

WHAT YOU SHOULD KNOW ABOUT

Glioblastoma (GBM)

Learning the basics of glioblastoma

If you or someone you know has been diagnosed with glioblastoma (GBM), this brochure will provide information that can help you learn about the disease and focus on what matters most to you. Whether you have GBM or are helping to care for a loved one who was diagnosed with the disease, you are taking a positive step by learning and taking an active role in its treatment.

On the next pages, you will find information about GBM and suggestions on how to speak with your health care team. Remember to always discuss any questions you may have with your doctor and health care team, and keep this resource on hand to refer to as you gather important information throughout your journey.



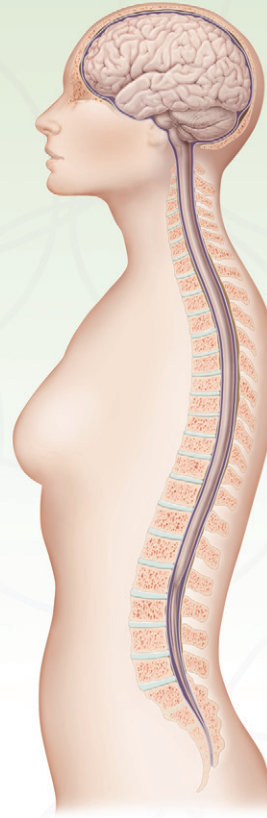
Your treatment glossary:

Boldface words are defined in a glossary on page 15. If there are words about your condition or treatment that you do not understand, ask your doctor or health care team to explain them further.

What is glioblastoma (GBM)?

Understanding your central nervous system

Understanding your central nervous system is key to helping you understand GBM. GBM is a mass of abnormal cells that has grown out of control to form a **tumor** in the central nervous system, which is made up of the brain and spinal cord. Both organs play important roles in controlling different functions of your body. The spinal cord, a long mass of nerves that extends down the spine from the brainstem, controls movement and sensation. The brain, a more complex organ, is a spongy mass of cells that is protected by the skull. It controls your emotions, thoughts, speech, physical coordination, vision, hearing, movement, and sensation.





Understanding GBM

Glioblastoma is also called grade IV astrocytoma or GBM. It is the most common type of **primary brain tumor** and is usually fast growing. Like most brain cancers, GBM can spread throughout the brain tissue but rarely spreads to other areas outside of the central nervous system.

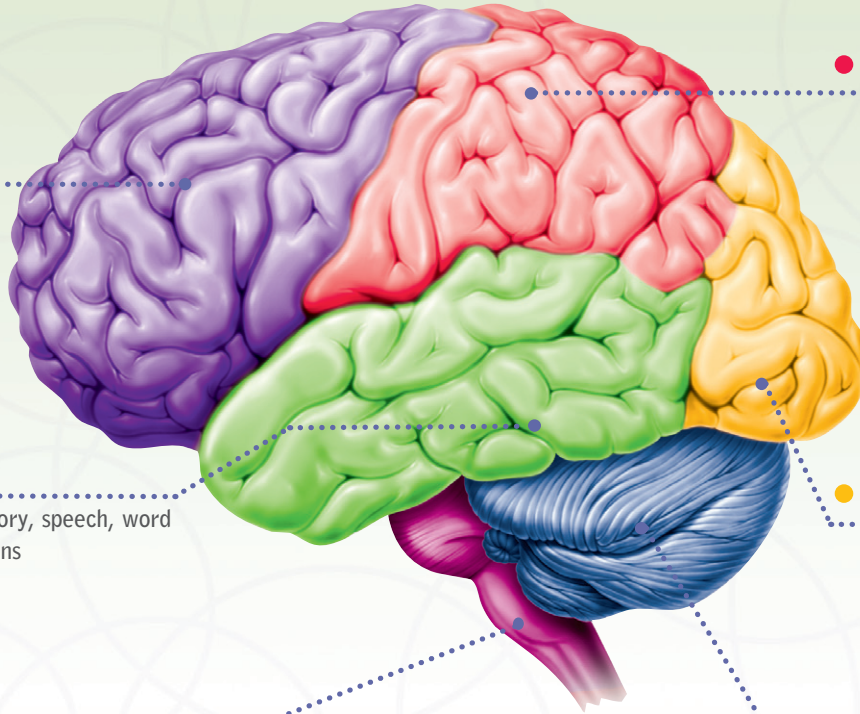
A common feature of fast-growing tumors is having many abnormal blood vessels. All GBM tumors have these blood vessels, which deliver necessary oxygen and nutrients to the tumor and help it grow and spread. GBM tumors are a challenge to treat because these abnormal blood vessels easily mix with normal brain tissue.

Understanding the symptoms of GBM

GBM can develop in any area of the brain. The brain is divided into 2 halves (left and right), called hemispheres. Each hemisphere is made up of different lobes and areas, which control different functions.

The first symptoms of GBM are usually due to increased pressure on the brain because the skull cannot expand in response to a growing tumor. These symptoms can include headache, nausea, vomiting, and drowsiness. Other symptoms you may experience, such as weakness, sensory impairment on one side of the body, seizures, memory or language problems, and visual changes, depend on the location of the tumor. As the brain tumor grows, it may interfere with the normal functions of that part of the brain.

Understanding the symptoms of GBM (continued)



● Frontal Lobe:

Responsible for reasoning, planning, judgment, emotions, parts of speech, movement, problem solving, memory, personality, behavior, and impulse control

● Temporal Lobes (left and right):

Responsible for hearing, memory, speech, word recognition, smell, and emotions

● Brainstem:

Responsible for breathing, blood pressure, heartbeat, and swallowing

● Parietal (pah-ri'e-t'l) Lobe:

Responsible for understanding and processing information (intelligence), reasoning, telling right from left, language, sensation (pain, touch, pressure, and temperature), and reading

● Occipital (ok-sip'i-t'l) Lobe:

Responsible for many aspects of vision, including color recognition

● Cerebellum (ser-ah-bel'um):

Responsible for balance, coordination, and fine muscle control

You're unique, and so is your cancer

Whether you have cancer for the first time, or cancer that has **relapsed**, you are unique, and so is your cancer. This means that you will need to talk about your health and personal goals with your doctor and health care team to make sure that you are getting the maximum benefit from each and every treatment you decide to take. Some factors that may influence the type of treatment you and your health care team decide to choose include:

- Size and location of tumor
- Age
- Your physical health
- Prior treatment
- Your personal and treatment goals



Your health care team wants to know

Your health care team, which includes your oncologist, your primary doctor, nurses, and your family members, plays a vital role in your treatment. When discussing and creating a plan to fight your tumor, **be sure to tell your health care team how you feel.** Let them know what you think about the therapies available to you. Every person approaches treatment differently, so try to work with your health care team to come up with the right plan for you.

Taking an active role

Even though you have GBM, you still have a life to live. Taking an active role means doing everything you can to feel better and to manage your treatment goals and plans. Here's how you can start:

- 1. Understand your treatment.** Know the anticancer treatments you are given and what to expect. Keep a record of your medicines, when to take them, and the possible side effects. Work with your doctor and health care team—ask questions so that you can understand how your medicines work. See the example questions on page 10 to get started.
- 2. Talk to your doctor about your treatment goals.** Share your medical history with your doctor, and share your goals for treatment. Some discussions may feel uncomfortable because you are sharing personal information, but being honest about what you want from your treatment can help ensure that you get the best treatment available for you.
- 3. Keep track of how you're feeling, and let your health care team know about it.** Keeping a notebook can help you understand how you are feeling and help you keep track of changes in your health. Write down any side effects you notice, and then talk to your doctor or nurse. Knowing how you're doing on treatment can help your health care team provide the best care for you.
- 4. Stay involved in all decision making.** Learn as much as you can about GBM by seeking out information or talking with other people with GBM. The following pages have contact information to help you learn more about GBM. Knowing more about your disease will help you and your health care team make the best possible treatment decisions for you.

Staying on therapy

Doing everything you can do to get the most out of your therapy includes following your treatment plan as closely as possible. This means sticking to your doctor's directions and staying on therapy for as long as needed.

If you experience a side effect that makes it difficult to stay on therapy, talk to your doctor or health care team about figuring out a way to make it easier. A member of your care team may be able to help you manage a side effect that bothers you or that does not go away, such as nausea or vomiting.



Questions to ask your health care team

Having open, honest discussions with your health care team means asking questions and understanding what will happen before, during, and after your treatments. Here are a few questions to help you get started:



1. Which treatments will I be receiving, and what will they do?
2. What can I do to take care of myself during treatment?
3. Should I change my diet?
4. What is the schedule of my treatments?
5. Where will I go for treatment?
6. How long will I be on each treatment?
7. How will I know if the treatment is working?
8. Which side effects should I look for?
9. Whom do I call if I want more information and support?

Caregiver: Taking care of yourself

Taking care of a loved one with GBM can produce a great deal of stress, worry, and anxiety for you. You probably want to do all you can to help. Your role is extremely important, and that's why it's just as important to take care of yourself and your own needs. Here are a few suggestions.

Delegate responsibilities

As one person, you can't do everything by yourself. Make things easier for yourself by asking family and friends to help out. Make a list of what needs to be done, and delegate responsibilities as needed. Consider each person's abilities, and assign tasks accordingly. This will allow you some time off from caregiving.

Learn to say no

Don't add unnecessary stress and work to your day. Learn to say no to added responsibilities. You may feel guilty at first, but it's important to think of yourself and stay strong for your loved ones. Be realistic about what you can handle, both physically and emotionally. Remember, you're only human.

Find the support you need

Remember, support can come in different ways—through a friend, online, or from a professional organization. Here are some suggestions for places to start your search for support.

National Brain Tumor Society

Provides a patient and caregiver support network, support groups across the country, and patient information about treatments, tumor types, and coping.
1-800-934-2873
www.braintumor.org

National Family Caregivers Association

Educates, supports, empowers, and speaks up for those who care for loved ones with a chronic illness or disability.
1-800-896-3650
www.thefamilycaregiver.org

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Support



Many people living with cancer find that they can learn and get the support they need when they read about cancer or talk to others who are also living with cancer. Remember that you are not alone in your fight against cancer. Here are some ways to connect with other people and get and give support:

- Join a support group, either in person or on the Web
- Volunteer to help others with GBM—offer your story
- Become a GBM educator or speaker
- Attend social events to meet other people who are living with GBM
- Ask a member of your health care team if you could call him or her for support. Calling a health care professional who has a strong presence in your care may help you stay connected and feel less alone

Where to find support groups and resources

Many national organizations offer local and online support groups for people with cancer and their family members or friends. Some places to start your search for a local group include:

American Brain Tumor Association*

Offers information and support to brain tumor patients and their families.

1-800-886-2282

www.abta.org

CancerCare*

Provides free professional help to people with all cancers through counseling, education, information, referral, and direct financial assistance.

1-800-813-HOPE (1-800-813-4673)

www.cancercares.org

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Cancer Support Community

Offers professionally led support groups, educational workshops, and mind/body programs to help cancer patients and their families.

1-888-793-WELL (1-888-793-9355)

www.cancersupportcommunity.org

National Brain Tumor Society*

Provides a patient and caregiver support network, support groups across the country, and patient information about treatments, tumor types, and coping.

1-800-934-2873

www.braintumor.org

Local hospitals and cancer clinics are also good sources for finding support groups. Doctors, nurses, or hospital social workers may have information about support groups such as their location, size, type, and how often they meet. Hospitals also have social services departments that usually provide information about cancer support programs.

Glossary

Primary brain tumor: The original tumor (eg, a primary brain tumor is one that first appears in the brain as opposed to a metastatic tumor, which would develop in a different location as a result of the spreading of the primary tumor cells). (See page 4.)

Relapse(d): The return of a tumor after a period of improvement. (See page 7.)

Tumor: An abnormal lump or mass of tissue, which can be cancerous or noncancerous. (See page 3.)

Some of the glossary definitions were adapted from the National Cancer Institute's *Dictionary of Cancer Terms*.

Resources

There are many resources with useful information for people with cancer and their families. Take advantage of all the information to help you learn more and stay well informed.

American Brain Tumor Association*

Offers information and support to brain tumor patients and their families.
1-800-886-2282
www.abta.org

American Cancer Society*

Cancer information services, community programs, and research and advocacy resources.
1-800-ACS-2345 (1-800-227-2345)
www.cancer.org

Cancer Support Community

Offers professionally led support groups, educational workshops, and mind/body programs to help cancer patients and their families.
1-888-793-WELL (1-888-793-9355)
www.cancersupportcommunity.org

National Cancer Institute*

Current information about cancer, clinical trials, and resources.
1-800-4-CANCER (1-800-422-6237)
www.cancer.gov

National Brain Tumor Society*

Provides a patient and caregiver support network, support groups across the country, and patient information about treatments, tumor types, and coping.
1-800-934-2873
www.braintumor.org

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