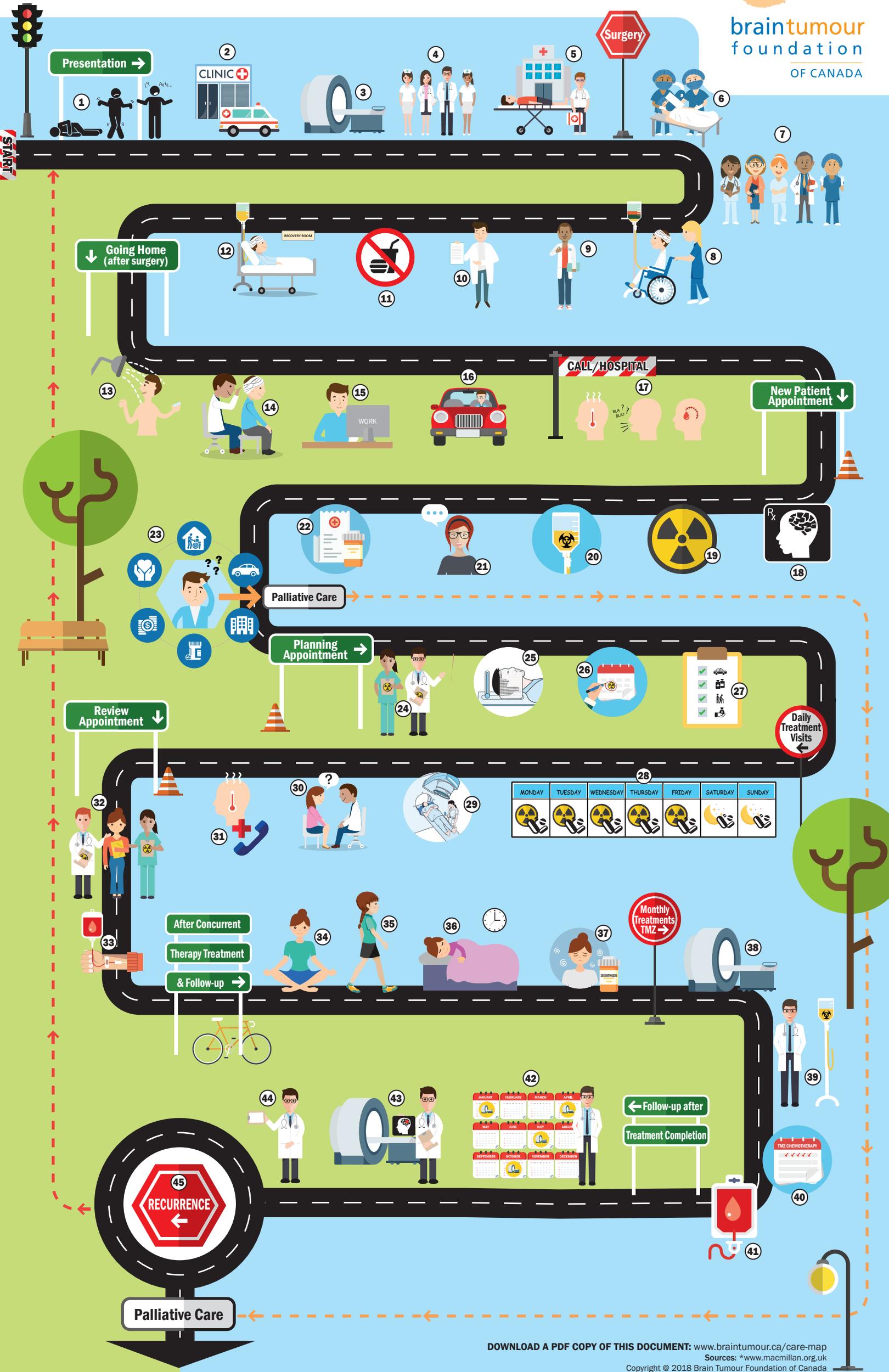


# Care Map for Patients with High-Grade Gliomas

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# Palliative Care and Brain Tumours

## What is Palliative care?

Palliative care is an area of medicine which focuses on supporting people living with terminal illness by improving their quality of life.

A team of doctors, nurses, social workers, and other health care professionals who work with your neurooncology team provide you with an extra level of support, and help you access services and programs within your community.

Palliative care focuses on addressing the following concerns:

- Physical symptoms
- Emotional and Psychosocial Concerns
- Spiritual Concerns
- Functional Concerns
- Advance Care Planning

## Who can provide palliative care and where is it provided?

- Basic palliative care is provided by your oncology team while receiving medical treatment for your brain tumour.
- If you or your neuro-oncology team feel that your palliative care needs are increasingly complex, your oncology team can refer you to an outpatient palliative care consult team.
- In some geographic regions in the country, community based palliative care teams can visit you in your home.
- During the later stages of illness, palliative care can be provided in a palliative care unit within a hospital, in a residential hospice, or in your home.

## What steps should I take if I want to receive palliative care services?

- You are your own best advocate! If you are interested in receiving palliative care support, please let your oncology team know.
- They can either provide basic palliative care to you or refer you to specialty palliative care team, depending on your needs.

**\*For more information on Palliative Care, see page 7 of the attached document.**





# CARE MAP for Patients with High-Grade Gliomas

Every day 27 Canadians are diagnosed with a brain tumour. Brain tumours are unpredictable and complex. They can affect vision, speech, hearing, memory, personality, balance and mobility. Their effects are physical, emotional, financial, and may last a lifetime. There is no cure.

We are here to help anyone affected by any type of brain tumour. Support from donors, corporations, and community foundations means the estimated 55,000 Canadians living with a brain tumour can find hope. **Hope through research. Hope through patient and survivor support. Hope for a cure.**

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## PRESENTATION

1. You may “present” with neurological symptoms that indicate something is wrong in your brain. These symptoms may include seizures, confusion, personality changes, inability to speak, or weakness on one side of your body. Symptoms of this sort may cause you to seek medical care through your family doctor or in a local emergency room.
2. If sent to your local emergency room by your family doctor, a family member, or another person in the health care field, you may arrive by ambulance or walk in accompanied by a family member.
3. After the medical team in the emergency room has examined you, an MRI or CT scan of your head is ordered by a health care professional to look for any abnormalities, like a brain tumour or stroke.
4. If a brain tumour is found, the neurosurgery team will become involved to determine if the tumour can be removed and how quickly this should be done.
5. If you are at a hospital where there is no neurosurgery service, you will be transferred to another facility where a neurosurgeon can care for you.

## SURGERY

6. If the neurosurgery team determines you need brain surgery right away, you will be admitted to the hospital in order to prepare you for surgery.
7. Preparing for surgery typically includes meeting with a team of health care providers which may include nurses, nurse practitioners, a social worker, physiotherapist, occupational therapist, and an anesthesiologist in addition to the neurosurgeon.
8. You may have a nurse practitioner assigned to your care.
9. If you are in a teaching hospital, you will likely have residents and students involved in your care.
10. You and your family will receive information about what the surgery will be like, and how to recover once the surgery is over.
11. You will not be able to eat or drink from midnight the night before your surgery.
12. You may have an intravenous (IV) inserted to receive fluids and medication.
  - You will wake up in the recovery room and a nurse will check you frequently to see how you are feeling.
  - Depending on the location of your tumour, you may be awake throughout the surgery. If this is the case, you will be made comfortable throughout the procedure.
  - You will have a dressing to cover the surgical incision from the operation on your scalp.
  - You will have an IV and will receive pain and other medications through this. When you can swallow, you will receive oral medications.
  - You may also be given an oxygen mask to wear.
  - After leaving the recovery room, you will be moved to the neurosurgery ward and most likely spend a day or two in the hospital to recover.
  - If you need help at home your health care team will make arrangements for home care services.

## GOING HOME AFTER SURGERY

Your health care team will assess your readiness for discharge from the hospital. You may be advised to rent or purchase some equipment to assist you at home.

13. You may shower and get the incision wet 4 to 5 days after surgery unless your health care team tells you otherwise.
14. Usually, your family doctor or other health care professional will remove the staples on your incision about 10 to 14 days after the surgery.
15. You will be unable to work for a period as advised by your surgeon and/or oncologist.



**16.** You may drive once your surgeon says it is ok to drive. However, if you have had a seizure, driving restrictions may apply and vary from province to province.

**17. Please call your team or return to the hospital if:**

- You have a fever
- Your incision is red, inflamed or is leaking fluid
- You become confused or weak
- You develop headaches, slurred speech, or changes in your ability to walk
- You have a seizure

## NEW PATIENT APPOINTMENT

**18.** A referral is made by the neurosurgery team to a nearby cancer centre to see a radiation oncologist and neuro-oncologist or medical oncologist.

- You may be asked to bring your post-operative scans and pathology reports to the appointment.
- Bring all of your medications to your first appointment so they can be reviewed.
- The team will take a medical history and examine you.
- It is recommended that you bring a family member or friend with you to the initial appointments at the cancer centre.

**19.-20.** Once the pathology and the postoperative scans are reviewed, a treatment plan will be reviewed with you, and will likely include radiation treatments and chemotherapy.

- The treatments will last between 3 or 6 weeks depending on your age and how you recovered from surgery.
- Simultaneous radiation therapy and chemotherapy may be recommended, but this will be discussed with you and your family to decide what is the right treatment plan for you.
- Information about chemotherapy and its side-effects will be provided to you. These may include nausea, vomiting, constipation, fatigue, and the risk of infection or bleeding from reduced blood counts.
- You will also receive information about the side effects of radiation, which may include fatigue, hair loss, headaches, and possibly short-term memory loss.
- Everyone is different and may respond differently to treatment. Some people have very few side effects and others have more significant side effects.

**21.** We encourage you to meet with a social worker who can discuss your practical needs, such as how you will travel to your treatments and how you will pay for treatments (if there is a cost). The social worker will also introduce you to various supports and resources available to help you and your family cope with the challenges that a brain tumour diagnosis can cause.

A radiotherapy planning appointment will be made for you to meet with the radiation oncology team and prepare you to receive radiation treatments.

**22.** Chemotherapy is usually provided by the cancer centre, but you may pick up other medications, such as nausea medications, from your local community pharmacy.

**23. Common concerns and questions are addressed at the New Patient Appointment:**

- Home support
  - How are you managing your activities of daily living, such as showering, dressing, preparing meals?
  - Are there people available to assist you, either through family or formal supports?



- Transportation
  - Patients are usually advised not to drive during radiotherapy, or even for a period after treatment depending upon their unique circumstances.
  - Radiotherapy is only provided in cancer centers, daily travel to and from the centre will be necessary.
  - You will need to consider whether you have family/friends who can commit to daily transportation or if alternative transportation needs to be explored.
- Lodging
  - If you live a distance from the treatment centre, there may be lodging options for you to stay during the week. Please consult with your oncology social worker or other members of your health care team.
- Drug coverage
  - You will likely be prescribed a course of chemotherapy that will be taken at home. The cost of this chemotherapy may be covered by your provincial health care or by your extended benefits plan. In some cases, the cost of the chemotherapy is not covered and will need to be paid by the patient
  - Your prescription drug coverage will be discussed, and options explored for decreasing the cost of prescription drugs that are paid by you.
  - Drug coverage may require applications to your insurer for prior authorization; applications to provincial drug assistance programs and referrals to patient assistance programs through pharmaceutical companies.
- Finances
  - If you were working before your diagnosis, this will cause an interruption in earnings.
  - Income replacement programs will be discussed to ensure you have applied for, or initiated the process of applying for, income replacement options for which you are eligible.
- Palliative Care | Supportive Care
  - You will be introduced to some of the supportive care programs available to you and your family during your care.

### WHEN MIGHT I WANT TO RECEIVE PALLIATIVE CARE | SUPPORTIVE CARE SERVICES?

People often think that palliative care is only necessary during the later stages of illness or at the end of life. Palliative care can be provided at any stage during your illness, even alongside the medical treatment that you are receiving for your brain tumour.

Studies have shown that people who access palliative care services and programs earlier in the course of their illness may experience benefits such as improved quality of life, less depression and anxiety, improved satisfaction with care, and that they may even live longer (See **page 7** for additional information).

### PLANNING APPOINTMENT

24. At the radiotherapy planning appointment, you will meet with the radiation therapist who will deliver your treatment.
25. They will make a mask that will keep your head in place during your radiation treatments; for targeted radiation to a specific area of your brain.



The radiation therapist will review the side-effects of radiation treatments with you and answer any questions you have.

**26.** You will be given the start date for radiation and chemotherapy soon after this appointment.

#### Common concerns addressed at the planning appointment:

**27.** You will have the chance to again discuss:

- Transportation options
- Radiotherapy side effects
- How you are managing with your day-to-day care
- If you have additional questions about drug coverage or other financial issues, the need for home support, or any other concerns, the radiation therapist can help you connect with the appropriate members of the team to ensure that these concerns are addressed.

#### DAILY TREATMENT VISITS

**28.** If you are receiving temozolomide (TMZ) chemotherapy with the radiotherapy, you will take the TMZ capsules about one hour before your radiation appointment every day.

- You will take a medication to prevent nausea 45 minutes before the TMZ.
- On the weekends and any other days when you do not have a radiation appointment, you will take the TMZ chemo before you go to bed or as advised by your health care team.

**29.** At each treatment visit you will see the radiation therapist who administers the radiation treatment.

**30.** The radiation therapist will answer your questions or concerns or call the radiation oncologist or nurse practitioner to help if needed.

**31.** **If you have fevers, signs of infection or bleeding call the clinic. If it is after hours or on the weekends, call the physician on call (if available) or go to your local emergency room.**

#### Common concerns addressed during your daily treatments:

- During the course of your daily treatments you will have the chance to discuss your concerns:
  - Home support
  - Income support
  - Other services such as dietitians, social workers, and psychosocial resources
- Functional concerns:
  - At some point, you may find you need help with activities of daily living such as dressing, bathing, eating, and managing your household.
  - Palliative care teams can provide help in adjusting to, and coping with, these day-to-day functional changes; they can also refer you to community providers to help you with any challenges you may encounter.
- Such providers may include personal support workers, social workers, occupational therapists, physiotherapists, and case managers.

#### REVIEW APPOINTMENT (radiation oncologist/radiation nurse)

**32.** The radiation oncologist or the radiation nurse will meet with you regularly to check in and see how you are feeling during your treatment.

- Radiotherapy may cause swelling in the brain as the tumour cells are eradicated. Dexamethasone is a steroid medication that may be prescribed to treat uncomfortable symptoms of brain swelling, such as headache or nausea.



- The oncologist or nurse practitioner may adjust the dexamethasone dose at these visits, depending on how you are feeling. They will also guide you to gradually taper the dose of this medication when it is safe to do this.

**33.** If you are receiving chemotherapy, you will have bloodwork drawn regularly during treatment as well.

#### AFTER CONCURRENT THERAPY TREATMENT AND FOLLOW UP (medical or neuro-oncologist)

- 34.** Once your radiation and chemotherapy treatments are done you will have a 4-6 week break with no treatment. This is a time for rest and recovery.
- 35.** You will feel tired and need to rest, but should also be as active as possible during the day. Long naps in the daytime may affect your ability to sleep at night, and those who are able to engage in regular activity are more likely to prevent physical deconditioning which can lead to even more fatigue.
- 36.** It is important to listen to your body and consider following periods of activity with periods of rest. The response to treatment is quite variable and recovery from treatment side effects will also vary from individual to individual.
- 37.** You may experience neurological problems such as headaches, weakness in the legs or arms, difficulties with speech, seizures, or confusion. Report any changes in your condition to your health care team promptly so that problems can be addressed.

**If you have any concerns about your health, please call your health care team.**

#### Common concerns after concurrent treatment ends:

- In the period following your daily treatments you will have the chance to discuss your concerns:
  - Home support
  - Income support
  - Other services such as dietitians, social workers and psychosocial resources
- You can also discuss a return to work plan with your team if this seems reasonable.

#### MONTHLY TREATMENTS WITH TMZ

- 38. - 39.** After radiotherapy you will meet with your medical or neuro-oncologist to discuss further treatment with TMZ chemotherapy.
- 40.** This phase of TMZ treatment is given for 5 days in a row every month for 6 months.
- 41.** You will have bloodwork monthly to make sure that your blood counts are within a safe range for chemotherapy.
- You will have MRIs every two months, or as directed by your oncologist, to assess your tumour's response to treatment.

**If you have fevers or any signs of infection or bleeding call the clinic. If it is after hours or on the weekends, go to your local emergency room.**

#### FOLLOW-UP AFTER TREATMENT HAS COMPLETED

- 42. - 43.** At the end of six months of treatment, you will have MRI scans at regular intervals and meet with your radiation oncologist, neuro-oncologist, or medical oncologist.
- 44.** If you have any new symptoms, you should call in to the clinic to discuss with your doctor or nurse.



## RECURRENCE

45. Unfortunately, malignant brain tumours often become active again at some point after treatment. This is usually discovered during a routine MRI, but sometimes symptoms occur that indicate the tumour is growing. These symptoms are often like the ones that occurred at the time of your diagnosis.

- You will meet with your neuro/medical oncologist to discuss the MRI results or your new symptoms and what type of treatment is best for your situation.
- Sometimes, another surgery is recommended. Surgery can help determine if the new symptoms or changes in your scan are related to side-effects of radiation (called radiation necrosis) or if the disease itself has returned.
- Surgery can also help to reduce the amount of tumour in your brain – this is called “debulking” or a re-resection. This can be helpful in relieving neurological symptoms such as headache.
- Re-irradiation is rarely considered, but if you are a candidate for this treatment you will discuss this option with your radiation oncologist.
- Your neuro/medical oncologist may discuss other types of oral chemotherapy with you such as TMZ or lomustine.
- Bevacizumab is an intravenous treatment that may also be considered. This treatment affects the blood vessels that supply nourishment to the tumour and can also reduce swelling in the brain.

## PALLIATIVE CARE AND BRAIN TUMOURS

### What is Palliative care?

- Palliative care is an area of medicine which focuses on supporting people living with terminal illness by improving their quality of life.
- A team of doctors, nurses, social workers, and other health care professionals who work with your neuro-oncology team provide you with an extra level of support, and help you access services and programs within your community.

Palliative care focuses on addressing the following concerns:

- Physical Symptoms
  - Your brain tumour and its treatments may create uncomfortable physical symptoms such as:
    - Headaches
    - Nausea
    - Vomiting
    - Fatigue
    - Sleepiness
  - Palliative care providers prescribe medications and discuss strategies to help with these discomforts.
- Emotional and Psychosocial Concerns
  - Living with a brain tumour may create feelings such as anxiety, sadness, frustration, helplessness, grief, and sometimes depression.
  - Palliative care providers can help you manage some of these difficult emotions with supportive counseling, referrals to community supports, and medications, if needed.
  - The stresses of living with a brain tumour can affect your relationships with your family and friends. Palliative care providers can help you and your loved ones manage the challenges that occur due to having a brain tumour.



- Spiritual Concerns
  - Being diagnosed with a terminal illness is a life altering experience which may impact the way you view your place in the world, what is meaningful to you, what you value, and what you hope for moving forward. These are very big concerns that are sometimes difficult to cope with on your own.
  - Palliative care providers help support you as you work to make sense of the reality of your diagnosis and address its impact on your spiritual life.
  - Discussing your spiritual concerns may help you and your loved one's cope with the challenges of living with a brain tumour.
- Functional Concerns
  - At some point, you may find that you need help with day-to-day activities of living, such as dressing, bathing, eating, and managing your household.
  - Palliative care teams can provide help in adjusting to and coping with these day-to-day functional changes.
  - They can also refer you to community providers that can help you meet the challenges of daily living.
- Advance Care Planning
  - Advance care planning is a process of considering, discussing, and documenting your wishes for future medical and end-of-life care.
  - Your neuro-oncology and palliative care providers can help you to identify a substitute decision maker (SDM) and have conversations with your SDM about your preferences for care.
  - Having advance care planning conversations early and regularly during the course of your illness can help to ensure that the care that you receive is always in line with your values, your wishes, and your goals.
  - Please refer to [www.advancecareplanning.ca](http://www.advancecareplanning.ca) for provincial information around advance care planning and substitute decision makers (SDM).

### Who can provide palliative care and where is it provided?

- Basic palliative care is provided by your oncology team while receiving medical treatment for your brain tumour.
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