Brain Cancer
Gliomas

CENTRAL NERVOUS SYSTEM CANCERS

Available online at NCCN.org/patients
Melanie

In January 2015, I was 33 years old, married to the love of my life, and mother to our precious son. Everything changed when my husband found me in our bed mid-seizure. Arriving at the ER, we were flooded with questions—Have you ever had a seizure before? Any changes to your vision, seeing spots? Any headaches?—to all of which the answer was no. After a blood draw and a CT scan, the doctor uttered those dreadful words, “your blood work returned normal, but the scan showed a mass on your brain.” As an NCCN employee, I knew what those words meant—the possibility of brain cancer. I was transferred to a hospital that specialized in neurological procedures.

The first step of my treatment was surgery. Later at my follow up, we would learn that I received a subtotal resection. The piece of tumor remaining was less than 5% of the whole tumor. Side effects were pretty significant—the biggest being slow/slurred speech. Cognitively, I knew what I wanted to say but the brain-to-mouth connection was not working. Walking and writing were difficult for several weeks post-surgery, but with physical therapy at home, my ability to walk and write returned. My follow-up was 2 weeks post-seizure and the diagnosis was Anaplastic Astrocytoma Low Grade III Brain Cancer (malignant). A wave of shock hit me. How could this happen? Is it hereditary? How long will I have to live?! My main focus was how do we fight this horrible monster that invaded my body? The answer was radiation therapy.

Before the process of radiation began, my family and I decided a second opinion was a must. After a suggestion from another physician, we went to another specialist, who recommended radiation therapy with chemotherapy. Dealing with side effects was difficult. But every time my husband placed a kiss on my bald head, my son showed his glowing smile, the strength to fight grew stronger. My goal was to push through all the treatment and I achieved it!

Now after almost 2 years, my 3-month MRIs have not changed since my surgery, meaning zero growth! Fear was the hardest emotion to cut through, but with the support from many loved ones, I’m still here. Every moment with my son and husband are the blessings that will continue to help me.

I BEAT BRAIN CANCER!

I hope my story and this guide help you through your journey. The information and resources this guide has to offer will assist you with understanding brain cancer, your treatment process, and help you to communicate with your doctors.

- Melanie Moletzsky
  Anaplastic Astrocytoma Grade III Survivor
  National Comprehensive Cancer Network Project Specialist, Continuing Education
Learning that you have or may have cancer can be overwhelming.

The goal of this book is to help you get the best cancer treatment. It explains which cancer tests and treatments are recommended by experts in gliomas among adults.

The National Comprehensive Cancer Network® (NCCN®) is a not-for-profit alliance of 27 of the world’s leading cancer centers. Experts from NCCN have written treatment guidelines for doctors who treat gliomas. These treatment guidelines suggest what the best practice is for cancer care. The information in this patient book is based on the guidelines written for doctors.

This book focuses on diagnosis and treatment of gliomas. Key points of the book are summarized in the NCCN Quick Guide™ for Gliomas. NCCN also offers patient resources on leukemia, sarcoma, lymphoma, and other cancer types. Visit NCCN.org/patients for the full library of patient books, summaries, and other resources.
These patient guides for cancer care are produced by the National Comprehensive Cancer Network® (NCCN®).

The mission of NCCN is to improve cancer care so people can live better lives. At the core of NCCN are the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®). NCCN Guidelines® contain information to help health care workers plan the best cancer care. They list options for cancer care that are most likely to have the best results. The NCCN Guidelines for Patients® present the information from the NCCN Guidelines in an easy-to-learn format.

Panels of experts create the NCCN Guidelines. Most of the experts are from NCCN Member Institutions. Panelists may include surgeons, radiation oncologists, medical oncologists, and patient advocates. Recommendations in the NCCN Guidelines are based on clinical trials and the experience of the panelists. The NCCN Guidelines are updated at least once a year. When funded, the patient books are updated to reflect the most recent version of the NCCN Guidelines for doctors.

For more information about the NCCN Guidelines, visit NCCN.org/clinical.asp.

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NCCN Foundation was founded by NCCN to raise funds for patient education based on the NCCN Guidelines. NCCN Foundation offers guidance to people with cancer and their caregivers at every step of their cancer journey. This is done by sharing key information from the world’s leading cancer experts. This information can be found in a library of NCCN Guidelines for Patients® and other patient education resources. NCCN Foundation is also committed to advancing cancer treatment by funding the nation’s promising doctors at the center of cancer research, education, and progress of cancer therapies.

For more information about NCCN Foundation, visit NCCNFoundation.org.
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Who should read this book?

Gliomas are the most common type of cancer that starts in the brain or spinal cord. The focus of the book is treatment for gliomas among adults. Patients and those who support them—caregivers, family, and friends—may find this book helpful. It may help you discuss and decide with doctors what care is best.

Where should I start reading?

Part 1 is a good starting point to learn about gliomas. It explains the types of gliomas. Part 2 briefly describes cancer tests and treatments so you will understand your options. Options for astrocytomas and glioblastomas are listed in Part 3, and oligodendrogliomas and oligoastrocytomas are addressed in Part 4. For brain and spinal ependymomas, read Part 5. Part 6 gives tips for anyone making treatment decisions.

Does the whole book apply to you?

This book includes information for many situations. Your medical team can help. They can point out what parts of the book apply to you. They can also give you more information. As you read through this book, you may find it helpful to make a list of questions to ask your doctors.

Help! What do the words mean?

In this book, many medical words are included. These are words you will likely hear from your treatment team. Most of these words may be new to you, and it may be a lot to learn.

Don’t be discouraged as you read. Keep reading and review the information. Don’t be shy to ask your treatment team to explain a word or phrase that you do not understand.

Words that you may not know are defined in the text or in the Dictionary. Acronyms are also defined when first used and in the Glossary. Acronyms are short words formed from the first letters of several words. One example is DNA for deoxyribonucleic acid.
Glioma basics

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You’ve learned that you have or may have a cancer called a glioma. It’s common to feel shocked and confused. Part 1 reviews some basics that may help you learn about gliomas.

Glial cells

Your central nervous system consists of your brain and spinal cord. The brain is the command center of your body. It enables you to breathe, move, plan, talk, and much more. Your spinal cord relays messages between your brain and body.

Cells are the building blocks of the body. Your brain and spinal cord are made of more than one type of cell. Nerve cells (neurons) transmit messages through chemical and electric signals. Glial cells surround and support neuron cells. There are many more glial cells than neurons.

There are four types of glial cells in your central nervous system. They include astrocytes, oligodendrocytes, ependymal cells, and microglial cells. See Figure 1.

One job of astrocytes is to maintain the proper balance of chemicals in the brain. The main job of oligodendrocytes is to make a fatty membrane called myelin. Ependymal cells help to make a fluid that’s in your brain and spine (cerebrospinal fluid). Microglial cells defend your brain from disease-causing factors.

A disease of cells

Cancer is a disease of cells. Gliomas are cancers of glial cells. Doctors know a lot about how cancer cells differ from normal cells. Yet, they are still trying to learn what causes normal cells to become cancer cells.

Inside of cells are coded instructions for building new cells and controlling how cells behave. These instructions are called genes. Genes are a part of DNA (deoxyribonucleic acid), which is grouped together into bundles called chromosomes. See Figure 2.

There can be abnormal changes in genes called mutations. Some types of mutations that are linked to cancer are present in all cells. Other mutations are present only in cancer cells. Mutations cause cancer cells to not behave like normal cells and sometimes, look very different from normal cells.
**Figure 1**  
**Glial cells**

Glial cells are the most common cell type in your brain and spinal cord. They support the work of nerve cells. Astrocytes (green), Oligodendrocytes (light blue), Ependymal cells (light pink), Microglial cells (red)


**Figure 2**  
**Genetic material in cells**

Most human cells contain the “blueprint of life”—the plan by which our bodies are made and work. The plan is found inside of chromosomes, which are long strands of DNA that are tightly wrapped around proteins. Genes are small pieces of DNA that contain instructions for building new cells and controlling how cells behave. Humans have an estimated 20,000 to 25,000 genes.

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Cancer’s threat

Cancer cells don’t behave like normal cells in three key ways. First, cancer cells grow more quickly and live longer than normal cells. Normal cells grow and then divide to form new cells when needed. They also die when old or damaged as shown in [Figure 3]. In contrast, cancer cells make new cells that aren’t needed and don’t die quickly when old or damaged. Over time, cancer cells form a mass called the primary tumor.

The second way cancer cells differ from normal cells is that they can grow into (invade) normal tissue. If not treated, most gliomas can invade normal tissue in the brain or spine. More invasive cancers can cause an organ like the brain not to work as it should. They are also harder to remove during an operation.

Third, unlike normal cells, cancer cells can break away from tissue and travel to other body sites. This process is called metastasis. Some gliomas travel in cerebrospinal fluid to other sites in the nervous system. This is called Leptomeningeal disease. Metastasis outside the nervous system is called extraneural metastasis and is very rare.

The rate of growth and spread differs between gliomas. Some gliomas grow slowly while others grow fast. Fast-growing gliomas are described as “aggressive” by doctors. In the next section, cancer grades are described. The cancer grade tells which gliomas are likely to grow fast.

[Figure 3]
Normal cell growth vs. cancer cell growth

Normal cells increase in number when they are needed and die when old or damaged. In contrast, cancer cells quickly make new cells and live longer. Some gliomas consist of cells that very quickly increase in number and crowd out normal cells.
Cancer grade

The cancer grade is a rating of how much the cancer cells are like normal cells. It is used to predict the outlook (prognosis) of the cancer and plan treatment. A doctor needs to view the cancer cells with a microscope to assess the cancer grade. Gliomas are grouped into 4 grades.

- **Grade I** means that the cancer cells look almost normal. These cancers grow slowly. Most people with grade I gliomas live a long time.

- **Grade II** means the cancer cells look somewhat abnormal. These cancers grow slowly but can invade normal tissue. Sometimes, they return after treatment as a higher-grade glioma.

- **Grade III** means the cancer cells don’t look much like normal cells. These cancer cells quickly increase in number. Grade III gliomas are called anaplastic cancers.

- **Grade IV** means the cancer cells don’t look like normal cells. These cancers grow very quickly.

Gliomas are often described as either low- or high-grade cancers. Low-grade gliomas include grades I and II. High-grade gliomas include grades III and IV.

Tumors often contain cells of different grades. The highest grade will be used to grade the cancer. The highest grade is used even if most of the tumor is a lower grade.
Types of gliomas

There are multiple types of gliomas. Most gliomas that occur in adults are listed in Guide 1. The main types of gliomas are grouped by the glial cell from which they derived. Microglial cells do not become cancer cells. However, they are sometimes found in and around glial tumors.

Gliomas differ by their cell of origin and by other features, too. Research has found that glioma cells can differ in tiny parts, called molecules. Key molecular features of gliomas are discussed in Part 2. This information has recently been used by WHO (World Health Organization) to further group gliomas.

Cancer grades differ among the cancer types. Astrocytomas range from grade I to grade IV. Pilocytic astrocytomas are quite different from other astrocytomas. They rarely occur in adults but commonly occur in children. Only astrocytes can be grade IV. Grade IV astrocytomas include glioblastoma and gliosarcoma.

Symptoms of gliomas

Larger glial tumors are likely to cause symptoms. The symptoms that may occur partly depend on where the glial tumor is in the nervous system and how fast it grows. Common symptoms include memory problems, headaches, personality changes, seizures, speech problems, and numbness or weakness in the arms, legs, or face.

Guide 1. Gliomas in adults

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1 Glioma basics

Review

- Astrocytes, oligodendrocytes, ependymal cells, and microglial cells are glial cells. Their job is to support nerve cells.

- Gliomas are cancers of glial cells.

- Cancer consists of cells that grow faster than normal cells, invade into normal tissue, and spread to other areas.

- Some gliomas grow and spread faster than others. There are four cancer grades. Low-grade gliomas don’t grow or spread as fast as high-grade gliomas.

- There are multiple types of gliomas. Types of gliomas are named after the cell from which they derived and other cell features (molecular markers).

- Larger gliomas are more likely to cause symptoms. Which symptom will occur partly depends on where the tumor is in the central nervous system and how fast it grows.

Helpful Tip

✓ There will be those who say ‘so and so had cancer so I know all about it,’ even if ‘so and so’ has an entirely different cancer. It is ok to stress to them that every cancer is different and every patient reacts differently. Your cancer is your cancer, and sadly, no one will truly understand what you are going through.
# Test and treatment overview

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Part 2 briefly describes the tests and treatments used for gliomas. This information may help you understand your options. Options are listed for each type of glioma in Parts 3 through 5.

Imaging tests

Your doctor will want you to get an imaging test if you have symptoms of glioma. Imaging tests make pictures (images) of the insides of your body. They can show which sites in your nervous system might have cancer. Certain imaging tests also reveal some features of a tumor and its cells.

A radiologist is a doctor who’s an expert in reading images. A neuroradiologist is an expert in images of the nervous system. Your radiologist will convey the imaging results to your doctor. This information helps your doctor decide what the next steps of care should be.

You will be told how to prepare for an imaging test. You may need to stop taking some medicines and stop eating and drinking for a few hours before the scan. Tell your doctors if you get nervous when in small spaces. You may be given a sedative to help you relax.

Some imaging tests use contrast. Contrast is a dye that will be injected into your vein. It makes the pictures clearer. Some people have an allergic reaction to the dye. Tell your doctor if you’ve had problems with contrast in the past.

Brain and spinal MRI

MRI (magnetic resonance imaging) is an imaging test that uses a magnetic field and radio waves to make pictures. For a brain MRI, a device will be placed around your head that sends and receives radio waves. For spinal MRI, no device is worn.

Images will be made with and without contrast.

It's important to lie still during the test. Thus, straps may be used to help you stay in place. You may be given a sedative beforehand if you feel nervous.

During MRI, you will be inside the MRI machine. An open MRI scanner may be an option at some health centers. The machine makes loud noises but you can wear earplugs. After an MRI, you will be able to resume your activities right away unless you took a sedative. A brain MRI may cause your head to feel a bit warm.

MRI is used at multiple points of care for gliomas. It should be done if your doctor thinks you may have a brain or spinal tumor. It is also used to assess the results of treatment. Once treatment is done, MRIs are repeated over time to find any new tumor growth early.

MR spectroscopy | MR perfusion

These imaging tests may be used if the MRI is unclear. MR perfusion is a special type of MRI that measures blood flow in tumors. It requires that you be injected with a dye. MR spectroscopy uses both MRI and a series of tests to assess the chemical make-up of tumors and normal tissue.
CT scan
Not everyone can have an MRI. The magnetic fields can be an issue. You cannot get an MRI if you have a pacemaker, some types of cardiac monitors, or certain types of surgical clips.

Instead of MRI, you may get a CT (computed tomography). CT takes many pictures of a body part from different angles using x-rays. A computer combines the x-ray images to make a detailed picture. Images will be made with and without contrast. Getting a CT scan is like getting a MRI scan.

Brain PET
A PET (positron emission tomography) scan is not typically used for diagnosis. It is sometimes used in addition to MRI or CT scans if the cancer returns after treatment. For PET, a sugar radiotracer will first be injected into your body. After a few hours, the radiotracer is detected with a special camera during the scan. Cancer cells appear brighter than normal cells because they use sugar more quickly.

Helpful Tips
- Once home from surgery, use a recliner that lays back but is inclined.
- Get a shower chair. You should not stand until you're stable on your feet.
- Get help with washing your hair to keep clear of the incision. Have someone in the bathroom to make sure nothing happens.

Surgery
You will likely undergo surgery if there may be a primary tumor in your brain or spine. One goal of surgery is to confirm the diagnosis. Tissue from the tumor must be removed and tested to know for certain if there's cancer. Another goal of surgery is to remove as much of the tumor as possible. For brain tumors, surgery may be used to relieve pressure inside the skull or to treat seizures that are hard to control.

The types of surgery used for gliomas are briefly described next. Your treatment team can provide more information. A neurosurgeon—an expert in surgery of the nervous system—will perform your surgery.

Resection
Resection is a major surgery that removes a large piece of tissue. A gross total resection removes all of the cancer that your surgeon can see. A subtotal resection removes part of the tumor. Carmustine wafers may be inserted into your brain after surgery. This treatment is described more in the section, Chemotherapy.

Brain resection
You will be given medicine to help you relax or sleep during the surgery. Your scalp will also be numbed. The brain does not feel pain, which is why you can be awake.

Imaging and sometimes other tests are used to get the best results. Your surgeon needs to know where in your brain is the tumor and the key brain areas (eg, speech, movement). Tests will be received before and sometimes during the operation. You may need to be awake during the operation so that the key brain areas can be found.

Your surgeon will first cut your scalp and fold back your skin. Next, he or she will use a small drill to
Test and treatment overview

Surgery

remove a piece of your skull. A cut into your brain may be needed to reach the tumor. After the tumor is removed, the piece of your skull will be fastened with hardware (eg, screws, plates). Your scalp will be stitched back together.

Spinal tumor resection.
You will be given general anesthesia to make you sleep during the surgery. Your surgeon will first make a cut into your body above the tumor. Some spinal bones will then be removed. A second cut will be made to access your spinal cord and remove the tumor. Sometimes hardware is used to keep the spinal bones in place after surgery. Stitches are used to close the cuts and a bandage will be placed over your skin.

Biopsy
A biopsy is a type of surgery that removes samples of tissue. Doctors use biopsies for two reasons. Some types of biopsy are used to guide resections. Biopsies are also used when most or all of the tumor can't be removed. Spinal tumors are treated more often with biopsy than resection. There are two types of biopsy advised by NCCN experts for gliomas.

Open biopsy
This biopsy is a major surgery. It is performed much like a resection. Small surgical knives will be used to remove a tissue sample.

Stereotactic biopsy
This biopsy is often done when a brain tumor is in a hard-to-reach or vital area. Your surgeon will use an imaging test and a computer system to guide the biopsy. A head frame or small scalp markers will also be used. Your surgeon will make a small cut into your scalp and drill a very small (burr) hole into your skull. A thin needle will be inserted into the hole to remove some of the tumor.

Side effects of surgery
Side effects are unhealthy or unpleasant physical or emotional responses to treatment. You may experience side effects from the general anesthesia or the surgery itself. Side effects of general anesthesia include a sore throat from the breathing tube, nausea with vomiting, confusion, muscle aches, and itching.

Common side effects of any surgery are pain, swelling, and scars. If you had brain surgery, you won't feel pain in your brain because it has no pain receptors. However, you may have headaches from swelling and your scalp may hurt without pain medicine. A burning or tingling pain sometimes occurs after spinal surgery. Pain and swelling often fade away in the weeks following surgery. Feeling tired after surgery is also common.

Some rare risks of brain surgery include infection (pneumonia), major bleeding, blood clots, seizures, and brain damage. You may have a short-term increase in neurological symptoms after surgery due to swelling. Some rare risks of spinal surgery include new numbness, blood clots, infection, and spinal cord injury.

Not all side effects of surgery are listed here. Please ask your treatment team for a complete list of common and rare side effects. If a side effect bothers you, tell your treatment team. There may be ways to help you feel better.
Cancer lab tests

Tissue samples from surgery will be sent to a pathologist. A pathologist is a doctor who’s an expert in testing cells to find disease. For brain or spinal tumors, the pathologist should be a neuropathologist. He or she will examine the samples using a microscope.

All lab results are recorded in a pathology report. It’s a good idea to get a copy of your pathology report. It’s used to plan treatment. A meeting between all your doctors may be helpful for treatment planning once the pathology report is finished.

**Histologic typing**
If cancer is present, the pathologist will study the parts of the cancer cells to classify the disease. This is called histologic typing. The pathology report will state if the cancer started in the central nervous system or elsewhere. If the cancer is a glioma, the subtype will be noted in the report.

**Molecular testing**
Any of your body’s molecules that can be measured to assess your health is known as a biomarker. Gliomas can differ between people by which biomarkers are present. Pathologists may conduct molecular (aka biomarker) testing to help with diagnosis and treatment planning. After surgery, testing of three biomarkers is often performed if the cancer is a glioma. These biomarkers are described next.

**1p19q co-deletion**
A translocation is a switching of parts between two chromosomes. A hallmark of oligodendrogliomas is a translocation that results in the loss of the new chromosome. See Figure 4. This marker also occurs in many oligoastrocytomas.

The translocation occurs between chromosomes 1 and 19. When both parts of the new chromosome...
are lost, it is called a 1p19q co-deletion. PCR (polymerase chain reaction) and FISH (fluorescence in situ hybridization) are tests that can show if a deletion is present. Test results are used for diagnosis and treatment planning. Radiation and chemotherapy appear to treat cancer cells with 1p19q co-deletion better than cells without the co-deletion.

**IDH1 and IDH2 mutations**

IDH1 and IDH2 (isocitrate dehydrogenase 1 and 2) are proteins in cells. Many grade II and III gliomas have mutations in the genes of these proteins. These mutations are also found in glioblastomas that began as grade II or III gliomas.

IHC (immunohistochemistry), PCR, or pyrosequencing are tests for IDH1 or IDH2 gene mutations. Test results can help with diagnosis and treatment planning. People treated with radiation or alkylator chemotherapy tend to live longer if the cancer cells have IDH1 or IDH2 gene mutations.

**MGMT promoter status**

MGMT (methylguanine methyltransferase) is a protein in cells that repairs damaged DNA. It helps repair DNA that was damaged by alkylator chemotherapy.

The gene that helps to make MGMT is silenced in some high-grade gliomas. The MGMT gene is silenced when the part of DNA that turns it on (called a promotor region) is methylated. Methylated DNA has added chemicals called methyl groups.

Tests for MGMT promoter methylation are PCR and pyrosequencing. Test results are used for treatment planning. Alkylator chemotherapy works better overall for glioblastoma that has methylated MGMT promotor regions compared to unmethylated regions.

Radiation therapy is used to treat gliomas that can’t be removed by surgery. It is also used after surgery to kill any cancer cells that remain in the brain. Read Parts 3 through 5 to learn when radiation is an option. What you can expect during radiation therapy is briefly described next.

Radiation therapy is a cancer treatment that uses high-energy, highly focused rays. The rays can be x-rays, photons, or protons. The rays are delivered to the tumor to damage DNA. This either kills the cancer cells or stops new cancer cells from being made.

Radiation can also harm normal cells. Thus, your radiation oncologist will use methods that limit how much normal tissue receives radiation. A radiation oncologist is a doctor who’s an expert in treating cancer with radiation.

Depending on the type of glioma, radiation will be delivered to the tumor plus some tissue around it that may harbor cancer cells. The treated tissue around the tumor is called the margin. Your radiation plan will be tailored to you, your tumor, and your brain. You are not radioactive after receiving radiation therapy.

**Simulation**

To receive radiation, you must have a planning (simulation) session. First, you will be guided and adjusted into the position needed for treatment. After this, pictures of your head and the tumor will be taken with an imaging test. Usually, a CT scan is used.
For a brain tumor, you will need to wear a head mask. The mask will keep your head still during treatment. It also helps keep you in the same treatment position at every visit.

The mask is made with a mesh material and will be shaped to your face before simulation. First, the mask will be warmed in water and then pressed down into the contours of your face. Afterward, the mask will be removed and will harden in several days.

For a spinal tumor, a special mold of your body may be made. The mold helps to place you in the right position for treatment. You may also have small ink marks tattooed on your skin to help direct treatment.

Using the pictures, your radiation team will plan the best radiation dose, number and shape of radiation beams, and number of treatment sessions. A team consists of doctors, medical physicists, and technical experts in radiation planning. The radiation dose is shaped with computer software and hardware added to the radiation machine.

Conformal techniques
EBRT is given to shape the radiation dose to the tumor so healthy tissue around the tumor is spared. However, some healthy tissue still gets radiated. The types of conformal radiation include:

- **3D-CRT** (three-dimensional conformal radiation therapy) uses photon beams from different angles that match the shape of the tumor.

- **IMRT** (intensity-modulated radiation therapy) is a more precise form of 3D-CRT. The radiation beam is divided into smaller beams at many different angles and the strength of each beam can vary. The beams intersect at the tumor. During treatment, the radiation machine will move around you.

- **VMAT** (volumetric arc-based therapy) is like IMRT but delivers treatments in an arc shape around the tumor.

- **Craniospinal radiation** treats the entire brain and spinal cord with conformal radiation. It is sometimes used to treat brain tumors that have spread into the spine.

- **Proton therapy** is very much like 3D-CRT but uses proton beams instead of photon beams. Proton beams deliver radiation mostly within the tumor. You can only receive proton therapy at some treatment centers because it requires special machines. Your doctor may use proton beams for craniospinal radiation if he or she thinks it may cause fewer side effects.

- **Stereotactic radiosurgery** (SRS, for short) uses photon or proton beams that deliver a large radiation dose within a small area. It may be used for gliomas that have returned after the first round of therapy. It may also sometimes be used for spinal tumors.

Receiving radiation
During treatment, you will lie on a table in the same position as done for simulation. To treat brain tumors, you must wear your mask. Other devices may be used to keep you from moving. For spinal treatment, a body mold may be used to keep you from moving.
You will be alone while the technician operates the machine from a nearby room. He or she will be able to see, hear, and speak with you through an intercom and video system. As treatment is given, you may hear noises and see lights. One session can take about 15 to 20 minutes.

The total dose of radiation is split into a number of treatments called fractions. The number of treatments varies among people with gliomas as noted below. Your doctor will see you every week to review how you are doing.

**Radiotherapy**
- Fractionated EBRT consists of one session 5 days a week for about 5 to 6 weeks.
- You may have more or fewer treatments. Hyperfractionated EBRT consists of fewer sessions. Your doctor will discuss how many treatments you will receive.

**Radiosurgery**
- Stereotactic radiosurgery is typically given in one treatment session.
- Fractionated stereotactic radiotherapy is radiosurgery given in up to 5 sessions.

**Side effects of radiation**
Side effects from radiation therapy differ among people. Factors like tumor type, tumor site, radiation dose, and length of treatment play a role. Side effects are cumulative meaning they are the worse at the end of treatment.

The most common side effect of radiation is extreme tiredness despite sleep (fatigue). You may also have hair loss where treatment was received. Other side effects of radiation include swelling and loss of appetite. In rare cases, your skin may become pink, like a sunburn.

A rare side effect of radiation is death of tissue (necrosis). This is like scarring but in the brain. This tissue can cause swelling in the brain and may cause symptoms. In some cases, necrosis can only be seen on brain images.

Not all side effects of radiation are listed here. Please ask your treatment team for a complete list of common and rare side effects. They can give you a full list and let you know which ones you are more likely to get. If a side effect bothers you, tell your treatment team. There may be ways to help you feel better. There are also ways to prevent some side effects.

**Helpful Tips**
- Use a satin pillowcase. Satin is smooth whereas cotton is rough, causing your sensitive hair follicles to be painful and pulled out.
- Your scalp may get irritated. Take a washcloth, soaking it in saline, and place on tender spots. It will help cool the irritated sections.
Chemotherapy

Chemotherapy, or “chemo,” includes drugs that disrupt the life cycle of cancer cells. Some chemotherapy drugs kill cancer cells by damaging their DNA or by disrupting the making of DNA. Other drugs interfere with cell parts that are needed for making new cells. Thus, no new cells are made to replace dying cells. Chemotherapy can affect both cancer and normal cells.

As shown in Figure 5, some chemotherapy drugs work when cells are in an active growth phase. During the active growth phase, cells grow and divide to form a new cell. Chemotherapy drugs that disrupt the growth phase work well for cancer cells that are growing and dividing quickly. Other chemotherapy drugs work in any growth or resting phase.

Regimens

Chemotherapy regimens used for gliomas are listed in Guide 2. Sometimes, only one drug is used. Temozolomide is a commonly used single agent for gliomas.

Other times, more than one drug is used because drugs differ in the way they work. PCV (lomustine, procarbazine, vincristine) is a common regimen. Also, cisplatin or carboplatin—drugs made with platinum—is used with another drug. These regimens are called platinum-based chemotherapy.

Alkylator chemotherapy appears to be a good treatment for oligodendrogliomas. It may work even better if a 1p19q co-deletion is present. Alkylator chemotherapy includes carboplatin, carmustine, cisplatin, cyclophosphamide, lomustine, and procarbazine.

Figure 5
Chemotherapy and the cell cycle

A cell goes through many changes to divide into two cells. Science has grouped these changes into 7 main phases. There may be another phase of rest, too. Some chemotherapy drugs work in any phase. Other chemotherapy drugs work in one or two growth phases.
Receiving chemotherapy
The way chemotherapy is received differs among the drugs. Some are liquids that are injected into a vein. Others are made as pills. One drug, carmustine, is also made as a wafer. Your medical neuro-oncologist will discuss your options with you. A medical neuro-oncologist is a doctor who’s an expert in treating tumors in the nervous system.

Liquid chemotherapy travels in your bloodstream to treat cancer throughout your body. Likewise, chemotherapy pills dissolve in your stomach and enter your bloodstream. Doctors use the term “systemic” when talking about a cancer treatment for the whole body.

Systemic chemotherapy is given in cycles of treatment days followed by days of rest. The cycles vary in length depending on which drugs are used. Common cycles are 14, 21, or 28 days long. Giving chemotherapy in cycles gives your body a chance to recover after receiving chemotherapy. If you will have chemotherapy, ask your doctor how many cycles and days of treatment there are within a cycle.

Some treatments can be placed in the nervous system where there is cancer. Doctors call this “local delivery.” Carmustine wafers are placed into the brain within the space left by the removed tumor. Up to 8 wafers may be used. They dissolve over time. Carmustine wafers treat cancer cells that may remain in the normal-looking tissue that surrounded the tumor.

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

Some side effects can be very serious while others can be unpleasant but not serious. Most side effects

Guide 2. Drug treatment for gliomas

<table>
<thead>
<tr>
<th>Generic name</th>
<th>Brand name (sold as)</th>
<th>Type of treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bevacizumab</td>
<td>Avastin®</td>
<td>Targeted therapy</td>
</tr>
<tr>
<td>Carboplatin</td>
<td>–</td>
<td>Chemotherapy</td>
</tr>
<tr>
<td>Carmustine</td>
<td>BiCNU®</td>
<td>Chemotherapy</td>
</tr>
<tr>
<td>Carmustine implant</td>
<td>GLIADEL® Wafer</td>
<td>Chemotherapy</td>
</tr>
<tr>
<td>Cisplatin</td>
<td>Platinol®</td>
<td>Chemotherapy</td>
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<tr>
<td>Cyclophosphamide</td>
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<td>Chemotherapy</td>
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<td>Etopophos® Preservative Free</td>
<td>Chemotherapy</td>
</tr>
<tr>
<td>Irinotecan hydrochloride</td>
<td>Camptosar®</td>
<td>Chemotherapy</td>
</tr>
<tr>
<td>Lomustine</td>
<td>CeeNU®</td>
<td>Chemotherapy</td>
</tr>
<tr>
<td>Procarbazine hydrochloride</td>
<td>Matulane®</td>
<td>Chemotherapy</td>
</tr>
<tr>
<td>Temozolomide</td>
<td>Temodar®</td>
<td>Chemotherapy</td>
</tr>
<tr>
<td>Vincristine sulfate</td>
<td>–</td>
<td>Chemotherapy</td>
</tr>
</tbody>
</table>
Chemotherapy

appear shortly after treatment starts and will stop after treatment. However, other side effects are long-term or may appear years later.

For systemic chemotherapy, most side effects are caused by the death of fast-growing cells in the body. These cells are found in the blood, gut, hair follicles, and mouth. Thus, common side effects of chemotherapy include low blood cell counts, not feeling hungry, nausea, vomiting, diarrhea, hair loss, and mouth sores. Ask your doctor which drugs cause which side effects.

Side effects of carmustine wafers somewhat differ from systemic chemotherapy. A common side effect is new or worse seizures in the days following surgery. Other side effects include swelling in the brain, problems with wound healing, nausea, vomiting, constipation, and depression. Sometimes, cerebrospinal fluid leaks. Brain infections like meningitis are rare.

Not all side effects of chemotherapy are listed here. Please ask your treatment team for a complete list of common and rare side effects. If a side effect bothers you, tell your treatment team. There may be ways to help you feel better. There are also ways to prevent some side effects. Read the NCCN Guidelines for Patients: Nausea and Vomiting to learn about preventing and managing these symptoms.

Helpful Tips

- You have a higher chance of being sick. Think about telling those around you to please keep their distance. A simple cold can turn into bronchitis or pneumonia for you.
- You can experience constipation. Use a stool softener and a natural slow laxative. Drink plenty of liquids.
Targeted therapy

Targeted therapy is a cancer treatment that affects molecules that are key to cancer cells. It differs from classic chemotherapy, which affects a wider range of cells. As such, targeted therapy is less likely to harm normal cells than chemotherapy.

At this time, only one targeted therapy is advised by NCCN experts for gliomas. It is briefly described next. Some side effects are listed. Ask your treatment team for a full list of common and rare side effects. Parts 3 through 5 address when targeted therapy is an option.

VEGF pathway
Cancer cells need the food and oxygen in blood to grow. Cancer cells get blood from blood vessels that have grown into the tumor. VEGF (vascular endothelial growth factor) is one of the molecules that triggers the growth of these blood vessels.

VEGF is made by cancer cells. It travels from cancer cells to endothelial cells. Endothelial cells form blood vessels. VEGF attaches to surface receptors on the outside of endothelial cells. Attachment of VEGF to surface receptors triggers growth signals.

Bevacizumab
Bevacizumab attaches to VEGF before it attaches to receptors on endothelial cells. See Figure 6. As a result, VEGF can’t attach to receptors. No growth signals caused by VEGF are started.

Bevacizumab is given by infusion. It takes about 90 minutes to get the first dose and 30 minutes for later doses. It may be received alone or with chemotherapy to treat some types of gliomas.

Common side effects of bevacizumab are high blood pressure, diarrhea, and feeling tired and weak. You might also have nosebleeds, shortness of breath, and abnormal levels of protein in your urine (proteinuria). Rare but serious side effects include stroke, blood clots, heart attack, kidney damage, holes in the intestine, and bleeding in your body including your head.

Figure 6
VEGF targeted therapy
Cancer cells need blood to grow. They send VEGF to endothelial cells to start the growth of blood vessels. Bevacizumab disables VEGF from attaching to receptors. As a result, VEGF can’t start cell growth.
Alternating electric field therapy

Alternating electric field therapy is a cancer treatment that uses low-intensity electromagnetic energy. It is also called TTFields (Tumor Treating Fields). This treatment may be an option for glioblastomas. Read Part 3 to learn when it is an option.

TTFields disrupt the process by which cells make copies of themselves. This approach relies on the theory that no new cancer cells are made. Existing cancer cells also die.

Treatment will be received through 4 patches safely taped to your scalp. You will have to shave your head. The patches will be attached to an energy-producing device and a battery that can be carried with you. As such, you will be able to go home and do most daily activities. The patches are worn for at least 18 hours a day for at least 4 weeks. The most common side effect is skin irritation.

Clinical trials

New tests and treatments aren’t offered to the public as soon as they’re made. They first need to be studied. A clinical trial is a type of research that studies a test or treatment in people. Joining a clinical trial is encouraged.

Clinical trials study how safe and helpful tests and treatments are for people. When found to be safe and helpful, they may become tomorrow’s standard of care. Because of clinical trials, the tests and treatments in this book are now widely used to help people with glioma. Future tests and treatments that may have better results than today’s treatments will depend on clinical trials.

New tests and treatments go through a series of clinical trials to make sure they’re safe and work. Without clinical trials, there is no way to know if a test or treatment is safe or helpful. Clinical trials have four phases. Some examples of the four phases for treatment are:

- **Phase I** trials aim to find the best dose of a new drug and the best way to give it with the fewest side effects. These trials often involve about 20 people.
- **Phase II** trials assess if a drug works for a specific type of cancer.
- **Phase III** trials compare a new drug to the standard treatment. These trials often involve hundreds or thousands of people.
- **Phase IV** trials test new drugs approved by the U.S. FDA (Food and Drug Administration) in many patients with different types of cancer.

Joining a clinical trial has benefits. First, you’ll have access to the most current cancer care. Second, you will receive the best management of care. Third, the results of your treatment—both good and bad—will be carefully tracked. Fourth, you may help other people who will have cancer in the future.

Clinical trials have risks, too. Like any test or treatment, there may be side effects. Also, new tests or treatments may not help. Another downside may be that paperwork or more trips to the hospital are needed.

To join a clinical trial, you must meet the conditions of the study. Patients in a clinical trial are often alike in terms of their cancer and general health. This is to know that any progress is because of the treatment and not because of differences between patients.
To join, you’ll need to review and sign a paper called an informed consent form. This form describes the study in detail. The study’s risks and benefits should be described and may include others than those described above.

Ask your treatment team if there is an open clinical trial that you can join. There may be clinical trials where you’re getting treatment or at other treatment centers nearby. You can also find clinical trials through the websites listed in Part 6.

Supportive care

Supportive care doesn’t aim to treat cancer but aims to improve quality of life. It can be received at any point during your cancer journey. When the cancer is advanced, supportive care is often called palliative care.

Supportive care can address many needs. One example is treatment for physical and emotional symptoms. Some common symptoms that may need management are described next.

- Swelling (edema) in your central nervous system may occur because of the cancer or cancer treatments. Corticosteroids (steroids, for short) are used to control the amount of swelling.

- Seizures are common among people with brain tumors. If you’ve never had seizures, preventing them with seizure medicine is not advised in general. However, preventing seizures after surgery is reasonable. If you have seizures, you may take seizure medicine to stop them. Be aware that certain seizure medicines limit how well chemotherapy works.

- A blood clot in a deep vein (deep venous thrombosis) commonly occurs in people with high-grade gliomas. It occurs in 20 to 30 out of every 100 people with glioblastoma (ie, 20%–30%). The blood clot can travel to your lungs and block the vein (pulmonary embolism). Check your limbs for skin redness, swelling, or a feeling of discomfort. Seek help right away if symptoms appear.

- Endocrine disorders are health problems within your hormone system. A general decline in your sense of well-being may be related to an endocrine disorder. Your doctor will assess if your hormone glands are working properly.

Helpful Tips

- Depending on location of the tumor you may experience slow/slurred speech; longer time to complete sentences; difficulty writing.

- Some people will interrupt you when struggling to speak, be sure to continue with your thought. If need be, explain to them what is happening.
Fatigue is a severe tiredness despite getting enough sleep. Learning how to conserve energy may help. If you’re healthy enough, some exercise can also lessen fatigue.

Depression and anxiety can be very overwhelming. Medicine, talk therapy, and exercise are some ways to lessen these symptoms. Ask your treatment team for help.

Supportive care can also help with treatment decisions as you may have more than one option. It can also help with coordination of care between health providers. Talk with your treatment team to plan the best supportive care for you.

MRI and other imaging tests make pictures of the insides of your body. Imaging tests are used for diagnosis, treatment planning, and assessing treatment results.

Surgery removes tissue in order to confirm there’s cancer and to rid your body of cancer as much as possible.

Tissue from the tumor will be tested for markers that help to diagnose the disease and plan treatment.

Radiation therapy uses high-energy rays to destroy cancer cells or stop them from increasing in number.

Chemotherapy aims to stop cancer cells from completing their life cycle so they can’t increase in number.

Targeted therapy is a cancer treatment that affects molecules that are key to cancer cells.

Clinical trials give people access to new tests and treatments that they otherwise can’t receive. If proven to work well, they may in time be approved by the FDA.

Supportive care aims to improve your quality of life. It includes symptom management.

Complementary and alternative medicine

CAM (complementary and alternative medicine) is a group of treatments that aren’t often given by doctors. There is much interest today in CAM for cancer. Many CAMs are being studied to see if they are truly helpful. Complementary medicines are treatments given along with usual medical treatments. While CAMs aren’t known to kill cancer cells, they may improve your comfort and well-being. Two examples are acupuncture for pain management and yoga for relaxation.

Alternative medicine is used in place of usual medicine. Some alternative medicines are sold as cures even though they haven’t been proven to work in clinical trials. If there was good proof that CAMs or other treatments cured cancer, they would be included in this book.

It is important to tell your treatment team if you are using any CAMs. They can tell you which CAMs may be helpful and which CAMs may limit how well medical treatments work.
3
Treatment guide: Astrocytomas and glioblastomas

32 Pilocytic astrocytomas
This section addresses treatment for grade I astrocytomas.

32 Diffuse astrocytomas
This section presents options for grade II astrocytomas.

36 Anaplastic astrocytomas
This section presents options for grade III astrocytomas.

40 Glioblastomas and gliosarcomas
This section presents options for grade IV astrocytomas.

46 Review
Part 3 is a guide to the treatment options for adults with astrocytoma. Options are based on the cancer grade. Also, you may have an option of joining a clinical trial. This information is taken from the treatment guidelines written by NCCN experts for doctors treating gliomas. Your doctors may suggest other treatments than those listed in Part 3 based on your health and personal wishes.

Pilocytic astrocytomas

Pilocytic astrocytomas are the most common type of grade I astrocytomas. These tumors have well-defined edges. They also rarely become a higher grade astrocytoma. Therefore, pilocytic astrocytomas are often cured with surgery. In this case, no further treatment is needed. If the tumor wasn’t fully removed, you may receive radiation therapy.

Diffuse astrocytomas

The best treatment for grade II diffuse astrocytomas still needs to be confirmed. A team of health experts can discuss what treatment is best for you. Your team may consist of a neurosurgeon, radiation oncologist, medical neuro-oncologist, and other experts. At this time, NCCN experts believe that surgery is still very important for diagnosis and treatment. The first goal of surgery is to remove enough tissue for diagnosis and cancer grading.

Guide 3 lists treatment options for diffuse astrocytomas. Your surgeon will assess how much of the tumor he or she can remove. The amount that will be removed depends on where the tumor is, your age and health, and other factors. Your surgeon does not want you to be less able to think, speak, and move afterward.

Maximal safe resection

A maximal safe resection is a treatment plan to remove all or most of the tumor as is safe. Hopefully, the whole tumor will be removed. Removal of the whole tumor is called a gross total resection. However, your surgeon may decide during surgery that the whole tumor can’t be removed. Removing only part of the tumor is called a subtotal resection.

Other surgeries

There are other options if it is known before surgery that a maximal safe resection can’t be done. These options are a subtotal resection, open biopsy, and stereotactic biopsy. The removed tissue will be tested to confirm diagnosis and cancer grade.

Observation

Surgery is advised in general. However, for some people, observation may be an option. Observation consists of one or more cancer tests repeated over a period of time. Treatment to remove the cancer or to relieve symptoms may be started if the status of the cancer changes.

Tests after surgery

The removed tissue will be sent to a pathologist for testing. The pathologist will confirm if there’s cancer, and if so, the cancer grade. If the cancer is partly an oligodendroglioma, your doctor may want the cancer cells to be tested for 1p19q deletions. This test may help your doctor predict the outlook (prognosis) of the cancer.

You should receive a brain MRI if you had a gross total or subtotal resection. MRI should be done within 24 to 72 hours after surgery. Images will be made with and without contrast. This test can confirm how much of the cancer was removed. If you can’t have MRI, you may receive a CT scan with and without contrast.
# Diffuse astrocytomas

## Guide 3. Diagnosis and treatment

### Surgery

<table>
<thead>
<tr>
<th>Your surgery status</th>
<th>What are the options?</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Approved and agree to removing most of the tumor</td>
<td>• Maximal safe resection</td>
</tr>
<tr>
<td>• Approved and agree to removing some of the tumor</td>
<td>• Subtotal resection</td>
</tr>
<tr>
<td>• Open biopsy</td>
<td></td>
</tr>
<tr>
<td>• Stereotactic biopsy</td>
<td></td>
</tr>
<tr>
<td>• Not approved or decline surgery</td>
<td>• Observation</td>
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</table>

### Post-surgery treatment

<table>
<thead>
<tr>
<th>Type of surgery</th>
<th>What are the options?</th>
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<tbody>
<tr>
<td>• You had a gross total resection and are 40 years of age or younger</td>
<td>• Observation</td>
</tr>
<tr>
<td></td>
<td>• Fractionated EBRT</td>
</tr>
<tr>
<td></td>
<td>• Chemotherapy</td>
</tr>
<tr>
<td>• You had a gross total resection and are older than 40 years of age,</td>
<td>• Fractionated EBRT followed by PCV</td>
</tr>
<tr>
<td>• You had a subtotal resection,</td>
<td>• Fractionated EBRT followed by temozolomide</td>
</tr>
<tr>
<td>• You had an open biopsy, or</td>
<td>• Temozolomide during and after fractionated EBRT</td>
</tr>
<tr>
<td>• You had a stereotactic biopsy</td>
<td>• Observation</td>
</tr>
</tbody>
</table>

**Post-surgery treatment**

You may have had a gross total resection and are 40 years of age or younger. In this case, you may have 3 options. You may be able to start observation and wait to see if more treatment is needed. Other options include receiving fractionated EBRT or chemotherapy now. PCV or temozolomide is advised for chemotherapy.

For older people who had a total resection and for people who had other surgeries, there are four options. Starting treatment now is advised for most cases. You may receive fractionated EBRT followed by 6 cycles of PCV. This option had good results in a well-designed clinical trial. A second option is fractionated EBRT followed by temozolomide. Likewise, you may receive temozolomide during and after fractioned EBRT. The last option for some people with stable or no symptoms is observation.
### Guide 4. Follow-up care

<table>
<thead>
<tr>
<th>Test</th>
<th>Test schedule</th>
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</thead>
<tbody>
<tr>
<td>Brain MRI</td>
<td>• Every 3–6 months for 5 years&lt;br&gt;◦ If results are stable, then repeat every year</td>
</tr>
</tbody>
</table>

### Guide 5. Progression or recurrence

**You didn’t have radiation therapy before**

<table>
<thead>
<tr>
<th>Your surgery status</th>
<th>What are the options?</th>
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</thead>
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<tr>
<td>Approved and agree to surgery</td>
<td>Surgery&lt;br&gt;• Fractionated EBRT + chemotherapy&lt;br&gt;• Fractionated EBRT&lt;br&gt;• Chemotherapy</td>
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<tr>
<td>Not approved or decline surgery</td>
<td>• Fractionated EBRT + chemotherapy&lt;br&gt;• Fractionated EBRT&lt;br&gt;• Chemotherapy</td>
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**You did have radiation therapy before**

<table>
<thead>
<tr>
<th>Your surgery status</th>
<th>What are the options?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Approved and agree to surgery</td>
<td>• Surgery followed by chemotherapy</td>
</tr>
<tr>
<td>Not approved or decline surgery</td>
<td>• Chemotherapy</td>
</tr>
</tbody>
</table>

### What are the options if the cancer progresses after chemotherapy?

- A different chemotherapy
- Radiation therapy again
- Best supportive care
Guide 4 addresses follow-up care. Follow-up care is started when your doctor thinks the cancer has been fully treated. A brain MRI is advised every 3 to 6 months for 5 years. If results are stable for 5 years, a brain MRI is needed every year. If you can’t have MRI, you may receive a CT scan with and without contrast.

Guide 5 lists treatment options for cancer progression or recurrence. In addition, a clinical trial may be another option. Cancer progression is further growth or spread of cancer that’s already been found. A recurrence is the return of cancer after not having signs of cancer for a period of time. Your surgeon may obtain a tissue sample to confirm that the cancer is back and to assess the cancer grade.

Progressive and recurrent cancers are treated the same. Options are based on whether you had fractionated EBRT for first-time treatment. If you will receive chemotherapy, it may consist of PCV, temozolomide, lomustine, or carmustine.

No radiation therapy before
Your surgeon will assess if surgery is an option. If you undergo surgery, a brain MRI is advised within 24 to 72 hours to assess surgery results. If you can’t have MRI, you may receive a CT scan. Images will be made with and without contrast.

After surgery, observation may be started if all the cancer was removed. However, for most people, surgery should be followed by fractionated EBRT with or without chemotherapy or followed by chemotherapy only. If surgery isn’t an option, you may have three options. One option is fractionated EBRT with chemotherapy. The second option is fractionated EBRT without chemotherapy. A third option is chemotherapy without radiation therapy.

Radiation therapy before
Your surgeon will assess if surgery is an option. If you undergo surgery, a brain MRI is advised within 24 to 72 hours to assess surgery results. If you can’t have MRI, you may receive a CT scan. Images will be made with and without contrast.

Chemotherapy may be received after surgery or as the sole treatment if surgery isn’t an option. During chemotherapy, it’s typical to get MRI scans every 2 to 3 months.

The cancer may progress after chemotherapy. In this case, you may have three options. One option is to think about changing to a different chemotherapy. Your radiation oncologist may think radiation therapy is another option. The third option is supportive care. Supportive care aims to improve your quality of life. It includes treatment for symptoms caused by the cancer or prior treatment.
Anaplastic astrocytomas

Guide 6. Diagnosis and treatment

Surgery

<table>
<thead>
<tr>
<th>Your surgery status</th>
<th>What are the options?</th>
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<tr>
<td>Approved and agree to removing most of the tumor</td>
<td>• Maximal safe resection ± carmustine wafer</td>
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<tr>
<td>Approved and agree to removing some of the tumor</td>
<td>• Stereotactic biopsy</td>
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<tr>
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<td>• Open biopsy</td>
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<td>• Subtotal resection</td>
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Post-surgery treatment

<table>
<thead>
<tr>
<th>Your performance status</th>
<th>What are the options?</th>
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<td>KPS ≥60</td>
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<td>• Fractionated EBRT and temozolomide</td>
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<tr>
<td></td>
<td>• PCV or temozolomide</td>
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<tr>
<td>KPS ≤59</td>
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<tr>
<td></td>
<td>• PCV or temozolomide</td>
</tr>
<tr>
<td></td>
<td>• Best supportive care</td>
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Anaplastic astrocytomas are one of the most common brain cancers in adults. Surgery is very important for diagnosis and treatment. The goals of surgery are to remove enough tissue for testing, relieve symptoms, extend life, and decrease the need for corticosteroids. Corticosteroids are used to reduce swelling in the brain.

Guide 6 lists the treatment for anaplastic astrocytoma. Your surgeon will assess how much of the tumor he or she can remove. The amount that will be removed depends on where the tumor is, your age and health, and other factors. Your surgeon does not want you less able to think, speak, and move afterward.
Maximal safe resection
A maximal safe resection is a treatment plan to remove all or most of the tumor as is safe. Hopefully, the whole tumor will be removed but fully removing anaplastic astrocytoma is often hard to do. Removal of the whole tumor is called a gross total resection. During surgery, your surgeon may decide that the whole tumor can’t be removed. Removing only part of the tumor is called a subtotal resection.

Carmustine wafers
Placement of carmustine wafers during surgery may be an option. Wafers are sometimes used for high-grade gliomas. Carmustine is a type of chemotherapy. The wafers will be placed into the space where the tumor was and will dissolve after the surgical cut is closed.

Research has shown that this added treatment may help extend life. However, if you receive more chemotherapy after surgery, you may have more severe side effects than if you hadn’t had carmustine. Also, you may not be able to join some clinical trials because you received carmustine wafers.

Other surgeries
There are other options if it is known before surgery that a maximal safe resection can’t be done. These options are a subtotal resection, open biopsy, and stereotactic biopsy. The removed tissue will be tested to confirm diagnosis and cancer grade.

Tests after surgery
The removed tissue will be sent to a pathologist for testing. The pathologist will confirm if there’s cancer, and if so, the cancer grade. Molecular markers of gliomas will also be assessed.

You should receive a brain MRI if you had a gross total or subtotal resection. MRI should be done within 24 to 72 hours after surgery. Images will be made with and without contrast. This test can confirm how much of the cancer was removed. If you can’t have MRI, you may receive a CT scan with and without contrast.

Post-surgery treatment
Guide 6 also lists options for treatment after surgery. Options are based on your performance status, which is your ability to do activities. The KPS (Karnofsky Performance Status) is a rating system used to score performance status. Scores range from 0 to 100. The lower the score, the less able you are to care for yourself.

You may have three options if your KPS score is 60 or higher. One option is to receive fractionated EBRT. Another option is fractionated EBRT with temozolomide. Temozolomide is often received during and after EBRT. The third option is chemotherapy with PCV or temozolomide.

You may have three options if your KPS score is 59 or less. One option is to receive EBRT. Hyperfractionated is preferred over fractionated radiation. Another option is chemotherapy with PCV or temozolomide. The third option is supportive care. Supportive care aims to improve your quality of life. It includes treatment for symptoms caused by the cancer or prior treatment.
Guide 7. Follow-up care

<table>
<thead>
<tr>
<th>Test</th>
<th>Test schedule</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brain MRI</td>
<td>• At 2–6 weeks after radiation therapy has ended</td>
</tr>
<tr>
<td></td>
<td>◦ If results are stable, then repeat every 2–4 months for 2–3 years</td>
</tr>
<tr>
<td></td>
<td>◦ If results are stable, then repeat less often</td>
</tr>
</tbody>
</table>

Guide 8. Recurrence

The cancer isn’t widespread

<table>
<thead>
<tr>
<th>Your surgery status</th>
<th>What are the options?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Approved and agree to surgery</td>
<td>• Surgery ± carmustine wafer • Chemotherapy</td>
</tr>
<tr>
<td></td>
<td>• Radiation therapy again</td>
</tr>
<tr>
<td></td>
<td>• Best supportive care</td>
</tr>
<tr>
<td>Not approved or decline surgery</td>
<td>• Best supportive care</td>
</tr>
</tbody>
</table>

The cancer is widespread

<table>
<thead>
<tr>
<th>Your performance status</th>
<th>What are the options?</th>
</tr>
</thead>
<tbody>
<tr>
<td>KPS ≥60</td>
<td>• Chemotherapy</td>
</tr>
<tr>
<td></td>
<td>• Surgery for large tumors causing symptoms</td>
</tr>
<tr>
<td>KPS ≤59</td>
<td>• Best supportive care</td>
</tr>
</tbody>
</table>
Guide 7 addresses follow-up care. Follow-up care is started when your doctor thinks that the cancer has been fully treated. A brain MRI is advised at 2 to 6 weeks after radiation therapy has ended. Images will be made with and without contrast.

At first, your brain may look worse in the scans because of the radiation. However, these results may not mean that the cancer is growing. Instead, early scans are used to give you the right dose of steroids and check for tumor growth beyond where radiation was given.

Later scans are used to find any new brain tumors early. A brain MRI is advised every 2 to 4 months for 2 to 3 years. If these results are stable, then MRIs are needed less often. If you can’t have MRI, you may receive a CT scan with and without contrast.

Guide 8 lists treatment options for a recurrence. In addition, a clinical trial may be another option. A recurrence is the return of cancer after a period of time without signs of cancer. MRI results during follow-up care may have suggested a recurrence. However, tissue death from radiation can look like a tumor on an MRI scan. Getting an MR spectroscopy, MR perfusion, or brain PET may help your doctor decide if there’s cancer.

If there’s a recurrence, options are based on if the cancer is or is not widespread in your brain. These options include chemotherapy. Regimens for a recurrence are temozolomide, lomustine, carmustine, PCV, irinotecan, cyclophosphamide, etoposide, and platinum-based regimens. Bevacizumab (targeted therapy) may also be received. Chemotherapy may be added to bevacizumab if it doesn’t work by itself.

The cancer isn’t widespread
Your surgeon will assess if surgery is an option. If you undergo surgery, you may have the option to receive carmustine wafers. The wafers will be inserted into your brain after the tumor is removed.

You may not be able to join some clinical trials if you receive carmustine wafers.

After surgery, a brain MRI is advised within 24 to 72 hours to assess results. If you can’t have MRI, you may receive a CT scan. Images will be made with and without contrast.

After surgery, you may receive more treatment if you are healthy enough. One option is to receive chemotherapy. Another option is to receive radiation therapy again. Radiation may work well if it’s been a long time since your last radiation treatment or it worked well before.

Supportive care aims to improve your quality of life. It includes treatment for symptoms caused by the cancer or prior treatment. It is an option if you can’t have more cancer treatment after surgery. It is also an option if the recurrence can’t be treated with surgery.

The cancer is widespread
Widespread cancer may be treated with chemotherapy if you are healthy enough. A KPS score of 60 or higher is a sign of good health. However, you and your doctor should discuss what’s best for you. Surgery may also be an option for large tumors causing symptoms. If your KPS score is 59 or less, you may receive supportive care to improve your quality of life.
Glioblastomas and gliosarcomas

Guide 9. Diagnosis and treatment

Surgery

<table>
<thead>
<tr>
<th>Your surgery status</th>
<th>What are the options?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Approved and agree to removing most of the tumor</td>
<td>• Maximal safe resection ± carmustine wafer</td>
</tr>
<tr>
<td>Approved and agree to removing some of the tumor</td>
<td>• Stereotactic biopsy</td>
</tr>
<tr>
<td></td>
<td>• Open biopsy</td>
</tr>
<tr>
<td></td>
<td>• Subtotal resection</td>
</tr>
</tbody>
</table>

Glioblastoma is the most common brain cancer in adults. Among every 100 adults with brain cancer, 54 have a glioblastoma. Thus, there is more research on which to base treatment compared to other gliomas. Gliosarcoma is a rare type of glioblastoma.

Surgery is very important for diagnosis and treatment. The goals of surgery are to remove enough tissue for testing, relieve symptoms, extend life, and decrease the need for corticosteroids. Corticosteroids are used to reduce swelling in the brain.

Guide 9 lists treatment options for glioblastoma. Your surgeon will assess how much of the tumor he or she can remove. The amount that will be removed depends on where the tumor is, your age and health, and other factors. Your surgeon does not want you to be less able to think, speak, and move afterward.

Maximal safe resection

A maximal safe resection is a treatment plan to remove all or most of the tumor as is safe. Hopefully, the whole tumor will be removed but fully removing glioblastoma is often hard to do. Some tumors have a tentacle-like growth pattern.

Removal of the whole tumor is called a gross total resection. During surgery, your surgeon may decide that the whole tumor can’t be removed. Removing only part of the tumor is called a subtotal resection.

Carmustine wafers

Placement of carmustine wafers during surgery may be an option. The wafers are sometimes used for high-grade gliomas. Carmustine is a type of chemotherapy. The wafers will be placed into the space where the tumor was and will dissolve after the surgical cut is closed.

Research has shown that this added treatment may help extend life. However, if you receive more chemotherapy after surgery, you may have more severe side effects than if you hadn’t had carmustine. Also, you may not be able to join some clinical trials because you received carmustine wafers.
Other surgeries
There are other options if it is known before surgery that a maximal safe resection can’t be done. These options are a subtotal resection, open biopsy, and stereotactic biopsy. The removed tissue will be tested to confirm diagnosis and cancer grade.

Tests after surgery
Tissue removed by any type of surgery will be sent to a pathologist for testing. The pathologist will confirm if there’s cancer, and if so, the cancer grade. Molecular markers of gliomas will also be assessed.

You should receive a brain MRI if you had a gross total or subtotal resection. MRI should be completed within 24 to 72 hours after surgery. Images will be made with and without contrast. This test can confirm how much of the cancer was removed. If you can’t have MRI, you may receive a CT scan with and without contrast.
Guide 9 continued
Post-surgery treatment
Your performance status: KPS ≥60

<table>
<thead>
<tr>
<th>Your age</th>
<th>MGMT promotor status</th>
<th>What are the options?</th>
</tr>
</thead>
</table>
| ≤70 years | Methylated          | • Temozolomide during and after fractionated EBRT  
|          |                      | ◦ With alternating electric field therapy for upper brain tumors |
|          | Unmethylated or unknown | • Temozolomide during and after fractionated EBRT  
|          |                      | ◦ With alternating electric field therapy for upper brain tumors |
|          |                      | • Fractionated EBRT    |

| ≥71 years | Methylated          | • Hypofractionated EBRT  
|          |                      | • Temozolomide during and after hypofractionated EBRT |
|          |                      | • Temozolomide during and after fractionated EBRT  
|          |                      | ◦ With alternating electric field therapy for upper brain tumors |
|          |                      | • Temozolomide          |
|          | Unmethylated or unknown | • Hypofractionated EBRT  |
|          |                      | • Temozolomide during and after fractionated EBRT  
|          |                      | ◦ With alternating electric field therapy for upper brain tumors |

Your performance status: KPS ≤59

**What are the options?**

- Fractionated EBRT if 70 years of age or younger
- Hypofractionated EBRT
- Temozolomide if methylated MGMT promotor regions
- Best supportive care
Post-surgery treatment
Guide 9 also lists options for treatment after surgery. Options are based on your performance status, which is your ability to do activities. The KPS (Karnofsky Performance Status) is a rating system used to score performance status. Scores range from 0 to 100. The lower the score, the less able you are to care for yourself.

KPS ≥60 | Age ≤70 years
Temozolomide with fractionated EBRT is the standard of care for people 70 years of age or younger. The benefit of receiving temozolomide for more than 6 months is unknown. Alternating electric field therapy may be added to standard of care for tumors in the top half of the brain (supratentorial). A second option for cancer with unmethylated MGMT promotor regions or unknown status is fractionated EBRT.

KPS ≥60 | Age ≥71 years
Hypofractionated EBRT is an option if you are 71 years of age or older. It has been shown to treat glioblastoma in older adults. Treatment is often finished within 2 to 4 weeks.

Temozolomide has been shown to work well for cancer cells with methylated MGMT promotor regions. In this case, temozolomide may be received with hypofractionated or fractionated EBRT. The benefit of receiving temozolomide for more than 6 months is unknown. Alternating electric field therapy may be added for tumors in the top half of the brain (supratentorial). Another option for cancer with unmethylated MGMT promotor regions may be temozolomide alone.

Temozolomide likely doesn’t work as well for cancer cells with unmethylated MGMT promotor regions. Due to some benefit, receiving it with fractionated EBRT may be an option for cancer with unmethylated or unknown status of the MGMT promotor region. Receiving temozolomide for more than 6 months may or may not help. More research is needed.

Alternating electric field therapy may be added for tumors in the top half of the brain (supratentorial).

KPS ≤59 | Age ≤70 years
Some cancer treatments can be harmful to your health if your KPS score is 59 or less. Thus, treatments that are the least likely to harm your body are advised. Fractionated EBRT may an option if you’re 70 years of age or younger. There are also three options for people of any age that are discussed next.

KPS ≤59 | All ages
Hyperfractionated EBRT may an option because it is less likely to cause severe side effects. If fractionated or hyperfractionated EBRT may be too harsh, temozolomide may be another option. It should only be used if the cancer cells have methylated MGMT promotor regions. Supportive care is an option for everyone.
Guide 11. Recurrence

The cancer isn’t widespread

<table>
<thead>
<tr>
<th>Your surgery status</th>
<th>What are the options?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Approved and agree to surgery</td>
<td>• Surgery ± carmustine wafer&lt;br&gt;• Chemotherapy&lt;br&gt;• Radiation therapy again&lt;br&gt;• Alternating electric field therapy&lt;br&gt;• Best supportive care</td>
</tr>
<tr>
<td>Not approved or decline surgery</td>
<td>• Best supportive care</td>
</tr>
</tbody>
</table>

The cancer is widespread

<table>
<thead>
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<th>Your performance status</th>
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<tbody>
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<td>KPS ≥60</td>
<td>• Chemotherapy&lt;br&gt;• Surgery for large tumors causing symptoms&lt;br&gt;• Alternating electric field therapy</td>
</tr>
<tr>
<td>KPS ≤59</td>
<td>• Best supportive care</td>
</tr>
</tbody>
</table>
Guide 10 addresses follow-up care. Follow-up care is started when your doctor thinks that the cancer has been fully treated. A brain MRI is advised at 2 to 6 weeks after radiation therapy has ended. Images will be made with and without contrast.

At first, your brain may look worse in the scans because of the radiation. However, these results may not mean that the cancer is growing. Instead, early scans are used to give you the right dose of steroids and check for tumor growth beyond where radiation was given.

Later scans are used to find any new brain tumors early. A brain MRI is needed every 2 to 4 months for 2 to 3 years. If these results are stable, then MRIs are needed less often. If you can't have MRI, you may receive a CT scan with and without contrast.

Guide 11 lists treatment options for a recurrence. In addition, a clinical trial may be another option. A recurrence is the return of cancer after a period of time without signs of cancer. Nearly all glioblastomas recur.

MRI results during follow-up care may have suggested a recurrence. However, tissue death from radiation can look like a tumor on an MRI scan. Getting an MR spectroscopy, MR perfusion, or brain PET may help your doctor know if there's cancer.

If there's a recurrence, options are based on if the cancer is or is not widespread in your brain. These options include chemotherapy. Regimens for a recurrence are temozolomide, lomustine, carmustine, PCV, cyclophosphamide, and platinum-based regimens. Bevacizumab (targeted therapy) may also be received. Chemotherapy may be added to bevacizumab if it doesn't work by itself.

The cancer isn't widespread
Your surgeon will assess if surgery is an option. Deciding factors for surgery include where the tumor is in your brain, your performance status, and the size of the tumor. Your surgeon may decide surgery is too risky if the tumor is in a critical spot, your health is poor, or the tumor is large.

If you undergo surgery, another option is to receive carmustine wafers. The wafers will be inserted into the space where the tumor was removed. You may not be able to join some clinical trials if you receive carmustine wafers.

After surgery, a brain MRI is advised within 24 to 72 hours to assess results. If you can't have MRI, you may receive a CT scan. Images will be made with and without contrast.

After surgery, you may receive more treatment if you are healthy enough. One option is to receive chemotherapy. Another option is to receive radiation therapy again. Radiation may work well if it's been a long time since your last radiation treatment or it worked well before. A third option may be alternating electric field therapy. It may cause fewer severe side effects than chemotherapy.

Supportive care aims to improve your quality of life. It includes treatment for symptoms caused by the cancer or prior treatment. It is an option if you can't have more cancer treatment after surgery. It is also an option if the recurrence can't be treated with surgery.

The cancer is widespread
Widespread cancer may be treated with chemotherapy if you are healthy enough. A KPS score of 60 or higher is a sign of good health. However, you and your doctor should discuss what's best for you. Surgery may also be an option for large tumors causing symptoms. A third option may be alternating electric field therapy. It may cause fewer severe side effects than chemotherapy. If your KPS score is below 60, you may receive supportive care to improve your quality of life.
3 Astrocytomas

Review

- Grade I pilocytic astrocytomas are often cured with surgery.

- Surgery is often used to confirm the diagnosis and treat astrocytomas of all grades. If the cancer is grade III or IV, carmustine wafers placed into your brain during surgery may be an option. MRI is needed after major surgery to assess how much of the cancer was removed.

- More treatment is often received after surgery. Only some grade II astrocytomas may be observed rather than treated. Deciding factors for more treatment differ between cancer grades. In general, radiation therapy, chemotherapy, or both are received. Alternating electric field therapy may be added to treatment for glioblastomas.

- MRI scans are needed on a regular basis to track treatment results.

- If a grade II astrocytoma returns, surgery may be an option. Treatment after surgery depends on your treatment history. You may receive radiation, chemotherapy, or both. Likewise, radiation, chemotherapy, or both may be received if surgery isn’t an option.

- If a grade III or IV astrocytoma returns, treatment options depend on where the cancer is and its extent. Surgery may be an option followed by chemotherapy, radiation, or for glioblastoma, alternating electric field therapy. When surgical treatment isn’t an option, other options include chemotherapy, surgery for symptoms, alternating electric field therapy (glioblastoma), and supportive care.
4

Treatment guide: Oligodendrogliomas and oligoastrocytomas

48 Grade II
This section presents options for grade II pure and mixed cancers.

52 Grade III anaplastic
This section presents options for grade III pure and mixed cancers.

57 Review
Part 4 is a guide to the treatment options for adults with oligodendrogliomas and oligoastrocytomas. Also, you may have an option of joining a clinical trial. This information is taken from the treatment guidelines written by NCCN experts for doctors treating gliomas. Your doctors may suggest other treatments than those listed in Part 4 based on your health and personal wishes.

Grade II

The best treatment for grade II oligodendrogliomas and oligoastrocytomas still needs to be confirmed. At this time, surgery is still very important for diagnosis and treatment. The first goal of surgery is to remove enough tissue for diagnosis and cancer grading.

Guide 12 lists treatment options for grade II oligodendrogliomas and oligoastrocytomas. Your surgeon will assess how much of the tumor he or she can remove. The amount that will be removed depends on where the tumor is, your age and health, and other factors. Your surgeon does not want you less able to think, speak, and move afterward.

Maximal safe resection
A maximal safe resection is a treatment plan to remove all or most of the tumor as is safe. Hopefully, the whole tumor will be removed. Many grade II oligodendrogliomas can be fully removed. Removal of the whole tumor is called a gross total resection. However, your surgeon may decide during surgery that the whole tumor can’t be removed. Removing only part of the tumor is called a subtotal resection.

Other surgeries
Sometimes, the tumor can’t be fully removed because it is in a key area of the brain. There are other options if it is known before surgery that a maximal safe resection can’t be done. These options are a subtotal resection, open biopsy, and stereotactic biopsy.

Observation
Surgery is advised in general. However, for some people, observation may be an option. Observation consists of one or more cancer tests repeated over a period of time. Treatment to remove the cancer or to relieve symptoms may be started if the status of the cancer changes.

Tests after surgery
The removed tissue will be sent to a pathologist for testing. The pathologist will confirm if there’s cancer, and if so, the cancer grade. Molecular markers of gliomas will also be assessed.

You should receive a brain MRI if you had a gross total or subtotal resection. MRI should be done within 24 to 72 hours after surgery. Images will be made with and without contrast. This test can confirm how much of the cancer was removed. If you can’t have MRI, you may receive a CT scan with and without contrast.

Post-surgery treatment
Guide 12 also lists options for treatment after surgery. Options are mainly based on what type of surgery you had. Molecular markers also are important in some cases.

You may have had a gross total resection and are 40 years of age or younger. In this case, you may have 3 options. You may be able to start observation and wait to see if more treatment is needed.

Other options include receiving fractionated EBRT or chemotherapy now. PCV or temozolomide is advised for chemotherapy. Chemotherapy may have good results for grade II oligodendroglioma, especially if the cells have 1p19q deletions. However, more research is needed to know for certain.
Grade II

Guide 12. Diagnosis and treatment

**Surgery**

<table>
<thead>
<tr>
<th>Your surgery status</th>
<th>What are the options?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Approved and agree to removing most of the tumor</td>
<td>Maximal safe resection</td>
</tr>
<tr>
<td>Approved and agree to removing some of the tumor</td>
<td>Subtotal resection</td>
</tr>
<tr>
<td></td>
<td>Open biopsy</td>
</tr>
<tr>
<td></td>
<td>Stereotactic biopsy</td>
</tr>
<tr>
<td>Not approved or decline surgery</td>
<td>Observation</td>
</tr>
</tbody>
</table>

**Post-surgery treatment**

<table>
<thead>
<tr>
<th>Type of surgery</th>
<th>What are the options?</th>
</tr>
</thead>
<tbody>
<tr>
<td>• You had a gross total resection and are 40 years of age or younger</td>
<td>Observation</td>
</tr>
<tr>
<td>• You had a gross total resection and are older than 40 years of age,</td>
<td>Fractionated EBRT</td>
</tr>
<tr>
<td>• You had a subtotal resection,</td>
<td>Chemotherapy</td>
</tr>
<tr>
<td>• You had an open biopsy, or</td>
<td></td>
</tr>
<tr>
<td>• You had a stereotactic biopsy</td>
<td></td>
</tr>
<tr>
<td>• You had a gross total resection and are older than 40 years of age,</td>
<td>Fractionated EBRT followed by PCV</td>
</tr>
<tr>
<td>• You had a subtotal resection,</td>
<td>Fractionated EBRT followed temozolomide</td>
</tr>
<tr>
<td>• You had an open biopsy, or</td>
<td>Temozolomide during and after fractionated EBRT</td>
</tr>
<tr>
<td>• You had a stereotactic biopsy</td>
<td>Observation</td>
</tr>
</tbody>
</table>

For older people who had a total resection and for people who had other surgeries, you may have four options. Starting treatment now is advised in most cases. You may receive fractionated EBRT followed by 6 cycles of PCV. This option had good results in a well-designed clinical trial. EBRT with PCV is advised when a 1p19q co-deletion is present.

A second option is fractioned EBRT followed by temozolomide. Likewise, you may receive temozolomide during and after fractioned EBRT. For some people with stable or no symptoms, you may start observation. The role of starting treatment versus observation in low-grade gliomas is debated among health experts.
Guide 13. Follow-up care

<table>
<thead>
<tr>
<th>Test</th>
<th>Test schedule</th>
</tr>
</thead>
</table>
| Brain MRI  | • Every 3–6 months for 5 years  
  ◦ If results are stable, then repeat every year |

Guide 14. Progression or recurrence

You didn’t have radiation therapy before

<table>
<thead>
<tr>
<th>Your surgery status</th>
<th>What are the options?</th>
</tr>
</thead>
</table>
| Approved and agree to surgery        | Surgery  
  ◦ Fractionated EBRT + chemotherapy  
  ◦ Fractionated EBRT  
  ◦ Chemotherapy |
| Not approved or decline surgery      | Fractionated EBRT + chemotherapy  
  ◦ Fractionated EBRT  
  ◦ Chemotherapy |

You did have radiation therapy before

<table>
<thead>
<tr>
<th>Your surgery status</th>
<th>What are the options?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Approved and agree to surgery</td>
<td>Surgery followed by chemotherapy</td>
</tr>
<tr>
<td>Not approved or decline surgery</td>
<td>Chemotherapy</td>
</tr>
</tbody>
</table>

What are the options if the cancer progresses after chemotherapy?

• A different chemotherapy
• Radiation therapy again
• Best supportive care
Guide 13 addresses follow-up care. Follow-up care is started when your doctor thinks the cancer has been fully treated. A brain MRI is advised every 3 to 6 months for 5 years. If results are stable for 5 years, a brain MRI is needed every year. If you can’t have MRI, you may receive a CT scan with and without contrast.

Guide 14 lists treatment options for cancer progression or recurrence. In addition, a clinical trial may be another option. Cancer progression is further growth or spread of cancer that’s already been found. A recurrence is the return of cancer after not having signs of cancer for a period of time. Your surgeon may obtain a tissue sample to confirm the cancer’s back and to assess the cancer grade.

Progressive and recurrent cancers are treated the same. Options are based on whether you had fractionated EBRT when first treated. If you will receive chemotherapy, it may consist of PCV, temozolomide, lomustine, carmustine, or platinum-based regimens.

No radiation therapy before
Your surgeon will assess if surgery is an option. If you undergo surgery, get a brain MRI within 24 to 72 hours to assess surgery results. If you can’t have MRI, you may receive a CT scan. Images will be made with and without contrast.

After surgery, observation may be started if all the cancer was removed. However, for most people, surgery should be followed by fractionated EBRT with or without chemotherapy or followed by chemotherapy only. Chemotherapy may have good results for grade II oligodendroglioma, especially if the cells have 1p19q deletions. However, more research is needed to know for certain.

EBRT without chemotherapy. A third option is chemotherapy only. Chemotherapy may have good results for grade II oligodendroglioma, especially if the cells have 1p19q deletions. However, more research is needed to know for certain.

Radiation therapy before
Your surgeon will assess if surgery is an option. If you undergo surgery, get a brain MRI within 24 to 72 hours to assess surgery results. If you can’t have MRI, you may receive a CT scan. Images will be made with and without contrast.

Chemotherapy should be received after surgery or as the sole treatment if surgery isn’t an option. During chemotherapy, get MRI scans every 2 to 3 months to assess treatment results.

The cancer may progress after chemotherapy. In this case, you may have three options. One option is to think about changing to a different chemotherapy. Chemotherapy may have good results for grade II oligodendroglioma, especially if the cells have 1p19q deletions. However, more research is needed to know for certain.

For cancer that has progressed, your radiation oncologist may think radiation therapy is another option. The third option is supportive care. Supportive care aims to improve your quality of life. It includes treatment for symptoms caused by the cancer or prior treatment.
Grade III anaplastic

Guide 15. Diagnosis and treatment

Surgery

<table>
<thead>
<tr>
<th>Your surgery status</th>
<th>What are the options?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Approved and agree to removing most of the tumor</td>
<td>• Maximal safe resection ± carmustine wafer</td>
</tr>
<tr>
<td>Approved and agree to removing some of the tumor</td>
<td>• Stereotactic biopsy</td>
</tr>
<tr>
<td></td>
<td>• Open biopsy</td>
</tr>
<tr>
<td></td>
<td>• Subtotal resection</td>
</tr>
</tbody>
</table>

Anaplastic oligodendrogliomas are rare in adults but have a better outlook than other grade III gliomas. Surgery is very important for diagnosis and treatment. The goals of surgery are to remove enough tissue for testing, relieve symptoms, extend life, and decrease the need for corticosteroids. Corticosteroids are used to reduce swelling in the brain.

Guide 15 lists treatment options for anaplastic oligodendrogliomas and oligoastrocytomas. Your surgeon will assess how much of the tumor he or she can remove. The amount that will be removed depends on where the tumor is, your age and health, and other factors. Your surgeon does not want you to be less able to think, speak, and move afterward.

Maximal safe resection
A maximal safe resection is a treatment plan to remove all or most of the tumor as is safe. Hopefully, the whole tumor will be removed. Many grade III oligodendrogliomas can be fully removed. Removal of the whole tumor is called a gross total resection. During surgery, your surgeon may decide that the whole tumor can’t be removed. Removing only part of the tumor is called a subtotal resection.

Carmustine wafers
Placement of carmustine wafers during surgery may be an option. Wafers are sometimes used for high-grade gliomas. Carmustine is a type of chemotherapy. The wafers will be placed into the space where the tumor was and will dissolve after the surgical cut is closed.

Research has shown that this added treatment helps extend life. However, if you receive more chemotherapy after surgery, you may have more severe side effects than if you hadn’t had carmustine. Also, you may not be able to join some clinical trials because you received carmustine wafers.

Other surgeries
Sometimes, the tumor can’t be fully removed because it is in a key area of the brain. There are other options if it is known before surgery that a maximal safe resection can’t be done. These options are a subtotal resection, open biopsy, and stereotactic biopsy.
Tests after surgery
The removed tissue will be sent to a pathologist for testing. The pathologist will confirm if there's cancer, and if so, the cancer grade. Molecular markers of gliomas will also be assessed.

You should receive a brain MRI if you had a gross total or subtotal resection. MRI should be done within 24 to 72 hours after surgery. Images will be made with and without contrast. This test can confirm how much of the cancer was removed. If you can't have MRI, you may receive a CT scan with and without contrast.
Guide 15 continued
Post-surgery treatment
Your performance status: KPS ≥60

<table>
<thead>
<tr>
<th>Status of 1p19q</th>
<th>What are the options?</th>
</tr>
</thead>
<tbody>
<tr>
<td>With 1p19q co-deletion</td>
<td>• PCV either before or after fractionated EBRT</td>
</tr>
<tr>
<td></td>
<td>• Temozolomide during and after fractionated EBRT</td>
</tr>
<tr>
<td>Without 1p19q co-deletion</td>
<td>• Fractionated EBRT</td>
</tr>
<tr>
<td></td>
<td>• Temozolomide during and after fractionated EBRT</td>
</tr>
<tr>
<td></td>
<td>• PCV or temozolomide</td>
</tr>
</tbody>
</table>

Your performance status: KPS ≤59

<table>
<thead>
<tr>
<th>What are the options?</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Hypofractionated (preferred) or fractionated EBRT</td>
</tr>
<tr>
<td>• PCV or temozolomide</td>
</tr>
<tr>
<td>• Best supportive care</td>
</tr>
</tbody>
</table>

Guide 16. Follow-up care

<table>
<thead>
<tr>
<th>Test</th>
<th>Test schedule</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brain MRI</td>
<td>• At 2–6 weeks after radiation therapy has ended</td>
</tr>
<tr>
<td></td>
<td>◦ If results are stable, then repeat every 2–4 months for 2–3 years</td>
</tr>
<tr>
<td></td>
<td>◦ If results are stable, then repeat less often</td>
</tr>
</tbody>
</table>
Post-surgery treatment

Guide 15 also lists options for treatment after surgery. Options are based on your performance status, which is your ability to do activities. The KPS (Karnofsky Performance Status) is a rating system used to score performance status. Scores range from 0 to 100. The lower the score, the less able you are to care for yourself.

Performance status: KPS ≥60
If there’s 1p19q co-deletion, fractionated EBRT with chemotherapy is advised. PCV may be received either before or afterward. Temozolomide can be received during and after EBRT.

You may have three options if there’s one or no 1p19q deletions. Fractionated EBRT is one option. The second option is to receive temozolomide during and after EBRT. The third option is chemotherapy with either PCV or temozolomide.

Performance status: KPS ≤59
You may have three options if your KPS score is 59 or less. One option is to receive EBRT. Hyperfractionated is preferred over fractionated radiation. Another option is chemotherapy with PCV or temozolomide. The third option is supportive care. Supportive care aims to improve your quality of life. It includes treatment for symptoms caused by the cancer or its treatment.

Guide 16 addresses follow-up care. Follow-up care is started when your doctor thinks that the cancer has been fully treated. Get a brain MRI at 2 to 6 weeks after radiation therapy has ended. Images will be made with and without contrast.

At first, your brain may look worse in the scans because of the radiation. However, these results may not mean that the cancer is growing. Instead, early scans are used to give you the right dose of steroids.

Later scans are used to find any new brain tumors early. A brain MRI is needed every 2 to 4 months for 2 to 3 years. If these results are stable, then MRIs are needed less often. If you can’t have MRI, you may receive a CT scan with and without contrast.
Guide 17. Recurrence
The cancer isn’t widespread

<table>
<thead>
<tr>
<th>Your surgery status</th>
<th>What are the options?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Approved and agree to surgery</td>
<td>• Surgery ± carmustine wafer</td>
</tr>
<tr>
<td></td>
<td>• Chemotherapy</td>
</tr>
<tr>
<td></td>
<td>• Radiation therapy again</td>
</tr>
<tr>
<td></td>
<td>• Best supportive care</td>
</tr>
<tr>
<td>Not approved or decline surgery</td>
<td>• Best supportive care</td>
</tr>
</tbody>
</table>

The cancer is widespread

<table>
<thead>
<tr>
<th>Your performance status</th>
<th>What are the options?</th>
</tr>
</thead>
<tbody>
<tr>
<td>KPS ≥60</td>
<td>• Chemotherapy</td>
</tr>
<tr>
<td></td>
<td>• Surgery for large tumors causing symptoms</td>
</tr>
<tr>
<td>KPS ≤59</td>
<td>• Best supportive care</td>
</tr>
</tbody>
</table>

Guide 17 lists treatment options for a recurrence. In addition, a clinical trial may be another option. A recurrence is the return of cancer after a period of time without signs of cancer. MRI results during follow-up care may have suggested a recurrence. However, tissue death from radiation can look like a tumor on an MRI scan. Getting an MR spectroscopy, MR perfusion, or brain PET may help your doctor decide if there’s cancer.

If there’s a recurrence, options are based on if the cancer is or is not widespread in your brain. These options include chemotherapy. Regimens for a recurrence are temozolomide, lomustine, carmustine, PCV, irinotecan, cyclophosphamide, etoposide, and platinum-based regimens. Bevacizumab (targeted therapy) may also be received.Chemotherapy may be added to bevacizumab if it doesn’t work by itself.

**The cancer isn’t widespread**
Your surgeon will assess if surgery is an option. If you undergo surgery, you may have the option to receive carmustine wafers. The wafers will be inserted into your brain after the tumor is removed. You may not be able to join some clinical trials if you receive carmustine wafers.

After surgery, get a brain MRI within 24 to 72 hours to assess results. If you can’t have MRI, you may...
receive a CT scan. Images will be made with and without contrast.

After surgery, you may receive more treatment if you are healthy enough. One option is to receive chemotherapy. Another option is to receive radiation therapy again. Radiation may work well if it's been a long time since your last radiation treatment or it worked well before.

Supportive care aims to improve your quality of life. It includes treatment for symptoms caused by the cancer or prior treatment. It is an option if you can’t have more cancer treatment after surgery. It is also an option if the recurrence can’t be treated with surgery.

The cancer is widespread
Widespread cancer may be treated with chemotherapy if you are healthy enough. A KPS score of 60 or higher is a sign of good health. Surgery may also be an option for large tumors causing symptoms. If your KPS score is 59 or less, you may receive supportive care to improve your quality of life.

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**Review**

- Surgery is often used to confirm the diagnosis and treat oligodendrogliomas and oligoastrocytomas. Molecular testing is also important for diagnosis and treatment planning. If the cancer is grade III, carmustine wafers placed into your brain during surgery may be an option. MRI is needed after major surgery to assess how much of the cancer was removed.

- More treatment is often received after surgery. Only some grade II cancers may be observed rather than treated. Treatment may consist of radiation therapy, chemotherapy, or both. Radiation with chemotherapy is the most proven treatment for grade III anaplastic oligodendrogliomas with 1p19q co-deletion.

- MRI scans are needed on a regular basis to track treatment results.

- If a low-grade oligodendroglioma and oligoastrocytoma returns, surgery may be an option. Treatment after surgery depends on your treatment history. You may receive radiation, chemotherapy, or both. Likewise, radiation, chemotherapy, or both may be received if surgery isn’t an option.

- If a high-grade oligodendroglioma and oligoastrocytoma returns, treatment options depend on where the cancer is and its extent. Surgery may be an option followed by chemotherapy or radiation. When surgical treatment isn’t an option, other options include chemotherapy, surgery for symptoms, and supportive care.
5

Treatment guide: Ependymomas

60 Diagnosis and treatment
This section presents options to confirm and treat ependymomas.

64 Follow-up care
This section presents how often to receive cancer tests after treatment.

64 Return of cancer
This section presents options for if the cancer returns.

66 Review
Part 5 is a guide to the treatment options for adults with ependymoma in either the brain or spine. Also, you may have an option of joining a clinical trial. This information is taken from the treatment guidelines written by NCCN experts for doctors treating gliomas. Your doctors may suggest other treatments than those listed in Part 5 based on your health and personal wishes.

Subependymoma is one of two types of grade I ependymoma. These tumors do not grow into nearby tissue. They can be cured by surgery alone and don’t recur. Thus, Part 5 focuses on other ependymomas including grade I myxopapillary ependymoma.
Diagnosis and treatment

Guide 18. Surgery

<table>
<thead>
<tr>
<th>Your surgery status</th>
<th>What are the options?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Approved and agree to removing most of the tumor</td>
<td>- Maximal safe resection</td>
</tr>
<tr>
<td>Approved and agree to removing some of the tumor</td>
<td>- Stereotactic biopsy</td>
</tr>
<tr>
<td></td>
<td>- Open biopsy</td>
</tr>
<tr>
<td></td>
<td>- Subtotal resection</td>
</tr>
</tbody>
</table>

More research on the treatment of ependymoma is needed. At this time, surgery is very important for diagnosis and treatment. Tissue needs to be removed to confirm the diagnosis and for cancer grading.

Guide 18 lists treatment options for ependymoma. Your surgeon will assess how much of the tumor he or she can remove. The amount that will be removed depends on where the tumor is, your age and health, and other factors. Your surgeon does not want you to be less able to think, speak, and move afterward.

**Maximal safe resection**
A maximal safe resection is a treatment plan to remove all or most of the tumor as is safe. Hopefully, the whole tumor will be removed. Removal of the whole tumor is called a gross total resection.

Your surgeon may decide during surgery that the whole tumor can’t be removed. Removing only part of the tumor is called a subtotal resection. Your surgeon may advise a second surgery to try to remove the whole tumor.

**Other surgeries**
There are other options if it is known before surgery that a maximal safe resection can’t be done. These options are a subtotal resection, open biopsy, and stereotactic biopsy. Your surgeon may advise a second surgery to try to remove the whole tumor.

**Tests after surgery**
The removed tissue will be sent to a pathologist for testing. The pathologist will confirm if there’s cancer, and if so, the cancer grade.

You should receive brain and spine MRIs after surgery. If you can’t have MRI, you may receive CT scans. Images will be made with and without contrast.

The brain MRI should be done within 24 to 72 hours after surgery. The images will show how much of the brain tumor was removed. If you had a spinal tumor, a brain MRI will be used to assess if there’s cancer in the brain, too.

The spine MRI should be done 2 to 3 weeks after surgery. Images will be less affected by surgery by then. Images will show how much of the spinal tumor
was removed. If you had a brain tumor, images will be used to assess if there’s cancer in your spine, too. to lab for testing. Testing may find cancer that wasn’t detected by MRI.

After the spine MRI, a lumbar puncture to obtain spinal fluid is needed. Your spinal fluid will be sent
Guide 19. Post-surgery treatment for grades I and II

Brain tumor

<table>
<thead>
<tr>
<th>Metastatic spread</th>
<th>Your prior treatment</th>
<th>What are the options?</th>
</tr>
</thead>
<tbody>
<tr>
<td>No spread of cancer</td>
<td>Total resection</td>
<td>• Limited-field fractionated EBRT</td>
</tr>
<tr>
<td></td>
<td>Subtotal resection or biopsy</td>
<td>• Observation</td>
</tr>
<tr>
<td>The cancer has spread</td>
<td>Any</td>
<td>• Limited-field fractionated EBRT</td>
</tr>
</tbody>
</table>

Spinal tumor

<table>
<thead>
<tr>
<th>Metastatic spread</th>
<th>Your prior treatment</th>
<th>What are the options?</th>
</tr>
</thead>
<tbody>
<tr>
<td>No spread of cancer</td>
<td>Total resection</td>
<td>• Observation</td>
</tr>
<tr>
<td></td>
<td>Subtotal resection</td>
<td>• Limited-field fractionated EBRT</td>
</tr>
<tr>
<td>The cancer has spread</td>
<td>Any</td>
<td>• Craniospinal radiation therapy</td>
</tr>
</tbody>
</table>

Guide 20. Post-surgery treatment for grade III

Brain or spinal tumor

<table>
<thead>
<tr>
<th>Metastatic spread</th>
<th>What are the options?</th>
</tr>
</thead>
<tbody>
<tr>
<td>No spread of cancer</td>
<td>• Limited-field fractionated EBRT</td>
</tr>
<tr>
<td>The cancer has spread</td>
<td>• Craniospinal radiation therapy</td>
</tr>
</tbody>
</table>
Guide 19 lists treatment options following surgery for grades I and II ependymoma. Options are grouped by brain or spinal tumor.

**Brain tumor**

MRI and the spinal fluid test may find no proof that the cancer has spread. In this case, options are based on the type of surgery. After a total resection, NCCN experts advise doctors to consider limited-field fractionated EBRT. Observation can be started after total resection of a tumor in the top half of the brain (supratentorial). If the tumor wasn’t fully removed, limited-field fractionated EBRT is advised. Research suggests that this treatment helps to extend life.

The MRI or spinal fluid test may show that the cancer has spread. When there is metastasis, craniospinal radiation therapy should be received.

**Spinal tumor**

MRI and the spinal fluid test may find no proof that the cancer has spread. In this case, options are based on the type of surgery. After a total resection, observation can be started since the chance of the cancer returning is low. However, limited-field fractionated EBRT may be a better option for a myxopapillary ependymoma. If the tumor wasn’t fully removed, limited-field fractionated EBRT is advised. Research suggests that this treatment helps to extend life.

The MRI or spinal fluid test may show that the cancer has spread. When there is metastasis, craniospinal radiation therapy should be received.

Guide 20 lists treatment options following surgery for a grade III ependymoma. Treatment options are the same for brain and spinal tumors. If there is no proof of cancer spread, limited-field fractionated EBRT is advised. If the cancer has spread, craniospinal radiation therapy is needed.
Follow-up care


<table>
<thead>
<tr>
<th>Test</th>
<th>Test schedule</th>
</tr>
</thead>
</table>
| MRI of brain, spine, or both | • Every 3–4 months for 1 year  
  ◦ If results are stable, then repeat 4–6 months for 1 year  
  ◦ If results are stable, then repeat every 6–12 months |

Return of cancer

Guide 22. Treatment for recurrence

<table>
<thead>
<tr>
<th>Your surgery status</th>
<th>What are the options?</th>
</tr>
</thead>
</table>
| Approved and agree to surgery | • Surgery  
  • Limited-field fractionated EBRT if not received before  
  • Stereotactic radiosurgery in some cases |
| Not approved or decline surgery | • Limited-field fractionated EBRT if not received before  
  • Stereotactic radiosurgery in some cases |

Guide 23. Treatment for progression

<table>
<thead>
<tr>
<th>What are the options?</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Limited-field fractionated EBRT</td>
</tr>
<tr>
<td>• Stereotactic radiosurgery in some cases</td>
</tr>
<tr>
<td>• Chemotherapy</td>
</tr>
<tr>
<td>• Best supportive care</td>
</tr>
</tbody>
</table>
Guide 21 addresses follow-up care. Follow-up care is started when your doctor thinks the cancer has been fully treated.

If you had a brain tumor, brain MRIs are needed. If you had a spinal tumor, spinal MRIs are needed. If cancer was found in both your brain and spine, brain and spinal MRIs are needed. If you can't have MRI, you may receive a CT scan with and without contrast.

Get a MRI scan every 3 to 4 months for 1 year. If results are stable during this first year, get scans every 4 to 6 months for 1 year. If results are stable during this second year, get scans every 6 to 12 months.

Guide 22 lists treatment options for a recurrence. In addition, a clinical trial may be another option. A recurrence is the return of cancer after a period of time without signs of cancer. To help plan treatment, you should receive MRIs of both your brain and spine and a lumbar puncture.

Your surgeon will assess if surgery is an option. If you undergo surgery, you may receive limited-field fractionated EBRT afterward if you haven’t had it before. Some people may receive stereotactic radiosurgery depending on the shape of the tumor.

If surgery isn’t an option, you may have two options. One option is limited-field fractionated EBRT if you haven’t had it before. Some people may receive stereotactic radiosurgery depending on the shape of the tumor.

Testing after treatment
Brain and spine MRIs are used to assess treatment results and if there’s cancer in other sites. If you can’t undergo MRI, you may receive CT scans. Images will be made with and without contrast.

If you had surgery, the timing of the MRIs is important. The brain MRI should follow surgery within 24 to 72 hours. The spine MRI should be done 2 to 3 weeks after surgery. Images of your spine will be less affected by surgery by then.

Guide 23 lists treatment options if the cancer progresses after recurrence treatment. Radiation therapy may be an option whether you had it before or not. Some people may receive stereotactic radiosurgery depending on the shape of the tumor. Chemotherapy may be another option if surgery or radiation was not successful.

Supportive care is always an option. It aims to improve your quality of life. It includes treatment for symptoms caused by the cancer or prior treatment.
Review

- Grade I subependymomas are often cured with surgery.

- For other ependymomas, surgery is often the first step to confirm the diagnosis and treat the cancer. Brain and spine MRIs are used to assess treatment results and if there's cancer in other sites. A sample of your spinal fluid will also be tested for cancer.

- More treatment is often received after surgery. Only some grade I and II ependymomas may be observed rather than treated. If there is no metastasis, limited-field fractionated radiation therapy is advised. Metastases are treated with craniospinal radiation therapy.

- MRIs of your brain, spine, or both are needed on a regular basis to track treatment results.

- If the cancer returns, you should receive MRIs of both your brain and spine and a lumbar puncture. When surgery is an option, it may be followed by radiation therapy if you haven't had it before. When surgery isn't an option, radiation therapy may be received if you haven't had it before. If the cancer grows or spreads again, radiation therapy, chemotherapy, and supportive care may be options.
Making treatment decisions

68  It’s your choice
69  Questions to ask your doctors
73  Weighing your options
73  Websites
74  Review
Making treatment decisions

It’s your choice

Having cancer is very stressful. While absorbing the fact that you have cancer, you have to learn about tests and treatments. In addition, the time you have to accept a treatment plan feels short. Parts 1 through 5 described the cancer and the test and treatment options recommended by NCCN experts. These options are based on science and agreement among NCCN experts. Part 6 aims to help you make decisions that are in line with your beliefs, wishes, and values.

On the other hand, you may want to take the lead or share in decision-making. Most patients do. In shared decision-making, you and your doctors share information, weigh the options, and agree on a treatment plan. Your doctors know the science behind your plan but you know your concerns and goals. By working together, you are likely to get a higher quality of care and be more satisfied. You’ll likely get the treatment you want, at the place you want, and by the doctors you want.

It’s your choice

The role patients want in choosing their treatment differs. You may feel uneasy about making treatment decisions. This may be due to a high level of stress. It may be hard to hear or know what others are saying. Stress, pain, and drugs can limit your ability to make good decisions. You may feel uneasy because you don’t know much about cancer. You’ve never heard the words used to describe cancer, tests, or treatments. Likewise, you may think that your judgment isn’t any better than your doctors’. Letting others decide which option is best may make you feel more at ease. But, whom do you want to make the decisions? You may rely on your doctors alone to make the right decisions. However, your doctors may not tell you which to choose if you have multiple good options. You can also have loved ones help. They can gather information, speak on your behalf, and share in decision-making with your doctors. Even if others decide which treatment you will receive, you still have to agree by signing a consent form.
Questions to ask your doctors

You may meet with experts from different fields of medicine. Strive to have helpful talks with each person. Prepare questions before your visit and ask questions if the person isn’t clear. You can also record your talks and get copies of your medical records. It may be helpful to have your spouse, partner, or a friend with you at these visits. A patient advocate or navigator might also be able to come. They can help to ask questions and remember what was said. Suggested questions to ask include:

What's my diagnosis and prognosis?

It’s important to know that there are different types of cancer. Cancer can greatly differ even when people have a tumor in the same organ. Based on your test results, your doctors can tell you which type of cancer you have. He or she can also give a prognosis. A prognosis is a prediction of the pattern and outcome of a disease. Knowing the prognosis may affect what you decide about treatment.

1. Where did the cancer start? In what type of cell?

2. Is this cancer common?

3. Is this a fast- or slow-growing glioma?

4. Has the cancer spread to other areas?

5. What other tests results are important to know?

6. How often are these tests wrong?

7. Would you give me a copy of the pathology report and other test results?

8. How likely is it that I’ll be cancer-free after treatment?

9. How likely will the cancer return (recurrence) after treatment?
What are my options?

There is no single treatment practice that is best for all patients. There is often more than one treatment option along with clinical trial options. Your doctor will review your test results and recommend treatment options.

1. What will happen if I do nothing?

2. Can I just carefully monitor the cancer?

3. Do you consult NCCN recommendations when considering options?

4. Are you suggesting options other than what NCCN recommends? If yes, why?

5. Do your suggested options include clinical trials? Please explain why.

6. How do my age, health, and other factors affect my options?

7. What if I am pregnant?

8. Which option is proven to work best?

9. Which options lack scientific proof?

10. What are the benefits of each option? Does any option offer a cure? Are my chances any better for one option than another? Less time-consuming? Less expensive?

11. What are the risks of each option? What are possible complications? What are the rare and common side effects? Short-lived and long-lasting side effects? Serious or mild side effects? Other risks?

12. What can be done to prevent or relieve the side effects of treatment?

13. What are my chances that the cancer will return?
What does each option require of me?

Many patients consider how each option will practically affect their lives. This information may be important because you have family, jobs, and other duties to take care of. You also may be concerned about getting the help you need. If you have more than one option, choosing the option that is the least taxing may be important to you:

1. Will I have to go to the hospital or elsewhere? How often? How long is each visit?
2. What do I need to think about if I will travel for treatment?
3. Do I have a choice of when to begin treatment? Can I choose the days and times of treatment?
4. How do I prepare for treatment? Do I have to stop taking any of my medicines? Are there foods I will have to avoid?
5. Should I bring someone with me when I get treated?
6. Will the treatment hurt?
7. How much will the treatment cost me? What does my insurance cover?
8. Will I miss work or school? Will I be able to drive?
9. Is home care after treatment needed? If yes, what type?
10. How soon will I be able to manage my own health?
11. When will I be able to return to my normal activities?
What is your experience?

More and more research is finding that patients treated by more experienced doctors have better results. It is important to learn if a doctor is an expert in the cancer treatment he or she is offering.

1. Are you board certified? If yes, in what area?

2. How many patients like me have you treated?

3. How many procedures like the one you’re suggesting have you done?

4. Is this treatment a major part of your practice?

5. How many of your patients have had complications?
Weighing your options

Deciding which option is best can be hard. Doctors from different fields of medicine may have different opinions on which option is best for you. This can be very confusing. Your spouse or partner may disagree with which option you want. This can be stressful. In some cases, one option hasn’t been shown to work better than another, so science isn’t helpful. Some ways to decide on treatment are discussed next.

2nd opinion
The time around a cancer diagnosis is very stressful. People with cancer often want to get treated as soon as possible. They want to make their cancer go away before it spreads farther. While cancer can’t be ignored, there is time to think about and choose which option is best for you.

You may wish to have another doctor review your test results and suggest a treatment plan. This is called getting a 2nd opinion. You may completely trust your doctor, but a 2nd opinion on which option is best can help.

Copies of the pathology report, a DVD of the imaging tests, and other test results need to be sent to the doctor giving the 2nd opinion. Some people feel uneasy asking for copies from their doctors. However, a 2nd opinion is a normal part of cancer care.

When doctors have cancer, most will talk with more than one doctor before choosing their treatment. What’s more, some health plans require a 2nd opinion. If your health plan doesn’t cover the cost of a 2nd opinion, you have the choice of paying for it yourself.

If the two opinions are the same, you may feel more at peace about the treatment you accept to have. If the two opinions differ, think about getting a 3rd opinion. A 3rd opinion may help you decide between your options. Choosing your cancer treatment is a very important decision. It can affect your length and quality of life.

Support groups
Besides talking to health experts, it may help to talk to patients who have walked in your shoes. Support groups often consist of people at different stages of treatment. Some may be in the process of deciding while others may be finished with treatment. At support groups, you can ask questions and hear about the experiences of other people with glioma.

Compare benefits and downsides
Every option has benefits and downsides. Consider these when deciding which option is best for you. Talking to others can help identify benefits and downsides you haven’t thought of. Scoring each factor from 0 to 10 can also help since some factors may be more important to you than others.

Websites
American Brain Tumor Association
abta.org

American Cancer Society
cancer.org/cancer/braincnsstumorsinadults/detailedguide/index

National Cancer Institute
cancer.gov/types/brain

National Coalition for Cancer Survivorship
canceradvocacy.org/toolbox

NCCN
www.nccn.org/patients
Review

- Shared decision-making is a process in which you and your doctors plan treatment together.

- Asking your doctors questions is vital to getting the information you need to make informed decisions.

- Getting a 2nd opinion, attending support groups, and comparing benefits and downsides may help you decide which treatment is best for you.
Glossary

76  Dictionary

78  Acronyms
Dictionary

alternating electric field therapy
A cancer treatment that uses low-intensity electromagnetic energy. Also called TTFields (Tumor Treating Fields).

anesthesia
Loss of feeling with or without loss of wakefulness that is caused by drugs.

astrocyte
A type of glial cell that maintains the proper balance of chemicals in the nervous system.

biopsy
Removal of small amounts of tissue or fluid to be tested for disease.

board certified
A status to identify doctors who finished training in a specialized field of medicine.

cancer grade
A rating of how much cancer cells are like normal cells.

central nervous system
The brain and spinal cord.

chemotherapy
Drugs that stop the life cycle of cells so they don’t increase in number.

clinical trial
Research on a test or treatment to assess its safety or how well it works.

computed tomography (CT)
A test that uses x-rays to view body parts.

contrast
A dye put into your body to make clearer pictures during imaging tests.

diagnosis
To identify a disease.

ependymal cell
A type of glial cell that makes cerebrospinal fluid.

external beam radiation therapy (EBRT)
Radiation therapy received from a machine outside the body.

fractionated radiation
A treatment schedule of one time a day for 5 days for about 6 weeks.

gene
Instructions in cells for making and controlling cells.

general anesthesia
A controlled loss of wakefulness from drugs.

glial cell
A type of cell that supports nerve cells.

gross total resection
An operation that removes the whole tumor.

hyperfractionated radiation
A treatment schedule of once a day or less for 1 week.

intensity-modulated radiation therapy (IMRT)
Radiation therapy that uses small beams of different strengths based on the thickness of the tissue.

invasion
A mass of cancer cells that has grown from one structure into another.

magnetic resonance imaging (MRI)
A test that uses radio waves and powerful magnets to see the shape and function of body parts.

magnetic resonance (MR) perfusion
An imaging test that makes pictures of blood flow in organs.

magnetic resonance (MR) spectroscopy
An imaging tests that measures the chemical make-up of tissue.

metastasis
The spread of cancer cells from the first tumor to another body part.

microglial cell
A type of glial cell that defends the nervous system from disease-causing factors.

molecular testing
Tests of molecules in the body that can be measured to assess health. Also called biomarker testing.
Dictionary

**mutation**
Abnormal changes in the instructions within cells for making and controlling cells (genes).

**neuropathologist**
A doctor who's an expert in studying cells within the nervous system to classify disease.

**neurosurgeon**
A doctor who's an expert in surgery within the nervous system.

**observation**
A period of testing for cancer growth.

**neuron**
A type of cell in the nervous system that transmits information.

**neuroscience**
The study of the nervous system.

**neurotransmitter**
A chemical that transmits information between neurons.

**performance status**
A rating of one's ability to do daily activities.

**pharmacology**
The study of drug effects and actions.

**platinum-based chemotherapy**
Treatment with two chemotherapy drugs, one of which is platinum-based.

**positron emission tomography (PET)**
A test that uses radioactive material to see the shape and function of body parts.

**primary tumor**
The first mass of cancer cells of their kind.

**prognosis**
The expected pattern and outcome of a disease based on tests.

**proton therapy**
Radiation therapy that uses protons to treat a disease. Also called hadron therapy.

**radiologist**
A doctor who's an expert in reading imaging tests.

**sedative**
A drug that helps a person to relax or go to sleep.

**side effect**
An unplanned physical or emotional response to treatment.

**simulation**
The steps needed to prepare for radiation therapy.

**stereotactic biopsy**
Removal of tissue samples through a small opening in the skull.

**stereotactic radiosurgery**
Treatment with large doses of radiation within a small area.

**subtotal resection**
An operation that removes a large piece of tissue.

**supportive care**
Treatment for symptoms of a disease.

**targeted therapy**
Drugs that stop the growth process that is specific to cancer cells.

**three-dimensional conformal radiation therapy (3D-CRT)**
Radiation therapy that uses beams that match the shape of the tumor.

**translocation**
The switching of parts between chromosomes.
Acronyms

3D-CRT
three-dimensional conformal radiation therapy

CAM
complementary and alternative medicine

CT
computed tomography

DNA
deoxyribonucleic acid

EBRT
external beam radiation therapy

FDA
Food and Drug Administration

FISH
fluorescence in situ hybridization

IDH
isocitrate dehydrogenase

IHC
immunohistochemistry

IMRT
intensity-modulated radiation therapy

KPS
Karnofsky Performance Status

MGMT
methylguanine methyltransferase

MRI
magnetic resonance imaging

NCCN
National Comprehensive Cancer Network

PCR
polymerase chain reaction

PET
positron emission tomography

SRS
stereotactic radiosurgery

TTFields
tumor treating fields

VMAT
volumetric arc-based therapy

VEGF
vascular endothelial growth factor

WHO
World Health Organization
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Acute Lymphoblastic Leukemia
Adolescents and Young Adults (AYAs) with Cancer
Breast Cancer
Carcinoma in Situ (Stage 0)
Early-Stage (Stages I and II)
Stage III Breast Cancer
Stage IV Breast Cancer
Chronic Lymphocytic Leukemia
Chronic Myelogenous Leukemia
Colon Cancer
Esophageal Cancer
Hodgkin Lymphoma
Kidney Cancer
Lung Cancer (Non-Small Cell Lung Cancer)
Lung Cancer Screening
Malignant Pleural Mesothelioma
Melanoma
Multiple Myeloma
Myelodysplastic Syndromes
Nausea and Vomiting
Non-Hodgkin’s Lymphomas
Diffuse Large B-cell Lymphoma
Follicular Lymphoma
Mantle Cell Lymphoma
Mycosis Fungoides
Peripheral T-cell Lymphoma
Ovarian Cancer
Pancreatic Cancer
Prostate Cancer
Soft Tissue Sarcoma
Stomach Cancer

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