

DANA-FARBER/BRIGHAM AND WOMEN'S

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CANCER CENTER



## Living with a Brain Tumor: A Guide for Patients and Families

Dana-Farber/Brigham and Women's Cancer Center  
Center for Neuro-Oncology

[www.dana-farber.org/braintumor](http://www.dana-farber.org/braintumor)

## Introduction

Dear patient and family member,

We know that the first few weeks after diagnosis of a brain tumor can be overwhelming. This booklet is intended to provide explanations and offer resources to help you navigate the road ahead.

The Center for Neuro-Oncology at Dana-Farber/Brigham and Women's Cancer Center offers a highly experienced, multidisciplinary team of experts. You can receive the latest treatments for cancer of the brain or nervous system, such as precise neurosurgical techniques, radiation therapy that targets tumors while sparing surrounding tissues, and a variety of chemotherapy drugs tailored to your type of cancer. We are leaders in clinical trials, offering a robust research program in our search for newer and better treatments.

Last but not least, you will find many types of support, from individual counseling to a support group specifically for brain tumor patients and their families.

At this difficult time in your lives, we want to assure you that you have come to the right place. We will do everything possible to help you achieve a good outcome and maintain the highest possible quality of life.

*With our best wishes,  
The Neuro-Oncology Team  
Dana-Farber/Brigham and Women's Cancer Center*



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## What Is Cancer? What Is a Brain Tumor?

Cancer is a disease in which cells grow and multiply in an abnormal, uncontrolled way. The body's cells normally grow and divide at a certain rate. Occasionally, the signals that control cell division are lost, leading to rapid, uncontrolled growth and the formation of a tumor.

The brain is made up of glial cells that support and nourish nerve cells. Some glial cells are called astrocytes, and others are called oligodendrocytes. When one of these cells becomes cancerous, it may result in a brain tumor.

## How Brain Tumors are Classified

Brain tumors are classified as primary or secondary. Primary brain tumors develop inside the brain and almost never spread outside the brain or spine. Secondary, or metastatic, brain tumors start in another part of the body and then spread to the brain.

Most primary brain tumors in adults are gliomas. Gliomas are named for the type of brain cell that they resemble. Two common types of gliomas are astrocytomas and oligodendrogliomas. Some gliomas have features of both; these tumors are called oligoastrocytomas or mixed gliomas.

Gliomas are graded on a scale from 1 to 4. In general, the higher the grade, the more quickly and aggressively the tumor grows. Grade 1 tumors occur almost always in children. Grade 2 tumors are often referred to as low-grade or benign gliomas. Grade 3 and 4 tumors are often referred to as high-grade malignant gliomas. Grade 3 tumors are also called anaplastic gliomas. Grade 4 tumors are called glioblastomas or glioblastoma multiforme.

The following table summarizes possible glioma types.

Glioma Type	Grade 2	Grade 3	Grade 4
<b>Astrocytoma</b> (As-tro-cy-toma)	Low-grade (diffuse) astrocytoma	Anaplastic astrocytoma	Glioblastoma
<b>Oligodendroglioma</b> (Oli-go-den-dro-gli-oma)	Low-grade oligodendroglioma	Anaplastic oligodendroglioma	Glioblastoma
<b>Oligoastrocytoma</b> (mixed glioma) (Oli-go-as-tro-cy-toma)	Low-grade oligoastrocytoma	Anaplastic oligoastrocytoma	Glioblastoma

The functional units of the brain include: the four lobes of the cerebrum, the brainstem, and the cerebellum.

The **frontal lobe** is mainly involved in motor function, judgment, motivation, planning, and speech.

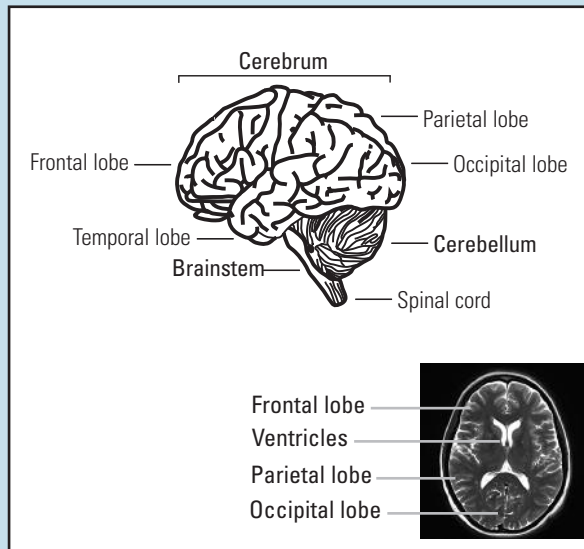
The **parietal lobe** plays an important role in sensation and attention.

The **temporal lobe** is involved in memory and emotion and understanding speech.

The **occipital lobe** is important for vision.

The **brainstem** controls eye movements, facial expression, breathing, and many other functions. It connects the brain to the spinal cord.

The **cerebellum** is mainly involved in motor coordination.





## Common Brain Tumor Symptoms

Symptoms vary widely depending on the size of the tumor, how quickly it is growing, and the location in the brain. Because many of these symptoms respond well to treatment, it is important to report them to your doctor or nurse. Some of the most common issues include:

- Headaches (These are particularly common in patients with large tumors or tumors that interfere with the flow of cerebrospinal fluid inside the brain.)
- Seizures
- Fatigue
- Weakness\*
- Numbness or tingling\*
- Difficulty walking
- Change in coordination\*
- Slurred speech
- Changes in peripheral vision\*

*\*These symptoms often occur only on one side of the body.*

### What Other Symptoms May Occur?

Brain tumors may also cause cognitive, behavioral, and emotional problems. In some cases, these symptoms are severe enough that you may need round-the-clock supervision from a family member, friend, or health care provider:

#### *Language difficulty*

*(common with tumors on the left side of the brain)*

- Trouble with speaking
- Trouble understanding speech
- Trouble with reading or writing

### *Memory and problem-solving difficulties*

- Poor short-term memory
- Trouble with doing tasks
- Changes in judgment

### *Behavioral issues*

- Personality changes
- Loss of the ability to control urges or impulses
- Agitation and feelings of anger or frustration
- Unpredictable outbursts

### *Emotional issues*

- Depressed mood
- Anxiety




## How Brain Tumors are Treated

Brain tumor treatments are tailored to your diagnosis and medical situation. Here are some common options that your health care team may recommend.

**Surgery.** In most cases, treatment begins with surgery. Depending on the tumor's size, location, and type, you may need a biopsy or a resection. A biopsy involves removing a very small piece of the tumor tissue in order to determine the tumor type. A resection involves removing as much of the tumor as possible.

After surgery, the tissue is sent to a pathologist for review. The pathologist's report helps your physician determine the best treatment approach for your tumor. In most cases, the pathology review takes about one week. Sometimes, further tests are needed to confirm the tumor type or determine your treatment.



**Radiation Therapy.** Brain tumors are often treated with radiation. Treatment takes place over 6-7 weeks, five days a week. Each session is painless and takes less than 15 minutes. Radiation therapy for high-grade gliomas starts 2-5 weeks after surgery (a short delay is necessary to permit healing of the surgical wound).

*Common side effects of radiation*

- Fatigue
- Skin irritation
- Temporary hair loss in the area of the radiation
- Memory issues that may develop after treatment ends

*Less common side effects*

- Brain edema (swelling)
- Seizures
- Permanent hair loss
- Radiation necrosis (the injured tumor tissue becomes inflamed and may cause symptoms by pressing on brain tissue)

**Chemotherapy.** Chemotherapy may be used alone, in combination with radiation therapy, or following radiation. Different chemotherapy options are available, and the treatment plan will depend on a variety of factors that your doctor will discuss with you.

Options include drugs that kill tumor cells; specific targeted agents; or drugs that attack the blood vessels of your tumor (anti-angiogenic therapy). Some are given by mouth and others by intravenous infusion.

The most frequently used chemotherapy drug is called temozolomide (Temodar), which is given in a pill form and may be obtained from your local or mail-order pharmacy or our outpatient pharmacy. Temodar dosing is based on your height and weight, which are checked every month before a Temodar prescription is written.



### *Common side effects of Temodar*

- Fatigue
- Nausea
- Constipation
- Lowering of blood counts (particularly white blood cells and platelets)

Severe blood count problems are rare, but you will have your numbers checked either at Dana-Farber or near your home on a regular basis. In most cases, weekly blood tests will be necessary during the first 3 or more months of Temodar treatment.


Other medications you may take with Temodar include:

- Ondansetron (Zofran) – an anti-nausea medication. Other medications are available if Zofran is not enough to control nausea.
- Bactrim DS – an antibiotic used to prevent pneumonia that can occur with daily chemotherapy or steroid use. If you have a sulfa allergy, other medications may be used.

Surgery, radiation therapy, and chemotherapy are intended to shrink or slow down the growth of your tumor. Other measures may be recommended to treat symptoms or issues that your tumor may cause, such as:

**Brain swelling (edema).** This may occur at the time of diagnosis, after surgery, or during or after radiation therapy. Symptoms often include headaches, nausea or vomiting, darkening of vision, seizures, severe sleepiness, and worsening of other problems. The standard treatment is steroid medication, usually dexamethasone (Decadron).

**Seizures.** These tend to occur in newly diagnosed patients or when a tumor begins to grow back after treatment. Many different medications may be used to control seizures.



**Blood clots.** A brain tumor raises the risk of clots in the large veins of the legs (deep venous thrombosis, or DVT) and in the lungs (pulmonary embolism, or PE). Staying physically active is the best way to prevent this. If you do develop a blood clot, you will likely need to take a blood-thinning medication prescribed by your doctor.

**Fatigue.** Fatigue may result from the tumor itself or from treatment. Your physician or nurse can offer suggestions to help increase your energy.

**Memory problems.** Certain medications are useful in treating memory issues.

**Gastrointestinal discomfort.** Your doctor and nurses are skilled in treating these problems with medication or other approaches.

**Hydrocephalus.** In some cases, a tumor can interfere with the flow of cerebrospinal fluid (CSF) in the ventricles. Increased pressure may cause the ventricles to expand, a condition known as hydrocephalus. Treatment generally involves placement of a tube that drains fluid from the ventricles into the abdominal cavity. This relieves the pressure and related symptoms, such as headache.

## Our Weekly Multispecialty Clinic

The Multispecialty Clinic for Patients and Families at the Center for Neuro-Oncology is a weekly clinic that gives patients and family members a single time and place to meet with many different DF/BWCC specialists, including specialists in surgical, medical, and radiation oncology.

The clinic is held every Friday from 7:30 to 11 a.m., on the 10th floor of Dana-Farber's Yawkey Center. To schedule an appointment, call **877-442-3324**.



## What If My Tumor Begins to Grow Back?

Most gliomas do eventually grow back, even with treatment. Regrowth is usually seen on an MRI scan before any symptoms develop. The treatment approach for a recurrent tumor is determined on a case-by-case basis. Your care team will work with you to discuss the options that apply to your diagnosis.

## Why Consider a Clinical Trial?

Because most gliomas are not curable, physicians and researchers are working hard to find better treatments. Clinical trials enable testing of new medications to see whether they are safe and more effective than standard treatments. The information collected during a clinical trial may be helpful to future brain tumor patients.

If your physician suggests a clinical trial, also known as a clinical research protocol, he or she will describe the drug or drugs involved, the schedule of tests and visits required, and known side effects. Participation in clinical trials is voluntary. You will receive a detailed informed consent form that explains why the study is being done, what is involved, the possible risks and benefits, other options, and your rights as a patient involved in research.

If you decide to be in a clinical trial, screening tests will determine if you are eligible. If the tests show that you cannot be in the research study, other options will be discussed with you. You can remain on a study as long as your tumor does not grow or you do not have side effects that your physician feels are harmful to you.

To learn more about clinical trials and find a list of frequently asked questions, visit our website at [www.dana-farber.org/clinicaltrials](http://www.dana-farber.org/clinicaltrials).

## Why Might I Stop Active Treatment?

Besides surgery, radiation, standard chemotherapy or participation in a clinical trial, you can choose at any time to focus on comfort-related care and quality of life.



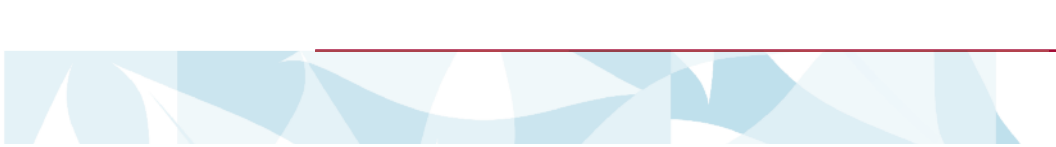
## When to Call Your Doctor or Nurse

A physician is on call at all times. If you experience any of the following symptoms, please call our office at **617-632-2166** during business hours or **617-632-3352** after hours or on weekends.

- **A fever of 100.5F or above.** It could mean that you have an infection. If you have a low white blood cell count, an infection can be serious or even life-threatening. You may be treated with antibiotics or be admitted to the hospital.
- **Low energy.** This could mean that you have too few red blood cells, or anemia. If this becomes severe, you may need a blood transfusion.
- **Shortness of breath.** This may point to blood clots in the lungs, a potentially serious problem.
- **Easy bruising or bleeding.** This could mean a low platelet count, which can be serious, and a platelet transfusion may be needed.
- **Any symptom that worries you** or a family member.

## Neuro-Oncology Team Members and Roles

**Neuro-oncologists** are physicians who oversee your care. They prescribe chemotherapy and other medications that may be needed to help manage your brain tumor. They may



also refer you to specialists in neurosurgery, radiation oncology, psychiatry, or internal medicine.

**Nurse Practitioners (NPs), Physician Assistants (PAs), and Program Nurses** work with neuro-oncologists to oversee all aspects of your care.

**Neurosurgeons** perform brain tumor surgery, including biopsy, resection (tumor removal), or placement of a shunt to relieve pressure. We consult with a number of neurosurgeons in the Brigham and Women's Hospital Department of Neurosurgery. You may meet with a neurosurgeon before surgery and afterwards, as needed.

**Radiation Oncologists** are physicians who specialize in radiation therapy for brain tumors. During the period of radiation, you will see your radiation oncologist on a regular basis. We consult with radiation oncologists in the Department of Radiation Oncology at Brigham and Women's Hospital.

**Social Workers** help patients and families cope with the emotional impact of diagnosis and treatment. They are available to provide emotional support and counseling to individuals, couples, families, and children. They can direct you to supportive programs at Dana-Farber/Brigham and Women's Cancer Center and in your local community. They can also connect you with resources for financial assistance, insurance coverage, Social Security disability, and transportation.

You and your family are key members of the care team. We understand your illness, but you understand your own body. We welcome your questions and value your participation as we make decisions together.



## Other Resources to Help You

Patients and their loved ones sometimes face financial challenges after a brain tumor diagnosis. This can happen, for example, if patients need to reduce their work hours or stop working altogether. As family members adjust to new roles and responsibilities, they, too, are sometimes forced to make changes in their work life.

Your fellow brain tumor patients and their families can often provide you with information on resources they have used or helpful coping strategies. Consider attending the Brain Tumor Support Group (see below) to learn from people who know first-hand about the challenges you face.

There are programs at Dana-Farber/Brigham and Women's Cancer Center and in the community that offer assistance. A brief overview of those programs follows. Talk with your social worker for additional information.

## Brain Tumor Support Group

The Brain Tumor Support Group provides a confidential venue in which patients and caregivers can discuss work and family life, finances, relationships, treatment, and many other important issues. It is co-led by a social worker and a health care provider. Please ask your treatment team for a meeting schedule.

The group is designed so that patients and family members can attend whenever they choose. There is no registration and no cost. Call 617-732-6826 for more information.

## Dana-Farber Resource Specialists

Our resource specialists help patients and families with a variety of needs. To learn more, call 617-632-5570 or talk with your social worker. Resource specialists help patients and family members with:

- Parking
- Transportation to/from medical appointments
- Short-term accommodations for family members (if you live far away or you are admitted to Brigham and Women's Hospital for treatment)
- Guidance on disability benefits
- Financial issues
- Community resources (e.g., Meals on Wheels, elder services, durable medical equipment, child care, food, homemaking services)

### **Insurance Questions**


Our specialists can help you with questions or concerns about insurance. Call Financial Information Services at 617-632-3455 or visit [www.dana-farber.org/financial](http://www.dana-farber.org/financial).

### **Office of Patient and Family Assistance**

This office offers need-based financial assistance, legal services, and coaching sessions for eligible patients, families and survivors. To learn more, talk with your social worker or a resource specialist.

### **The Eleanor and Maxwell Blum Patient and Family Resource Center**

Part reference library and part lending library, the Blum Resource Center is staffed by professionals and volunteers



who are committed to helping you obtain information so you can make good decisions about your care.

First floor of Dana-Farber's Yawkey Center  
800-525-5068

[www.dana-farber.org/resourcecenter](http://www.dana-farber.org/resourcecenter)

## How to Get Spiritual Care and Support

If you would like to talk with someone who can offer comfort and support, ask to speak with a chaplain. Dana-Farber/Brigham and Women's Cancer Center has chaplains from many faiths on staff who work with patients and families from all religious backgrounds (including the unaffiliated).

Chaplains can visit you during your outpatient treatments at Dana-Farber and they can visit you at the bedside if you are admitted to Brigham and Women's Hospital (BWH). They can also provide many sacraments, rites, and rituals that you would normally receive from your local faith community, or they can arrange for clergy in the area to visit you during your hospital stay.

- Dana-Farber – Spiritual Care: 617-632-3908
- BWH – Chaplaincy Services: 617-732-7480

## Concerns about Sexuality and Intimacy

In the early stages of your treatment, your focus – and that of your health care team – will be on immediate issues of symptoms, treatments, side effects, and expectations for the future. Once this initial phase has passed, other important feelings and concerns might surface, including questions about how you and your partner experience sexuality and intimacy. Talk with your physician or nurse about any sexual side effects of your treatment. You can also learn more at [www.dana-farber.org/sexualhealth](http://www.dana-farber.org/sexualhealth).



## Will a Brain Tumor Affect Fertility?

If your plans for the future include having children, it is important to discuss those wishes prior to starting treatment. Some cancer treatments may cause infertility or increase the risk of birth defects. Fortunately there are safe, effective options for both men and women to preserve your chances for having healthy children.

Your doctor, nurse, or social worker can discuss these options in more detail. In many cases, your provider might refer you to a reproductive endocrinologist (a physician who specializes in reproductive health and fertility).

Fertile Hope is a national, nonprofit organization dedicated to providing reproductive information, support, and hope to cancer patients and survivors whose medical treatments present the risk of infertility. While we encourage you to discuss your questions/concerns about fertility with your oncology team here at DF/BWCC, many of our patients and their partners have found Fertile Hope to be an excellent source of information and support.

Fertile Hope  
855-220-7777  
[www.fertilehope.org](http://www.fertilehope.org)

## Integrative or Complementary Therapies

Many patients find help and relief through integrative therapies (also known as complementary or alternative therapies), in addition to the medications and treatments prescribed by their oncologists. The Leonard P. Zakim Center for Integrative Therapies, located on the sixth floor of Dana-Farber's Yawkey Center, offers patients services such as acupuncture, massage, yoga, meditation,

music therapy, dance, and creative arts. Integrative and nutritional consultations can help match your goals and needs with the most appropriate therapies.

For information, call 617-632-3322.

[www.dana-farber.org/zakim](http://www.dana-farber.org/zakim)



## Appendix: Local and National Organizations

Several local and national agencies and associations support brain tumor patients and their families. These organizations offer educational programs, support groups, financial assistance, and more. Visit their websites or call to learn more about how they may be helpful to you.

American Brain Tumor Association (ABTA)

800-886-2282

[www.abta.org](http://www.abta.org)

National Brain Tumor Society

617-924-9997

[www.braintumor.org](http://www.braintumor.org)

For general cancer-related services and support:

American Cancer Society

800-227-2345

[www.cancer.org](http://www.cancer.org)

(visit website to find resources near you)



## Notes



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