Know About Brain Metastases and Treatment

For patients and families living with brain metastases

Read this resource to learn:

• What are brain metastases .............................................................. 2
• How can the Brain Metastases Clinic help you .............................. 3
• How can brain metastases affect you ............................................ 4
• When to get medical help ............................................................. 8
• Your treatment options ............................................................... 9
• Your follow-up appointments ....................................................... 20
• Who to call for more information ................................................. 22

To learn more about brain metastases and treatment options, visit the Brain Metastases Clinic website: wwwuhnca/PrincessMargaret/PatientsFamilies/Clinics_Tests/Brain_Metastasis
A brain metastasis is a tumour that forms in the brain when cancer cells spread there from another place in the body. For example, if a patient has lung cancer, cancer cells that spread to the brain from the lung(s) are known as brain metastases.

- A single tumour that spreads to the brain is called “metastasis”.
- 2 or more tumours that spread to the brain are called “metastases”.
- Brain metastases are not the same as brain cancers that start in the brain (also called “primary brain cancer”). Treatment for cancer that starts in the brain is different from treatment for brain metastases.

About half of patients who have brain metastases will have more than one tumour in the brain. Most patients who have brain metastases already have a known cancer in another part of their body.

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

- lung
- breast
- melanoma (skin)
- kidney
- colon

When a patient is first told they have cancer, they may have:

- No known brain metastases, or
- One or more brain metastases.

Up to 50% to 80% of people (or 5 to 8 people out of 10) who have cancer that has spread to other parts of the body (like lung, liver, or bone) also have brain metastases.
For a small group of people, brain metastases are how they first find out they have cancer. For an even smaller group of people, the primary tumour (place in the body where the brain metastases have spread from) is never found.

How can the Brain Metastases Clinic help you?

The Princess Margaret Cancer Centre’s Brain Metastases Clinic is a specialized clinic that is focused on helping patients with brain metastases. Your health care team at the clinic will talk to you about treatment options and give you the treatment you need.

Treatment for brain metastases can include many areas of medicine. For this reason, you will meet a few types of health care team members, including:

- neurosurgeons (brain and spine surgeon)
- radiation oncologists (cancer doctor who helps provide radiation treatment)
- nurses
- radiation therapists

Your health care team works with your medical oncologist (cancer doctor) to talk about all of the treatment options for your brain metastases.

Your health care team plans your treatment for brain metastases to work with any other treatments you may be getting.

Your health care team at the Brain Metastases Clinic has a team approach, so you may see different doctors and specialists each time you visit the clinic. But all of the clinic’s doctors will know about your unique case and health history since they review your files as a group before each of your visits.
You may be able to take part in clinical trials for brain metastases. Clinical trials are research studies that look at how safe and helpful new treatments are to use. Ask a member of the clinic’s health care team if you would like more information about clinical trials.

**How can brain metastases affect you?**

In some patients, the diagnosis of brain metastases comes after they get new symptoms (signs) that may mean their cancer has spread to the brain.

In other patients, brain metastases may be found before any symptoms are noticed. This is often due to:

- Imaging tests done for staging purposes (tests that look all over the body to see where cancer may have spread)
- Tests done as patients join clinical trials

Common imaging tests include a:

- CT scan (computed tomography scan)
- MRI scan (magnetic resonance imaging)

Most patients with a known primary tumour will go through imaging tests. Your cancer doctor or cancer care team can often make a diagnosis of brain metastases by looking at the results of your imaging tests.

In some cases, doctors may think they see brain metastases on imaging tests but the patient has never had a diagnosis of cancer before. If this happens, surgery may be needed to remove a sample of brain tissue and test it for cancer cells.
What symptoms (signs) can brain metastases cause?

Symptoms from brain metastases may be due to one or more of these causes:

• pressure on the brain from the tumour, or swelling next to the tumour

• loss of neurological function (control of your body) because brain tissue that has been taken over by the cancer cells is not able to work the way it used to

• seizures (an electrical event causing unnatural movements, or shaking)

• hydrocephalus (fluid build-up within the brain due to blockage of paths to drain it)

Because different parts of the brain control different things, the symptoms (signs) caused by brain metastases depend on where the tumours are and where they are spreading in your brain.

Your brain metastases can cause any of the symptoms below. Based on where the brain metastases are in your brain, you are more likely to have the symptoms that have been checked off below:

 headaches

 nausea (feeling of having to throw up) and vomiting (throwing up) due to increased pressure in the brain

 change in level of consciousness or alertness

 changes in mental function (mood, personality, ability to think clearly)
☐ weakness affecting the part(s) of your body circled below:

☐ changes in your sensation (numbness, tingling) to the part(s) of your body circled below:
Where are your brain metastases located?

The image below lists the many parts of the brain and what they control. Ask your doctor to circle the areas where your brain metastases are. Read to see how they may affect you.
Call the Brain Metastases Clinic Nurse at 416 946 4501, extension 6325 or 2901 if you notice any of the symptoms (signs) below in between your clinic visits:

• severe (very bad) headaches that do not go away with medication
• changes to your vision, or eyesight (such as seeing double or blurry vision)
• increased (more) confusion
• 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.

If you are not able to speak with the Clinic Nurse, call the Clinic Coordinator and tell them about your symptoms: 416 946 4501, extension 2901.

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

• loss of consciousness
• uncontrolled seizures

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 family member) are getting treatment for brain metastases.

Do not call Telehealth during an emergency.

Do not come to the Princess Margaret since it does not have an emergency department.
Your treatment options

The treatment recommended by your health care team is planned just for you. The type of treatment you get is based on:

- the type of primary cancer (place in the body where the brain metastases have spread from) that you have
- the number of brain metastases found
- the size and place of your brain metastases
- the kind of symptoms you have
- how well controlled the primary cancer is in the rest of your body

Treatment can involve one or more of the following:

- surgery to remove tumours
- radiation treatment (to the whole brain)
- radiosurgery (or Gamma Knife)
- medical treatment (like chemotherapy, targeted drugs, immune therapy)

The use of chemotherapy in helping treat brain metastases is changing. New targeted chemotherapy drugs are being made and can be useful in the treatment of some brain metastases.

Read below for more details on each treatment option.
Surgery

Surgery might be an important part of your treatment plan. Surgery may be used to treat brain metastases when:

• The diagnosis of brain metastases is not certain. This means surgery is needed to remove a sample of the tumour for testing.

• A patient has a single, large tumour (about 3 centimetres or larger) in an area where it is safe to remove with surgery.

• A patient has many tumours, but has one (or more) large tumours that may be removed to help improve symptoms.

• A tumour that was first treated with radiation treatment keeps growing.

• “Radiation necrosis” (a serious but uncommon side-effect of radiation treatment) occurs and does not get better with medical treatment. Radiation necrosis occurs when tissue in the area where prior radiosurgery treatment was done is destroyed.

This reaction may cause brain swelling around the treated area and may occur 6 to 18 months after your surgery. The tumour and the “necrosis” reaction may need to be removed surgically.

If you get surgery, you will often have the following appointments:

✓ a visit with your neurosurgeon before the surgery

✓ a visit with a member of the anesthesia team (people who give you medication to help you relax, and sleep through the surgery) before surgery

✓ imaging tests of the brain which will be used to guide the surgeon during your surgery (e.g. MRI scan of the brain)

✓ a visit with your neurosurgeon after surgery (often a few weeks after surgery)
Surgery is often done under general anesthetic (medication to help you relax, and sleep through the surgery).

In some cases, your surgeon may discuss with you the option of an “awake-surgery”. Awake-surgery is done with local anesthetic (medication that numbs a part of your body). This means the anesthesia team keeps you calm and relaxed but not fully asleep.

Awake-surgery allows your surgeon to test how well your brain works nearby your tumour(s), and allows them to do the surgery in a way that lessens any risk to the healthy parts of your brain.

The risk of a complication from surgery is less than 5% (5 out of 100). Possible side effects of surgery can include:

- Infection
- bleeding
- seizures

Ask your surgeon about any other side effects you may notice. After healing from surgery, you will meet with a radiation oncologist (cancer doctor who helps provide radiation treatment) at the Brain Metastases Clinic. They will tell you if you need radiation treatment.
Radiation Treatment

Whole brain radiation
Whole brain radiation treatment is treatment with x-rays given to you with a machine (linear accelerator) that directs radiation to the whole brain. This treatment is not done outside the brain.

This is an image of a linear accelerator. Someone trained in working this machine will use it to direct radiation to the whole brain.
Whole brain radiation is used to treat brain metastases when:

You have more than 4 metastases

- A large tumour cannot be removed by surgery and is too big to be safely treated with radiosurgery (see page 15 to read about this).
- Whole brain radiation may also be used to improve control of your brain metastases in the following cases:
  - With radiosurgery to lower the chance of getting new brain metastases or growth of the old brain metastases.

With surgery to lower the chance of the cancer cells growing back in the area where surgery was done, or in other parts of the brain.

If you get whole brain radiation, you will have the following appointments:

- **Simulation (Planning):** You will have a mask made to keep your head in the same position each day for treatment.
  You will then have a CT scan done while wearing the mask so that the radiation can be tailored to you. This appointment takes about 15 to 30 minutes.

This is an image of a standard immobilization mask. This mask helps you stay still while getting radiation, and helps tailor radiation treatment to your needs.
Possible side effects of whole brain radiation can include:

• fatigue (feeling of tiredness that does not go away with rest or sleep)
  You will feel more fatigue over the time that you get radiation treatment.
  Get help coping with fatigue by going to the Princess Margaret’s Fatigue Clinic (2nd Floor, Cancer Survivorship Centre). Ask a member of your health care team for a referral to attend the Fatigue Clinic, or contact the clinic at: 416 946 4501, extension 2363.

• headaches

• nausea (feeling of having to throw up)

• feeling like your ears are plugged

• an increase in your initial (early) symptoms (see page 5 for a list of these)

• complete hair loss on your head
  Hair loss is temporary (short-term), and tends to start many weeks after starting radiation treatment. Your hair will likely grow back many months after radiation treatment is done.

• skin redness
  Your skin (scalp) may look slightly red and may feel warm, dry and itchy.

• loss of short-term memory
  This often means a loss of verbal memory (things said to you). Short-term memory loss can occur months to years after radiation treatment. People may notice different amounts of memory loss, from none to more major memory problems. This is more common if you are older.
  Get help coping with short-term memory loss by attending the Princess Margaret’s Neurocognitive Clinic. Ask a member of your health care team for a referral to attend the Fatigue Clinic, or contact the clinic at: 416 946 4501, extension 2363.
Radiosurgery (or Gamma Knife)

At the Princess Margaret Cancer Centre, radiosurgery is done with a machine called a “Gamma Knife Unit”. This special machine provides targeted (direct) treatment to areas of the brain.

This is an image of a Gamma Knife unit. Someone trained in working this machine will use it to direct radiation to parts of the brain.

Radiosurgery may be an option to treat brain metastases in the following cases:

• You have few, small brain metastases less than 3 centimetres long
• There are less than 4 brain metastases when the tumours are first found
• Cancer has returned after prior radiation treatment for brain metastases, and there are less than 6 metastases
• To treat the area where surgery was done
• To treat any tumour that might be left behind
If you get radiosurgery, you will have the following appointments:

- Simulation (Planning): You will have a special MRI of your brain that will be used to plan your specific radiosurgery treatment.

- Radiosurgery Treatment Day. You will go through 4 steps on your radiosurgery treatment day:

1. You will arrive at the Princess Margaret early in the morning. The time you arrive will depend on when the neurosurgeon (person who does radiosurgery treatment) is free.

   You will have 4 local anesthetic injections (shots of medication that numbs a part of your body) into your scalp. The local anesthetic will numb the areas where you had the shots. It will also sting and burn for about 30 seconds.

2. When the local anesthetic starts to work, a stereotactic (metal) frame is placed on your head.

   This is an image of a metal frame. The metal frame makes sure you do not move during radiosurgery. This allows your doctors to target your tumours with radiation very well.
3. You will then be taken for a CT scan. The results of the CT scan will be looked at along with the MRI you already had during your Simulation (Planning).
   This is done to ensure that the radiosurgery treatment plan is accurate before you have your treatment.

4. After the CT scan, you will get radiosurgery treatment. Your treatment will take place in the Gamma Knife unit. The amount of time your treatment will take depends on the size, shape and number of tumours you are getting treated.

   Radiosurgery treatment length can range from 15 minutes to a few hours. You will be able to talk to the radiation therapists during treatment, and take a break if you need one.

Possible side effects of radiosurgery treatment can include:

- Fatigue (feeling of tiredness that does not go away with rest or sleep). This is often mild.

- Headaches. You may experience “tension headaches” (banding, or squeezing pain) from the stereotactic (metal) frame. These headaches can start in the first few days after treatment and last as long as a couple weeks.

- An increase in your initial (early) symptoms (see page 5 for a list of these).

- Radiation necrosis. This is when tissue in the area where radiosurgery treatment was done is destroyed. This may cause brain swelling around the treated area and may occur 6 to 18 months after your surgery.
What medications are used to help treat brain metastases?

Common medications
Dexamethasone (also known as “Decadron”) is a medication that lessens swelling and soreness that may be caused by a tumour. Dexamethasone is used to lessen swelling after surgery and radiation treatment.

The amount of dexamethasone given to you by a doctor is often changed to manage your symptoms. This process is called “tapering”. Tapering of dexamethasone is done to make sure you get the most help from the medication, while reducing the side effects.

Common early side effects can include:

• trouble sleeping
• desire to eat more
• weight gain (due to more water in your body, and desire to eat more)
• possible increase in blood sugars

Side effects with longer use can include:

• muscle weakness. This makes it hard to get up from a chair or walk up stairs.
• thinning skin
• acne-type rash
• bone thinning
• high blood sugar
• mood changes
• feeling easily bothered, or irritated
**Anti-seizure medications**

Common medications used to help manage seizures include:

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

This is not a complete list and your doctor may prescribe (give) you another type of anti-seizure medication.

**Anti-nausea medications**

Common medications used to help manage nausea include:

- Gravol (also called “dimenhydrinate”)
- Ondansetron

This is not a complete list and your doctor may prescribe (give) you another type of anti-nausea medication.

Speak to the Brain Metastases Nurse (see page 8 for details) if you have any questions or concerns about medications used to help treat brain metastases.
Your follow-up appointments

After your first treatment, you will return to the Princess Margaret’s Brain Metastases Clinic for ongoing follow up. Your first follow up appointment will be 2 to 4 months after treatment.

Your follow-up visits will include:

• Repeated brain imaging (pictures of the brain). This will include:
  • MRI scan
  • CT scan if you are not able to have an MRI scan.
• Clinic appointments to meet with your radiation oncologist and/or neurosurgeon

You will do follow-up imaging of your brain and visit with your health care team every 2 to 4 months. This time frame can change based on your symptoms and overall cancer care.

In some cases, your brain imaging may get booked after your clinic appointment.

If this happens, call 416 946 2901 so that the clinic can re-book your appointments.

If you are coming to the Princess Margaret from far away, your health care team can work with your local doctors to arrange for your follow-up brain imaging closer to home.
How do you book follow-up appointments?
Your clinic visits can be set up in person at the Princess Margaret, or by calling Telehealth Ontario. Telehealth is a free telephone service run by the Government of Ontario.
You can call Telehealth to:

- get health advice and health information from a nurse
- book clinic visits in your city, or in other parts of Ontario

All of the information you share with Telehealth is kept private.

What should you know about life after brain metastases?
Life after brain metastases may change. You may find it hard to manage some symptoms and treatment side effects and need help coping. For example, some patients may not be able to drive due to the safety risks posed by their symptoms and treatment side effects.

Talk to your health care team about any symptoms or treatment side effects you have. Ask your nurse or doctor to speak with a social worker if you need help coping with the stress and anxiety of life after brain metastases.

Driving (operating a motor vehicle)
Please discuss our clinic’s policy on driving with your clinical team.
Who to call for more information

The Brain Metastases Clinic
(Level 2B, Princess Margaret Cancer Centre)

The Brain Metastases Clinic is focused on giving you the care you need. At the clinic, your health care team works closely with you to talk about treatments for your brain metastases.

Clinic Hours: 9:00 am – 12:30 pm

For questions about your treatment schedule or appointments, call or email:
Brain Metastases Clinic Coordinator
Phone: 416 946 2901
Email: brainmetsclinic@rmp.uhn.on.ca
Hours: 9:00 am – 5:00 pm

Have feedback about this document?
Please fill out our survey. Use this link: surveymonkey.com/r/uhn-pe

Visit www.uhnpatienteducation.ca for more health information. Contact pfep@uhn.ca to request this brochure in a different format, such as large print or electronic formats.

© 2023 University Health Network. All rights reserved. Use this material for your information only. It does not replace advice from your doctor or other health care professional. Do not use this information for diagnosis or treatment. Ask your health care provider for advice about a specific medical condition. You may print 1 copy of this brochure for non-commercial and personal use only.

Form: D-8575 | Author: Brain Metastases Clinic staff | Reviewed: 2023