

TREATMENT UPDATE:

Glioblastoma

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Each year, about 26,000 adults in the United States are diagnosed with a malignant primary brain tumor, a cancer that begins in the brain's cells, membranes, nerves, or glands.

Tumors arising from the supportive tissue of the brain are called gliomas. Almost 75 percent of malignant brain tumors are gliomas. Glioblastomas (also called glioblastoma multiforme, or GBM) are the most common form of this cancer, accounting for about 55 percent of cases.

The symptoms of primary brain tumors vary. Not everyone with a brain tumor will have these symptoms, and having some of these symptoms doesn't necessarily mean that a brain tumor is the cause. Talk with your doctor if you experience any of these general or specific signs and symptoms.

General signs and symptoms

- Headaches
- Seizures
- Changes in personality
- Memory lapses
- Nausea and vomiting
- Changes in vision

Specific signs and symptoms, depending on the location of the tumor

- Headache
- A feeling of pressure in the head or headache
- Loss of balance
- Impaired fine-motor skills, such as the ability to type
- Impaired judgment
- Muscle weakness or paralysis
- Changes in speech, hearing, memory, or emotional state
- Problems understanding or retrieving words
- Extreme sensitivity to touch
- Arm or leg weakness on one side of the body
- Confusing the left and right sides of the body

If a brain tumor is suspected, an MRI (magnetic resonance imaging) is often performed. An MRI uses magnetic fields to detect tumors within the body. Other imaging tests, such as PET (positron emission tomography) and CT (computerized tomography) may also be performed.

If a tumor is found, it is removed surgically (if possible) and tested for cancer cells in order to decide on a treatment approach. If the tumor is located in a part of the brain where surgery would pose a serious risk, a biopsy may be performed. In a biopsy, surgeons use computers to guide a needle into the skull, allowing for a small piece of the tumor to be removed. That sample is then examined under a microscope to see if it contains cancer cells.

Treatment Options

This booklet will focus on the treatment of glioblastoma, the most common type of malignant brain tumor. The standard of care for glioblastoma is surgery, followed by radiation and chemotherapy. By removing or shrinking glioblastomas, doctors relieve the pressure on the brain these tumors can cause. Treatment also reduces other symptoms such as seizures, headaches, or difficulty with balance.

Surgery

Using a procedure called a craniotomy, the surgeon opens the skull and removes as much of the glioblastoma as possible. Special computers hooked up to MRI monitors allow surgeons to view a “map” of different parts of the brain, helping to find and remove tumors more easily and safely.

Swelling in the brain (edema) can be caused by surgery, or by the tumor itself. After surgery, doctors usually prescribe dexamethasone or another steroid medication to reduce edema and its symptoms, which can include seizures, memory problems, or confusion. Because they are powerful medications, the use of steroids must be monitored carefully by a doctor.

Radiation

After a brain tumor is surgically removed, some cancer cells may be left behind. These cells can act as seeds, sparking the growth of another tumor. To help get rid of these cells, the area of the brain which surrounded the tumor is usually treated with radiation. Radiation works by damaging the DNA of cancer cells. People with glioblastomas typically get 30 radiation treatments, spaced over the course of six weeks.

“External beam radiation” is commonly used in treating glioblastomas. Standard external beam radiation uses a machine that directs a beam (or multiple beams) of radiation to the tumor. The use of CT, MRI, and PET scans allows radiation oncologists to accurately target tumors, shaping the radiation beams to the size and dimensions of the tumor to help spare healthy tissues.

Intensity-modulated radiation therapy (IMRT) is a form of external beam radiation that allows a higher dose of radiation to be directed to the tumor, while minimizing the amount of radiation received by healthy brain tissue. The use of IMRT may result in fewer side effects compared to standard external beam radiation. A newer form of radiation called SBRT (stereotactic radiation) can deliver higher doses of radiation in shorter time periods, minimizing the impact on healthy tissue.

Chemotherapy

Following the 6-week course of radiation, patients with glioblastoma are typically prescribed temozolomide (Temodar), a chemotherapy taken orally (by mouth). Approved by the U.S. Food and Drug Administration (FDA) in 2005 for the treatment of adult patients with newly-diagnosed glioblastomas, the goal of temozolomide is to stop or slow cell growth. (The use of temozolomide in treatment of types of brain tumors other than glioblastoma continues to be explored.)

The chemotherapy carmustine (Bicnu, Gliadel) is sometimes used to treat certain types of brain tumors, including glioblastoma. Carmustine is administered as a wafer, placed in the area where the tumor was removed during surgery.

Targeted Treatments

Targeted treatments focus on specific molecules and cell mechanisms thought to be important for cancer cell survival and growth, taking advantage of what researchers have learned in recent years about how brain tumors grow. Targeted treatments are meant to spare healthy tissues and cause less severe side effects than chemotherapy.

In 2009, the FDA approved the targeted treatment bevacizumab (Avastin) as a treatment for glioblastoma when this form of brain cancer continues to progress following standard therapy. Bevacizumab is designed to stop angiogenesis (the growth of new blood vessels that feed tumors) by binding to and inactivating a protein called vascular endothelial growth factor (VEGF). Studies have shown that, when added to chemotherapy, bevacizumab can help extend the time until glioblastomas start growing again after surgery.





Tumor Treatment Fields

In 2011, the FDA approved Optune, a portable, wearable device designed to treat glioblastoma that recurs or progresses after receiving chemotherapy and radiation therapy. Electrodes placed on the surface of the patient's scalp deliver low-intensity electrical fields called "tumor treatment fields" (TTFs) to the site of the tumor, which disrupt the rapid cell division exhibited by cancer cells.

In 2015, Optune's FDA approval was extended to treat patients with newly-diagnosed glioblastoma. Following surgery and radiation, Optune is administered along with the chemotherapy drug temozolomide.

The Importance of Clinical Trials

Clinical trials are the standard by which we measure the worth of new treatments and the quality of life of patients as they receive those treatments. For this reason, doctors and researchers urge people with cancer to take part in clinical trials.

Your doctor can guide you in making a decision about whether a clinical trial is right for you. Here are a few things that you should know:

- Often, people who take part in clinical trials gain access to and benefit from new treatments.
- Before you participate in a clinical trial, you will be fully informed as to the risks and benefits of the trial.
- Most clinical trials are designed to test a new treatment against a standard treatment to find out whether the new treatment has any added benefit.
- You can stop taking part in a clinical trial at any time for any reason.

Treatments Being Studied

There is promising research being done on treatment approaches for glioblastoma, including:

- **Genomic drivers.** Researchers have intensified their efforts to learn more about the genomic drivers of brain tumors (the identification of genes that carry mutations). It is thought that a deeper understanding of this process can lead to the development of additional, more effective treatments. For example, one large study recently identified a gene called IDH1, which is often involved in the growth of glioblastoma tumors.
- **New ways to deliver chemotherapy.** When anti-cancer drugs are given in pill form or through a vein, they have to travel throughout the body before getting to the brain. As the drugs travel, they can cause side effects, such as nausea. Researchers continue to develop chemotherapy that can be delivered directly into the brain tumor itself. One technique that is being explored is “convection-enhanced delivery of chemotherapy,” in which doctors put one to four tiny tubes into a brain tumor and connect the tubes to a pump that delivers large doses of chemotherapy directly into the brain.
- **Radiation sensitizers.** These are drugs that get into the cells of a brain tumor and make them more likely to be treated successfully by radiation. As a result, doctors can use lower doses of radiation, reducing treatment side effects.
- **New targeted therapies.** In November 2016, a study was published suggesting that a protein called RSK2, which regulates cell growth, is heightened in many patients with glioblastoma, and can push malignant cells into the

surrounding healthy brain tissue. This discovery may help researchers develop new therapies targeting this protein.

Additionally, immunotherapy is an exciting area of research for the treatment of glioblastoma. The immune system is the body's natural defense against disease. But usually this system is not strong enough to stop tumor growth. A number of treatments intended to strengthen the immune system are being studied, including:

- **Vaccines**, designed to attack cancer cells bearing antigens (molecules that can suppress the body's immune system).
- **Immune checkpoint inhibitors**, drugs designed to remove the molecules which "shield" tumor cells from the immune system.
- **Monoclonal antibodies**, lab-generated molecules that target specific tumor antigens.

Researchers are hopeful that immunotherapy can have long-term benefits by keeping the immune system "supercharged" after therapy has ended.



Managing Treatment Side Effects

All cancer treatments can cause side effects. It's important that you report any side effects that you experience to your health care team so they can help you manage them. Report them right away—don't wait for your next appointment. Doing so will improve your quality of life and allow you to stick with your treatment plan. It's important to remember that not all patients experience all side effects, and patients may experience side effects not listed here.

Side Effects of Radiation Therapy

Changes to the skin are the most common side effects of radiation therapy; those changes can include dryness, swelling, peeling, redness, and blistering. If a reaction occurs, contact your health care team so the appropriate treatment can be prescribed. It's especially important to contact your health care team if there is any open skin or painful areas, as this could indicate an infection. Infections can be treated with an oral antibiotic or topical antibiotic cream.

Side Effects of Chemotherapy

The side effects of chemotherapy depend on the type and dose of drugs given and the length of time they are used, and can include:

- Fatigue
- Nausea or vomiting
- Hair loss
- Increased risk of infection (from having too few white blood cells)
- Easy bruising or bleeding
- Changes in memory or thinking
- Peripheral neuropathy (numbness or tingling in hands and feet)

Mouth sores (mucositis) are also a side effect of chemotherapy. Your doctor may recommend treatments such as:

- **Coating agents.** These medications coat the entire lining of your mouth, forming a film to protect the sores and minimize pain.
- **Topical painkillers.** These are medications that can be applied directly to your mouth sores.
- **Over-the-counter treatments.** These include rinsing with baking soda or salt water, or “magic mouthwash,” a term given to a solution to treat mouth sores. Magic mouthwash usually contains at least three of these ingredients: an antibiotic, an antihistamine or local anesthetic, an antifungal, a corticosteroid, and/or an antacid.

Chemotherapy can cause changes in the way food and liquids taste, including causing an unpleasant metallic taste in the mouth. Many people find that switching to plastic utensils helps. It may also help to avoid eating or drinking anything that comes in a can, and to use enamel-coated pots and pans for food preparation.

Side Effects of Targeted Therapy

Targeted therapy drugs don't have the same effect on the body as do chemotherapy drugs, but they can still cause side effects. Common side effects of targeted therapy include diarrhea, liver problems (such as hepatitis and elevated liver enzymes), problems with blood clotting and wound healing, and high blood pressure.

Managing Digestive Tract Symptoms

Nausea and vomiting

- Avoid food with strong odors, as well as overly sweet, greasy, fried, or highly seasoned food.
- Eat meals cold or at room temperature, which often makes food more easily tolerated.
- Nibble on dry crackers or toast. These bland foods are easy on the stomach.
- Having something in your stomach when you take medication may help ease nausea.

Diarrhea

- Drink plenty of water. Ask your doctor about using drinks such as Gatorade which provide electrolytes as well as liquid. Electrolytes are body salts that must stay in balance for cells to work properly.
- Over-the-counter medicines such as loperamide (Imodium A-D and others) and prescription drugs are available for diarrhea but should be used only if necessary. If the diarrhea is bad enough that you need medicine, discuss it with your doctor or nurse.
- Choose foods that contain soluble fiber—for example beans, oat cereals, oranges, and flaxseeds. High-pectin foods such as peaches, apples, oranges, grapefruit, bananas, and apricots can also help to avoid diarrhea.
- Avoid food high in refined sugar and those sweetened with sugar alcohols such as sorbitol and mannitol. Look for this low-calorie sweetener on food labels; the names of this type of sweetener usually end with the letters “ol.”

- Low fat food choices are less likely to cause diarrhea than fatty, greasy, or fried foods. The fats you eat should come from healthy sources, such as olive oil, canola oil, avocado, olives, nuts, and seeds.
- Limit or avoid lactose, especially if you are lactose-intolerant. There are plant-based milk alternatives you can try, such as soy or rice milk. If lactose is an essential part of your diet, there are dairy products with added lactase (which breaks down lactose) and dietary lactase supplements.

Managing loss of appetite

- To help maintain your weight, eat small meals throughout the day. That's an easy way to take in more protein and calories. Try to include protein in every meal.
- To keep from feeling full early, avoid liquids with meals or take only small sips (unless you need liquids to help swallow). Drink most of your liquids between meals.



- Be as physically active as you can. Sometimes, taking a short walk an hour or so before meals can help you feel hungry.
- Keep high-calorie, high-protein snacks on hand such as hard-boiled eggs, peanut butter, cheese, ice cream, granola bars, liquid nutritional supplements, puddings, nuts, canned tuna, or trail mix.
- Eat your favorite foods any time of the day. For example, if you like breakfast foods, eat them for dinner.
- If you are struggling to maintain your appetite, talk to your health care team about whether appetite-building medication could be right for you.

Managing Fatigue

Fatigue (extreme tiredness not helped by sleep) is one of the most common side effects of many cancer treatments. If you are taking a medication, your doctor may lower the dose of the drug, as long as it does not make the treatment less effective. If you are experiencing fatigue, talk to your doctor about whether taking a smaller dose is right for you.

There are a number of other tips for reducing fatigue:

- Take several short naps or breaks.
- Take short walks or do some light exercise, if possible.
- Try easier or shorter versions of the activities you enjoy.
- Ask your family or friends to help you with tasks you find difficult or tiring.
- Save your energy for things you find most important.

The Importance of Treatment Summaries

A treatment summary, sometimes called a “shadow chart,” is a document you create and which remains in your possession. Maintaining your own records allows you and your family members instant access to the specifics of your diagnosis and treatment. A treatment summary should include:

- Your name and date of birth.
- Date of diagnosis.
- Name, affiliation, and contact information of the doctor who gave the diagnosis.
- Prescribed therapy/therapies; include dates started and stopped, and dosages when appropriate.
- Dates and types of post-diagnosis testing, and the results.
- Other medication and supplements you are taking.
- Names, affiliations, and contact information of all members of your health care team.

Talk to your doctor or a member of your health care team about your intention to create a treatment summary, and ask them what else they suggest be included. Take your treatment summary with you when you visit any doctor, not just your oncologist.

Communicating With Your Health Care Team

As you manage your cancer, it's important to remember that you are a consumer of health care. The best way to make decisions about health care is to educate yourself about your diagnosis and get to know the members of your health care team, including doctors, nurses, dietitians, social workers and patient navigators.

In addition to creating a treatment summary, here are some tips for improving communication with your health care team:

Start a health care journal. Having a health care journal or notebook will allow you to keep all of your health information in one place. You may want to write down the names and contact information of the members of your health care team, as well as any questions for your doctor. Keep a diary of your daily experiences with symptoms related to your illness or treatment. You can separate your journal or notebook into different sections to help keep it organized.

Prepare a list of questions. Before your next medical appointment, write down your questions and concerns. Because your doctor may have limited time, you should ask your most important questions first, and be as specific and brief as possible.

Bring someone with you to your appointments. Even if you have a journal and a prepared list of questions or concerns, it's always helpful to have support when you go to your appointments. The person who accompanies you can serve as a second set of ears. He or she may also think of questions to ask your doctor or remember details about your symptoms or treatment that you may have forgotten.

Write down your doctor's answers. Taking notes will help you remember your doctor's responses, advice and instructions. If you cannot write down the answers, ask the person who accompanies you to do that for you. If you have a mobile device, ask if you can use it to take notes. Writing notes will help you review the information later.

Record your visit if your doctor allows it. Recording the conversation with your doctor gives you a chance to hear specific information again or share it with family members or friends.

Incorporate other health care professionals into your team.

Your oncologist and oncology nurse are essential members of your health care team, but there are other health care professionals who can help you manage your care:

- Your primary care physician should be kept updated about your glioblastoma treatment and any test results.
- Your local pharmacist is a great source of knowledge about the medications you are taking; have all of your prescriptions filled at the same pharmacy to avoid the possibility of harmful drug interactions.
- Make sure your oncologist knows of any other medical conditions you have, or any pain you are experiencing, so that he or she can consult with your primary care physician or your specialist if needed.

Remember, there is no such thing as over-communication. Your health care team wants to know about how you're feeling overall, which includes your level of pain, your energy level, your appetite, and your mood and spirits.



CancerCare's Free Support Services and Programs

It is very difficult to receive a diagnosis of glioblastoma, and adjusting to the necessary changes in your life can be challenging.

CancerCare can help. We are a national nonprofit organization providing free, professional services to anyone affected by cancer. Our licensed oncology social workers can provide support and education, help in navigating the complicated health care system, and provide information on support groups and other resources.

To learn more about how CancerCare helps, call us at 800-813-HOPE (4673) or visit www.cancercare.org.

You will likely also build your own personal support network, comprised of family and friends. In doing so, it's best to take some time to think about the people in your life and how they are best suited to help. Match the task to their strengths—ask a family member who loves to shop to pick up something for you at the store; ask a friend who's a good listener to come over for a chat.

Frequently Asked Questions

Q. I've just been diagnosed with glioblastoma. I know I should seek treatment at a cancer center with experience treating this type of brain tumor. What questions should I ask when I meet with a specialist?

A. The following questions are good to ask during your first meeting. Other questions, specific to your situation, will likely arise during your course of treatment.

- What are my treatment options?
- What are the risks and benefits of the recommended treatment?
- What research has been done on this treatment?
- What are the likely side effects?
- Do I have time to get a second opinion before starting treatment?
- Can treatment wait?
- What will happen if there is no treatment?
- At this center, who is the key nurse or doctor I can talk to if there's a problem?

Q. Does cognitive therapy have benefits for people with glioblastoma?

A. It is not uncommon for people being treated for glioblastoma to experience some degree of cognitive change, including problems with attention, memory, and information processing. Cognitive therapy (also called cognitive remediation) can help patients cope with and overcome these challenges. Cognitive therapy includes:

- Teaching strategies to help you carry out daily activities, such as using a notebook or daily planner.
- Using “task analysis”—breaking tasks into steps to make them easier to achieve.
- Incorporating attention-enhancing games and exercises, designed to improve retention and recall, into your daily life.



Q. Is it common for people with glioblastoma to have seizures?

A. It is not unusual for people with brain tumors, including glioblastoma, to have seizures. Many times, a seizure is what leads a person with an undiagnosed brain tumor to seek medical care. Seizures can also occur during treatment. To prevent seizures, doctors may prescribe an anti-seizure medication such as phenytoin (Dilantin and others).

Q. Can eating organic foods and taking nutritional supplements help treat brain tumors?

A. There is no scientific evidence that organic foods and nutritional supplements help treat brain tumors. But one of the best things a person with a brain tumor can do is eat as healthfully as possible and stay physically active. People who have not been particularly active can start by walking regularly. Be sure to talk with your doctor about how vigorous your activity should be. Also, be sure to tell your doctor about any vitamins, minerals, herbs, or other supplements you take. Some over-the-counter supplements can interact with medications, particularly anti-seizure drugs; other supplements may raise the risk of excess bleeding.

Notes

Resources

CancerCare®

800-813-HOPE (800-813-4673)

www.cancer.org

American Cancer Society

800-227-2345

www.cancer.org

Cancer.Net

Patient information from the American Society of Clinical Oncology

888-651-3038

www.cancer.net

National Cancer Institute

800-422-6237

www.cancer.gov

Cancer Support Community

888-793-9355

www.cancersupportcommunity.org

National Coalition for Cancer Survivorship

877-622-7937

www.canceradvocacy.org

American Brain Tumor Association

800-886-2282

www.abta.org

The Brain Tumor Foundation

212-265-2401

www.brainumorfoundation.org

CLINICAL TRIALS WEBSITES

Coalition of Cancer Cooperative Groups

www.cancertrials.org

EmergingMed

www.emergingmed.com

National Cancer Institute

www.cancer.gov

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