National Comprehensive Cancer Network®

2026

NCCN Guidelines for Patients®

Cancer care recommendations from leading experts at the National Comprehensive Cancer Network® (NCCN®)

Brain Cancer Glioma



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NCCN Guidelines for Patients®

The essential guide for people facing cancer.

Based on care recommendations from leading cancer experts.

Explains high-quality cancer care provided at state-of-the-art cancer centers.

Reviewed and revised every year.

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Because cancer care is always evolving, NCCN develops and frequently updates evidence-based cancer care recommendations used by health care providers worldwide. These recommendations are known as the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®).

The NCCN Guidelines for Patients plainly explain these expert recommendations, so you can talk with your care team about the best care for you.

These NCCN Guidelines for Patients are based on the NCCN Guidelines® for Central Nervous System Cancers, Version 3.2026 – August 17, 2026.

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About Glioma

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Being diagnosed with a brain tumor can be frightening and overwhelming. This guide will help you make sense of all the information that's out there. It will also describe your options for treatment. Gliomas can be challenging to treat, but treatment is improving.

What is a glioma?

A glioma is a type of tumor that occurs in the brain and sometimes the spinal cord.

Gliomas develop from cells that look like glial cells. Glial cells support the function of neurons (nerve cells) in the central nervous system (the brain and the spinal cord).

A tumor is an abnormal growth of cells. Many types of tumors can develop from cells in the central nervous system. Only those that look like glial cells become gliomas.

Gliomas start and grow in the central nervous system. It's rare for them spread to another area of the body.

What makes gliomas so complicated is that they invade and blend into the normal parts of the brain. So gliomas can be very difficult to treat without harming the healthy parts of the brain.

Gliomas are the most common type of malignant (cancerous) brain tumor in adults. Gliomas can happen at any age but occur more often in adults than in children.

Normal cells vs. cancer cells

Normal cells follow the body's rules. Normal cells increase in number only when they're needed and die when they're old or damaged.

Cancer cells don't follow the rules. Cancer cells can multiply quickly and avoid dying. Cancer cells can crowd out normal cells and take their place. Eventually this damages the body and often results in symptoms.

What causes a glioma?

No one knows exactly what causes most brain tumors, including gliomas.

What experts do know is that brain tumors often start with an abnormality (mutation) in certain cells. This abnormality causes these cells to grow out of control (become cancerous).

This type of mutation happens on its own. It's not typically passed down in families (hereditary mutation).

Gliomas occur in both children and adults. This book discusses gliomas only in adults.

Are there different types of glioma?

There are several types of glioma tumors. The 3 most common types are astrocytomas, oligodendrogliomas, and glioblastomas. They're made of different kinds of glial cells.

- **Astrocytomas** start in star-shaped glial cells called astrocytes. The main job of astrocytes is to maintain the chemical environment that allows communication between nerve cells.
- **Oligodendrogliomas** begin in oligodendrocytes, which are glial cells that protect electrical signaling in nerve cells.
- **Glioblastomas** come from the same immature cells that give rise to normal brain cells. However, the immature glioma cells are defective. Glioblastomas are the most aggressive type of glioma.

Besides tumor type, gliomas are also categorized by grade. The grade indicates how fast the tumor is likely to grow. The higher the grade, the more rapidly the glioma tends to grow.

Although it helps to put gliomas into categories, it's important to note that each glioma can have its own different molecular characteristics and behavior. That also means that each person's glioma is unique. The glioma's individual characteristics and behavior will factor into your progress and experience.

Survival statistics may not reflect improvements offered by today's diagnostic tests and treatments.

Gliomas often occur in the upper part of the brain where they can disrupt important brain functions.

Most gliomas in adults have an indistinct shape with vague borders. They blend deeply into normal brain tissue and look blurry on imaging scans. This makes them very difficult to remove entirely.

When the tumor is removed, some tumor cells must be left behind to avoid damaging nearby brain tissue.



How are gliomas treated?

The main treatments for a glioma are surgery, radiation therapy, and chemotherapy. These are often combined with one another for more complete treatment.

Another option is participating in a clinical trial for a potential new treatment.

Treatment may be able to stop the glioma from growing for a period of time, reduce its symptoms, and prolong life. Treatment may last for months or years, and surgery may eliminate certain well-defined gliomas for life.

However, many gliomas blend into the brain tissue and appear indistinct on imaging scans. They cannot be entirely removed and may eventually come back or continue growing. So periodic follow-up visits and additional rounds of treatment are essential.

Many people diagnosed with a glioma have a difficult road ahead. Still, there's hope. In the past few years, experts have learned a lot about the molecular alterations and genetic mutations of gliomas. Nowadays, glioma tumors are routinely tested for these alterations and mutations. This information can help personalize the diagnosis and treatment.

Meanwhile, new therapies designed to treat specific types of gliomas are currently being studied in clinical trials. The number of these trials has increased in recent years, offering more hope to people living with this disease.

Also, current survival statistics come from research done several (or many) years ago. Those statistics may not reflect the improvements offered by today's diagnostic tests and treatments.

How this guide can help you

Making decisions about cancer care is stressful. There's a lot to learn, and you don't know what the future holds.

Use this guide to get the information and support you need.

Patients, doctors, and other health care professionals trust the NCCN Guidelines for Patients. This guide uses clear, everyday language to explain current cancer care recommendations made by respected experts in the field. Their recommendations are based on the latest research and practices at leading cancer centers.

Your health is unique to you, so your cancer care should be, too. As you read this guide, you'll learn which treatments are likely to provide the best results for you. And you'll be better prepared to talk with your care team.

How can I get the best care?

Advocate for yourself. You have an important role to play in your care. Many people feel more satisfied when they actively take part in planning their cancer care.

The NCCN Guidelines for Patients will help you play a larger role in your care. Discuss the recommendations in this guide with your care team. Ask questions about your options and share your goals and concerns.

Don't know what to ask? You're not alone. That's why we include suggested questions to ask at the end of chapters.

Keep reading to find the best care for you.



We want your feedback!

Our goal is to provide helpful and easy-to-understand information on cancer. Take our survey to let us know what we got right and what we could do better.
NCCN.org/patients/feedback

"Try to remember that everyone's journey is different. Your physiological, mental, emotional, and spiritual response is unique."

A message to caregivers and loved ones

This guide is for you, too. It will help you understand this disease and the challenges it presents. People with tumors in the central nervous system (the brain and spinal cord) commonly develop problems with brain function. This can show itself in multiple ways, such as slower thinking, memory loss, difficulty moving or walking, trouble speaking, inability to do everyday activities, changes in behavior, losing one's sense of self, and other problems.

Helping a person with a brain tumor can be challenging and time-consuming. You may be providing physical, mental, emotional, and hands-on support. You may be taking the patient to appointments, helping to lessen side effects, and even assisting with treatment decisions.

Gather as much help as you can. Start with the online resources listed in the back of this guide.

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Different tests are needed to find out whether you have a glioma and what type it is. Testing also suggests what kind of therapy is most appropriate for you.

You'll need a variety of tests to diagnose a brain tumor and to make a treatment plan. (If you've already had testing and received a glioma diagnosis, you can turn to *Chapter 3: Types of treatment* to read about your treatment options.)

Testing begins with an examination of your general health and an evaluation of your symptoms. Bring someone with you to listen, ask questions, and write down the answers.

Your care team needs to have all of your health information. They'll ask you about any health problems and treatments you've had. Be prepared to talk about any illness or injury you've had and when it happened.

You can also ask questions of your doctor and care team to make sure you understand your treatment plan.

Bring a family member or friend to take notes during your visits. Loved ones often want to help but aren't sure how. You might be surprised how many are happy to share visits with you.

Diagnosis vs. prognosis

Diagnosis: The identification of an illness based on tests. The diagnosis names what illness you have.

Prognosis: The likely course and outcome of a disease. The prognosis predicts how your disease will turn out.

How are gliomas diagnosed?

A glioma is often found when it starts causing symptoms. Symptoms provide clues that something may be wrong.

Each part of the brain has its own job to do. Different parts of the brain manage different parts of the body. Symptoms occur when an area of the brain isn't working properly.

Symptoms are often related to the location and size of the tumor. Be sure to tell your doctor and care team about any and all symptoms you're having, even if they seem unrelated.

Symptoms

Symptoms develop as the glioma grows against, or weaves itself into, a part of the brain. This growth can cause swelling (edema) and pressure on the brain tissue around the tumor. Sometimes a tumor blocks the flow of fluid (cerebrospinal fluid) in and around the brain.

Common symptoms include:

- **Headaches** – Headaches are very common and are often the first symptom in people with a glioma. They can be worse in the morning, wake you up in the middle of the night, and occur with nausea and vomiting.
- **Seizures** – Seizures are also common in people with brain tumors. They are often an early sign of a glioma, especially low-grade gliomas.
- **Fatigue** – Fatigue is another common symptom of a glioma. It can be debilitating, frequent, emotionally overwhelming, and not related to how much sleep you get or how active you are. However, physical activity or exercise can sometimes help.
- **Nausea and vomiting** – Nausea and vomiting can be caused by the tumor putting increased pressure on the brain.
- **Problems with thinking and speech** – Examples of problems with thinking and speech include confusion, memory loss, and speech difficulties.
- **Weakness or problems moving** – People with a brain tumor may have muscle weakness on one side of the body, or difficulty with walking or balance.
- **Changes in personality or mood** – Changes in behavior, mood, and personality can occur in people whose tumors are located in parts of the brain that control mood and personality.

“Fatigue is more than just being tired. It can be physical, cognitive, or emotional. It can be created from external sources, such as noise, or internal sources, such as medication, not eating properly, or not getting enough exercise.”

Other symptoms also sometimes occur. Gliomas can cause vision problems, such as blurred vision, double vision, or loss of peripheral (side) vision. Sensory disturbances include numbness, tingling, or burning sensations, often on one side of the body.

Some people have many symptoms while others don’t have any. Low-grade gliomas generally grow slowly and can develop for years before causing symptoms. Some people with low-grade gliomas never have symptoms.

High-grade gliomas can cause a range of symptoms. These gliomas can grow quickly, developing in months or even weeks. High-grade gliomas are linked to blood clots in the legs and the lungs, which can cause leg swelling, chest pain, and shortness of breath.

However, symptoms can also be caused by medical problems other than tumors. So for the most accurate diagnosis, different tests, physical exams, and surgical procedures are required.

Neurological exam

A neurological exam involves some simple tests to check your alertness, thinking, balance, coordination, reflexes, strength, hearing, and senses of touch and smell. You may also have an eye exam to check the health of the nerves in the back of your eyes.

Performance score

Your team will want to know how well you can do ordinary day-to-day activities—like working, taking a walk, climbing stairs, cooking dinner, carrying laundry, or taking a bath or shower. They'll also want to know how much time you're inactive—when you're lying down or sitting.

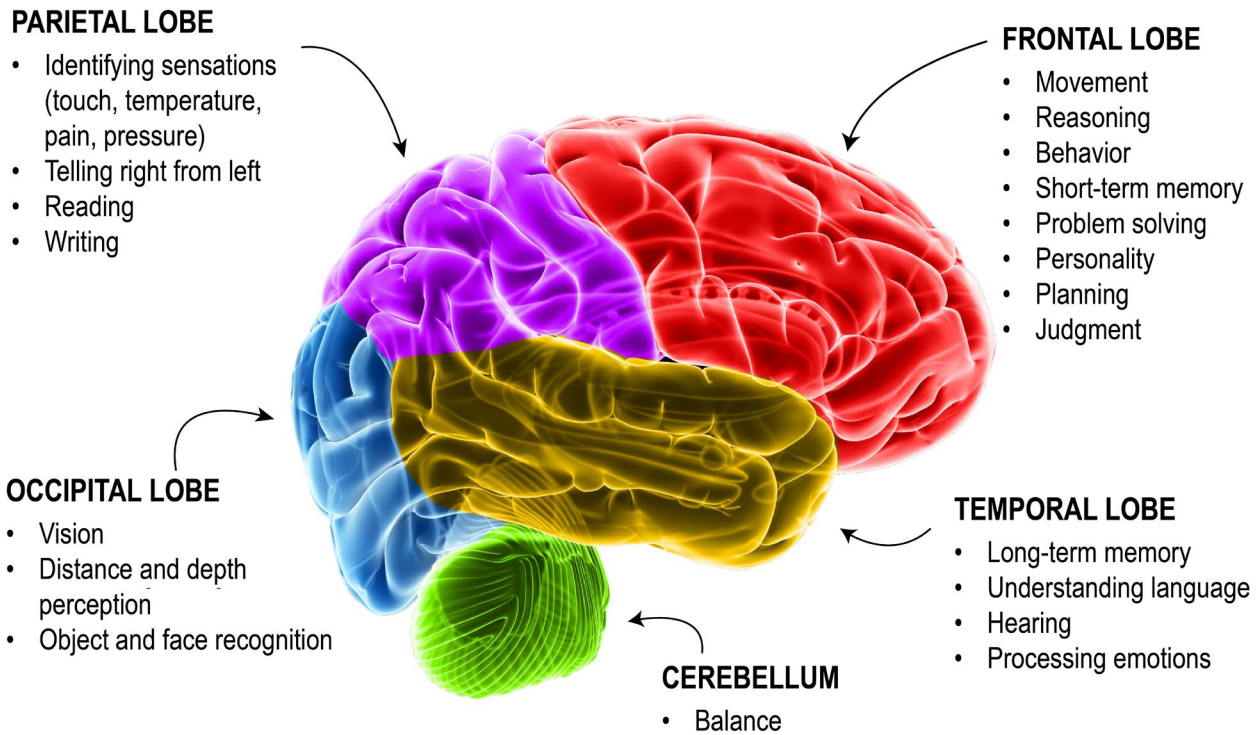
This evaluation is called performance score (or status). The more activities you can do, the better your performance score.

Your care team uses this evaluation to get a sense of the intensity of treatment you may be able to handle and whether you may be eligible for a clinical trial.

Imaging

If you have signs or symptoms of a brain tumor, your care team will want to try to find it and see what it looks like. This is where imaging comes in.

Areas of the brain and their functions



Imaging tests are used to take pictures (images) of the inside of your body. The images can reveal a tumor's location, size, and other features.

MRI

Magnetic resonance imaging (MRI) is the most useful imaging test for identifying a glioma. MRI scans are good at showing the soft tissues, including the brain, as well as other details that help plan surgery.

MRI uses a magnetic field and radio waves to take pictures of the inside of the body. During an MRI, you'll lie on a table that slides into the scanning machine. (An open MRI scanner may be an option at some health care centers.)

It's important to lie still during the test to get the best pictures. You may be given a padded head brace or other devices to help you stay motionless. The machine makes loud noises, but you can wear earplugs and listen to music.

You'll have multiple MRI tests throughout diagnosis and treatment. MRI is also used after treatment to see how well the treatment worked. You'll have more MRIs during follow-up to watch for recurrence or new growth.

CT

If MRI is unavailable or not recommended for you, you might have a computed tomography (CT or CAT) scan instead. A CT scan uses x-rays to take many images of your body from different angles. A computer then combines the pictures to make a series of cross-sectional images of your brain.

Do you have scanxiety?

Most people with cancer feel dread and anxiety before getting an imaging scan—and often feel even more worried afterward while waiting for the imaging results. Some people have anxiety during the scan itself.

This anxiety is very real and very common. It stems from the fear of getting bad news.

If you feel this way, tell your doctor or care team. They can offer ways to reduce the stress before and after scanning. You may still feel anxiety, but you'll have strategies to keep it under control. Just knowing that there's a name for it, and that most people with cancer also suffer from it, can give you a leg up.

After imaging

After the MRI or CT scan, your images will be studied by a radiologist, an expert in analyzing images of the nervous system. The radiologist will convey the imaging results to your care team. This information helps your team plan what the next steps of your care should be.

If your images seem to show a glioma, the next step may be a biopsy.

Biopsy

If imaging scans show something that may be a glioma, your care providers will usually want to take a sample and evaluate it. A surgical procedure that removes a small piece of tissue for testing is called a biopsy.

A tumor biopsy is the most reliable way to get an accurate diagnosis of your condition. Analysis of the biopsy tissue gives your care team clues on how to treat your tumor.

Resection

A surgical procedure called a resection does double duty as both a biopsy and a treatment.

In a resection, your neurosurgeon (an expert in surgery of the nervous system) will attempt to remove (resect) the entire tumor, or remove as much of it as can be done safely. Removing the tumor can relieve symptoms and help you live longer. Also, a large sample of the tumor can be tested to give the most complete pathology results.

Sometimes a resection isn't possible. This happens when the glioma is in a difficult place to reach or is located in a vital (essential) part of the brain. In these cases, your provider will schedule a biopsy.

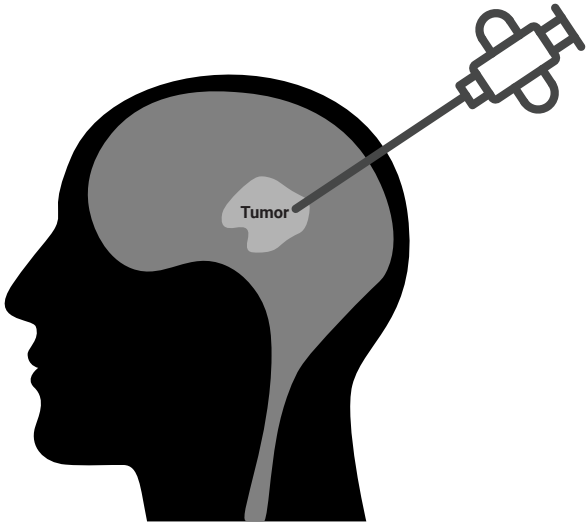
There are 2 types of standard biopsies for gliomas: stereotactic biopsy and open biopsy.

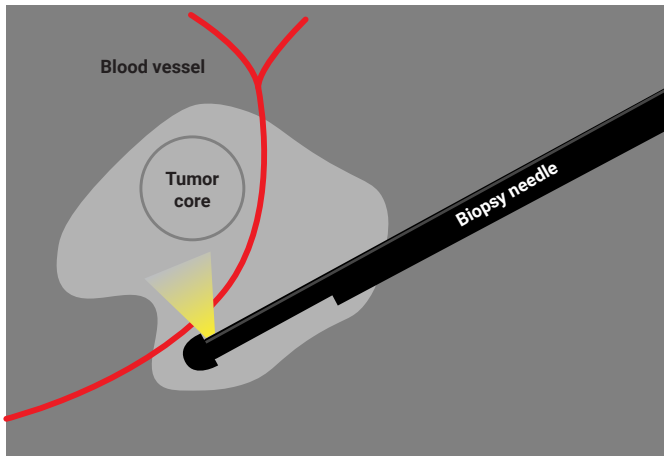
Stereotactic biopsy

This is a very precise procedure that's often used when a brain tumor is in a hard-to-reach or vital area. It aims to remove only enough of the tumor to make a diagnosis.

Stereotactic biopsy

A stereotactic biopsy is one way to obtain tumor tissue to diagnose a glioma. In this procedure, a thin, hollow needle is inserted into the brain to remove a sliver of the tumor. The sample is sent to a lab to be tested for cancer cells.





A stereotactic biopsy is done by a neurosurgeon in an operating room. First, you'll be fitted with a frame or several tiny markers around your head to aid the surgery. Next, you'll be given anesthesia to go to sleep. A small area of your hair will be trimmed down to the scalp.

The neurosurgeon will then make a small opening in your skull and then insert a thin, hollow needle into the brain to remove a sliver of the tumor. A computerized navigation system, connected to MRI or CT imaging, will allow the surgeon to target and remove the sample with a high degree of precision.

After removal, the opening in your scalp will be closed with sutures. You may be able to go home the next day.

Open biopsy

Like a resection, an open biopsy is a surgical procedure that involves making a small opening in the skull (craniotomy).

First, you'll be given anesthesia that will let you sleep through the procedure. Your neurosurgeon will cut open a section of your scalp and then remove a piece of skull bone.

Using small surgical knives and other special instruments, the neurosurgeon will carefully remove a piece or pieces of the tumor. The segment of skull bone will be replaced and the incision will be sewn up.

Lab testing

After any type of biopsy, the tissue sample will be sent to a laboratory for analysis. A specialist called a neuropathologist will examine the tissue under a microscope.

Sometimes, the sample is taken straight to the neuropathologist while you're still in the operating room. The neuropathologist will perform an analysis right away and send the results back to the neurosurgeon.

The results may also include the preliminary diagnosis, including the type and grade of the glioma. Knowing the preliminary diagnosis during your surgery helps the neurosurgeon decide how much of the tumor to remove.

The neuropathologist will also do molecular (genetic) testing on the sample, which indicates the type and growth rate of the glioma and other specific features.

All this information will help your care team figure out the best treatment plan for you.

If your hospital or medical center doesn't have a neuropathologist, you can ask to have your biopsy sent to one.

Your tumor type

If molecular testing was done on your biopsy sample, the pathology report should reveal your tumor type. It's important to identify the exact type of tumor you have to predict the course of your disease and plan your treatment.

You can classify a glioma by its histology, grade, and biomarkers. Let's look at each of these classifications in turn.

Histology

Histology is a way to classify a tumor by looking at it under a microscope and seeing what cells make up the tumor.

Gliomas are classified by the glial cells that they resemble. For example, a glioma with cells that look like astrocytes is likely to be an astrocytoma. A glioma with cells that look like oligodendrocytes is probably an oligodendroglioma.

Grade

Another way to classify a tumor is by grade, which is a rating of how abnormal its cells are. The grade indicates how quickly the glioma is likely to grow and spread. The more abnormal its cells, the faster and farther the tumor is likely to grow.

Grades are used to predict the outlook (prognosis) of the tumor and to plan treatment.

Gliomas are graded from 1 to 4 based on their microscopic features and, for some tumors, their molecular findings. The grade estimates how aggressively the tumor is likely to behave.

Low-grade gliomas include grades 1 and 2. **High-grade gliomas** include grades 3 and 4.

- **Grade 1** tumors grow slowly and are considered benign (not cancerous). Many people with grade 1 gliomas can be treated with surgery alone. But if the tumor grows back, additional therapy may be given. Grade 1 gliomas are more common in children than in adults.
- **Grade 2** tumors grow slowly and may invade normal tissue. They may not grow back for many years. A grade 2 diffuse (not well defined) glioma can come back as a grade 2 glioma, or it may progress over time to a higher-grade glioma.
- **Grade 3** tumor cells quickly increase in number and invade nearby tissue. All high-grade tumors (grades 3 and 4) require additional therapy—like radiation and chemotherapy—after surgery.
- **Grade 4** tumors grow and spread very quickly. Glioblastomas are the most common grade 4 gliomas. They're typically treated with radiation and chemotherapy.

Biomarkers

A glioma is also identified by its biomarkers. A biomarker is something found in the body that's a sign of a condition, disease, or abnormality. Tests for biomarkers provide more details about the glioma tumor.

In cancer care, biomarker testing looks for changes in genes, proteins, and other markers. Many of these changes are called mutations. A mutation is an abnormal change in your DNA—your body's genetic instructions. A mutation can disrupt how some cells behave, which can cause diseases like cancer.

Each type of glioma has its own biomarker or set of biomarkers. For example, an astrocytoma may have a mutation in the *IDH* gene. So it would be called an *IDH*-mutant astrocytoma.

The results of biomarker testing can be used to improve the accuracy of your diagnosis, to help determine your prognosis, and to fine-tune your treatment. If testing detects a certain mutation, you might be able to receive treatment that's targeted more precisely to your glioma.

Right now, only a few targeted treatments are available for very specific kinds of glioma. But researchers are working on hundreds of clinical trials to find more.

The biomarkers listed in **Guide 1** aren't the only biomarkers of gliomas, but they're the most commonly tested. Finding these biomarkers (or not finding them) can provide specific information about your glioma.

Guide 1
Biomarkers that identify specific gliomas

Each type of glioma is identified by the biomarkers it has (✓), those it doesn't have (✕), as well as some biomarkers that the tumor may or may not have and/or aren't needed to diagnose the tumor (±). A blank space means that biomarker doesn't apply to that tumor.

	Oligodendroglioma grade 2 or 3	Astrocytoma grade 2 or 3	Astrocytoma grade 4	Glioblastoma grade 4
***IDH1* or *IDH2* mutation**	✓	✓	✓	✕
1p/19q co-deletion	✓	✕	✕	
***ATRX* mutation**	✕	±	±	
***TERT* promoter mutation**	✓	✕	✕	✓
7 gain/ 10 loss				✓
***EGFR* mutation**				✓*
CDKN2A/B		±	✓**	

*The specific mutation is *EFGR* amplification.
**The specific mutation is homozygous deletion of *CDKN2A/B*.

For example, high-grade gliomas are commonly tested for **MGMT promoter methylation**. Finding this biomarker is important for predicting the glioma's response to treatment. Specifically, temozolomide chemotherapy tends to work better and leads to longer survival in a glioma with an MGMT promoter that's turned off (methylated) than in one with an MGMT promoter that's turned on (unmethylated).

Ask if any biomarker testing is available for your glioma. Some hospitals and treatment centers aren't able to provide a full range of biomarker tests. In that case, you can request your tissue sample to be sent to another lab for biomarker testing.

When these 3 classifications—histology, grade, and biomarkers—are put together, it provides a full description of the glioma. For example, an "*IDH*-mutant astrocytoma grade 2" names its biomarker (*IDH*-mutant), its cell type (astrocytoma), and its growth rate (grade 2).

Biomarkers of specific gliomas are explained further in upcoming chapters.

What's next?

After you've been diagnosed and have gone through further testing, your care team will discuss your results with you. They'll also talk about your options for treatment based on your test results.

The next chapter discusses the different options for treating gliomas.

> **"Brain tumors are insidious because the symptom burden can feel like an attack on the very nature of the self, including personality changes, language and memory impairment, physical impairment, and poor prognosis."**

Key points

- Gliomas are diagnosed with a surgical biopsy or a resection.
- Symptoms of a brain tumor are related to its location as well as its size. Symptoms develop as the glioma grows against and into the brain tissue.
- Imaging tests are used to help with diagnosis, treatment planning, and assessing treatment results. Imaging scans can identify a tumor's location, size, and other features.
- The most common imaging test for gliomas is an MRI, or magnetic resonance imaging.
- A neuropathologist will inspect a tissue sample from your biopsy under a microscope. This can confirm whether you have a glioma and what type it is.
- Low-grade tumor cells grow very slowly and may not come back for years after surgery. High-grade tumor cells look very different from normal cells and typically grow very quickly.
- Biomarker testing analyzes the glioma for abnormal changes in genes, proteins, and other markers. Biomarker testing is needed for a final diagnosis as well as for fine-tuning your treatment plan.

Questions to ask

- What tests will I have?
- Do the tests have any risks?
- Where will I go for testing, and how long will it take?
- Do you offer genetic testing for tumors? If not, where do you refer patients for genetic testing of the tumor?
- How soon will I know the results and who will explain them to me?



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Treatment options vary depending on the cell type, grade, and size as well as the location of the tumor. Your care team will explain the benefits and risks of all your available options.

This chapter explains all the possible treatments for the tumors described in this guide. Further chapters explain which of these treatments are appropriate for particular types of tumors.

There are many ways to try to treat a glioma, but none are perfect. The first treatment is usually surgery to remove as much of the tumor as possible or to biopsy the tumor.

Next, you may have radiation therapy and chemotherapy to destroy the tumor cells left behind. For example, surgery may remove the majority of the tumor. Then radiation therapy can attack what's left of the tumor cells.

Surgery

The first aim of surgery is to safely remove as much of the tumor as possible (resection). In general, the more tumor that's removed, the better your prognosis.

Surgery may also relieve pressure inside the skull and lessen seizures or other symptoms that are hard to control.

Another aim of surgery is to confirm the diagnosis. During surgery, tissue is removed from the tumor and tested to confirm whether it's a glioma and, if so, what type of glioma it is.

A neurosurgeon (an expert in surgery of the nervous system) will do your surgery. Deciding which procedure to perform is a complex and difficult decision. Should it be a resection, a partial resection, or a biopsy? Is surgery even possible? Not all people with gliomas will be able to have surgery.

The neurosurgeon will talk with your multidisciplinary team, and they'll consider many factors:

- Your age
- Your performance score
- Expected tumor type and grade
- How close the tumor is to "eloquent" areas of the brain
- Whether the surgery might relieve pressure on the brain
- Whether the tumor can be easily and safely removed
- The time since your last surgery (for people with a recurrent glioma)

Eloquent areas of the brain are those that control important functions like speech, vision, hearing, and movement.

Damage to an eloquent area can impair the related function in the body. This is why surgeons must be careful about how much tissue they remove.

Resection

Resection is a major surgery that removes a large piece of tissue. In a **full resection** (also called a gross total resection), the neurosurgeon removes all of the tumor that can be detected with imaging.

A full resection offers a better chance for fewer symptoms and a longer life.

A **partial resection** removes part of the tumor. This may be the best option if the entire tumor can't be removed safely.

You may need to be awake during part of the operation so that the key brain areas can be found. You'll still be given some anesthesia to help you relax during an awake surgery.

The surgeon will use a small drill to remove a piece of your skull (craniotomy). A cut into your brain may be needed to reach the tumor.

This is a delicate and precise operation. Surgeons often use computers programmed with MRI or CT scans of your tumor to guide the surgery. This technology is like a GPS for your brain. It helps the surgeon precisely locate and carefully remove as much tumor as possible without removing nearby brain tissue.

After the tumor is removed, the small piece of your skull will be replaced, and you'll be given time to recover. You'll have another MRI or CT the day after the surgery to confirm how much of the tumor was removed.

For most gliomas, microscopic tumor cells that can't be seen, even with imaging systems like MRI, remain in the tissue outside the tumor. So some tumor cells are almost always left behind after the tumor is removed.

What is awake surgery?

You may need to be awake during part of the operation if your tumor is located near parts of the brain that control senses, movement, or speech. The neurosurgeon will stimulate these functional areas while asking you questions.

You'll be conscious but given local anesthesia and a light sedative so that you won't feel pain.

To locate areas for movement, the surgeon may ask you to wiggle your toes or your fingers. To identify language areas, you may be asked to count out loud or perform other speech tests. This lets the surgeon know what tissue can be taken out and what needs to stay.

After the tumor tissue is removed, you'll be sedated for the rest of the operation.

"Go to a hospital that specializes in brain tumors."

Radiation therapy

You may be given radiation therapy after you recover from surgery to try to destroy any glioma cells that remain. Radiation therapy is used to treat both fully resected and partially resected tumors.

Radiation therapy is typically used to treat grade 3 and 4 gliomas, including glioblastomas, as well as some lower-grade tumors with certain risk factors.

Radiation therapy focuses high-energy x-rays on tumor cells. The radiation is delivered to the tumor area, and any nearby areas likely to have glioma cells, to damage the tumor DNA inside the cells. This either kills the tumor cells or stops new tumor cells from being made.

You won't see or feel the radiation. It passes through your skin and other tissues to reach the tumor.

A radiation oncologist—an expert in using radiation to treat cancer—will manage your radiation treatment. Your radiation oncologist will use methods that avoid and lessen the risk of harm to normal brain tissues. Your radiation plan will be tailored to you, your tumor, and your brain.

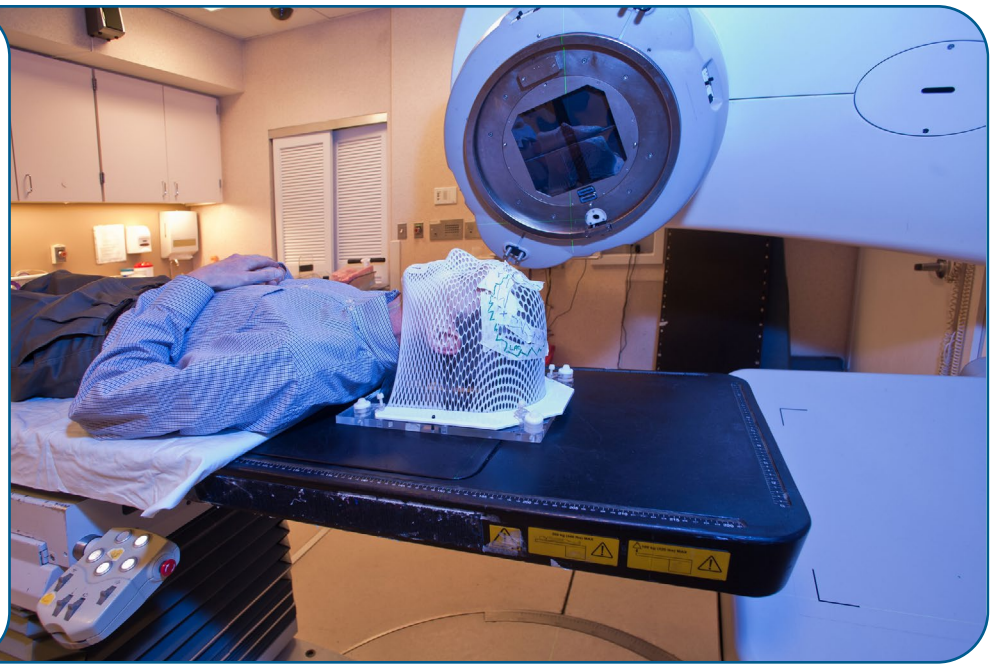
Receiving radiation

During treatment, you'll lie on the treatment table and be told how to get into the position needed for treatment. You must remain completely motionless during radiation treatment.

You'll be fitted with a special head mask to help you hold still. Other devices or techniques may also be used to help position you accurately and help you remain in position during the treatment.

Radiation therapy

To receive radiation therapy, you may be fitted with a mesh mask to help hold your head still. While you stay still during treatment, the radiation machine moves around you.



The total dose of radiation is spread out over a number of treatments (fractions). The number of treatments varies among patients. Treatments are usually given once a day, up to 5 days a week, for 5 to 6 weeks. Depending upon the circumstances, other treatment schedules may be used.

One session takes about 15 to 30 minutes. Half of the session is used to confirm that you're in precise position every day, with only a few minutes of actual radiation time.

Your radiation oncologist will see you every week to check in.

Side effects of radiation

Your radiation oncologist will discuss the possible side effects of radiation. These side effects differ among people.

Factors like the amount of swelling in the brain, tumor location, radiation dose, length of treatment, and other factors all play a role. Side effects are cumulative, meaning they intensify over the course of treatment.

The most common side effect of radiation is tiredness despite sleep (fatigue). You may also have hair loss or mild irritation on your scalp where treatment was applied.

Other side effects of radiation include swelling (which may feel like pressure inside your head), headache, and sometimes nausea or loss of appetite.

Less common side effects include seizures, hearing loss, speech or memory problems, and worsening of symptoms you had before treatment started.

Possible long-term side effects include a decrease in mental functioning. Your multidisciplinary team will work with you to treat these problems and to help minimize the risk of them.

These aren't the only side effects of radiation. Ask your care team for a complete list of common and rare side effects.

If a side effect bothers you, tell your care team. Your doctor can prescribe medications to manage side effects and help you feel better. There are also ways to prevent some side effects.

Chemotherapy

Chemotherapy uses drugs to damage and destroy rapidly dividing cells throughout the body. Because tumor cells divide and multiply rapidly, they're a good target for chemotherapy.

Chemotherapy can harm healthy cells, too. That's why it can cause side effects.

Receiving chemotherapy

A single chemotherapy drug or a combination of drugs can be used for treatment. Temozolomide (Temodar) is a standard single chemotherapy drug for glioma.

A combination of drugs is sometimes chosen because these drugs work better when they're used together. A common drug combination treatment for certain gliomas is procarbazine, lomustine, and vincristine (or PCV).

Chemotherapy is usually given in combination with radiation therapy. The timing of chemotherapy is based on the tumor's grade and growth rate, your health and performance score, the success of surgical tumor removal, and other factors.

Your neuro-oncologist or medical oncologist will discuss your chemotherapy options with you.

Chemotherapy is given in cycles. One cycle involves a few days of treatment followed by several days of recovery. The cycles vary in length depending on which drugs are used. Common cycles are 14, 21, or 28 days. Having chemotherapy in cycles gives your body a chance to recover after receiving the treatment. If you're going to have chemotherapy, ask your medical oncologist how many cycles there are and how many days of treatment are in each cycle.

Some chemotherapy drugs are given through an intravenous (IV) infusion into a vein in your arm or another part of your body. Other chemotherapy drugs (like temozolomide) can be taken as a pill.

One chemotherapy drug, carmustine (Gliadel), is given as a dissolvable implant called a wafer. It must be placed inside the brain at the time of surgery. Each wafer is about the size of a dime. Up to 8 wafers may be used.

The wafers are placed into the brain during total resection, in the space where the tumor had been. The implants dissolve over time, letting out chemotherapy little by little. They destroy the leftover tumor cells in the surrounding tissue with fewer side effects expected than with standard chemotherapy.

Be aware that this treatment is only for high-grade gliomas as an additional (adjuvant) therapy after your initial therapy. Also know that receiving this treatment may disqualify you from joining a clinical trial.

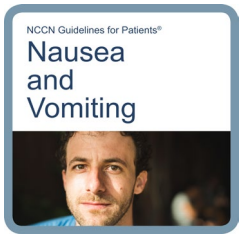
Side effects of chemotherapy

The side effects of chemotherapy depend on many things. These include the drug, the amount taken, the length of treatment, and the person. Some people have many side effects. Others have few.

Some side effects can be very serious. Others are not serious but are still unpleasant. Most side effects appear while you're having treatment then stop after treatment is over. Other side effects are long-term or may even appear years later.

Common side effects of chemotherapy include low blood cell counts, not feeling hungry, nausea, vomiting, diarrhea, hair loss, fatigue, and mouth sores. Ask your neuro-oncologist or medical oncologist which drugs cause which side effects. Medication is available to manage or prevent some side effects.

To learn about preventing and managing nausea and vomiting, read *NCCN Guidelines for Patients: Nausea and Vomiting*, available at NCCN.org/patientguidelines and on the NCCN Patient Guides for Cancer app.



Important side effects of carmustine wafers include seizures, pressure in the skull, and slow wound healing.

Not all side effects of chemotherapy are listed here. Ask your team for a complete list of common and rare side effects, and what treatments are available.

Targeted therapy

Targeted therapy drugs attack certain parts of tumor cells to slow their growth and spread.

They're effective only against gliomas that multiply or spread through the specific mutation, enzyme, protein, or other molecule that they target. For example, a BRAF inhibitor only works against tumor cells that have a mutation in the *BRAF* gene.

Because targeted therapy is aimed only at tumor cells, not healthy cells, it doesn't have the same side effects as standard chemotherapy.

Targeted therapies for gliomas include drugs that block (inhibit) mutant *IDH*, *VEGF*, and *BRAF* genes.

IDH inhibitors – Vorasidenib (Voranigo) targets grade 2 astrocytomas or oligodendrogliomas with *IDH1* or *IDH2* mutations. Given after surgery, vorasidenib can significantly delay tumor growth as well as the need for radiation or chemotherapy.

Ivosidenib (Tibsovo) is an IDH inhibitor that can be used by people with low-grade, *IDH1*-mutant gliomas who can't take vorasidenib.

VEGF inhibitors – Bevacizumab (Avastin) blocks a protein called vascular endothelial growth factor (VEGF). VEGF helps tumors form new blood vessels (a process called angiogenesis), which they need to grow.

Bevacizumab is used mainly to treat glioblastomas and other fast-growing gliomas.

Bevacizumab can help shrink some tumors or slow their growth, especially when combined with chemotherapy. Its main benefit is that it helps reduce swelling around the tumor, so people being treated with bevacizumab can often get lower doses of the steroid dexamethasone. This can be especially important for people sensitive to steroid side effects.

BRAF/MEK inhibitors – Used for rare gliomas carrying specific *BRAF* gene alterations.

Alternating electric field therapy

Alternating electric field therapy is a treatment that uses low-intensity energy to stop tumor cells from multiplying. It's also called tumor treating fields (TTFields).

This treatment is given as an addition to other treatments for certain people with newly diagnosed or recurrent glioblastomas. It uses electromagnetic field energy to disrupt the replication process of tumor cells. The energy is tuned specifically to glioblastoma cells to interfere with their cell division. The therapy destroys newly dividing tumor cells but doesn't affect healthy cells.

The TTFields device (called Optune Gio) looks something like a swim cap connected with wires to a carry-along battery pack. The electric field energy is distributed through electrodes attached to several patches that safely adhere to your scalp. The electrodes are linked to an energy-producing device and a battery you carry with you.

The treatment is intended to be used for at least 18 hours a day for at least 4 weeks. The most common side effect is skin irritation.

Observation

The recommended treatment for most gliomas is surgical removal (resection). However, observation may be a better or safer option for some people. Observation means your care team will check on your condition using regular tests over a period of time. No treatment is given unless symptoms appear or your condition changes.

Supportive care

Supportive care (also called palliative care) is health care for the symptoms of cancer and the side effects of cancer treatment.

Supportive care is appropriate for anyone, regardless of age, cancer stage, or the need for other therapies.

For more information, see *Chapter 7: Supportive care*.

Alternating electric field therapy

Alternating electric field therapy—also called tumor treating fields (TTFields)—uses low-intensity energy to stop tumor cells from multiplying. Electromagnetic field energy is distributed through electrodes attached to four patches taped to your scalp. The energy is tuned to glioblastoma cells and interferes with their cell division. TTFields destroy newly dividing tumor cells but don't affect healthy cells.

Photo: ©2026 Novocure. All rights reserved.



Clinical trials

NCCN experts recommend that everyone with a glioma consider joining a clinical trial for treatment.

A clinical trial is a type of medical research study. After being developed and tested in a lab, potential new ways of fighting cancer need to be studied in people.

If found to be safe and effective in a clinical trial, a drug, device, or treatment approach may be approved by the U.S. FDA.

Everyone with cancer should carefully consider all of the treatment options available for their cancer type, including standard treatments and clinical trials. Talk to your doctor about whether a clinical trial may make sense for you.

Phases

Most cancer clinical trials focus on treatment and are done in phases.

- **Phase 1** trials study the safety and side effects of an investigational drug or treatment approach.
- **Phase 2** trials study how well the drug or approach works against a specific type of cancer.
- **Phase 3** trials test the drug or approach against a standard treatment. If the results are good, it may be approved by the FDA.
- **Phase 4** trials study the safety and benefit of an FDA-approved treatment.



Finding a clinical trial

In the United States

NCCN Cancer Centers
NCCN.org/cancercenters

The National Cancer Institute (NCI)
cancer.gov/about-cancer/treatment/clinical-trials/search

Worldwide

The U.S. National Library of Medicine (NLM)
clinicaltrials.gov

Need help finding a clinical trial?

NCI's Cancer Information Service (CIS)
1.800.4.CANCER (1.800.422.6237)
cancer.gov/contact

Who can enroll?

It depends on the clinical trial's rules, called eligibility criteria. The rules may be about age, cancer type and grade, molecular status, treatment history, or general health. They ensure that participants are alike in specific ways and that the trial is as safe as possible for the participants.

Informed consent

Clinical trials are managed by a research team. This group of experts will review the study with you in detail, including its purpose and the risks and benefits of joining. All of this information is also provided in an informed consent form. Read the form carefully and ask questions before signing it. Take time to discuss it with people you trust. Keep in mind that you can leave and seek treatment outside of the clinical trial at any time.

Will I get a placebo?

Placebos (inactive versions of real medicines) are almost never used alone in cancer clinical trials. It is common to receive either a placebo with a standard treatment, or a new drug with a standard treatment. You will be informed, verbally and in writing, if a placebo is part of a clinical trial before you enroll.

Are clinical trials free?

There is no fee to enroll in a clinical trial. The study sponsor pays for research-related costs, including the study drug. But you may need to pay for other services, like transportation, lodging, or childcare. During the trial, you will continue to receive standard cancer care. This care is often covered by insurance.

“Ask about clinical trials available to you and the services your hospital and other facilities provide to cancer patients, such as counseling, nutritional advice, meditation, physical therapy, palliative care, and integrative medicine. Don’t be shy. Be your own advocate—or ask someone close to be one for you.”

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What’s next?

Now that you’ve been introduced to the various treatment options for different gliomas, the first step toward treatment is to come up with the best possible treatment plan. This plan involves many different health care providers.

Multidisciplinary care

During the course of your diagnosis and treatment, you’ll be cared for by numerous doctors, specialists, and allied health providers.

These may include a neuro-oncologist, neurosurgeon, radiation oncologist, medical oncologist, neuropathologist, radiologist, ophthalmologist, nurses, primary care doctor, nurse practitioners, physician assistants, palliative care specialist, pain specialist, psychologist, social workers, nutritionist, and rehabilitation specialists like physical, occupational, and speech therapists.

When all these providers are working and communicating as a team to help you, it's called multidisciplinary care.

Your multidisciplinary care team should clearly discuss your care goals with you. Removing or reducing the size of your tumor is one goal of your team. But other goals could include improving your overall well-being, maintaining your ability to do day-to-day activities, reducing pain, getting good nutrition, and lowering stress and anxiety.

Your multidisciplinary care team will meet to discuss your treatment and which options are best for you. Ask who will coordinate your care and what efforts can be made to schedule appointments together.

The next chapter explains what your specific treatment may be if you have a low-grade glioma. The chapter after that discusses treatment details if you have a high-grade glioma.

Key points

- Surgery is done to confirm the diagnosis and to remove as much of the tumor as possible.
- Radiation therapy uses high-energy rays to destroy tumor cells and stop them from increasing in number.
- Chemotherapy uses drugs to destroy tumor cells and stop them from increasing.
- Alternating electric field therapy uses low-intensity energy to stop tumor cells from multiplying.
- Targeted therapy is directed at a specific enzyme or another substance that's key to glioma cells.
- Clinical trials test new types of treatment. If an experimental treatment is proven to work well, it may be approved by the FDA and become widely available.
- Multidisciplinary care is when doctors, specialists, and allied health providers work and communicate as a team to provide expert diagnosis and treatment.

Questions to ask

- What are my treatment options?
- Does any option offer long-term cancer control?
- Do I have a choice of when to begin treatment?
- Is a clinical trial an option for me?
- How do I get a second opinion?

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Treatment for low-grade glioma

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33 Low-grade astrocytoma

34 Low-grade oligodendroglioma

36 Other low-grade gliomas

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37 Questions to ask

Low-grade gliomas are less common than high-grade gliomas. They also have a better prognosis. Some low-grade gliomas eventually evolve into high-grade gliomas.

About low-grade glioma

Low-grade gliomas include a variety of slow-growing grade 1 and grade 2 tumors. Low-grade gliomas typically occur in people between their teens and their 40s, but older adults can also get low-grade gliomas.

The most common symptom of low-grade gliomas is seizures (particularly in oligodendrogliomas). Other symptoms include headaches, muscle weakness, vision problems, and changes in mental function or behavior.

However, many people with low-grade gliomas have no symptoms. These tumors are often found during unrelated medical tests.

If your MRI scan shows what appears to be a low-grade glioma, the best possible plan is to remove the tumor surgically.

Tumor surgery

Although low-grade gliomas grow slowly, many eventually become high-grade gliomas. The main goal of treatment is to prevent or delay that from happening.

So, the primary treatment for a low-grade glioma is surgery to remove the tumor (resection). Your care team may be able to tell from your MRI whether all or just part of the tumor can be removed.

Gross total resection

A gross total resection is a surgical procedure that removes all, or nearly all, of the visible tumor. Ideally, the whole tumor can be removed. Removing the whole tumor is likely to help you live longer. It also helps to delay a low-grade glioma from becoming a high-grade glioma. Plus, it can further reduce seizures and other symptoms.

Partial resection

Sometimes the tumor can't be removed entirely, like when a glioma is diffuse or in an eloquent area of the brain. Removing part of the tumor is called a partial resection. Your surgeon may recommend a second surgery later on to try to remove the whole tumor, if possible.

Pathology

Whether or not the whole tumor is removed, a sample of it will be sent to a neuropathologist. The neuropathologist will identify the type of glioma and test it for certain biomarkers. These results can also indicate the type of treatment you may need.

The most common low-grade gliomas in adults are astrocytomas and oligodendrogliomas.

Low-grade astrocytoma

Low-grade astrocytomas are slow-growing, diffuse grade 2 tumors. (Grade 1 astrocytomas usually occur only in children.) A diffuse (or infiltrative) tumor weaves into the surrounding normal brain tissue. This gives the tumor unclear, indistinct edges. As a result, a diffuse tumor is difficult to remove entirely by surgery.

Most diffuse astrocytomas in adults occur in the frontal or temporal lobes of the brain. Common symptoms are seizures and headaches. Other symptoms due to pressure on the brain are vision changes, nausea, and vomiting. Then again, a low-grade astrocytoma may cause no symptoms.

Biomarkers

Biomarkers help identify the glioma type and help guide treatment.

- ***IDH1* or *IDH2*** – *IDH* mutation is a key marker of astrocytomas. Also, some therapies may work better in gliomas with an *IDH* mutation.

Treatment

The main treatment for a low-grade astrocytoma is surgery to remove all the tumor (gross total resection) or as much of it as possible (partial resection). Generally, the more cancer that's removed, the better the outcome will be.

After surgery, you'll be reevaluated for your next type of treatment (called adjuvant treatment). Adjuvant treatment is based on your performance score, which is an assessment used to estimate your ability to handle intense treatment.

Your care team will also consider the risks involved due to the tumor's size and whether you have any other gene mutations or neurological problems.

High performance score – A high performance score means you're able to do most tasks for a person your age, and you don't spend much extra time sitting or lying down. In other words, your body can handle more intense therapy.

For people with a high performance score, the type of additional treatment after surgery depends on how much of the tumor was removed. See **Guide 2**.

When some cancer is left behind, the astrocytoma typically has a higher risk to regrow. Additional treatment for a person with cancer left behind may involve a clinical trial.

Additional treatment with radiation and chemotherapy (PCV or temozolomide) may be a good option for some people, such as those who still have a large tumor after surgery or a tumor that's causing symptoms.

Sometimes, radiation therapy is both combined with and followed by temozolomide chemotherapy.

Radiation and chemotherapy is also an option if the cancer continues to grow after additional treatment with an IDH inhibitor.

Low performance score – A low performance score means that illness or disability limits a person's ability to perform daily activities or care for themselves.

People with a low performance score often aren't able to physically handle aggressive treatment. They might benefit from less intense therapy instead. See **Guide 3**.

Follow-up

After treatment, you'll have regular MRI (or CT) scans to make sure the tumor hasn't grown. The usual schedule for follow-up scans is a few times a year for several years, and then at least twice a year if the tumor remains stable.

The scans will also monitor the health of your brain and identify any side effects of radiation therapy or chemotherapy.

Recurrence

The signs and symptoms of the astrocytoma may disappear for months or even several years after treatment. However, most grade 2 astrocytomas eventually evolve over time and return as higher-grade astrocytomas.

To read about the recurrence of high-grade astrocytoma, see *Chapter 6: Recurrence and progression*.

Low-grade oligodendroglioma

Low-grade oligodendrogliomas are slow-growing, grade 2 tumors. (There are no grade 1 oligodendrogliomas.)

Oligodendrogliomas commonly develop in the frontal and temporal lobes of the brain. Tumors in these areas can result in symptoms such as seizures, headaches, weakness, and speech problems.

The most common of these is seizure. About 3 in 5 people with an oligodendroglioma have a seizure before being diagnosed.

Biomarkers

Characteristic biomarkers of oligodendrogliomas are *IDH* mutation and 1p/19q co-deletion.

- ***IDH1* or *IDH2*** – An *IDH* mutation is found in all oligodendrogliomas.
- **1p/19q** – All oligodendrogliomas have 1p/19q co-deletion, which is linked to better results from chemotherapy.
- ***TERT* promoter** – A *TERT* promoter mutation, when it occurs along with *IDH* mutation and 1p/19q co-deletion, helps confirm the diagnosis of oligodendroglioma.

Treatment

Initial treatment for a low-grade oligodendroglioma is similar to that for a low-grade astrocytoma. Ideally, all or almost all of the tumor should be surgically removed (gross total resection) or as much of it as possible (partial resection). Generally, the more cancer that's removed, the better the outcome will be.

After surgery, you'll be reevaluated for your next type of treatment (called adjuvant treatment). Adjuvant treatment is based on your performance score, which is an assessment used to estimate your ability to handle intense treatment.

Your care team will also consider the risks involved due to the tumor's size and whether you have any other gene mutations or neurological problems.

Guide 2
Additional treatment for people with high performance scores

How much of the cancer was removed?	Treatment options
All of the tumor was removed	• Observation • IDH inhibitor • Clinical trial
Some cancer was left behind, or cancer came back (and additional chemoradiation is not recommended)	• IDH inhibitor • Observation • Clinical trial
Some cancer was left behind, or cancer continues to grow using an IDH inhibitor (and additional chemoradiation is recommended)	• Clinical trial • Radiation therapy and procarbazine, lomustine, and vincristine (PCV) chemotherapy • Radiation therapy and temozolomide chemotherapy • Radiation therapy and temozolomide together, then temozolomide after

Guide 3
Additional treatment for people with low performance scores

Radiation therapy (concentrated into a shorter period of time) and temozolomide together, with or without temozolomide after
Temozolomide only
Radiation therapy (concentrated into a shorter period of time)
IDH inhibitor
Clinical trial
Supportive (palliative) care

High performance score – A high performance score means you're able to do most tasks for a person your age, and you don't spend much extra time sitting or lying down. In other words, your body can handle more intense therapy.

For people with a high performance score, the type of additional treatment after surgery depends on how much of the tumor was removed. See **Guide 2.**

When some cancer is left behind, the oligodendroglioma typically has a higher risk to regrow. Additional treatment for a person with cancer left behind may involve a clinical trial.

Additional treatment with radiation and chemotherapy (PCV or temozolomide) may be a good option for some people, such as those who still have a large tumor after surgery or a tumor that's causing symptoms.

Sometimes, radiation therapy is both combined with and followed by temozolomide chemotherapy.

Radiation and chemotherapy are also options if the cancer continues to grow after additional treatment with an IDH inhibitor.

Low performance score – A low performance score means that illness or disability limits a person's ability to perform daily activities or care for themselves.

People with low performance scores often aren't able to physically handle aggressive treatment. They might benefit from less intense therapy instead. See **Guide 3**.

Follow-up

After treatment, you'll have regular MRI or CT scans to make sure the tumor hasn't grown. The usual schedule for follow-up scans is a few times a year for several years, and then at least twice a year as long as the tumor remains stable.

The scans will also monitor the health of your brain and identify any side effects of radiation therapy or chemotherapy.

Recurrence

The signs and symptoms of the oligodendroglioma may disappear for months or even several years after treatment. However, most grade 2 oligodendrogliomas eventually evolve into high-grade oligodendrogliomas over time.

For more about the recurrence of low-grade oligodendrogliomas, see *Chapter 6: Recurrence and progression*.

Other low-grade gliomas

Other low-grade gliomas include pilocytic astrocytomas, pleomorphic xanthoastrocytomas, subependymal giant cell astrocytomas, gangliogliomas, and more. These gliomas are rare in adults and not covered in this guide.

Key points

- Seizure is the most common symptom of low-grade gliomas. However, many people with low-grade gliomas have no symptoms.
- The main treatment for a low-grade glioma is surgery to remove all of the tumor or as much of it as possible.
- Grade 2 glioma tumors don't have clearly defined edges. This makes them difficult to remove entirely by surgery.
- Oligodendrogliomas are diagnosed by the combination of two biomarkers: IDH mutation and 1p/19q co-deletion.
- Although low-grade gliomas grow slowly, many eventually become high-grade gliomas.

Questions to ask

- What is my cancer stage?
- How do my age, sex, overall health, and other factors affect my treatment options?
- What can be done to prevent or relieve the side effects of the treatments?
- How will you know if the treatment is working?
- What are my options if the treatment stops working?

"My doctor encouraged me to seek additional medical opinions to ensure I was comfortable with my treatment decision."

5

Treatment for high-grade glioma

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A high-grade glioma can come on quickly and grow rapidly. People with a high-grade glioma often have a poor prognosis. However, many people with these tumors are now living longer than the statistics suggest.

About high-grade gliomas

Most gliomas that occur in adults are high grade. High-grade gliomas are malignant (cancerous), rapidly growing grade 3 or grade 4 tumors.

Grade 3 gliomas include astrocytomas and oligodendrogliomas.

Grade 4 gliomas include astrocytomas and glioblastomas. These are aggressive, life-threatening gliomas.

Symptoms of grade 3 and grade 4 tumors can come on quickly. Symptoms may be due to the tumor as well as the swelling around the tumor pressing on the brain. This can cause nausea, vomiting, and severe headaches that are worse in the morning or in the middle of the night.

The location of the tumor can also affect symptoms. For instance, a high-grade tumor located near the motor cortex of the frontal lobe can affect movement or cause weakness on one side of the body. Seizures are another common symptom of these gliomas.

If the results of your MRI show what looks like a high-grade glioma, you should be able to meet with a multidisciplinary team that will work with you to come up with a treatment plan.

Developing a treatment plan may involve further examination and testing before therapy can begin. An essential part of testing is obtaining a biopsy of the glioma to confirm the type of tumor. Surgically removing most of the tumor (resection) may also be an option at this point.

Tumor surgery

The main goal of a resection is to relieve pressure on the brain and safely remove as much of the tumor as possible. This is called maximal safe resection. Your care team will look closely at your MRI scan to decide whether maximal safe resection is possible for you.

Your care team will consider the risks involved due to the tumor's size and whether you have any other gene mutations or neurological problems. Your team will also consider other factors, such as your performance score, your age, how fast the tumor is growing, and more.

The 2 surgical strategies (or outcomes) are maximal safe resection and partial resection/ biopsy.

Maximal safe resection – The goal of this surgery is to safely remove as much of the tumor as possible. This may involve awake surgery during which the neurosurgeon will stimulate critical areas of the brain near the tumor.

Within a day or two after the surgery, you'll have another MRI scan to find out how much of the tumor was removed.

Partial resection or biopsy – If your multidisciplinary team thinks maximal resection isn't possible or isn't a good option for you, then you might have a partial resection or a biopsy (stereotactic biopsy or open biopsy).

Within a day or two after the partial resection, you'll have another MRI scan to find out how much of the tumor remains.

In either type of resection, the neuropathologist will assess the tissue sample from your tumor. Histological and biomarker tests will indicate what type of glioma you have.

Additional treatment

Because a high-grade glioma blends into the surrounding brain tissue, removing the entire tumor isn't likely. So you'll also have additional treatment (called adjuvant treatment) to destroy as many of the remaining tumor cells as possible.

Additional treatment is based on your performance score, which is an assessment used to estimate your ability to handle intense therapy.

High performance score – A high performance score means you're able to do most tasks for a person your age, and you don't spend much extra time sitting or lying down. In other words, your body can handle more intense therapy.

Low performance score – A low performance score means that illness or disability limits a person's ability to perform daily activities or care for themselves. They might benefit from less intense therapy.

Your additional treatment could be receiving an experimental therapy in a **clinical trial**. NCCN experts recommend that anyone with a high-grade glioma consider a clinical trial for adjuvant treatment.

Now, let's look at treatment for each high-grade tumor. Types of high-grade gliomas include oligodendrogliomas, astrocytomas, and glioblastomas.

High-grade oligodendroglioma

High-grade oligodendrogliomas are typically rapidly growing, grade 3 gliomas. These tumors often have a better prognosis than other high-grade gliomas.

Oligodendrogliomas may appear almost anywhere in the central nervous system but often develop in the frontal or temporal lobes of the brain.

Biomarkers

Molecular testing can reveal specific biomarkers that may enhance the diagnosis, prognosis, and treatment of a high-grade oligodendroglioma. Notably, the combination of an *IDH* mutation and a 1p/19q co-deletion is necessary to diagnose an oligodendroglioma.

- ***IDH1* or *IDH2*** – An *IDH* mutation is required to diagnose an oligodendroglioma, which indicates a better chance for longer survival than gliomas without an IDH mutation.
- **1p/19q** – Chemotherapy is likely to work better in a glioma that has a 1p/19q co-deletion.

- ***TERT* promoter** – A *TERT* promoter mutation, when it occurs along with *IDH* mutation and 1p/19q co-deletion, helps confirm the diagnosis of oligodendroglioma.
- ***MGMT* promoter methylation** – In high-grade gliomas, temozolomide chemotherapy generally works better in tumor cells with a methylated (turned off) *MGMT* promoter than in those with an unmethylated (turned on) *MGMT* promoter.

Additional treatment

Because a high-grade oligodendroglioma blends into the surrounding brain tissue, removing the entire tumor usually isn't possible.

After the surgery, you'll have additional treatment based on your performance score. This score is used to estimate whether your body can handle intense therapy.

High performance score – In general, people with a high performance score can handle more intense therapy. See **Guide 4**.

When some cancer is left behind, a high-grade oligodendroglioma typically has a higher risk to regrow. Additional treatment with radiation and chemotherapy (PCV or temozolomide) may be a good option for some people, such as those who still have a large tumor after surgery or a tumor that's causing symptoms.

Although chemoradiation is the most common treatment for high-grade oligodendrogliomas, an IDH inhibitor may be an option for certain people with a slow-growing tumor.

Low performance score – People with low performance score often aren't able to physically handle aggressive treatment. They might benefit from less intense therapy instead. See **Guide 4**.

Follow-up

After treatment, you'll need regular MRI scans to find out if the oligodendroglioma is under control. These scans can also monitor the health of your brain and identify any side effects of radiation or chemotherapy.

Scans are scheduled every few months, depending on which additional treatment you had, for as many years as necessary.

Recurrence

A high-grade oligodendroglioma is likely to come back eventually. When it does, it may be even more aggressive. For more about recurrence, see *Chapter 6: Recurrence and progression*.

“It’s easy to lose your sense of identity when you have a brain tumor. Find something that ‘feels like you’—reading, yoga, being with family, whatever—and get back to that thing as quickly as you can. Recovering a sense of self amidst the uncertainty of a brain tumor diagnosis can help us maintain our resilience in the face of challenges.”

Guide 4
Additional treatment for high-grade oligodendroglioma, based on your performance score

Treatment options for high performance score
Clinical trial
Radiation therapy before procarbazine, lomustine, and vincristine (PCV) chemotherapy
Radiation therapy after PCV chemotherapy
Radiation therapy and temozolomide together, then temozolomide after
Radiation therapy, then temozolomide after
IDH inhibitor (in certain cases)
Treatment options for low performance score
Clinical trial
Radiation therapy (concentrated into a shorter period of time)
Radiation therapy (concentrated into a shorter period of time) and temozolomide together, with or without temozolomide after
Temozolomide only
IDH inhibitor (in certain cases)
Supportive (palliative) care

High-grade astrocytoma

High-grade (grade 3 and grade 4) astrocytomas are rapidly growing gliomas. The cells in these tumors have changed so much that they no longer look like normal glial cells.

Grade 4 astrocytomas often have necrosis, which is an area of dead tumor tissue. Grade 4 astrocytomas can also grow a large amount of new blood vessels, which feed their fast growth. Finding either or both of these features suggests the astrocytoma is more severe and is growing faster than a grade 3 astrocytoma.

High-grade astrocytomas can develop in almost any part of the central nervous system. But they occur most often in the brain's frontal or temporal lobes.

Biomarkers

Specific biomarkers of high-grade astrocytomas include:

- I***DH1* or *IDH2*** – An *IDH* mutation in a high-grade astrocytoma generally indicates longer survival and a better outcome from radiation therapy or chemotherapy.
- ***ATRX*** – An *ATRX* mutation that occurs with an *IDH* mutation can help confirm the diagnosis of astrocytoma.
- ***MGMT* promoter methylation** – In high-grade astrocytomas, temozolomide chemotherapy generally works better in tumor cells with a methylated (turned off) *MGMT* promoter than in those with an unmethylated (turned on) *MGMT* promoter.
- ***CDKN2A/B*** – Deletion of *CDKN2A* and *CDKN2B* genes is a trait that helps diagnose grade 4 astrocytomas. This is important to know because a grade 4 astrocytoma grows more quickly and has a more serious prognosis than a lower-grade astrocytoma.

Imaging aids surgery

To precisely guide surgery, a computer programmed with imaging scans can pinpoint the exact location of a brain tumor.



Additional treatment

After the surgery, you'll have additional treatment based on your performance score. This score is used to estimate whether your body can handle intense therapy.

High performance score – In general, people with a high performance score can handle more intense therapy. See **Guide 5**. Additional treatment with radiation and temozolomide chemotherapy may be a good option for some people, such as those who still have a large tumor after surgery or a tumor that's causing symptoms.

Although chemoradiation is the most common treatment for high-grade astrocytomas, an IDH inhibitor may be an option for certain people, depending on the characteristics of the tumor.

Low performance score – People with a low performance score often aren't able to physically handle aggressive treatment. They might benefit from less intense therapy instead. See **Guide 5**.

Guide 5
Additional treatment for grade 3 and grade 4 astrocytomas, based on your performance score

Treatment options for high performance score
Clinical trial
Radiation therapy, then temozolomide after
Radiation therapy and temozolomide together, then temozolomide after
IDH inhibitor (in certain cases of grade 3 astrocytoma only)
Alternating electric field therapy (grade 4 astrocytoma only)
Treatment options for low performance score
Radiation therapy (concentrated into a shorter period of time)
Radiation therapy (concentrated into a shorter period of time) and temozolomide together, with or without temozolomide after
Temozolomide only
IDH inhibitor (in certain cases of grade 3 astrocytoma only)
Supportive (palliative) care

Follow-up

After treatment, you'll need to have regular MRI scans to find out if the astrocytoma is under control. These scans also monitor the health of your brain and identify any side effects of treatment.

For grade 3 astrocytomas, scans are scheduled at least every 6 months as long as there's no recurrence. For grade 4 astrocytomas, scans are scheduled every 2 to 4 months for 3 years, and then every 3 to 6 months if there's no recurrence.

Recurrence

Although treatment may stop or slow the tumor for a while, a high-grade astrocytoma is likely to come back. Or it may continue to grow despite treatment.

For more information about recurrence, see *Chapter 6: Recurrence and progression*.

Glioblastoma

Glioblastomas are fast-growing and aggressive grade 4 tumors. They're the most common and most dangerous type of malignant brain tumor in adults.

Glioblastomas don't usually evolve from lower-grade gliomas—they typically emerge as grade 4 tumors right from the beginning (de novo). Glioblastomas can occur anywhere in the brain or spinal cord, but they develop most often in the temporal and frontal lobes of the brain.

What is the blood-brain barrier?

Your brain is a very important organ. It needs special protection to keep it safe and healthy. To block germs, infections, and other toxins from getting in, the brain has a unique security system. This protective layer is called the blood-brain barrier. It's like a moat that surrounds and protects a castle.

The blood-brain barrier does its job well—maybe too well. One problem with the barrier is that it won't permit most drugs in the blood to reach the brain. This includes many chemotherapy drugs.

However, scientists have learned that some chemotherapy drugs can cross the blood-brain barrier more easily than others. One such drug is vorasidenib (Voranigo). Vorasidenib is relatively new IDH inhibitor that was intentionally designed to pass through the blood-brain barrier with no difficulty.

Encouraged by this success, doctors and scientists continue to investigate new and better ways to send drugs through the blood-brain barrier to improve treatment for brain tumors.

Glioblastomas are highly infiltrative—they expand and merge deep into the surrounding brain tissue.

Glioblastomas are characterized by areas of dead cells (necrosis). They also produce a large amount of new blood vessels to feed their fast growth. Because glioblastomas grow quickly, they need to be diagnosed and treated as soon as possible.

Biomarkers

A glioblastoma has one or more of these biomarkers:

- ***IDH1* or *IDH2*** – One clue to identifying a glioblastoma is that it **doesn't have** an *IDH* mutation.
- ***TERT* promoter** – Most glioblastomas have a mutation in the *TERT* promoter. Finding this biomarker helps predict the prognosis of the disease.
- **7 gain/10 loss** – The combination of gaining chromosome 7 and losing chromosome 10 is a strong identifying biomarker of glioblastoma.
- ***MGMT* promoter methylation** – Nearly half of glioblastomas have *MGMT* promoter methylation. Finding this biomarker is important for treatment. A glioblastoma with a methylated (turned off) *MGMT* promoter tends to respond better to temozolomide chemotherapy and leads to longer survival than a glioblastoma with an unmethylated (turned on) *MGMT* promoter.
- ***EGFR*** – Mutations in the *EGFR* gene occur frequently in glioblastomas, which makes this a helpful biomarker for diagnosis.

Additional treatment

As with other gliomas, the first treatment for glioblastomas is to try to surgically remove most of the tumor.

But because glioblastoma cells invade so deeply into brain tissue, removing the entire tumor won't be possible. So additional treatments are needed. In some individuals, carmustine wafers could be inserted after the tumor tissue is surgically removed.

The purpose of additional treatment (also called adjuvant treatment) is to destroy as many of the remaining tumor cells as possible. NCCN experts highly recommend that people with glioblastomas consider a clinical trial as part of their treatment plan.

If a clinical trial isn't possible or available, additional treatment usually involves radiation and temozolomide chemotherapy.

Adjuvant treatment for adults over age 70 is often different from treatment for adults under age 70. In general, older adults are given less intense treatment. There are several reasons for this. Many older adults (although not all, of course) have:

- Additional health problems
- Limited physical capability (lower performance score)
- Reduced mental functioning
- Greater risk of developing side effects

Keep in mind that people over age 70 aren't all the same and aren't all treated the same. Some adults over age 70 can tolerate more intense treatment and get good results.

No matter what your age or condition, your care team will help you determine the best type of additional treatment for you.

Here are the most common adjuvant treatment options for glioblastomas based on age and physical ability:

Under age 70, with good physical ability – People under age 70 who have good performance score are generally able to handle stronger adjuvant treatment. Options include joining a clinical trial or having one of these treatments:

- Radiation therapy and temozolomide chemotherapy given together, followed by more temozolomide chemotherapy plus alternating electric field therapy (tumor treating fields, or TTFields)
- Radiation therapy and temozolomide chemotherapy given together, followed by more temozolomide
- Radiation therapy alone (only if you have an unmethylated *MGMT* promoter)

Under age 70, with limited physical ability – People under age 70 who have lower performance score are generally given less intense adjuvant treatment. You can look for a clinical trial that you're eligible for (preferred therapy). Or you can have one of these treatments:

- Hypofractionated (larger doses in fewer sessions) radiation therapy with or without temozolomide chemotherapy given at the same time or afterward
- Temozolomide only

Of course, supportive (palliative) care is always an option.

Over age 70, with good physical ability – People over age 70 who have good performance score are generally given a modified level of treatment. Options include treatment through a clinical trial or having one of these treatments:

- Hypofractionated radiation therapy and temozolomide chemotherapy given together, followed by more temozolomide chemotherapy
- Standard radiation therapy and temozolomide chemotherapy given together, followed by temozolomide chemotherapy plus alternating electric field therapy
- Standard radiation therapy and temozolomide chemotherapy given together, followed by temozolomide chemotherapy
- Temozolomide only
- Hypofractionated radiation therapy only

Over age 70, with limited physical capability – People over age 70 who have lower performance score are generally given less aggressive treatment that minimizes side effects. In addition to a clinical trial, adjuvant treatment options include:

- Hypofractionated radiation therapy only
- Temozolomide chemotherapy only
- Supportive care

Quality of life

Quality of life refers to a person's overall enjoyment of life, including their sense of well-being and ability to participate in their usual activities.

Your quality of life should be the main priority that guides your treatment and care.

Successful treatment isn't just about reducing the cancer. Other goals include minimizing cognitive problems, reducing pain, lowering anxiety and stress, carrying out regular activities, being with friends and family, and enjoying life as best as you can.

"Keeping a journal is a low-cost and practical tool to help you navigate this frightening and uncertain time. By tracking your daily symptoms, you are in a better position to see how you're doing over time, which can be clouded by one or two bad days."

Follow-up

After treatment, you'll need to have regular MRI scans to find out if the glioblastoma is under control. These scans also monitor the health of your brain and identify any side effects of radiation or chemotherapy. Scans are scheduled every 2 to 3 months for 3 years, and then every 2 to 4 months for as long as necessary.

Recurrence

Eventually, the glioblastoma will likely come back. Or it may continue to grow despite treatment. For more information about recurrence, see *Chapter 6: Recurrence and progression*.

Key points

- High-grade gliomas are rapidly growing and possibly life-threatening tumors.
- The main goal of high-grade glioma surgery is to relieve pressure on the brain and safely remove as much of the tumor as possible.
- Surgically removing all of a high-grade glioma won't be possible because these tumors have grown deep into the surrounding brain tissue.
- NCCN experts recommend that anyone with a high-grade glioma consider a clinical trial as part of their treatment plan.
- A high-grade oligodendroglioma is identified by the combination of two biomarkers: *IDH* mutation and 1p/19q co-deletion.
- Glioblastomas are the most common and the most dangerous of the gliomas. More than half of all gliomas in adults are glioblastomas.
- In general, older and/or frail adults receive less aggressive treatment. But there are exceptions to this—every person's case is different.

Questions to ask

- Are you suggesting options other than what NCCN recommends? If yes, why?
- What happens if I do nothing?
- What if I am pregnant, or planning to become pregnant?
- How long do I have to decide about treatment, and is there a social worker or someone who can help me decide?

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Recurrence and progression

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54 Questions to ask

For most people who've been treated for a glioma, the tumor will come back even after treatment (recurrence). Or the tumor may keep growing despite treatment (progression). Here's how you and your care team can manage recurrence or progression.

After the intense activity and frequent appointments involved with treatment, you'll begin a new phase of recovery: watch and wait.

Watch and wait is a period where your care team will closely monitor your condition to see if there are any changes, but without giving you any treatment. Your care team may call it active observation, active surveillance, or watchful waiting.

This quieter, less busy time can also be stressful in its own way.

Shifting from the active process of treatment to the inactive period of waiting and wondering can be difficult.

No one knows if, when, or how the tumor may come back. So it's important to keep going to follow-up appointments. You'll have periodic imaging scans as well as regular physical and neurological exams.

For most people, gliomas eventually do return. Very often, they come back with greater intensity and faster growth than before.

Low-grade glioma

If you have a low-grade glioma (grade 1 or grade 2) that continues to grow or comes back after treatment, you'll require additional treatment aimed at minimizing the tumor. You may have another biopsy or a partial resection to confirm the tumor has reccurred and to find out how quickly it's growing.

Your multidisciplinary care team will meet again and discuss the best options for you. Depending on your situation and what therapy you've had before, a recurrent or progressive low-grade glioma can be treated with one or more of these options:

- Clinical trial
- Radiation therapy plus chemotherapy
- Chemotherapy only or other systemic therapy only (see list below)
- Radiation therapy only (for well-defined tumors)
- Observation (for low-risk disease)
- Supportive care

Types of chemotherapy or other systemic therapies include:

- Temozolomide
- Lomustine
- Carmustine
- Procarbazine, lomustine, and vincristine (PCV)
- Orasidenib
- Ivosidenib (if you can't take vorasidenib)

High-grade glioma

If you have a low-grade glioma that comes back as a high-grade glioma (grade 3 or grade 4), or if you have a high-grade glioma that progresses or comes back, you have further options to treat the tumor.

Surgical resection may be possible for certain tumors, such as large tumors or those located all in one area (local tumor).

Otherwise, treatment options for recurrent or progressive high-grade gliomas include:

- Clinical trial
- Chemotherapy
- Radiation therapy plus chemotherapy
- Targeted therapy
- Alternating electric field therapy (for glioblastomas only)
- Supportive care

In certain individuals, more radiation therapy might be an option. An option in other cases is chemotherapy combined with targeted therapy.

Rehabilitation

Because gliomas can impair areas of the brain that control important senses and skills—like speech, vision, hearing, movement, and thinking—you may need rehabilitation after treatment. Rehabilitation can include:

Physical therapy – Involves training to improve movement, balance, and walking and to increase strength.

Occupational therapy – Assists you in regaining your ability to do day-to-day activities, such as working or doing household tasks.

Speech therapy – Can help you with difficulties in your ability to speak and communicate.

Low vision therapy – Offers solutions for visual problems such as vision loss, double vision, and blind spots.

Neuropsychiatric care – Helps with changes in mood, behavior, thinking, problem-solving, memory, and more.

What is pseudoprogression?

Pseudoprogression occurs when imaging scans show that the tumor appears to be growing after treatment, but what looks like tumor growth on the images is actually a reaction to treatment.

It can be difficult for your doctors to tell the difference between pseudoprogression and real tumor progression based on imaging alone. This is a common situation, and it can be very stressful. Additional imaging or having another biopsy or surgery may be necessary to confirm whether the tumor is truly progressing.

What's next?

You could have several types of treatment for a relapsed or progressive glioma. After any treatment, it's important to go to follow-up visits and stay in touch with your care team.

You may eventually reach a point where you want to stop treatment. For some people, how they spend their time is more important than how much time they have left.

It's common to feel frustration, anger, regret, despair, and uncertainty—even all at the same time. Know that you can have a brain tumor and still find happiness after diagnosis and treatment.

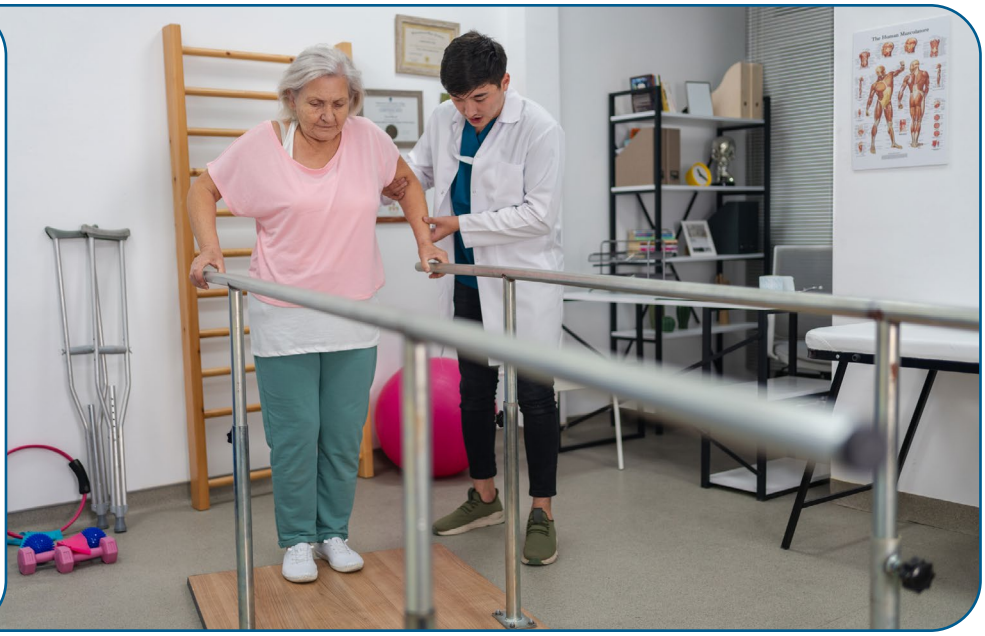
Try to enjoy life as much as possible. Talk with family or friends. Join a support group to learn how other patients are dealing with their cancer.

"Chemo is difficult. But watching and waiting is even more difficult—because doing something feels better than doing nothing."

Or talk to your doctor or another member of your care team. They can point you to professionals who can help you deal with these feelings and guide you toward your next steps.

Supportive care is appropriate for anyone, regardless of age, cancer stage, or the need for other therapies. For more information about supportive care and other resources, turn to the next chapter.

Because a glioma can impair areas of the brain that control important senses and skills—like speech, vision, hearing, movement, and thinking—you may need rehabilitation after treatment.



Key points

- Follow-up involves periodic imaging scans as well as regular physical and neurological exams.
- For most people, gliomas eventually do return. Very often, they come back with greater intensity and faster growth than before.
- Recurrence is when a tumor comes back after effective treatment.
- Progression is when the tumor keeps growing despite treatment.
- It’s common for people with cancer to feel frustration, anger, regret, despair, and uncertainty—even all at the same time.
- Supportive care is appropriate for anyone, regardless of age, cancer stage, or the need for other therapies.

Questions to ask

- Are you board-certified? If yes, in what area?
- What is your experience as well as your team's experience with treating the type of glioma I have?
- How many patients with my glioma type and molecular diagnosis have you and your center treated?
- Will you be consulting with experts to discuss my care? Who will you consult?
- How much will I have to pay for my treatment? What help is available to pay for medicines and other treatments?

“Please allow yourself to accept hard days, difficult moments, or disappointments. Speaking with a behavioral health specialist can help you to prepare for the emotional changes that you may face.”

7
Supportive care

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Supportive care addresses the symptoms and side effects of cancer and cancer treatments, as well as psychological, social, financial, and spiritual issues. Many resources are available to help you feel better and to answer your questions.

The main concern for most patients with cancer is to find a treatment that works. Having cancer is about more than just treatment, though. Cancer care can be a rollercoaster that includes many additional physical and emotional challenges. It's important to know that you can get support for these challenges.

What is supportive care?

Supportive care is an important part of cancer care. The goal is to improve your quality of life during and after cancer treatment. Supportive care is for everyone with cancer and their families, not just for those at the end of life.

Supportive care includes a wide range of services. Supportive care prevents or manages the symptoms of cancer and the side effects of cancer treatment, like pain and cancer-related fatigue. It also addresses the mental, social, emotional, and spiritual concerns faced by people with cancer.

"Don't be afraid to accept help from friends and family."

Supportive care provides help with additional needs, such as:

- Making treatment decisions
- Coordinating your care
- Paying for care
- Planning for advance care and end of life

Some health care professionals refer to palliative care as supportive care. They think these types of care are alike or overlap. Others think there are important differences, but both help people with cancer to live as well as they can. Your cancer center may have palliative care specialists, who can give you additional support and help coordinate your supportive care needs.

Read more about the types of support you may receive in *NCCN Guidelines for Patients: Palliative Care*, available at NCCN.org/patientguidelines and on the NCCN Patient Guides for Cancer app.



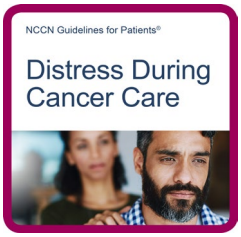
Ask questions and reach out to your care team if you need more information about supportive care. Some medical centers have patient navigators or other staff members who coordinate nonclinical supportive care.

Anxiety and depression

Depression, anxiety, fear, and distress are very common feelings for people with gliomas—as well as their loved ones and caregivers. You may feel anxious or experience depression during a hard part of treatment or because your life is different than it was before your brain tumor. These feelings can make it harder to deal with a brain tumor and with tumor treatment. They can hold you back even when you want to move forward.

Tell your care team if you're having these symptoms. Getting help when you're feeling worried or hopeless is an important part of your care. Help can include support groups, talk therapy, or medication. Patient navigators, social workers, and other experts at your medical center can help. Some people also feel better by exercising, talking with loved ones, or relaxing.

Read more about cancer and distress in *NCCN Guidelines for Patients: Distress During Cancer Care*, available at NCCN.org/patientguidelines and on the NCCN Patient Guides for Cancer app.



"Do whatever you can to connect with a support group. Being diagnosed with a brain tumor can be scary. It is priceless to be able to discuss diagnosis, treatment, or living with a tumor with someone who has gone through similar experiences as you have."

Support groups

Many people diagnosed with a brain tumor find support groups to be helpful. A support group provides the opportunity to talk with others who are going through, or have been through, similar experiences. Support groups often include people at different stages of treatment. Some people may be newly diagnosed, while others may be finished with treatment.

In a support group, people with common ground share information on their experiences, financial and emotional burdens, coping strategies, and knowledge about research and treatments. A support group can also be a good source of practical advice and helpful tips.

Ask your doctors or supportive care team about finding a brain tumor support community. If your hospital or community doesn't have support groups for people with brain tumors, look at the online resources listed on pages 62–63 of this book.

Financial concerns

The financial cost of a brain tumor can be overwhelming. As a result, many people with brain tumors and their loved ones struggle with the cost of treatment, as well as the stress of paying for it.

If you're having trouble paying for food, housing, treatment, follow-up care, or other expenses, or you have difficulty getting to appointments, talk with your care team's social worker, patient navigator, and hospital financial services staff. Many patient advocacy groups also have resources. They can help you find financial support and transportation options.

You can also talk to your care team about time off from work, health insurance, or money problems. Your team can include information in your treatment plan to help you manage your finances and medical costs. If your doctors and care providers don't talk about how to pay for treatment, it's OK for you to ask them about it first.

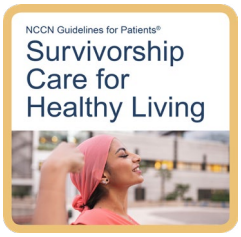
Survivorship

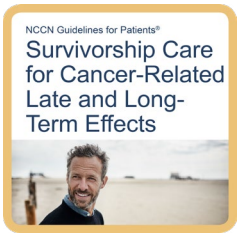
Survivorship focuses on the health and well-being of a person with a brain tumor, from diagnosis until the end of life. This includes the physical, mental, emotional, social, and financial effects of the brain tumor that begin at diagnosis, continue through treatment, and arise afterward.

Survivorship also includes concerns about follow-up care, late effects of treatment, tumor recurrence, and quality of life. Support from family members, friends, and caregivers is also an important part of survivorship.

> **"Report any unusual feelings of sadness, loss of interest in activities, anxiety, and sleep problems to your doctor. Many people experience these feelings, and they should not go untreated."**

Read more about survivorship in *NCCN Guidelines for Patients: Survivorship Care for Healthy Living and Survivorship Care for Cancer-Related Late and Long-Term Effects*, available at NCCN.org/patientguidelines and on the NCCN Patient Guides for Cancer app.





Advance care planning

When a glioma is diagnosed at an advanced stage or keeps progressing despite all treatment efforts, it may be time to consider what lies ahead. Even when brain tumors are curable, talking about future scenarios should begin when you start treatment. This exploration of what's important to you is called advance care planning.

Advance care planning is for everyone, not just for those who are very sick. Advance care planning means deciding what care you would want if you become unable to make medical

decisions for yourself. It's about making sure that your wishes are understood and respected. Patients with brain tumors can set up an advance care plan early to help them feel less stressed and better able to cope with their condition.

End-of-life considerations

End-of-life care provides medical, psychological, and spiritual support for people who are close to the end of life as well as the people who love them. The goal is comfort, not a cure. It may also be called comfort care or hospice.

Hospice is specialized care focused on quality of life for people thought to be in the final months of life. Hospice supports those at the end of life by bringing in additional care providers and resources, such as home care. In the United States, Medicare and many insurers generally require certification that life expectancy is approximately 6 months or less, if the illness follows its expected course.

Providing support for family members is a key part of hospice care. Most programs offer counseling and support groups for family members, including support after the patient has died. It can be very comforting to know that your loved ones will have that kind of support after you're gone.

For more information about supportive care, advance care planning, and end-of-life concerns, see *NCCN Guidelines for Patients: Palliative Care*, available at NCCN.org/patientguidelines and on the NCCN Patient Guides for Cancer app.



Key points

- Supportive care is for relieving symptoms and side effects as well as for other health issues related to brain tumors.
- Supportive care is given at any stage of disease, not just at the end of life.
- Supportive care is treatment that involves the whole person, not just their brain tumor.
- For help with financial support and transportation options, talk with your care team's social worker, patient navigator, and hospital financial services staff.
- Survivorship focuses on the health and well-being of a person with a brain tumor from diagnosis until the end of life.
- Advance care planning is done to ensure that your end-of-life wishes are understood and respected.
- Hospice care is for people who are close to the end of life. It's focused on comfort and quality of life.

Questions to ask

- Does this hospital or cancer center offer the best treatment for me?
- Will my insurance cover the treatment you're recommending?
- What follow-up care is needed after treatment?
- What supportive care and services are available to me and my caregivers?
- Who can help me with my concerns about work or school?

8
Other resources

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62 Where to get help

63 Questions to ask

Want to learn more? Here's how you can get additional help.

What else to know

This guide helps you know your options so you can make informed decisions and improve your cancer care. But it's not the only resource that you have.

Ask for as much information and help as you need. Many people with brain cancer are interested in learning more about:

- Finding a specialist who's an expert in brain tumors
- Talking to family, friends, and others about one's diagnosis
- Shared decision-making and being a part of the cancer care team
- Side effects of treatment
- Finding a support group or talking to others with gliomas
- Getting financial help
- Coping with distress and emotional concerns

What else to do

Your health care center can help you with next steps. It often has on-site resources to help meet your needs and find answers to your questions.

Health care centers can also inform you of resources in your community.

In addition to help from your providers, the resources listed in the next section provide support for many people like yourself.

Where to get help

Look through the list below and visit the provided websites to learn more about these organizations.

Bone Marrow and Cancer Foundation
bonemarrow.org

Brain Tumor Network
braintumornetwork.org

Cancer*Care*
cancercare.org

Cancer Hope Network
cancerhopenetwork.org

Cancer Survivor Care
cancersurvivorcare.org

EndBrainCancer Initiative
endbraincancer.org

Imerman Angels
imermanangels.org

International Brain Tumour Alliance (IBTA)
theibta.org

Musella Foundation
clinicaltrials.com

Patient Advocate Foundation
patientadvocate.org

Stupid Cancer
stupidcancer.org

Triage Cancer
triagecancer.org

Questions to ask

- How do I find clinical trials that I can participate in?
- How can I connect with others and build a support system?
- How much will I have to pay for my treatment? What help is available to pay for medicines and other treatments?
- Who can I talk to about help with housing, food, and other basic needs?
- What help is available for transportation, childcare, and home care?



Words to know

adjuvant therapy
Additional treatment given after the main treatment to lower the chances of the cancer returning.

advance care planning
Making decisions now about the care you would want to receive if you become unable to make medical decisions or to speak for yourself.

alternating electric field therapy
A treatment that uses low-intensity energy to stop tumor cells from multiplying. Also called tumor treating fields (TTFields).

astrocytoma
A glioma that looks like small, star-shaped cells (astrocytes) found in the central nervous system.

biomarker
Any chemical, substance, or other sign in your body that can be measured to assess your health.

biopsy
A procedure that removes fluid or tissue samples to be tested for a disease.

central nervous system
The brain and spinal cord.

chemotherapy
A drug treatment that damages and destroys rapidly dividing cells throughout the body.

chromosomes
The structures within cells that contain coded instructions for cell behavior.

clinical trial
A research study that assesses how well health tests or treatments work in people.

computed tomography (CT)
An imaging test that uses x-rays from many angles to make a picture of the inside of the body.

diagnosis
The identification of an illness based on tests.

follow-up care
Health care that involves regular check-ups, which begin after treatment has ended.

glioblastoma
A fast-growing, malignant, high-grade tumor found in the central nervous system.

glioma
A malignant tumor that develops from brain cells called glial cells.

high-grade glioma
A rapidly growing grade 3 or grade 4 brain tumor that develops from glial cells.

imaging
A technology that makes pictures (images) of the insides of the body.

infusion
A method of giving drugs slowly through a needle into a vein.

low-grade glioma
A slower-growing grade 1 or grade 2 brain tumor that develops from glial cells.

magnetic resonance imaging (MRI)
An imaging process that uses a magnetic field and radio waves to make pictures of the inside of the body.

multidisciplinary care
A treatment method where doctors, specialists, and other health providers work and communicate as a team to provide expert care for the patient.

mutation
An abnormal change in the genetic code (DNA) of a gene within cells.

neuropathologist
A doctor who specializes in testing cells and tissue of the central nervous system to find disease.

observation
A period of testing for changes in cancer status while not receiving treatment.

oligodendrocytes
Glial cells that cover and protect nerve cells in the brain and spinal cord.

oligodendroglioma
A slower-growing glioma that looks similar to oligodendrocytes in the central nervous system.

performance score
A rating of a person's overall health and ability to do ordinary activities.

prognosis
The likely course and outcome of a disease.

progression
The growth or spread of cancer after being treated.

pseudoprogression
The appearance on imaging that a tumor is growing when it's actually shrinking after treatment.

radiation therapy
A treatment that uses intense energy to destroy tumor cells.

recurrence
The return of disease after a period of improvement.

refractory cancer
Cancer that does not improve with treatment.

relapse
The return of cancer after a period of improvement.

remission
The absence of cancer signs and symptoms after treatment.

resection
Surgical removal of tissue.

supportive care
Health care for the symptoms of cancer and the side effects of cancer treatment. Also called palliative care.

surgical (resection) margin
The normal tissue around the edge of a tumor that is removed during surgery.

targeted therapy
A drug treatment that identifies and attacks a specific feature of cancer cells.

tumor
A mass of abnormal cells.

tumor grade
A rating based on how different tumor cells look from normal cells under a microscope. It's used to predict how fast the tumor is likely to grow.

NCCN Contributors

This patient guide is based on the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Central Nervous System Cancers, Version 3.2026. It was adapted, reviewed, and published with help from the following people:

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Boston, Massachusetts

Duke Cancer Institute
Durham, North Carolina

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Philadelphia, Pennsylvania

Fred & Pamela Buffett Cancer Center
Omaha, Nebraska

Fred Hutchinson Cancer Center
Seattle, Washington

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Indianapolis, Indiana

Johns Hopkins Kimmel Cancer Center
Baltimore, Maryland

Mass General Brigham Cancer Institute
Boston, Massachusetts

Mayo Clinic Comprehensive Cancer Center
Phoenix/Scottsdale, Arizona
Jacksonville, Florida
Rochester, Minnesota

Memorial Sloan Kettering Cancer Center
New York, New York

Moffitt Cancer Center
Tampa, Florida

O'Neal Comprehensive Cancer Center at UAB
Birmingham, Alabama

Robert H. Lurie Comprehensive Cancer Center
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Stanford Cancer Institute
Stanford, California

The Ohio State University Comprehensive Cancer Center -
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The UChicago Medicine Comprehensive Cancer Center
Chicago, Illinois

The University of Texas MD Anderson Cancer Center
Houston, Texas

UC Davis Comprehensive Cancer Center
Sacramento, California

UC San Diego Moores Cancer Center
La Jolla, California

UCLA Jonsson Comprehensive Cancer Center
Los Angeles, California

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San Francisco, California

University of Colorado Cancer Center
Aurora, Colorado

University of Michigan Rogel Cancer Center
Ann Arbor, Michigan

University of Wisconsin Carbone Cancer Center
Madison, Wisconsin

UT Southwestern Simmons
Comprehensive Cancer Center
Dallas, Texas

Vanderbilt-Ingram Cancer Center
Nashville, Tennessee

Yale Cancer Center/Smilow Cancer Hospital
New Haven, Connecticut

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