Brain Tumor Diagnosis and Care Guide
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Together We Deliver the Promise of Medicine

On the cover, Henry Brem, M.D., Director of the Johns Hopkins Department of Neurosurgery
Coping with a Brain Tumor Diagnosis

If you recently received a brain tumor diagnosis, you probably have many concerns and questions. It’s normal to feel worried and wonder what it will mean for your life. This guide aims to address your concerns and questions. It will help you make informed decisions so you don’t have to face your diagnosis alone.

Get a Second Opinion

After receiving your diagnosis, your first step is finding experienced brain tumor experts you’re comfortable with who can provide advanced treatment options. For some patients, this means learning about care options beyond their local area and looking for a second opinion.

“The more patients a certain center cares for, the better qualified it will be to take care of you.”

Jon Weingart, M.D.
Johns Hopkins Neurosurgeon

Consider getting a second opinion if:

- **You still have questions:** If you walk out of a consultation not understanding your diagnosis or treatment plan, you may want to talk to another expert. A second opinion helps you learn about all of your options so you can make informed choices.

- **Your doctor says the tumor is inoperable:** Not all doctors have extensive experience in treating brain tumors. A neurosurgeon at a brain tumor center may be able to remove tumors considered inoperable (unable to be removed with surgery) by others.

- **Previous treatments didn’t work:** Many people want a second opinion after standard treatments don’t work or when a doctor says they are out of treatment options.

If you go to a brain tumor center for a second opinion, make sure to bring any previous test results, MRI images or biopsy slides. You may also be able to send them ahead of time so experts can review them before your appointment.
Build Your Care Team

Choosing a doctor you trust is a top priority. Key questions to ask the physicians you meet include:

- How many patients with brain tumors have you treated?
- How many brain tumor surgeries have you performed?
- What experience do you have with this type of brain tumor?
- What types of advanced treatment options and/or clinical trials are available?

You will likely experience a team approach to your care. This means specialists will discuss your case during weekly meetings, so you get several experts focused on finding the best treatment for you.

Depending on your course of treatment, your care team may include:

- A **neurosurgeon** who specializes in removing brain tumors
- A **neuro-oncologist** who directs chemotherapy, which uses powerful drugs to combat tumors
- A **radiation oncologist** to manage radiation therapy, which uses invisible, high-energy beams to target and shrink tumors
- Dedicated **support staff** members, such as a nurse navigator, social worker and/or pharmacy specialist, to help coordinate treatment
- **Behavioral health professionals** to help you cope with the psychological effects of treatment

“When a person who’s having symptoms and an MRI scan that shows a mass should be seen by a specialist within a week.”

Jon Weingart, M.D.
Johns Hopkins Neurosurgeon

When to Call 911

If you’re having severe symptoms, including paralysis or new-onset seizures, call 911. Certain symptoms can be life-threatening. Medication can also help with symptoms while your doctor develops your treatment plan.
Diagnosing Brain Tumors

Getting an expert diagnosis is key to making sure you receive effective brain tumor treatment. Some tumors are benign (noncancerous) and do not require surgery. Others grow faster and need to be removed as soon as possible or are cancerous (malignant). The earlier you get a diagnosis, the more choices and better chances you’ll have.

Brain Tumor Symptoms

As tumors grow, they can increase pressure in the brain and may affect nearby tissue. Slow-growing tumors may not cause symptoms at all because the brain has enough time to make space for the tumor.

Tumor location may affect your symptoms. Common symptoms include:
- Frequent headaches
- Seizures
- Hearing or vision changes
- Difficulty thinking or speaking
- Weakness or paralysis in a specific location or side of the body
- Changes in personality or behavior

Common Diagnostic Procedures

Imaging and test procedures needed for diagnosis may include:

CT scan: A CT scan, which is a specialized X-ray, is often the first test a patient has, typically during an emergency room visit or to rule out life-threatening situations.

Neurological exam: Doctors use a series of tests to see how your nervous system is working. Your doctor may order a brain scan or refer you to a neurology specialist if the results are abnormal.

MRI scan: An MRI scan uses radio waves and magnets to provide detailed, 3-D pictures of your brain.

Biopsy: A tissue sample, or biopsy, allows pathologists (those who specialize in diagnosing disease) to look at tumor cells under a microscope to identify tumor type. Some brain tumor specialists will biopsy the tumor and remove it in the same surgery so you don’t need a second operation.

Lumbar puncture: Also called a spinal tap, this test requires placing a needle in your back. The purpose is to measure pressure and take fluid to see whether cancer cells are present.

Request an Appointment

To request an appointment, call the number below to receive a response in as little as 24 hours. Our expert team has helped many patients with tumors once diagnosed inoperable.

410-695-6741

To watch this video of neurosurgeon Jon Weingart, M.D., answering frequently asked questions about brain tumors, click the image above.
Brain Tumor Types and Grading

Specialists use imaging tests and analysis of tissue samples to determine the type of brain tumor. These tests also tell doctors whether a tumor is benign (noncancerous) or malignant (cancerous), as well as its grade. Grading describes the seriousness of a tumor, while staging refers to how much it has spread throughout the body. Tumors that start in the brain rarely spread to other organs of the body.

Types of Brain Tumors

Brain tumors are typically divided into two categories: primary brain tumors and metastatic brain tumors. Primary brain tumors start within or just outside the brain and can be benign or malignant. Metastatic brain tumors occur when cancer that started in another part of the body has spread to the brain.

Over 120 types of primary brain tumors exist. The most common primary brain tumors in adults include:

- **Meningioma**: This tumor forms in the outer layers of tissue covering the brain. Meningiomas are often benign, grow slowly and can go undetected for years.

- **Glioma**: This type of tumor starts in supportive tissues of the brain. Types of glioma include astrocytoma, ependymoma, oligodendroma and glioblastoma.

- **Skull base tumors**: This group of tumors grows in the bones that form the bottom of the head and the ridge of bone behind the nose and eyes. Their deep location makes them difficult to remove. Skull base tumors may be one of several types, including pituitary tumors, meningiomas or chordomas. Skull base tumors sometimes require endoscopic surgery. In this procedure, specialists remove the tumor through the nose using a small tube.

- **Acoustic neuroma**: Also called vestibular schwannoma, this type of tumor is benign. This tumor arises from the nerve responsible for hearing and may be associated with hearing loss.

- **Central nervous system lymphoma**: This type of malignant tumor forms in the blood cells of the brain, spinal cord or eyes.

An operation to remove a brain tumor is usually the first course of action because removal offers the best chance of survival. It also lets specialists get a tissue sample so they can more accurately identify the specific tumor type. It can be difficult to identify tumor type from an MRI scan alone. Doctors can tell you more after examining tumor tissue in the lab.
Grades of Brain Tumors

The World Health Organization classifies brain tumors into four grades. Doctors determine tumor grade based on imaging and pathology results, or how tumor cells look under a microscope. Low-grade tumors are those that typically grow slowly, while high-grade tumors tend to be more aggressive.

- **Grade 1** tumors are benign and slow growing. Patients with this type of tumor have the greatest chance of long-term survival.

- **Grade 2** tumors are relatively slow growing but may still spread to nearby tissue. A grade 2 tumor may come back, in some cases as a higher-grade tumor.

- **Grade 3** tumors are malignant. They actively create more abnormal cells and spread into nearby brain tissue. This type of tumor tends to come back, often as a higher-grade tumor.

- **Grade 4** tumors are the most malignant and fast-growing. Grade 4 tumors form their own blood vessels to support fast growth and spread into normal areas of the brain.

Even when tumors are aggressive, treatment may help relieve symptoms, slow tumor growth and help patients live longer.

The Johns Hopkins Brain Tumor Center has several specialty centers dedicated to treating specific types of tumors.

Learn more about our specialty centers by clicking on the links below:

- Acoustic Neuroma Center
- Glioma Center
- Meningioma Center
- Metastatic Brain Tumor Center
- Pituitary Tumor Center
- Skull Base Tumor Center
Brain tumor specialists typically use a combination of surgery, radiation therapy and/or chemotherapy to treat brain tumors. In some cases, watchful waiting or observation is the best thing to do. Working with a specialist at a comprehensive brain tumor center gives you access to more treatment options, including new therapies only available through clinical trials.

The specific treatment your doctor recommends will depend on factors such as:

- Tumor size and location
- Type of tumor
- Whether the tumor is benign or malignant
- Your health
- Previous treatments

**Surgery**

Surgery is the most common treatment plan and often the first step in treating brain tumors. While the idea of brain surgery may be frightening, having surgery at a comprehensive cancer center means you are in capable hands.

General types of surgery used in brain tumor treatment include:

- **Total resection:** Whenever possible, surgeons will completely remove (resect) brain tumors.

- **Partial resection:** It’s not always possible to remove a tumor entirely because it’s too big or too close to sensitive parts of the brain. However, partial removal may help relieve symptoms and make other treatments more effective.

- **Biopsy:** Biopsy is often performed if a tumor is nonresectable.

Because metastatic brain tumors occur when cancer has already spread, they can be difficult to remove surgically. Specialists typically use chemotherapy and radiation to treat metastatic tumors. Surgery may be possible if you have just one or two tumors. Even if doctors cannot completely remove tumors, surgery or other treatments may still be able to help.

**Radiation Therapy**

Radiation therapy uses invisible, high-energy beams to target and destroy cancer cells. A radiation oncologist gives this treatment, often working closely with a neuro-oncologist when a tumor is cancerous.

When used after surgery, radiation can help prevent or slow regrowth of tumor cells. When surgery is not possible, specialists may recommend radiation with or without chemotherapy to shrink brain tumors. A standard course of radiation typically takes place five times a week over six weeks.

**Chemotherapy**

Chemotherapy is a treatment that uses strong drugs to kill cancer cells. A neuro-oncologist directs this treatment, either alone or with surgery and/or radiation therapy. Your neuro-oncologist will customize the course of chemotherapy according to your test results and tumor type.

Chemotherapy can have major side effects, such as hair loss, nausea and low blood counts. However, there are now some newer drugs available that have fewer side effects. Your neuro-oncologist will tell you what you can expect and give you tips for dealing with side effects.

Certain chemotherapy drugs require IV injection, while others come in pill form. Each chemotherapy cycle lasts for several weeks. You may need multiple cycles over the course of treatment.

**Watchful Waiting**

Some brain tumors don’t require aggressive treatment, such as when they are very slow growing or when the patient doesn’t have symptoms. In these cases, cancer specialists will sometimes recommend watchful waiting.

During this time, you will need regular brain scans (MRI scans) to monitor whether tumors are growing. You should also tell your doctor if you experience any brain tumor symptoms.

If your physician recommends watchful waiting, you might ask questions, such as:

- What type of tumor do you think this is?
- Why are we doing scans on this particular schedule?
- What are my options if the tumor starts growing?
- What symptoms should I watch for?
Questions to Ask About Your Treatment Options

When evaluating your treatment options, you should feel comfortable asking your specialist anything.

Some questions to focus on as you work together to find the best treatment include:
• What is the goal of this treatment?
• What options do I have?
• What are the risks, benefits and potential side effects of each option?
• Can I participate in a clinical trial? (For more information on clinical trials, see page 16.)
• What does recovery involve?
• Is the tumor likely to return?
• How should I prepare for treatment?

You may also want to ask whether it makes sense to get a second opinion and how to follow up with questions.

“Through the research efforts of our department, we’ve seen more than a doubling of the average survival rate of patients with malignant brain tumors.”

Henry Brem, M.D.
Director of the Johns Hopkins Department of Neurosurgery
Brain Tumor Surgery Options

Surgery is only possible when the tumor can be reached and removing it won't damage important brain functions. Because brain surgery is so complex, it's important to work with a neurosurgeon experienced with treating brain tumors. Many patients are understandably nervous about getting brain surgery. Fortunately, many people have excellent results and go on to a full recovery after treatment.

Types of Brain Tumor Surgery

The type of operation you have will depend on your tumor location. Before your surgery, specialists will use advanced brain mapping and imaging technology to find the exact location of your tumor. This will help lower any effects on healthy tissue. Your neurosurgeon may also take images during the surgery itself for even more accurate tumor removal. Different types of operations for brain tumors include:

Craniotomy: This procedure involves temporarily removing part of the skull to access and remove brain tumors. Neurosurgeons use different types of craniotomy, depending on tumor type and location, and use minimally invasive approaches when possible. A craniotomy typically requires a hospital stay of three to seven days.

Endoscopic surgery: Neurosurgeons sometimes use endoscopic surgery to access hard-to-reach tumors. In this operation, a specialist puts a thin, flexible device through your nose or mouth to remove the tumor. This method has less pain and scarring than open surgery. You will only need to spend one to two days recovering in the hospital.

MRI-guided laser ablation: This method uses laser heat to destroy tumors that are deep, complex or near sensitive areas. During the procedure, the neurosurgeon puts a laser applicator through a small incision, using an MRI scan to guide the laser. MRI-guided laser ablation is less invasive than open craniotomy, lowering risk, scarring and time in the hospital.

Preparing for Brain Surgery

Your neurosurgeon will provide instructions for preparing for surgery and what to expect during recovery. Quit smoking as soon as possible to help recovery and promote a more successful treatment overall. When discussing surgery with your doctor, you’ll want to ask several questions:

- What are the risks and benefits?
- Will it reduce symptoms?
- What effects might I experience afterward?
- How long will I be in the hospital?
- How long will recovery take?
- Will I need rehabilitation?
- Do you think the tumor will return?
Recovery and Side Effects

Recovery time after surgery depends on:
- The individual
- The type of procedure
- The tumor location
- The brain area affected

Before you go home, doctors and nurses will provide instructions about home care, including when to call the doctor or 911.

Usually, patients can go back to work within a month and have normal energy levels by two to three months. Some patients need rehabilitation to regain strength and functions, such as speech, swallowing and coordination. Most patients do not need rehabilitation after surgery.

Recovery is different for every person, so be patient with yourself. It may take time, but many patients go back to full and active lives after surgery.

“\textbf{In the end, the decision to have surgery here is a very personal one. It’s not about the name. It’s about trusting another human being to help you, and that trust is the basis of a long-term relationship that doesn’t end with surgery.}”

Henry Brem, M.D.
Director of the Johns Hopkins Department of Neurosurgery

Johns Hopkins has a large team of neurosurgeons dedicated solely to treating brain tumors. We operate on over 1,000 patients every year. We also have a large neurosurgical critical care unit to provide round-the-clock monitoring and high-level care after brain surgery.

\textbf{Emerging Therapy: Tumor-Treating Fields}

Tumor-treating (TT) fields is a device for treating high-grade gliomas and metastatic brain tumors. The portable device has stickerlike electrodes that you wear on your scalp connected to a battery pack. The electrodes send mild electrical signals through the skin to slow tumor growth.

Patients with high-grade gliomas can be treated with TT fields, whether newly diagnosed or if tumors have returned. The TT fields device does not typically have severe side effects and can be used along with treatments like chemotherapy. Your doctor can help determine whether this treatment option is right for you.

Click on the image above to hear from Jon Weingart, M.D., about why patients choose Johns Hopkins for brain tumor treatment.
Radiation Oncology

The two most common types of radiation therapy are fractionated external-beam radiation and stereotactic radiosurgery. Radiation oncologists work closely with a dosimetrist, who calculates the exact dose of radiation needed to shrink tumors without unnecessary harm to healthy tissue.

**Fractionated external-beam radiation** is the standard type of radiation therapy specialists use to treat brain tumors.

External-beam radiation includes:

- **Image-guided radiation therapy**: This treatment allows radiation oncologists to take images immediately before and during radiation treatments for better accuracy.

- **Intensity-modulated radiation therapy (IMRT)**: This type of radiotherapy lets radiation oncologists move radiation beams around the shape of the tumor. IMRT helps deliver a stronger dose to the tumor while avoiding sensitive tissues.

- **Stereotactic radiosurgery (SRS)**: This uses image-guided technology to deliver a large dose of radiation to a precise area. Radiation oncologists sometimes use SRS right after surgery to target any remaining cancer cells. Despite the name, SRS is a nonsurgical procedure that is completely painless.

What to Expect

Radiation therapy requires major planning and preparation before you start treatment. After your initial referral and consultation, you will need to go in for a simulation session. During this session, a simulator gathers X-ray images to identify the exact location of the tumor. Radiation oncologists use these images to make a detailed map of your brain and to figure out the exact radiation dose, beam angle and treatment length.

Each radiation appointment can take up to 45 minutes, but the treatment itself is just a few minutes. During this time, you will have to lie still on a table while the radiation oncologist points the radiation beams at the tumors. You may also need to wear a special mask to hold your head in place. You will not feel anything during the treatment.

Radiation treatment can last a couple of days to a few weeks. The length depends on your type of radiation, tumor location and tumor type. In some cases, you will receive chemotherapy at the same time, or chemotherapy cycles may alternate with radiation courses. Specialists will carefully watch you throughout to make sure you can tolerate treatment and any side effects.
Questions to Ask Before Radiation

Before starting your radiation therapy, you’ll want to ask the radiation oncologist questions that include:
• What types of radiation therapy are available here?
• Will treatment involve radiation of the entire brain or just part of it?
• What are the immediate and long-term side effects?
• What kind of results do you expect?

You’ll also want to make sure you know whom to call if you have questions about your radiation therapy.

Side Effects of Radiation

• Headache
• Nausea
• Tiredness
• Swelling
• Skin irritation
• Hair loss
• Difficulty thinking clearly
• Changes in sensation or movement difficulties

It’s important to tell your doctor right away about symptoms or side effects. Certain problems may require special medication. Your doctor can also help keep you comfortable with medication for symptoms such as pain and nausea.

“Radiation oncologists and neuro-oncologists at Johns Hopkins work together to determine the best course of action for a patient. We understand that we’re not treating a machine — we’re treating a person.”

Matthias Holdhoff, M.D., Ph.D.
Johns Hopkins Neuro-oncologist
Chemotherapy and Targeted Treatments

Neuro-oncologists use a variety of chemotherapy drugs to treat tumors. Your doctor will choose your treatment based on tumor type and tissue analysis results.

General categories of chemotherapy drugs include:

- **Oral chemotherapy:** For many patients, oral chemotherapy has fewer side effects than traditional IV chemotherapy. Oral chemotherapy drugs include temozolomide, lomustine and procarbazine.

- **IV chemotherapy:** Doctors administer IV chemotherapy infusions in the hospital. Common IV chemotherapy drugs include carmustine and vincristine.

- **Chemotherapy implants:** An innovative treatment invented at Johns Hopkins, chemotherapy implants (Gliadel® wafers) are placed in the tumor site after surgery. As the wafers dissolve, they release a dose of chemotherapy drug to kill any cancer cells left behind.

**What to Expect**

Doctors give chemotherapy in cycles that last for several weeks at a time, including rest periods. Your neuro-oncologist may prescribe several cycles of chemotherapy in a row.

During your treatment, the neuro-oncologist will closely monitor your blood counts to determine if you need a dose adjustment. If your blood counts get too low, you may need to pause or stop treatment.

Chemotherapy can be difficult, but your care team will be with you at every step to closely watch your health and keep you as comfortable as possible. Palliative care teams can also provide personalized support and symptom management at every stage of treatment.
Side Effects of Chemotherapy

Your doctor may provide medication and tips for managing chemotherapy side effects. Not all chemotherapy drugs cause severe side effects. Oral medications may be easier to tolerate. Common side effects include:

- Nausea and vomiting
- Constipation or diarrhea
- Weight changes
- Fatigue
- Hair loss
- Low blood counts
- Itching, burning or tingling sensations

Questions to Ask Before Starting Chemotherapy

- Which chemotherapy drugs do you recommend and why?
- How do your recommendations compare to standard treatment guidelines?
- What are the risks and benefits of this chemotherapy plan?
- What are the side effects, and what do you do to help manage them?
- How likely is it that chemotherapy will help?
- Does my insurance company cover these medications?
- Who do I call if I have questions or concerns?

“When patients come to us, they can be sure that they will get the latest research, the newest technology and the best possible therapies. And we do that for every single patient we see.”

Henry Brem, M.D.
Director of the Johns Hopkins Department of Neurosurgery
What About Clinical Trials?

Clinical trials are research studies to evaluate experimental treatments not yet approved by the U.S. Food and Drug Administration (FDA). Almost all of the progress made in recent decades is the result of clinical trials. Participating in clinical trials gives you access to promising new therapies and helps scientists find a cure.

It’s best to ask about clinical trials as soon as possible after diagnosis to give you more treatment options to choose from.

Types of Clinical Trials

Different types of clinical trials exist for various stages of disease. Some clinical trials are for the newly diagnosed. Others are for patients with recurrent (returning) tumors or for those who have already undergone treatment.

Before a new treatment is eligible for FDA approval, it must go through three phases of clinical trials:

- **Phase I** clinical trials look at the safety of a new treatment. These trials involve a small number of patients as researchers work to determine safe dosing and potential side effects.

- **Phase II** clinical trials look at the effectiveness of the new treatment. Phase II clinical trials include more patients as researchers continue to study side effects.

- **Phase III** clinical trials compare the new treatment’s effectiveness against standard treatments. These trials require large numbers of patients from many hospitals. The increased time and cost means only the most promising treatments make it this far.

The final phase, phase IV clinical trials, take place after FDA approval. These trials continue to study the safety and effectiveness of approved drugs.

Hot Topics in Brain Tumor Research

Clinical trials constantly change, with thousands taking place at any given time. Current areas of interest among scientists include:

- **Immunotherapy** research focused on using the body’s immune system to destroy aggressive brain tumors
- **Stem cell research** aimed at genetically engineering brain cells to fight cancer
- **New chemotherapy drugs** and new ways of delivering them directly to tumors
Participating in a Clinical Trial

Each clinical trial has its own requirements, and not all patients can participate. A brain tumor specialist can help you understand the risks and find the best option.

Questions to ask include:
• What are the risks and benefits?
• Can I still receive carmustine/chemotherapy wafer treatment?
• Will I need to travel to participate?
• Who will pay for my treatment during the clinical trial?
• Is the clinical trial randomized?

How to Find a Clinical Trial

Ask your doctor about available clinical trials and their requirements. The sooner you learn about your options, the better. This will help you make more informed treatment choices.

You can find information about nationwide clinical trials on Clinicaltrials.gov. Some clinical trials are only available for patients at a certain hospital or academic research center.

“Our goal is to discuss all of the clinical trials available to a patient to see what might be a fit and to make sure the patient fully understands the pros and cons of participating.”

Matthias Holdhoff, M.D., Ph.D.
Johns Hopkins Neuro-oncologist

Johns Hopkins is the headquarters for the Adult Brain Tumor Consortium (ABTC). The ABTC is a group of 11 research centers focused on discovering new brain tumor treatments through research and clinical trials. Johns Hopkins oncologist Stuart Grossman, M.D., has led research studies at the ABTC for over 20 years.

Learn more about the ABTC or find out about clinical trials at Johns Hopkins.
Recovery and Rehabilitation

Brain tumors and their treatment can have major effects on your daily functioning. Some changes may be permanent, but rehabilitation can make a difference by improving your recovery. Patience and practice are important too, since it may take weeks or months to get back normal function.

Recovery

Brain surgery, chemotherapy and radiation can wear out your body. After treatment, it is normal to experience:

• Weakness
• Loss of balance or vision
• Dizziness
• Confusion or memory loss
• Stiffness or movement difficulties
• Trouble making decisions or performing complex tasks

It takes time for the brain to heal itself. After brain surgery, most people are back to work within about a month and have normal energy levels in two to three months. In some cases, you may have to get used to permanent changes.

Rehabilitation

Working with rehabilitation specialists offers the best chance for a successful recovery. Look for rehabilitation professionals who specialize in helping people with brain tumors or neurological disorders.

Types of rehab your doctor may recommend after treatment include:

• Physical therapy to improve your strength, balance and walking
• Occupational therapy to help you get back the ability to perform everyday tasks, like writing and driving
• Speech therapy to address side effects related to speech, eating and swallowing

Follow-Up Care

After your treatment is complete, you will need to keep seeing a neurosurgeon and neurologist for regular checkups and imaging tests. How often you need brain scans will depend on your diagnosis and treatment.
Support Groups

It’s natural to feel depressed or overwhelmed if you have a brain tumor or are struggling to cope with treatment. Friends and family can provide support, but sometimes it helps to talk with others going through the same challenges.

Support groups can help you make these connections. They allow patients and families to:
• Meet others who are going through brain tumor treatment.
• Get additional information from health care professionals.
• Learn practical tips for coping with diagnosis and treatment.

A wide variety of support groups exist at hospitals, in your local community and even online.

Counseling

In addition to finding a support group, you may find it helpful to speak with a counselor. Ideally, your counselor would have experience working with brain cancer patients. A doctor or nurse at your hospital may be able to point you in the right direction. Many brain tumor centers and cancer programs even have a social worker on staff who can provide free counseling.

“The goal is to get people through the treatment process quickly, get them home and get them back to their normal level of function as quickly as possible.”

Jon Weingart, M.D.
Johns Hopkins Neurosurgeon
Advocates and Caregivers

Advocates and caregivers are an important part of brain tumor treatment. Patients often need help organizing care and making decisions. This support helps make sure you or your loved one gets the best care possible.

Designate a Medical Advocate

A brain tumor can affect your ability to think clearly, especially in later stages of the disease. While you may feel OK now, it’s important to make plans in case you can’t make decisions in the future.

Also called a proxy or power of attorney, an advocate is someone chosen to make medical decisions for you. When you fill out your paperwork at your first appointment, a hospital representative will provide you with the appropriate paperwork.

You’ll want to make sure whoever you choose understands your treatment goals and preferences. Some people choose a close family member, while others choose a friend or relative with medical expertise.

Prepare for Appointments

One of the biggest ways advocates and caregivers can help is by going to appointments with the patient. They can also help patients prepare by:
- Using a calendar or planner to keep track of appointments and reminders
- Bringing a notebook to write down questions and notes
- Keeping a folder or binder to collect information provided by the care team
- Bringing any required documents or tests to appointments

Communicate with Doctors

As an advocate or caregiver, make sure you know whom to contact when you have questions about treatment. The patient will need to fill out paperwork allowing doctors to give your personal information protected by privacy laws.
Manage Insurance and Finances

Managing the financial side of treatment can be overwhelming for patients. Ways you can help include:
• Tracking bills in one place, such as an accordion folder
• Choosing a day to pay medical bills
• Using a notebook to take notes on conversations with insurance company representatives

Caregiver Tips

Being a caregiver can be stressful. It’s important to also care for yourself during this difficult time, so make sure to:
• Ask for help when you need it, and accept help when it’s offered
• Connect with other caregivers who can provide advice and support
• Give yourself permission to emotionally process any grief you’re experiencing
• Take time for self-care
• Focus on enjoying life as much as possible with your loved one

“What makes Johns Hopkins different is our multidisciplinary team that includes neurologists and oncologists who are 100 percent devoted to treating brain cancer.”

Matthias Holdhoff, M.D., Ph.D.
Johns Hopkins Neuro-oncologist

Johns Hopkins offers a weekly Caregiver Café, where you can meet other caregivers, ask questions and get support.

Learn more about all of our resource programs, including support groups, information sessions and spiritual support.

Our palliative care and pain program helps patients and caregivers cope with challenges at every stage of the treatment process. Palliative care focuses on pain and symptom management, while also providing emotional support and help making difficult decisions.
About the Johns Hopkins Comprehensive Brain Tumor Center

The Johns Hopkins Comprehensive Brain Tumor Center is one of the largest brain tumor treatment and research centers worldwide.

Patients from across the globe come to Johns Hopkins because we offer:

• **World-class brain tumor care:** We provide advanced treatment and personalized care that gives hope to people facing the fight of their lives.

• **Expert cancer specialists:** Our physicians and researchers are leaders in their field who have dedicated their entire careers to treating brain tumors.

• **Promising new treatments:** Through our extensive clinical trials program, patients have access to leading-edge treatments not yet available to the public.

Ranked #1 in the nation by *U.S. News & World Report* for more than 20 years.

About Johns Hopkins Medicine

Located in Baltimore, Maryland, Johns Hopkins Medicine is one of the nation’s most distinguished health care systems.

We bring together physicians, researchers and health care experts from both the Johns Hopkins University School of Medicine and The Johns Hopkins Hospital and Health System. Johns Hopkins Medicine includes dozens of hospitals, surgery centers and outpatient facilities.

*U.S. News & World Report* ranked Johns Hopkins Medicine #1 in the nation for more than 20 years in its annual Best Hospitals edition, including 21 years in a row between 1991 and 2011. Since 1889, our researchers and physicians have driven countless medical advances that have saved lives across the world.

Today, we are an internationally recognized medical system known for pushing the boundaries of science. We are the country’s leading academic institution in research spending, working to bring new discoveries from bench to bedside to save lives.

Get more information on [Johns Hopkins Medicine](https://www.hopkinsmedicine.org) or call 410-695-6741 to make an appointment with a brain tumor specialist.
Our Team of Experts

Neurosurgery

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Neurology

Jaishri Blakeley, M.D.
Director, Johns Hopkins Comprehensive Neurofibromatosis Center

John Laterra, M.D., Ph.D.
Co-Director, Brain Cancer Program
Johns Hopkins Kimmel Cancer Center

Oncology

Stuart Grossman, M.D.
Co-Director, Brain Cancer Research Program
Johns Hopkins Kimmel Cancer Center

Matthias Holdhoff, M.D., Ph.D.
Assistant Professor, Oncology

Nurses and Physician Assistants

Jill Anderson, M.S., P.A.-C.
Physician Assistant

Deanna Glass-Macenka, R.N., B.S.N., C.N.R.N.
Brain Tumor Program Coordinator/Nurse Navigator
Additional Resources and Support

Find out more about the Johns Hopkins Comprehensive Brain Tumor Center.

Brain Tumors

Learn more about basics of brain tumors and brain tumor grades, or find out about different types of brain tumors:
- Gliomas
- Meningioma
- Skull base tumors
- Metastatic brain tumors

Brain Tumor Treatments

Find out about brain tumor treatment, including:
- Brain tumor treatment questions
- Tumor-treating fields for brain tumors
- Clinical trials at the Johns Hopkins Kimmel Cancer Center

Other Resources

- Brain and Spinal Cord Tumors in Adults (American Cancer Society)
- National Brain Tumor Society
- American Brain Tumor Association
- National Comprehensive Cancer Network Guidelines

Discretion:

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