. It simply reflects how much a cancer diagnosis demands.

The **Princess Margaret Patient & Family Library** has many resources and information. Learn about rides to appointments by the Canadian Cancer Society, or free childcare at the Princess Margaret Cancer Centre during your appointments.

Waiting for Results

At different stages in your cancer journey, you may have to wait to hear the results of a test. It could be a blood test, CT scan, x-ray, biopsy, MRI, or one of many other tests used to detect and monitor your cancer and the side effects of treatment. This waiting period can be very hard. Some patients refer to this feeling as "scanxiety," a blend of the words "scan" and "anxiety."

"Scanxiety" is a very real and very normal feeling. You may notice that the feeling changes based on the type of results you are waiting for. If you are just being diagnosed, you may fear the unknown. This fear may be greater if you do not know about treatment options or how brain metastases may affect your life.

During treatment, you may worry about test results that tell you if your treatment is working or not. After treatment, your concerns may focus on cancer coming back or side effects. These results can often have a big impact on you. This includes the chance of celebrating remission (that your cancer has gone away) or the relief of knowing what is causing symptoms.

In any case, waiting for results can be a hard time for many people. You may find that the following tips help:

1. Acknowledge your "scanxiety"

- ✓ Notice your feelings. Sometimes, trying to ignore your feelings takes more energy than being aware of your feelings.
- ✓ Try talking to a friend or family member who listens well. They may feel anxious too, and relieved that you are talking about it.
- ✓ You may want to write in a journal instead of talking about your "scanxiety." This way you can express your thoughts without having to go anywhere or share them with anyone.

- ✓ Talk to counsellors, social workers or support groups about how you are feeling.

2. Prepare for getting your results

- ✓ Mark on your calendar when you expect to get your results. Note if you will get them by phone or in a follow-up appointment with your doctor. This gives you something to focus on. If you are not sure when or how you will get your results, ask your doctor or nurse.

  You can also see your results online on the myUHN Patient Portal. myUHN is a secure website for patients of University Health Network (UHN). The website lets you safely see your appointments and results from all UHN sites as soon as they are ready. To see your results on myUHN Patient Portal:

  - Ask for a registration code when you check in for your next appointment
  - Call myUHN Support at 416 340 3777

  Read more about myUHN on page 15 of this Guide Book.

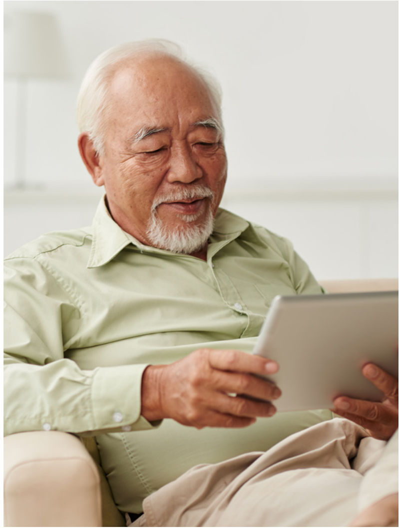
- ✓ Prepare a list of questions that you think you may have when you get your results. What information do you need? Try to remember what you needed to know the last time you got a result. This can help you make sure you find out this time.

- ✓ Think about who you want with you when you receive your results. Would you like to bring a friend or family member? What would you like them to do to help out? For example, they could:

  - Give you a ride to the appointment
  - Write questions and answers down
  - Give you some time to process the results you receive

  Make sure you tell your family and friends what you need. Understand that they may need to seek support too.

3. Do what has helped you before



- ✓ It may help to keep busy with work or other activities while you are waiting. Try and plan to have something to do during this time.
- ✓ It can be hard to sleep while you are waiting for results. Speak to your primary care provider (family doctor or nurse practitioner) if it is hard to get enough sleep.
- ✓ "Scanxiety" can make it hard to focus on work or other things. Do what works best for you during this time. Care for yourself as much as possible. Caring for yourself can include:
    - Getting more rest
    - Light exercise
    - Talking or writing about how you are feeling
    - Seeing a show
    - Listening to music
    - Reading
    - Sharing a laugh
    - Watching a game with friends
    - Whatever you like best
- ✓ Think about what has worked for you before while waiting for something important, or ask others for ideas.

As tough as the waiting period can be, the results will come. In the meantime, help yourself get through the waiting the best way you can. It may help to:

- ✓ Notice and accept your feelings
- ✓ Prepare for the results
- ✓ Use coping methods that have worked in the past
- ✓ Try new ways to deal with the wait

Managing Side Effects

Treatment for brain metastases can cause side effects. There is much that you can do to manage your side effects while you are getting treatment. Ways that you can manage side effects include things like:

- Drinking water to stay hydrated
- Being sure to eat enough to keep up your strength
- Noticing symptoms to report to your cancer care team

Managing Side Effects

You may be dealing with physical side effects of your cancer or treatment. You may be feeling emotions that you are unsure how to handle. Be aware of any physical issues you have and note how your emotions and feelings change over time.

Keeping track of how you feel helps you and your Brain Metastases Clinic care team notice patterns. This helps your team know if they should make changes to your treatment or do something to reduce side effects. It is also good to track how you are feeling over time. This way, you can let your Brain Metastases Clinic care team know if any conditions worsen or improve. The Cancer Journey Planner includes a Side Effects Tracker (page 63) to help you track your side effects.

Common Side Effects

You may notice some changes with yourself when you are first diagnosed, when you are in treatment or when you finish treatment. You may have physical side effects of your cancer and its treatment. You may also have emotions that you do not know how to handle. It is important to be aware of and monitor any physical or emotional issues you have. This section is about how to manage your physical and emotional health. It may help you to track how your side effects change over time.

Some common side effects of brain metastases include:

1. Confusion and memory loss/cognitive decline
2. Dizziness, balance, boordination
3. Headaches
4. Vision changes

If you notice any new or different symptoms, tell your oncologist as soon as possible. Attend all of your scheduled check-ups. This is to make sure that your oncologist is aware of any changes that may be related to your cancer.

Confusion and Memory Loss / Cognitive Decline

Many patients with brain metastases notice changes in their thinking, memory, and attention. These are known as cognitive changes.

Some common cognitive changes can affect your ability to:

- Focus on tasks such as reading or writing
- Pay attention for long periods of time
- Remember details such as names, dates, and phone numbers
- Understand what other people say
- Multitask (doing more than one thing at a time)
- Problem solve
- Remember what you want to tell someone

You may also:

- Feel lost or confused
- Have mood changes and mood swings
- Have trouble wanting to do things
- Feel upset about changes to your memory and thinking

What causes cognitive changes in brain metastases patients?

Cognitive changes are different for every patient. These changes may be caused by:

- The brain metastases themselves
- Treatments for the cancer and the brain metastases
- Medicines for cancer and non-cancer related medical problems
- Medicines for sleep or pain
- Stress about your cancer diagnosis
- Pain
- Lack of sleep

- Dehydration (when you don't drink enough water)
- Other changes to your body from cancer
- Lack of proper nutrition (diet and food)

Some patients will have more cognitive changes than others. Some patients will have more or less severe symptoms than others. This depends on many things, including:

- Your age
- The type of cancer you have
- The treatment you had
- The number, location, and size of your brain metastases
- Hormone changes (such as menopause – changes women go through when they stop having a period)
- Stress levels
- Sleep and being tired
- Mood troubles such as anxiety and depression

What can I do to manage my cognitive changes?

These tips may help you manage your symptoms:

✓ **Use calendars.** Use an agenda or day planner to keep track of things you want to remember. These may include dates and names. You can also use the calendar on your phone so you do not forget appointments and events.

✓ **Use sticky-notes.** Use sticky notes as reminders of things you need to do. Put them in places that you see often, like on your fridge.

✓ **Use electronic reminders.** Use your cell phone or iPad to remind you of things. You can set alarms for things you want to remember.

✓ **Take a picture.** Use your phone or camera to take a picture of what you need to remember. For example, take a picture of the sign showing where your car is parked.

- ✓ **Use GPS, maps, or directions.** Use GPS systems on your phone or in your car. This can help you know where to drive or walk.
- ✓ **Create regular routines.** Keep your routine the same every day or every week. This makes it less likely that you will forget something.
- ✓ **Return things to their proper place when you are finished using them.** For example, put your keys, phone and wallet in the same place every day. This will make it easier to find it when you need them.
- ✓ **Repeat.** Say things you want to remember silently or out loud. Ask people to repeat what they say to you. Hearing things more than once can help you remember them.
- ✓ **Write in your journal or diary before you go to sleep.** Include details you might want to remember in the future.
- ✓ **Relate new information to yourself or things you already know.** This might help you remember it later. For example, if you meet a new person, think of someone you know with the same name.
- ✓ **Avoid multitasking.** complete one task before starting another. It is easier to focus when you only do one thing at a time.
- ✓ **Give yourself extra time to do tasks.**
- ✓ **Stay active.** Do physical, social, and mental activities. These can help you feel better and have more energy.

  Examples of activities include:

  - Crossword puzzles
  - Painting
  - Playing music
  - Talking to friends.
- ✓ **Eat healthy meals.** Eat a balanced diet of fruits, vegetables, proteins, and grains. Your doctor can also send you to a dietitian for more information.
- ✓ **Stay hydrated.** Drink plenty of fluids, especially water.

- ✓ **Get enough sleep.** Try these tips to improve your sleep quality:
  - Go to bed and wake up at the same time every day.
  - Avoid electronic screens at least 1 hour before bedtime. Bright lights from screens can make it harder to fall asleep.
  - Talk to your doctor if you are having trouble sleeping.
- ✓ **Keep yourself well rested.** Cognitive changes can be worse when you are fatigued (when you have low energy) or stressed.
- ✓ **Reduce your stress.** Stress causes mental fatigue. Here are some things you can do to reduce stress:
  - Practice regular “breath” breaks. Take a few slow and deep breaths when you feel stressed.
  - Practice mindfulness – you can find mindfulness exercises and apps online. Mindfulness is a practice that helps you be calmer.
- ✓ **Reduce noise.** Noise can make it hard to pay attention. Try to make your spaces quiet. For example, turn the TV off when reading or talking.

Keep yourself safe when you have cognitive changes

Confusion, memory loss, and stress can cause safety concerns. For example, you can put yourself in danger if you forget to turn off your stove. The tips below can help you stay safe at home.

1. **Use timers.** Always use cooking timers when using the oven or stove. This will help you remember to turn them off. You can also set an alarm at bedtime to check that your doors are locked.
2. **Take your medicines safely.** When you have cognitive changes, it can be hard to remember to take your medicines at the right time. It can also be hard to remember what you talk about with your doctor. Here are tips to help you:
   - ✓ **Use your phone calendar.** Set a daily alarm in your phone calendar. Setting a daily alarm can help you remember to take your medicines.

- ✓ **Keep track of your medicines.** Ask your pharmacist to put your medicines in a blister pack. A blister pack puts your pills in small containers for each dose. It shows you what day and time to take your medicine. You can also buy a pill sorter at the drug store. You or a family member can put your pills in the sorter each week.
- ✓ **Write things down.** Keep track of questions you want to ask your doctor during your appointment. Write down the answers during your appointment. Also write down anything they teach you.
- ✓ **Involve family and friends.** Bring a friend or family member to your appointments. Your friend or family member can help you remember what is said at appointments.
- ✓ **Use a recording device.** Use your phone or a sound recorder to record medical information.
- ✓ **Talk to your doctor if you have questions about cognitive changes.** You doctor can help you manage these changes at home.

Dizziness, Balance, Coordination

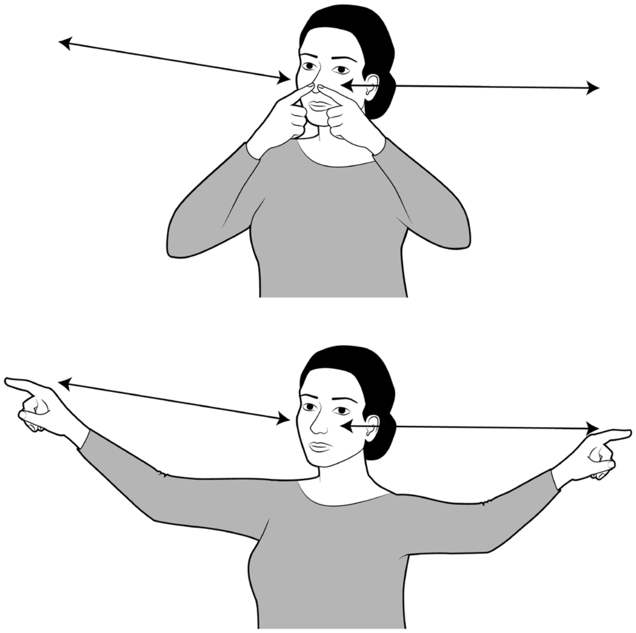
What is balance and coordination?

What is balance?

Balance means that you are able to stay upright. Our body depends on balance to stand, sit, and walk without falling over.

What is coordination?

Coordination means that you are able to use different parts of your body together. An example of coordination is the finger to nose test. To do this test, stretch your arms out to your sides. Touch your nose with the tip of your index finger. See the image on the next page on how to do the test.



How does the body maintain balance and coordination?

Many parts of the body are involved in balance and coordination. One example is the cerebellum. The cerebellum is a small part of the brain that plays an important role in balance and coordination.

The cerebellum receives information about where and how your body is moving. The cerebellum gets this information from your:

- Ears
- Eyes
- Arms
- Legs

The cerebellum then tells your muscles to work together. When your muscles work together, you stay balanced and coordinated. Other parts of the body that are involved in balance and coordination are the inner ear and spinal cord.

How does cancer cause balance and coordination problems?

What are balance problems?

Balance problems may cause you to feel unsteady or dizzy. You may notice this more when you stand or walk. If you have balance problems, you may:

- Fall or feel as if you are going to fall
- Stumble when you walk
- Feel light-headed or faint
- Feel as if the room is spinning
- Become confused

What are coordination problems?

Coordination problems mean it is hard for you to move the way you want. Some doctors might call this “cerebellar ataxia”. If you have coordination problems, you may:

- Stumble when you try to walk
- Have trouble with tasks such as writing or buttoning a shirt
- Have trouble with eating or swallowing
- Slur your speech

How do brain metastases affect balance and coordination?

Brain metastases can affect balance and coordination if they damage the cerebellum. The damage may be caused by the brain metastases themselves. For example, tumours may press upon the cerebellum. Or, the damage may be caused by cancer treatments, such as chemotherapy or radiation.

There are other causes of balance and coordination problems in cancer patients. For example, you may have dizziness as a side effect from medicines.

Another cause of balance and coordination problems is vomiting (throwing up) and diarrhea (loose, watery poo). This is because vomiting and diarrhea can cause you to become dehydrated. Dehydrated means that your body loses more water than it takes in. Being dehydrated can cause you to feel dizzy and unbalanced.

Other causes of balance and coordination problems include anemia (a low number of red blood cells) and low blood pressure.

Why is it important to manage balance and coordination problems?

The biggest concern for patients with balance problems is that they may trip or fall. Falling can lead to serious injuries, such as bone fractures or head injuries. Balance and coordination problems may also make it hard to perform everyday activities such as:

- Walking
- Eating
- Picking up objects

Patients may simply dislike feeling dizzy or unsteady.

What can I do to manage balance and coordination problems?

There are many steps that you can take to manage balance and coordination problems:

1. Move slowly and carefully.

Stand up slowly. This includes when you get up from a chair, couch, or bed. If you move too quickly, you can become dizzy.

2. Make changes to your home to prevent falls.

Below are things you can do to prevent falls in your home:

- ✓ **Wear proper footwear.** The best footwear is non-skid, rubber-soled shoes. Avoid wearing only socks on smooth surfaces such as wood floors or tile.
- ✓ **Remove clutter from the ground.** If you have an area rug, remove it or tape down the edges.

- ✓ **Use the handrails when climbing stairs.**
- ✓ **Install grab bars by the toilet and bathtub.** Grab bars will help you sit and stand safely.
- ✓ **Make sure there is good lighting in your home.**
- ✓ **Keep supplies in places that are easy to reach.** Reaching for objects may cause you to fall.
- ✓ **Ask for help with tasks that are not easy for you to complete.** For example, ask for help when changing lightbulbs.

3. Review your medicine list with your doctor or pharmacist.

Some medicines can cause you to feel dizzy. You should review your current medicines with your doctor. Your doctor may be able to make changes to make you feel less dizzy. For example, your doctor may change the dose or type of medicine.

4. Drink lots of liquids.

Drink at least 6 cups of liquid each day. The best liquid to drink is water. If you need to, you can drink:

- Milk
- Fruit juice
- Vegetable juice
- Soft drinks
- Broth and soups
- Sports drinks
- Tea
- Coffee

Avoid too many drinks with caffeine (coffee, tea, or energy drinks). Drinking liquids will prevent you from being dehydrated. Being dehydrated can cause you to feel dizzy.

Drinking liquids is more important if you have diarrhea or vomiting. This is because diarrhea and vomiting cause you to lose more water and become dehydrated.

5. Limit how much alcohol you drink

Limit the amount of alcohol you drink. Alcohol causes dehydration. Alcohol can also make balance and coordination worse. Alcohol affects the cerebellum and can increase the side effects of your medicines.

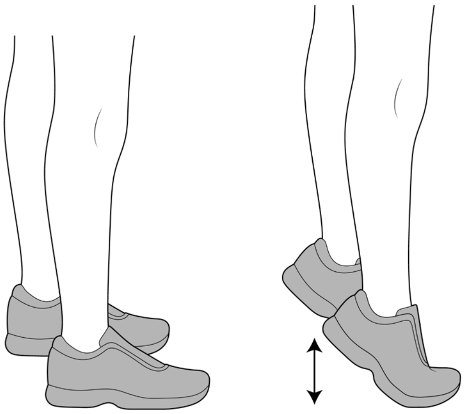
6. Check your vision and hearing often

Make sure your glasses and hearing aids are up-to-date. You are less likely to fall when you can see and hear well.

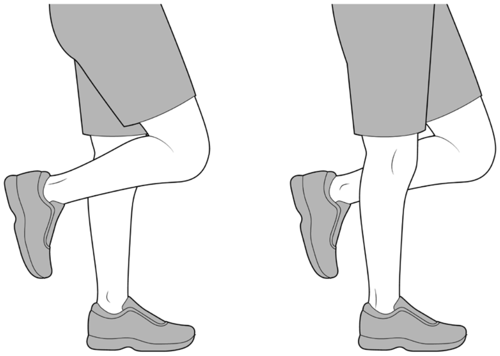
7. Do exercises to improve balance

Perform exercises that make your stomach, back, and pelvic muscles stronger. These exercises will improve balance and are simple enough to do in your home. While doing these exercises, make sure that you keep a steady support nearby like a counter top or chair. Wear proper footwear. For some balance exercises that you can perform at home, see pages 46-48. Look at the images to see how to do the exercises.

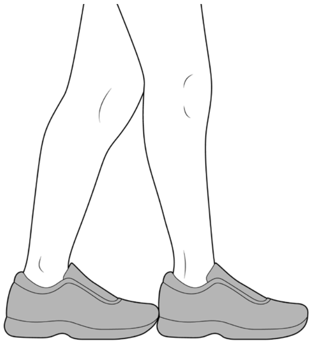
- **Calf raises:** Stand in place and slowly raise both heels up. You should be on your tiptoes. Lower your heels and repeat.



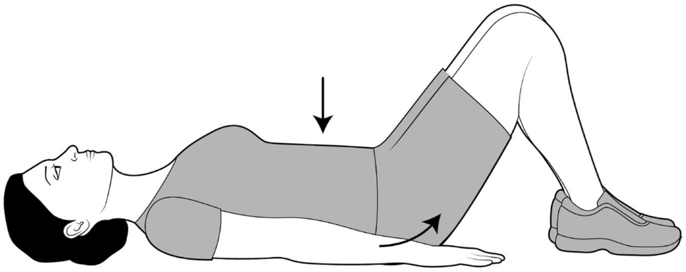
- **Single leg stand:** Stand on one foot for 5–10 seconds, then switch legs.



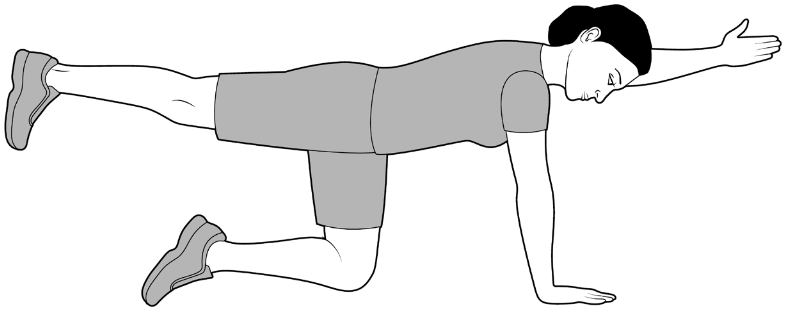
- **Tandem stand:** Put the heel of one foot in front of the toes of the other foot. This should look like you are walking on a tight rope. Hold for 10 seconds then repeat on the other foot.



- **Pelvic tilt:** Lie on your back with your knees bent. Your feet should be flat on the floor. Tighten the muscles in your stomach so that your back becomes flat. This will tilt your pelvis up slightly. Hold for 10 seconds. Relax your stomach muscles then repeat the exercise.



- **Bird-dog:** Start with your hands and knees on the floor. You should look like you're crawling. Place your knees hip-width apart and your hands under your shoulders. Extend one leg with both hands on the floor. Once balanced, slowly extend the arm on the opposite side. Hold for 10 seconds. Return to the starting position. Then extend the other leg and arm. Hold for 10 seconds.



Meet with a physiotherapist before you try these exercises. A physiotherapist is someone who uses physical methods (massage, heat, or exercise) to treat health problems.

A physiotherapist can plan the best exercises for you. This may include resistance training, such as weight lifting, to improve muscle and bone strength.

Other activities, such as yoga and tai chi, have also been shown to improve balance. You can ask your doctor for a referral to a physiotherapist.

8. Use a mobility aid

A mobility aid is a device designed to help you walk or move around such as a cane, walker, or crutches. Mobility aids provide a wider support base to help you stay stable and balanced. A physiotherapist or occupational therapist can help you choose the right mobility aid and learn how to use it. An occupational therapist is someone who helps you perform daily activities.

When you purchase a mobility aid, make sure that it is the correct height. When you are standing up straight, your walker hand grip should line up with the crease in your wrist. The mobility aid should also have a rubber tip to prevent slipping.

9. Eat a healthy diet

Ensure that you are eating three healthy meals each day. Include foods that contain calcium and vitamin D. Foods with calcium and vitamin D include:

- Cheese
- Milk
- Yogurt
- Eggs
- Leafy green vegetables
- Fatty fish (tuna, mackerel, and salmon)

Foods that contain calcium and vitamin D help keep your bones strong. Strong bones prevent fractures in case you fall. Avoid skipping meals. If you skip meals, your blood sugar level may become low, leading to dizziness and falls.

10. Take medicines to reduce dizziness

Your doctor may be able to suggest medicines to reduce dizziness. Some medicines will require a prescription (medicines ordered by a doctor) and some will not. Talk to your doctor before you begin to take a new medicine, even if it does not need a prescription.

When should I talk to my health care team?

If you notice any of the symptoms (signs) below in between your clinic visits, call the Brain Metastases Clinic at: 416 946 4501 ext. 6325:

- Severe (very bad) headaches that do not go away with medicines

- Changes to your vision or eyesight (such as seeing double or blurry vision)
- Increased confusion (you cannot think as clearly or quickly as normal)
- Weakness in your arms or legs

Call 911 or go to the nearest hospital emergency department right away if you have any of these signs:

- Loss of consciousness ("passing out")
- Uncontrolled seizures (muscle spasms)

Headaches

Why do brain metastases patients get headaches?

Patients with brain metastases can get headaches because the tumour causes pressure on the brain. Headaches may also be a side effect of treatments for brain metastases. Treatments include surgery or radiotherapy.

Other factors can cause or make headaches worse in patients with brain metastases. These factors include:

- Stress
- Anxiety
- Dehydration (when your body does not have enough water)
- Lack of sleep

Note: if a headache lasts for more than 1 day or gets worse despite treatment, call the Brain Metastases Clinic right away at: 416 946 4501 ext. 6325.

What to keep track of when you have a headache

Headaches can vary. Keep track of the following in the Side Effects Tracker of your planner (page 63) so your doctor can better understand your headaches:

1. **Timing** – when during the day the headache develops.
2. **Frequency** – how often the headaches occur. Headaches can occur every day or a few times a week.
3. **Duration** – how long the headache lasts. It may range from minutes to hours to days. Some headaches start and end very quickly. Others come and go over many hours or days.
4. **Location** – the place where the pain occurs. For example, you may feel pain over the eyes, your forehead, at the back of your neck, or on one side of your head.
5. **Severity** – the level of pain you feel. Pain can be mild, moderate or severe.
6. **Quality** – the type of pain. It can be a dull pain or a stabbing pain.
7. **Other symptoms** – some patients may feel other symptoms with their headache. These other symptoms include:
    - Nausea (feeling like you will throw up)
    - Vomiting (throwing up)
    - Dizziness
    - Blurry vision
    - Being sensitive to light or noise

If you have any of these symptoms, call the Brain Metastases Clinic right away at: 416 946 4501 ext. 6325.

What are some treatment options?

Treatment for headaches caused by brain metastases may include non-medical treatments such as rest and keeping a healthy lifestyle.

You may also get over-the-counter (OTC) medicines to manage your headaches. Talk to your doctor first before taking OTC medications.

Some OTC medicines can reduce the pain you may feel. Medicines that can reduce pain are called analgesics.

Analgesics include: acetaminophen (Tylenol) and non-steroidal anti-inflammatory drugs (NSAIDs) like ibuprofen (Advil). Ask your doctor what medicine you can take. Also, tell your doctor about any OTC pain medicine you take for your headaches.

Some headaches caused by brain metastases need treatments that only your doctor can give you. These are options that you can discuss with your doctor.

Contact the Brain Metastases Clinic right away if:

- Your headache lasts for more than 1 day
- Your headache gets worse even after taking analgesics
- You have other symptoms like nausea (feeling like you need to throw up), vomiting (throwing up), dizziness, blurry vision, or being sensitive to light or noise

Brain Metastases Clinic: 416 946 4501 ext. 6325

Vision Changes

Some people may never notice symptoms or have any vision changes.

Lack of symptoms or vision problems may be because the tumour is:

- Very small
- Far away from the part of the brain that controls vision

The only way to know how much your cancer has spread is by having imaging tests.

The vision changes you have will depend on where the tumour is in your brain. Different parts of the brain control different functions. For this reason, not all tumours affect vision. Most patients with brain metastases will never have vision changes.

There are two main types of possible vision changes from brain metastases:

1. Double Vision

Double vision is seeing two objects when you should only be seeing one. With normal vision, images from both eyes are joined to form one image.

Your eyes have many nerves. These nerves tell muscles to look in the direction you want. They also make sure both your eyes work together as a team.

Brain metastases can create problems in these nerves or muscles. Problems with nerves or muscles means that your eyes may not work well with each other. If your eyes do not work with each other, you might see two images instead of one.

Brain metastases might also increase the pressure inside your head. Increased pressure can lead to double vision. If you notice a headache and vision symptoms, see your doctor right away.

Double vision can also occur if cancer spreads to the brainstem (an area just below your brain). The brainstem is joined to nerves that control eye movement.

2. Vision Loss

Vision loss can be:

- Partial: affects only one eye or some parts of vision in both eyes
- Complete: affects both eyes

With partial vision loss, you may not see objects on one side of your body. For example, you might start bumping into objects a lot.

With complete vision loss, you will not be able to see at all. This is very rare in patients with brain metastases.

What do I do if I have vision changes?

If you start having vision changes, here are some things you can do to keep yourself and others safe:

- Avoid driving
- Get help when climbing stairs
- Be careful when using sharp objects like knives
- Use good lighting at home
- Remove small rugs that may make you trip
- Use magnifying mirrors when shaving to avoid cutting yourself

When you start having vision changes, see your doctor.

Symptom Relief: Double Vision

Medicine or surgery can improve double vision. Here are a few options that might help your double vision get better:

1. Wear an eyepatch: Sometimes double vision gets better by covering one eye. This means your brain will only see one image instead of two. Try covering each eye with your hand. If this helps your double vision, you can use an eyepatch.

2. Prism glasses: Double vision is mild if the images are seen very close together. If you have only a little double vision, you can try wearing glasses with special prisms. These can be put into your current glasses, or you can buy new glasses with prisms.

Your vision changes may also take time to improve. There is also a chance your vision changes will not improve. Your doctor will support you, and can answer your questions.

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:

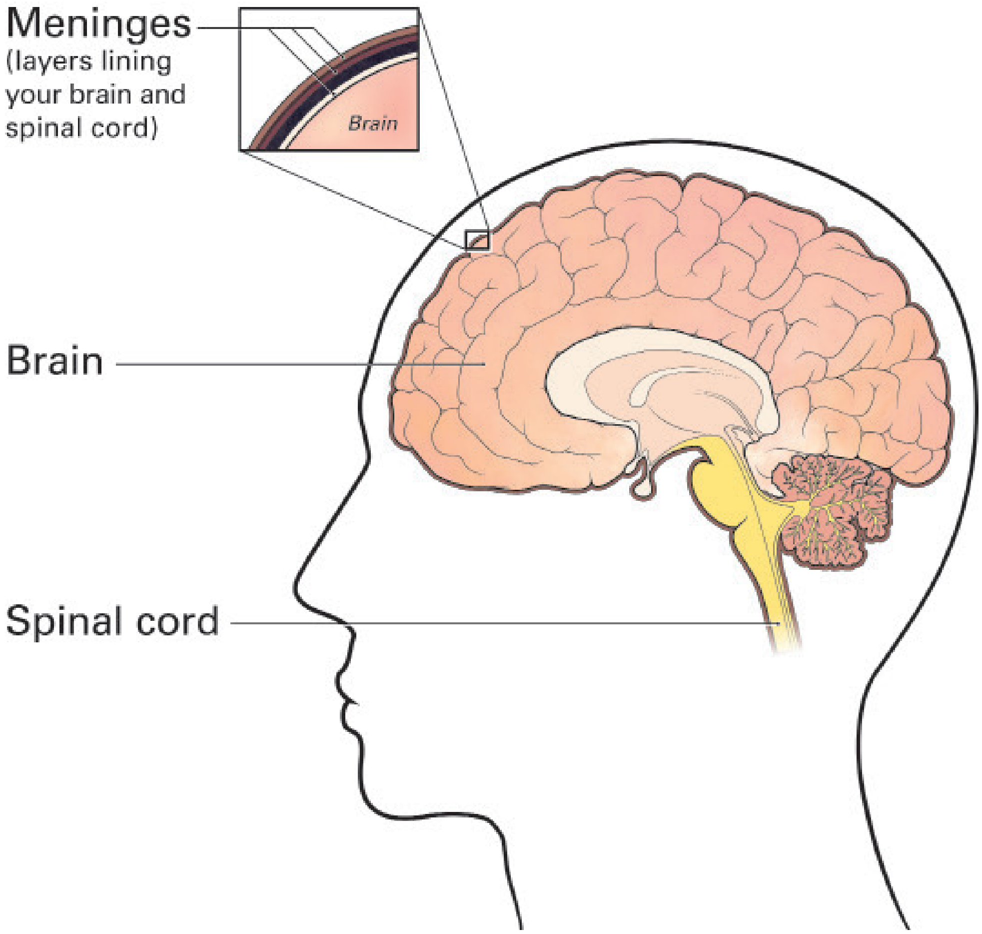
- Carcinoma meningitis
- Leptomeningeal carcinomatosis
- Leptomeningeal metastases
- Meningeal carcinomatosis
- Meningeal metastases
- Neoplastic meningitis

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?

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:

1. Intercranial hypertension (pressure around the brain):

- Nausea
- Headaches
- Confusion
- Seizures (uncontrolled muscle spasms)

- Sleepiness
- Lethargy (extreme lack of energy)

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

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

3. Focal neurologic (problems with nerves in the spinal cord or brain. Symptoms will depend on the area of the brain affected):

- Numbness on the face
- 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.

What are the diagnostic tests for leptomeningeal 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 leptomeningeal 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 leptomeningeal 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 below.

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.

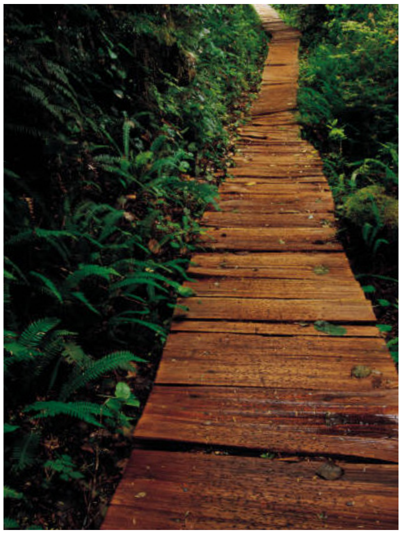
Psychosocial Oncology Clinic Princess Margaret Cancer Centre – 16th floor
Phone: 416 946 4525

Spiritual Care Professional Page us at: 416 719 1234 between 8:30 am to 11:00 pm.

For more information, contact the Patient & Family Library at Princess Margaret Cancer Centre – Phone: 416 946 4501 ext. 5383.

After Treatment

The effects of your treatment can last long after the treatment has finished. This section contains information on how to get the best care possible after you have finished treatment.



Charting Your Course: Seeking Information

Some people who have been through cancer treatment feel like they cannot get enough information. After their treatment is over, they have time to think. They often have questions about what has happened to them. On the other hand, some people would rather not focus on what has happened. They prefer to let their cancer care team advise them as needed.

Follow-Up Appointments

After your treatment, you will return to the Princess Margaret's Brain Metastases Clinic for your follow-up. The first follow up visit takes place 3 to 4 months after you finish treatment. You may see a different doctor (member of the team) at each appointment.

Your follow-up visits will include:

- Brain imaging (pictures of the brain), usually an MRI. If you cannot have an MRI (for example if you have metal inside your body) you will be given a CT scan
- Clinic appointments to meet with your radiation oncologist and/or neurosurgeon

You will get a letter in the mail with the appointment for your MRI or CT scan. Brain imaging is sometimes booked after your clinic appointment. If this happens, call 416 946 2130 to change your appointment for after the MRI or CT has been done. This is needed because the doctors need to see the MRI or CT pictures to know if the treatment is working.

You will have follow up appointments every 3 months. The decision of how often to schedule follow up appointments is based on your symptoms and health status.

If you live far away from Princess Margaret, your doctors here can work with your local doctors to arrange for follow-up imaging (MRI or CT) closer to home.

How to book follow-up appointments

Your clinic visits will be set up in person at the Princess Margaret Cancer Centre. If you live far away or have trouble getting to the hospital, your visits can be booked through TeleHealth Ontario. TeleHealth Ontario is a free phone service run by the Government of Ontario. This allows you to talk to the doctor in the Brain Metastases Clinic about:

- How you are feeling
- The results of your brain imaging
- Any issues that may have occurred

If you have questions about your treatment schedule/ appointments, please contact:

Brain Metastases Clinic Coordinator

- **Phone:** 416 946 2130
- **Email:** brainmetsclinic@rmp.uhn.on.ca
- **Hours:** 9 am to 5 pm, Monday to Friday

When should I call the Brain Metastases Clinic between clinic visits?

Call the clinic nurse or see your family doctor if you have:

- Severe (very bad) headaches that do not go away with medicines
- Changes to your vision or eyesight (such as seeing double or blurry vision)
- Increased confusion (you cannot think as clearly or quickly as normal)
- Weakness in your arms or legs

These may not be signs of an emergency, but you will need to tell your health care team about them. The clinic nurse can be reached at 416 946 4501 extension 6325. If you are unable to speak with the clinic nurse, call the clinic coordinator and tell them about your symptoms: 416 946 2130.

Call 911 or go to the nearest emergency department if you have any of the following:

- Loss of consciousness (fainting, not being able to wake up)
- Seizures (muscle spasms that you cannot control, smelling strange things, seeing or hearing things, brief moments when you black out)

These are signs of an emergency, and you will need help from a doctor or nurse to help manage them. Tell the hospital staff at the front desk that you (or your loved one) is getting treatment for brain metastases. Do not call TeleHealth during an emergency. Do not come to Princess Margaret Cancer Centre since there is no emergency department.

After Treatment Questions

You may have many questions about life after cancer treatment. You may have questions about:

- How to deal with your emotions
- Diet and exercise
- Practical issues such as going back to work
- What type of follow-up I will receive
- What kind of side effects I may experience and how to manage them

You will need to work with your Brain Metastases Clinic care team to find answers to these questions. Remember: no question is silly or not important.

Below are some sample questions to ask your Brain Metastases Clinic care team.* These questions can help you to know what you can expect once cancer treatment ends.

What treatments and medicines have I been given?

Ask your oncologist to provide a written record of:

- The type of cancer you had
- The treatments and medicines you had
- The side effects of these treatments

You can record this information in your **Cancer Journey Planner.**

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*From the Institute of Medicine of the National Academies: “Cancer Survivorship Care Planning”, Fact Sheet November 2005.

Do I need any follow-up care?

Ask for a schedule of when you should follow up with your Brain Metastases Clinic care team and what tests or scans (for example, MRI) need to be done before your appointment. Add these dates to your calendar to remind yourself about follow-up care.

Will I get brain metastases again?

Ask your Brain Metastases Clinic care team about the possibility of getting a new brain metastases after your initial treatment or recurrence of previously treated brain metastases. What signs or symptoms should you look for?

Because you may be at risk for new brain metastases, your team will continue to monitor you with scans and follow up visits after your treatment.

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

Funding for this resource is from the
**Robert & Andrée Rhéaume Fitzhenry
Brain Metastases Program.**