Manage Brain Metastases: A Guide Through Treatment and Beyond

For patients and families living with brain metastases

In this resource you will learn:

• who is part of your care team
• what to expect during treatment
• what to expect after treatment
Members of your care team
The Brain Metastases Clinic (sometimes called the Brain Mets Clinic) includes many people working together with you. The Brain Mets Clinic has a team approach. This means that you will speak with different health care professionals each time you visit. Each of the health care professionals will know about your medical history. Read the information below to learn about the team members involved in your care.

Nurse
A nurse cares for people who are sick. The clinic nurse will help to plan and manage your care. They can also show you more resources that may be helpful for you. If you have questions or new symptoms, call your nurse: 416 946 4501 ext. 6325.

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 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 medications to treat cancer. You will likely be seeing a medical oncologist to treat your primary cancer (the cancer that the brain metastases came from). Medical oncologists are not part of the Brian Mets Clinic but are in contact with your Brain Mets 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.

Physician Assistant
A physician assistant (PA) is an advanced health care practitioner who provides direct patient care under the supervision of a physician. The clinic PA takes your medical history, does physical examinations, orders and interprets tests, diagnoses and treats your condition.

Treatment of Brain Metastases

Stereotactic radiosurgery (also called Gamma Knife)
Stereotactic radiosurgery is radiation to certain parts of the brain. This is done using a machine called a Gamma Knife Unit.
Why is stereotactic radiosurgery done?
Stereotactic radiosurgery may be given to you to treat:
• brain metastases directly
• an area where surgery was done

Stereotactic radiosurgery may be a treatment option for you if:
• you have a few small brain metastases
• you have had a tumour surgically removed from your brain

How long is the treatment?
Radiosurgery takes place in 1 to 5 sessions. The length of the treatment depends on the size and number of metastases. It can take 1 to 3 hours.

You will have an MRI scan (detailed image of the brain) before the surgery to help your doctors plan your treatment. This may occur on the same day as your initial appointment. On the day of your surgery, the following will happen:

1. You are given a local anesthetic (shots of medication that numb part of your scalp). This makes the frame placement more comfortable.
2. Once your scalp is numb, a metal frame is attached to your head with pins.
   • The frame is used to make sure your head stays still during treatment.
3. You have a CT scan to help your doctors plan your treatment.

4. You have the radiosurgery.
   • Radiosurgery is done with a machine called a “Gamma Knife”. This special machine provides treatment to the tumours in your brain.
   • You will be awake during radiosurgery. A metal frame is placed onto your head to make sure the radiation treatment is sent to the right part of the brain.
   • You are given a local anesthetic to numb the areas where the frame is placed. Sometimes this metal frame is not needed. Instead you will wear a mask to keep your head in the same spot.

   Watch videos about frame and mask-based treatments on the Brain Mets website: https://wwwuhn.ca/PrincessMargaret/Clinics/BrainMetastasis#tab5

What are possible side effects?
   • Fatigue (a feeling of tiredness that does not go away with sleep)
   • Headaches
   • Bleeding or bruising around your head where the frame is attached
   • Radiation necrosis. This happens when tissue around the treatment area is destroyed. This can cause swelling in the brain for 6 to 18 months after surgery
Whole brain radiation
Treatment with high energy x-rays that are given with a machine. It directs radiation at the whole brain.

Why is whole brain radiation done?
Whole brain radiation may be done to reduce:

• the chance of getting new brain metastases
• the growth of current brain metastases

Whole brain radiation may be an option for you if:

• you have a large number of brain metastases
• a large tumour cannot be removed with surgery or treated with radiosurgery

How long is the treatment?
Whole brain radiation is given daily for 5 to 14 days. Each treatment session takes 15 to 30 minutes. Before your first radiation treatment, you will have an appointment.

During this appointment, your health care team:

• creates a mask that keeps your head in the same place during each treatment visit
• gives you a CT scan of your brain while wearing the mask to plan your treatment
What are possible side effects?

- Fatigue (a feeling of tiredness that does not go away with sleep)
- Nausea (feeling like you are going to throw up)
- Vomiting (throwing up)
- Headache
- Feeling like your ears are plugged
- An increase in your initial symptoms
- Hair loss
- Skin redness or darkening where the radiation was given
- Loss of short-term memory

Surgery

Surgery is a type of treatment that removes part of the tumour (biopsy) or the entire tumour(s) (tumour removal) from the brain.

Why is surgery done?

- Biopsy: a biopsy is done when doctors are not sure if you have brain metastases. The neurosurgeon will remove part of the tumour so that it can be studied
- Tumour removal: this is done to relieve symptoms the tumour may be causing

Tumour removal is an option when:

- there is 1, large tumour in a place in the brain where it is safe to operate
- there are many tumours, but taking out one tumour may help relieve your symptoms
- a tumour that was first treated with radiation keeps growing and needs to be removed
How long is the treatment?
The length of the surgery depends on where the tumour is in the brain. Before having surgery, you will meet with:

- a neurosurgeon (does the surgery)
- an anesthesiologist (doctor who keeps you relaxed and asleep with medicine during surgery)

Medical therapies
Medical therapies include medications that are given to you to help with your symptoms.

Dexamethasone
A medication used to decrease the swelling and pain caused by brain metastases. The amount of dexamethasone given to you by a doctor is often changed over time to manage your symptoms.

Side effects you may notice right away include: Trouble sleeping, desire to eat more, mood changes, weight gain and high blood sugar.

Side effects you may develop after taking dexamethasone for many weeks:

- muscle weakness
- thin skin and acne-type rash
- bone thinning
Anti-seizure medications
These medications are used to help prevent seizures. Seizures are muscle spasms that you cannot control. During a seizure, you may also:

- smell strange things
- see or hear things
- have brief moments when you black out

Common anti-seizure medications include:

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

Side effects will depend on the medication used and the dose. Some common side effects include:

- nausea and vomiting
- skin rashes
- fatigue (a feeling of tiredness that does not go away with sleep)
- feeling dizzy
- problems with memory (when you forget things)
- problems with speech
- liver damage
Anti-nausea medications
These medications are used to lessen the feeling of nausea (feeling like you are going to throw up) and reduce vomiting (throwing up). Common anti-nausea medications used include:

• Gravol
• Ondansetron

Side effects will depend on the medication used and the dose. Possible side effects include:

• fatigue (a feeling of tiredness that does not go away with sleep)
• feeling dizzy
• headache
• dry mouth
• constipation (not pooing enough)
• diarrhea (frequent, watery poo)
• anxiety (feeling nervous)
• mood changes

Clinical trials
Clinical trials use medications or treatments that are new and not yet the standard of care. Doctors are still testing the treatment option to see the benefits and side effects. There may be options for you to take part in clinical trials. Ask a member of your care team if you would like to learn more.
How will my treatment be chosen?
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.

Your health care team will look at:

• 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

What you should ask yourself:

• What treatments am I willing to have?
• What are the goals of this treatment plan?
• How will this treatment affect my current daily life?
• What side effects can I expect from this treatment?
• Is there more information that I would like before I make my decision?
After Treatment

Follow-up appointments

After your treatment, you will return to the Princess Margaret’s Brain Mets 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 2901 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 Mets 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 2901
Email: brainmetsclinic@rmp.uhn.on.ca
Hours: 9:00 am – 5:00 pm Monday to Friday

When should I call the Brain Mets 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 after taking medications
- 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 arm(s) or leg(s)
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 ext. 6325.

If you are unable to speak with the clinic nurse, call the clinic coordinator and tell them about your symptoms: 416 946 2901

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 support person) 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.

Living beyond brain metastases treatment

The goal of treatment for brain metastases is to improve symptoms and prevent problems that can occur due to the growth of tumours in your brain. These treatments can help improve your symptoms. However, you may continue to have some symptoms after the treatment. If this happens you may be referred to a doctor who works in palliative or supportive care to help manage your symptoms.
To know what help is available to you in the hospital and in the community, read the following pamphlets:

- Find Support for Brain Metastases
- Plan your Visits to the Princess Margaret
- Manage Life at Home
- Self-Care for Cancer Patients

See [www.uhnpatIENTeducation.ca](http://www.uhnpatIENTeducation.ca) to read these pamphlets or visit the Princess Margaret Patient and Family Library on the Main Floor of the hospital.