Barrow Brain Tumor Handbook

Ivy Brain Tumor Center
AT THE BARROW NEUROLOGICAL INSTITUTE

Barrow Neurological Institute | Dignity Health. St. Joseph's Hospital and Medical Center

Barrow Brain Tumor Handbook

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Dear Patient and Caregiver,

Each year, over 1200 patients undergo brain tumor surgery at the Barrow Neurological Institute – the most of any brain tumor center in the United States. Our multidisciplinary team of neurosurgical oncologists, clinical neuro-oncologists, radiation oncologists, nurse specialists, clinical therapists, and social workers is dedicated to providing you with state-of-the-art clinical care so that you can get back to your daily life as soon as possible. While your case is certainly not our first time dealing with this diagnosis, we recognize that it is yours. To help you and your family familiarize yourselves with your condition, we assembled this Handbook to provide an accurate framework to better understand brain tumors.

At the Barrow Neurological Institute, the treatment plan for each brain tumor patient is individualized, so not everything described in these pages will necessarily apply to you. Nevertheless, it is always easier to navigate the waters when you know what is in the realm of possibilities. By consolidating the latest information in a single booklet, we hope this knowledge will help you make informed decisions as we work in partnership to diagnose and treat your brain tumor.

For most brain tumor patients, dealing with a brain tumor is more of a marathon than a sprint, so we encourage friends and family members, not just you, to take care – get enough sleep, nutrition, and exercise to stay as healthy and focused. Step-by-step, our brain tumor team we will help take you through the diagnostic and treatment process, all the way from preoperative testing to neurosurgery and beyond. While you will meet many different specialists during this time, rest assured that we are all working in unison on your behalf.

As you will soon learn, research and technology play central roles in modern-day brain tumor management. During your care, you will be exposed to the next-generation neurosurgical techniques, advanced brain imaging modalities, cutting-edge clinical therapeutics, and precision radiation therapies. In many cases, state-of-the-art clinical trials also play a role in your care, as does basic science research. Because so many questions remained unanswered regarding the biology of your brain tumor, the Barrow Neurological Institute, in partnership with the Ben & Catherine Ivy Foundation, has recently created the Ivy Brain Tumor Center. This advanced brain tumor research program features the largest early-phase clinical trials program for brain tumor patients in the world. The Ivy Center's singular goal is to develop new therapies that specifically target your tumor. Our Center features the most advanced scientific and biological techniques available, including many that we have pioneered, ourselves. Please visit us at IvyBrainTumorcCenter.org for more information on our precision medicine trials.

Please look through the Handbook at your convenience and let us know your thoughts. We are always open to suggestions on how to better address your questions and concerns.

Sincerely yours,

Nader Sanai, MD

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Introduction

The purpose of this handbook is to help patients and families find up-to-date sources of information and support specific to the Ivy Brain Tumor Center at Barrow Neurological Institute. During your stay in the hospital, your care will be provided not only by a team of doctors and nurses who are brain tumor experts but also by many other staff members. We hope this handbook will help you to learn about your brain tumor and how to talk about it with your treatment team.

Members of Your Barrow Treatment Team

You may be seen by a number of doctors and staff during your stay in the hospital. Some of them will become members of your treatment team. The following is a description of the role some of your potential team members may have in your care.

Neurosurgeon: The surgeon who performs surgery to remove the brain tumor. The neurosurgeon also works with residents (doctors in training) who help provide care for you while you are in the hospital.

Neuro-oncologist: A neurologist with special training in the medical treatment of brain tumors using medications and chemotherapy. This doctor will closely follow your care and will address any new symptoms or concerns.

Neuropathologist: A doctor who makes the diagnosis of diseases of the brain and nervous system by examining the tissue under a microscope.

Radiation Oncologist: A doctor with special training who treats tumors with radiation. This doctor will also follow your care during radiation treatment sessions and afterward.

Nurse Practitioners (NPs): The NPs at the Barrow are advanced practice nurses with special training in the neuroscience field. The NPs work with the neurosurgeon to direct your medical plan of care. NPs have training and skills in assessment, physical diagnosis, and management of health needs in their specialty areas.

Nurse Navigator: A nurse who is a contact person to help bring you together with your care team after you leave the hospital. The nurse navigator can also help you connect with other sources of support. Please ask your nurse to have the nurse navigator see you.

Neuropsychologist: A doctor with special training in helping people who have trouble with their thinking and memory issues. If you need this doctor's help, you would make an appointment after you go home.

Speech Language Pathology (SLP) or Speech Therapist: SLPs will assess and treat speech, language, cognitive and swallowing issues that may be impacted by brain tumors or tumor surgery. Your SLP may provide therapy to address difficulties understanding (receptive) and formulating (expressive) language, as well as to introduce strategies for functional communication. Through a cognitive evaluation, potential difficulties with memory, attention, or problem solving may be addressed. SLPs also may conduct swallow evaluations and intervention to ensure safe eating and drinking.

Physical Therapist: Physical therapists are movement experts who focus on improving quality of life, restoring function and preventing/managing disability. They examine each patient's balance,

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coordination, leg strength and safety with walking. Your physical therapist will also teach you how to use equipment, such as a cane, walker, or wheelchair if indicated.

Occupational Therapist: Occupational therapy focuses on enabling the patient to achieve maximum performance, physically and psychologically. This can range from management of activities of daily living such as bathing, dressing, or feeding yourself to hobbies/lifestyle. In addition to addressing strength, range of motion and motor recovery, your OT may also focus on vision and adaptive equipment recommendations to encourage independence.

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Brain Tumor Team

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Director of Neuropathology

Division of Neuro Speech Therapy

Sarah Key, SLP

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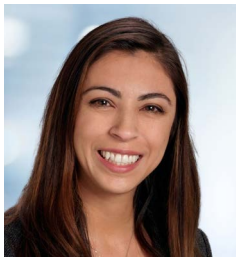

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Nurse Navigator

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Division of Ivy Brain Tumor Center Research Nurses

Kristin Hendrickson, RN, CCRC
Clinical Research Program Manager

Juliane White, RN
Clinical Research Nurse

Alyssa Ingurgio, RN
Clinical Research Nurse

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My Barrow Treatment Team

My neurosurgeon is:

Dr._____ Office Phone: _____

My neuro-oncologist is:

Dr._____ Office Phone: _____

My radiation oncologist is:

Dr._____ Office Phone: _____

My medical oncologist is:

Dr._____ Office Phone: _____

Other contact:

Dr._____ Office Phone: _____

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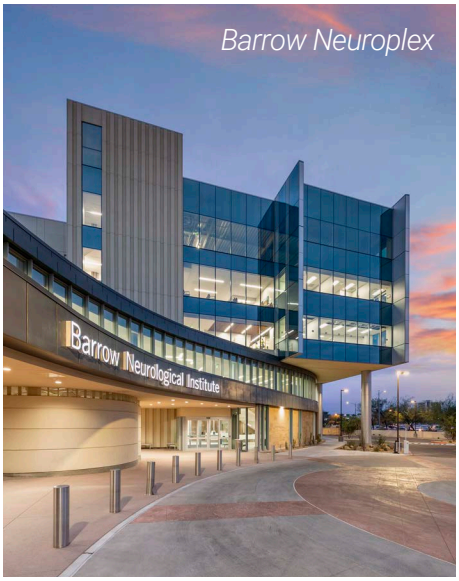
Finding Your Barrow Treatment Team Clinics

Your neurosurgeon has a clinic within St. Joseph's Hospital and Medical Center | Neuroplex at:



Barrow Brain and Spine
2910 North Third Avenue
Phoenix, Arizona 85013
BarrowBrainAndSpine.com
Office number: (602) 406-3181

If you had a visit in the hospital with a neuro-oncologist, you will follow up in the clinic located on the campus of St. Joseph's Hospital and Medical Center | Neuroplex at:

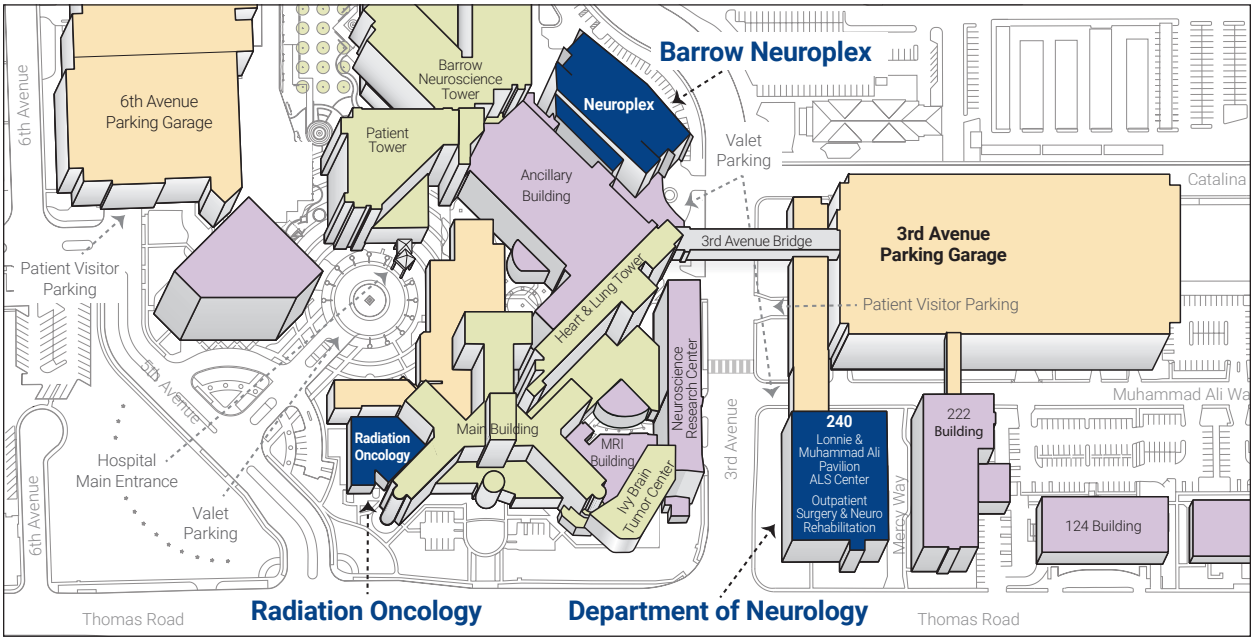
Barrow Neuro Oncology and Stroke Center
2910 North Third Avenue
Phoenix, Arizona 85013
Office number: (602) 406-6262
BarrowNeuro.org

If you had a visit in the hospital with a radiation oncologist, you will have follow up at the clinic located within St. Joseph's Hospital and Medical Center.

Radiation Oncology & CyberKnife Department
350 West Thomas Road
Phoenix, Arizona 85013
Office number: (602) 406-6761

Dignity Health.
St. Joseph's Hospital and Medical Center

Campus Map



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At Home After Surgery

Incision Care

You may have one or more incisions on your head closed with staples or sutures (stitches). These will be removed at your clinic follow-up visit seven to 14 days after surgery. Alternatively, you may have sutures that dissolve. These will not need to be removed and will absorb into your skin over the next few weeks. You may shower with mild soap and shampoo daily. Gently wash your incision and pat it dry. This is the only time you may touch your incision. Do not take a tub bath, go swimming, or get into a hot tub until the doctor says you can. Do not apply ointments, lotions, or creams to your incision.

To help reduce swelling and discomfort, you may apply an ice pack tto the area for 30 minutes on and 30 minutes off as you need it.

You should wear a hat outdoors to protect your head until your sutures or staples have been removed.

You may have some itching at your incision site, some jaw tightness, or trouble opening your mouth very wide for a few days after surgery. These conditions will improve as you continue to heal.

Avoid having your hair colored or permed for four to six weeks after surgery.

Activity

It is important to get out of bed and move around as soon as possible after surgery. While in the hospital the hospital staff will help you. Getting moving helps prevent complications such as blood clots, pneumonia and delirium. Once at home, continue to take walks daily and increase your tolerance as you are able. At the time of your first post operative visit with your surgeon, this is a good time to talk about what is appropriate activity for you as an individual.

For the first 3 days you are home, do only light activity around the house. After that, you can slowly increase your activity, starting with a short walk one to two times a day.

For 8 weeks after surgery, do not do anything that would put you at risk of head trauma (such as skiing, snowboarding, biking, or contact sports). It takes six to eight weeks for bone to heal.

Do not try to lift, push, or pull more than 10 pounds for four weeks after surgery.

Nutrition

Eat plenty of fruits and vegetables to prevent constipation. Drink six to eight cups of water each day, which will also help prevent constipation.

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Medicines

Pain Control

You may receive a prescription for an opiate pain medication when you go home from the hospital. Here are some facts about pain medication (opiates).

- Opiates are strong pain medicine and needs a prescription by a doctor or a NP to be electronically sent to a pharmacy.
- Some opiate medications also have acetaminophen (Tylenol) mixed in them.

oxycodone/acetaminophen (Percocet, Endocet) hydrocodone/acetaminophen (Vicodin, Norco)	**DO NOT TAKE EXTRA acetaminophen with these two types of pain pills. (Tylenol®)**
oxycodone hydrocodone hydromorphone (Dilaudid) codeine tramadol	You can also take 650 mg of acetaminophen (Tylenol®) every four to six hours, if needed, with these five types of pain pills.

When you feel that you no longer need your strong pain pills, you may take 650 mg of acetaminophen (Tylenol) every four to six hours, as needed.

Acetaminophen (Tylenol) is available over the counter—no Rx is needed.
Caution: Too much acetaminophen (Tylenol) can damage your liver. Do not take more than 4000mg in 24 hours.

To avoid side effects such as nausea, vomiting, or constipation, you should take your pain pills with food, and only as needed.

Do not drink alcohol or drive when taking prescription pain medication (opiates).

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Steroids for Swelling

You may go home from the hospital on a steroid, usually dexamethasone, to decrease brain swelling. These pills relieve symptoms caused by pressure or swelling from the tumor. Once the swelling is under control, the steroid dose will be slowly decreased each day until it is eventually stopped. You will receive specific written instructions for stopping your steroid pills before you go home from the hospital.

Possible side effects of steroids include:

- Appetite changes
- Emotional and behavior changes
- Heartburn
- Constipation
- Insomnia
- Increased blood sugar
- Water retention or swelling in face, legs or feet

Your brain tumor symptoms might return when your steroid dose is lowered or stopped. You may also feel tired and emotionally down for a few days. If you do not feel better or if your symptoms worsen, call your doctor.

Seizure Control

You may receive prescription (Rx) pills to control seizures. It is important to take these pills as directed and to not miss any doses. Discuss with your doctor whether you are allowed to drive.

Some common side effects of seizure pills are:

- Fatigue
- Constipation
- Rash
- Agitation
- Poor appetite

General Wellness

Here at the Barrow, we support CDC guidelines for vaccination status. It is important to stay up to date with all recommended vaccinations, such as the flu and COVID 19 vaccines. If you have any questions about vaccine, set up an appointment with you primary care provider. . Some vaccines are available in the hospital such as the flu and pneumonia vaccines. Most other vaccinations can be done at your primary care office or a pharmacy.

Centers for Disease Control and Prevention
CDC.gov

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Symptoms and Conditions Associated with Brain Tumors

This chart is to help patients and caregivers understand common symptoms and conditions patients with brain tumors may experience. It is a guide and if there is a question about the seriousness of the symptom please contact your doctor or go to an emergency room.

Seizures

Patients with certain types of brain tumors are at risk for seizures. Certain locations in the brain are more seizure prone (temporal lobe).

What a seizure may look like	What to do	Who to call
Partial seizure • Single limb on one side or muscle twitching, jerking, shaking **Generalized seizure (tonic clonic)** • Loss of consciousness followed by twitching and jerking type rhythmic movements • May lose control of bladder • May bite tongue • After affects are sleepiness, confusion, body aches **Absence seizure** • A type of seizure that involves brief and sudden loss of attention, as if the person is staring off into nowhere	**During seizure:** • Be sure person is breathing • Protect head from hitting floor • Do not try to put anything in persons mouth • Do not restrain limbs **After seizure:** • After seizure attempt to place person on their side • Stay with person until you reach physician for directions **It is important to note if the person is aware or unaware during the seizure. This information gives the doctor more details about the type of seizure the person may be having.*	• Seizure may not be an emergency if person is not in distress and has a known seizure disorder • Call 911 if not breathing or having difficulty breathing • Call 911 if seizure last longer than five minutes or multiple seizures happen • Call 911 if person is not awake • Call your treating neuro oncologist or treating doctor to describe seizure and for directions

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Motor, Sensory or Language Problems

Patients may have motor (movement) loss, weakness or sensation changes if the tumor is located or pressing on the frontal lobe. Patients may experience language difficulties from tumors in the left temporal lobe.

Description	What to do	Who to call
• Problems with movement on one side of body, arm, hand, leg or foot • Strange feeling on one side of body • Falls • Mobility issues • Face weakness • Difficulty getting words out • Difficulty understanding words or following direction	• Non urgent unless sudden onset of weakness and contact your doctor • Physical, Occupational and Speech therapy are helpful to help learn how to cope and compensate for loss of function • Support from family members is important	• Discuss Physical, Occupational and Speech therapy with your doctor and treatment team • Call 911 if sudden weakness or speech slurring occurs

Headaches

Patients have varying degrees of headaches. Some headaches are simply from surgery or from the tumor. Prescribed medication is sometimes necessary. Common medicines used are over the counter acetaminophen and Ibuprofen. Common prescribed medicines are opiates, steroids and some nerve pain medicines.

Description	What to do	Who to call
• Surgery location discomfort is expected and usually resolves in a few weeks • Ongoing headache that is worse in the morning but improves in a few hours • Daily headache that does not improve with pain medications	• Take acetaminophen over the counter dose as directed on the medication directions • Take Ibuprofen over the counter as directed on the medication directions • Take prescribed pain medicine as directed by your Doctor or Nurse Practitioner • Treat with medicine prescribed by doctor • Keep a diary of headaches of location and patterns	• Call your doctor if medications are not helping headaches • Call your doctor if headache is accompanied by fever or stiff neck • Call your doctor if headache is the highest degree of pain

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Deep Vein Thrombosis

A deep vein thrombosis is a blood clot most commonly found in the legs or arms. Patients who have surgery and have brain tumors are at a higher risk for forming blood clots than the average person. This is especially the case while in a hospital setting. There are medicines that can help prevent them while in the hospital. Each patient's risk is individually considered by the Doctor.

Description	What to do	Who to call
• Swelling or pain in the leg or arm	• Alert treating team as soon as possible • Seek medical care by treating team or by primary care office or ER • Anticoagulation medicine is generally the treatment • Some patients are candidates for inferior vena cava filters	• Call treating doctor

Pulmonary Embolism

Pulmonary embolism is a complication of a deep vein thrombosis and is a clot that travels to the lung usually from a DVT in the leg.

Description	What to do	Who to call
• Chest pain • Shortness of breath • Fast heart beat	• Call 911, Pulmonary embolism is a an emergency	• Call 911

Nausea and Vomiting

Description	What to do	Who to call
• Feeling sick to stomach • Can be associated with increased swelling in brain from a brain tumor • May be a side effect of medications such as chemotherapy or opiates	• Take prescribed anti nausea medicine • Eat a bland diet • Do not take opiate pain medicine on an empty stomach	• Call treating doctor during business hours

Vision Loss or Vision Disturbances

Description	What to do	Who to call
• Double vision or blind spots	• Certain compensatory therapies such as occupational therapy is helpful • Alert treating Doctor	• Call treating Doctor during business hours for discussion

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Cognitive and Behavioral Problems

Cognitive and behavior problems can be difficult to pin point for family members and also overlap in areas of cognitive domains.

	Description	What to do
Emotion and Personality changes	• Depression and anxiety • Irritability. Some medications such as steroids can cause irritability and agitation	• Discuss symptoms with treating Doctor during business hours • Psychotherapy • Medication therapy • Support groups
Memory and learning difficulties	• Short term memory difficulties • Difficulty processing information • Difficulty following directions	• Cognitive therapy • Avoid giving multistep directions
Attention and Concentration	• Easily distracted • Confusion	• Cognitive therapy • Medication therapy
Executive Functioning	• Difficulty with day to day planning such as paying bills or organizing a schedule • Impaired judgement	• Cognitive therapy • Consider naming a financial power of attorney and medical power of attorney

Fatigue

It is common to feel tired up to about 6 weeks after surgery. Treatments such as radiation therapy can cause fatigue.

Description	What to do	Who to call
• Feeling extremely tired after simple activities such as walking or therapies	• Resting in between periods of activity • Light activity such as walking	• Discuss symptoms with treating Doctor during business hours • Medication therapy

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Symptoms Based on Brain Tumor Location

Frontal Lobe

Weakness or paralysis on one side of the body, difficulties with planning, judgement, impulsiveness, personality changes, seizures and confusion

Parietal Lobe

Seizures, Paralysis, Problems with hand writing, Mathematical difficulty, Motor skill deficits, Loss of sense of touch

Occipital Lobe

Loss of vision, Visual hallucinations, Seizures

Temporal Lobe

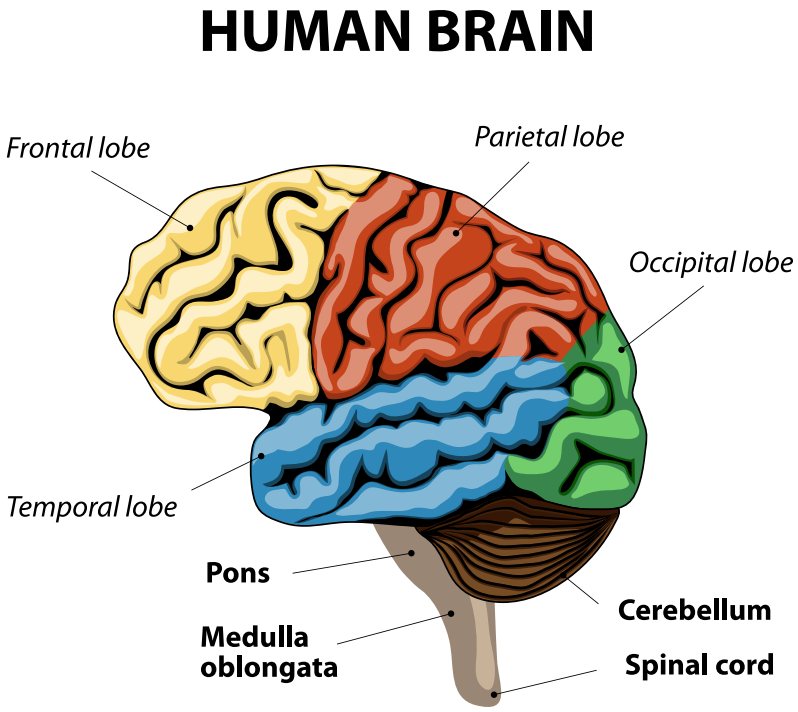
Seizures, Perceptual/spatial disturbances, Inability to understand multi-step commands (receptive aphasia)

Cerebellum

Loss of balance (ataxia), Loss of coordination, Headaches, Vomiting, dizziness

Hypothalamus

Emotional changes, Deficits in perception of temperature, Problems with growth/nutrition (in children)



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Call your neurosurgeon or go to the emergency room if any of the following occur:

- Clear or bloody drainage from your nose or ears
- Headache gets worse
- Seizure activity or jerking/twitching of face, arms, or legs
- Dizziness
- Ringing in ears
- Neck is stiff or hurts to move
- Weakness of your face, arms, or legs
- A fever of 101 degrees
- Redness, swelling, odor, or drainage at your surgery site
- Severe pain at your surgery site that is not controlled by your pain pills
- Nausea or vomiting
- Constipation lasting three days that is not helped by over-the-counter pills

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The Barrow Tumor Board

The Barrow Tumor Board meets once a week. It provides a means for patients to benefit from the opinions and advice of expert doctors from different specialties who attend each week—doctors from your treatment team (neurosurgery, neuro-oncology, radiation oncology) and other experts, such as a neuropathologist (a doctor who examines the tumor under a microscope and makes the diagnosis) and a neuroradiologist (a doctor who reads the diagnostic scans). This is a meeting consisting of physicians. Patients and family members do not attend.

Patient cases may be presented for a review of the tumor diagnosis or for discussion of the best treatment for the patient. Patient cases are typically presented after a new diagnosis, but also when they are at a critical point where input from the other experts would be helpful.

While you are in the hospital final pathology will likely not be available but some preliminary recommendations may be made for you. In most cases, final pathology is discussed during office visits with a detailed plan of care.

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Tumor Diagnosis

Tumor diagnosis may also be referred to as “tumor pathology.” During your surgery, your neurosurgeon will send a tumor sample to the pathology lab. The sample will be examined by a neuropathologist, and a preliminary diagnosis will be determined while you are still in the operating room. This preliminary diagnosis is also referred to as a “frozen section” diagnosis. It will require more time for more testing before a final tumor diagnosis is made.

The final tumor diagnosis can take an average of seven days after your surgery. For this reason, it is not uncommon to be discharged from the hospital before you receive information on your final tumor diagnosis. Your neurosurgeon or oncologist will discuss your tumor diagnosis at your postoperative office visit.

My preliminary diagnosis is: _____

My final diagnosis is: _____

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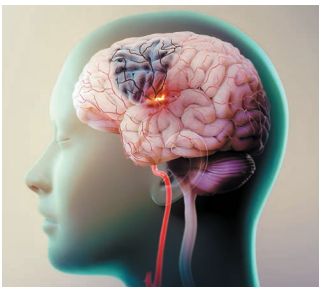
Brain Tumor Overview



Tumors that start growing in the brain are primary brain tumors and generally will not travel to other parts of the body. Tumors that start elsewhere in the body and spread to the brain are metastatic brain tumors.

Primary Brain Tumors

Primary brain tumors start in the brain. Typically, they are rated by a neuropathologist by the way they look under a microscope, using the World Health Organization (WHO) grading scale from I to IV (1 to 4):

- **Grade I (1):** Slow-growing tumor cells; almost normal appearance; least aggressive; usually curable by surgery alone
- **Grade II (2):** Relatively slow-growing cells; slightly abnormal appearance; can invade nearby tissue; may recur as a higher grade
- **Grade III (3):** Actively growing cells; abnormal appearance; infiltrates normal tissue; also referred to as "anaplastic tumors"
- **Grade IV (4):** Rapidly reproducing abnormal cells; very abnormal appearance; area of dead cells (necrosis) in center

The following are a list of primary brain tumors and their treatments:

- **High-grade gliomas** are tumors that grow from the cells that make up the brain tissue. The higher grade means the tumor is more aggressive compared to a lower grade tumor. Types of these tumors are called: astrocytoma, oligodendroglioma and glioblastoma. Treatment is surgery followed by combined radiation and chemotherapy. Treatment in a clinical trial may also be offered.
- **Low-grade gliomas** (grade II) include astrocytomas and oligodendrogliomas. Treatment after surgery may include radiation or chemotherapy. If these tumors are not growing rapidly or causing symptoms, sometimes they will just be observed without other treatment. Treatment in a clinical trial may also be offered.
- **Very low-grade gliomas** (grade I) such as Juvenile pilocytic astrocytomas grow from cells that make up brain tissue. Surgery alone is generally the treatment but is sometimes followed by radiation and chemotherapy if complete resection is not achieved.
- **Ganglioglioma and gangliocytomas** are tumors that come from cells or nerves that make up brain tissue. They are not very common and generally are grade 1 but rarely can be malignant. Treatment for low grade is surgery alone. For higher grade or an incomplete resection of a low grade may require radiation.
- **Meningiomas** grow from the lining of the brain and are graded I, II, or III. Grade 1 is the most common type and is generally treated with surgery alone. Grade 2 are less common and are treated with surgery followed by radiation in most cases. Grade 3 are rare and more aggressive therefore treatment is surgery followed by radiation and potentially chemotherapy.
- **Schwannomas** are tumors that come from the nerve cell, most commonly the vestibular nerve. The tumors are benign but can cause brainstem compression affecting hearing and potentially cause other conditions such as hydrocephalus. Treatment is surgery and or radiation therapy.

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- **Subependymomas** grow from the lining of the ventricles. Surgery alone is generally the treatment. These are very low grade tumors.
- **Ependymomas** grow from the lining of the ventricles. Treatment of low grade tumors is surgery alone. Treatment for higher grade will likely involve radiation after surgery.
- **Hemangioblastomas** are tumors that come from blood vessel cells. The most common location is cerebellum. They are generally benign tumors. Treatment is surgery possibly followed by radiation if the entire tumor is not removable.
- **Pineal tumors** come from the pineal gland in the center of the brain. Pineal gland tumors are rare and several different types of tumors can arise from the pineal gland requiring different treatments.
- **Medulloblastomas** are tumors that come from undeveloped cells in the cerebellum. These tumors are malignant but with correct treatment can be cured. These tumors are found in children.
- **Pituitary adenomas** grow from the pituitary gland. Some, but not all, tumors secrete hormones. Treatment is usually surgery. If the tumor cannot be safely removed with surgery, or if the tumor grows back after surgery, radiation may be recommended. Other doctors who are experts with hormones will also be part of your care.
- **Craniopharyngiomas** come from pituitary gland embryonic tissue. They are benign tumors. These tumors are more common in children but also affect adults. Treatment is surgery. Radiation is used sometimes if the entire tumor is not removed.
- **Primary central nervous system lymphoma** grows from lymphocytes (a type of white blood cell) in the brain. These are typically treated with chemotherapy and possibly radiation therapy.

Metastatic Tumors

- Metastatic tumors to the brain are tumors (cancers) that have spread from another part of the body. Metastatic tumors are the most common brain tumor. The most common cancers that spread to the brain are lung, breast, renal, melanoma, and colon cancer. These tumors are usually treated with surgery that is sometimes followed by radiation such as Gamma Knife or CyberKnife.
- In the case of a new cancer diagnosis, chemotherapy is prescribed to treat the primary tumor site. In the case of a known cancer diagnosis, it is important to follow up with your Oncologist after surgery.

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Brain Tumor Treatment

Treatment for a brain tumor depends on the type, size, and location of the tumor. Your age and overall health will also be considered in developing your personal treatment plan. Because a treatment plan is heavily determined by the specific tumor type, surgery is commonly recommended as the first line of treatment so that a tumor type (diagnosis) can be confirmed.

Imaging

MRI: stands for magnetic resonance imaging (MRI). Safe and painless test that uses a magnetic field to produce detailed images of the brain or spinal cord. No radiation is used. Most brain tumor patients have regular MRIs ordered by the surgeon or oncology team. The schedule of how often patients need a scan depends on the type of tumor and physician discretion. MRIs are generally safe and painless. The machine is somewhat enclosed which can be a challenge if people are claustrophobic. Light or heavy sedation can be arranged in those cases.

CT scan: Computed axial tomography scan (CAT scan). A painless test that uses X rays (radiation) to produce the images. CT is more open machine to be in and generally claustrophobia is not an issue. CT is generally safe but does use radiation therefore frequent exposure is monitored by your treating team.

X-rays are basic imaging test that show bone or implanted devices such as shunts. Tissue is not well evaluated by x-ray. X-rays are painless and generally safe but again radiation is used and very frequent exposure is monitored by your treating team.

Surgery

If the brain tumor is located in an area that can be safely reached in an operation, your neurosurgeon will work to remove as much of your brain tumor as possible. In some cases, tumors are small and easy to remove from nearby brain tissue, which makes complete removal possible. In other cases, tumors cannot be removed from the nearby tissue, or are next to sensitive areas in your brain, making surgery risky. In these cases your neurosurgeon may try to remove as much of the tumor as can be done safely. Even removing a part of the brain tumor may help reduce its symptoms. In some cases only a small piece (biopsy) is taken to confirm the diagnosis.

Surgery to remove brain tumors has risks, such as infection, bleeding and stroke. Other risks depend on the tumor location in the brain. For example, surgery on a tumor near the part of the brain that controls movement (motor cortex) may cause weakness on one side of the body after surgery. Specific risks will be discussed prior to surgery during the consent process.

Commonly Performed Types of Surgeries at BNI

Craniotomy (Asleep and an Awake Craniotomy)

Crani means bone, -otomy means temporarily removing and putting back. A craniotomy is a surgery that involves the removal of a piece bone for a procedure and the returning of that bone at the end of the surgery. Tumor surgery is an example of a surgery that often requires a craniotomy. The patient is put to sleep and then positioned on an operating table with their head fixed in a head rest. The skin where the incision will take place is washed to be sterile. An incision is then made on the skin usually over the location of the tumor. After the skin is spread apart, the surgeon drills an opening in the skull (this is the craniotomy). The bone is removed and kept sterile until the end of the surgery. The surgeon

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then performs the specific procedures on the brain. At the end, the bone is placed back and anchored with tiny screws and metal plates (the metal is not magnetic, cannot be felt through the skin, and does not set off metal detectors). The skin is closed and the surgery is completed.

Awake Craniotomy

If a tumor is located near the area of the brain that controls motor movement or language function, the surgeon may recommend an awake craniotomy. The craniotomy portion (the temporary removal and returning of bone) is the same as described in the craniotomy portion. The surgery starts with the standard steps of a skin incision, drilling of the bone, and the temporary removal of the bone. Once the brain is exposed, we wake the patient up (the "awake" portion of the case). Once awake, the patient will be asked follow commands by repeating words, naming objects, or moving parts of their body. Once we establish the patient can follow commands, we will ask the patient to repeat these tasks while the surgeon stimulates parts of their brain. If the patient is able to follow commands while a specific area of brain is stimulated, the surgeon knows that area of brain is safe to remove. If the patient is unable to follow commands when a specific area of brain is stimulated, the surgeon knows that area of brain is critical for function and will not remove it. Once language and motor function has been mapped out on the brain, the tumor is removed. After tumor removal, the bone is returned into placed and anchored with tiny screws and metal plates (the metal is not magnetic, cannot be felt through the skin, and does not set off metal detectors). The skin is closed and the surgery is completed.

Asleep Craniotomy

If a tumor is located near the area of the brain that controls motor movement, the surgeon may recommend an asleep craniotomy. The craniotomy portion (the temporary removal and returning of bone) is the same as described in the craniotomy portion. The surgery starts with the standard steps of a skin incision, drilling of the bone, and the temporary removal of the bone. Once the brain is exposed, we stimulate areas of the brain while watching the patient's body for any movement in the face, arms, or legs. If the stimulation of a specific area in the brain results in movement, the surgeon knows that area of brain is critical for movement and will not remove that area. If the stimulation of a specific area in the brain does not result in movement, the surgeon knows that area of brain is safe to be removed. Once the motor function has been mapped out on the brain, the tumor is removed. After tumor removal, the bone is returned into placed and anchored with tiny screws and metal plates (the metal is not magnetic, cannot be felt through the skin, and does not set off metal detectors). The skin is closed and the surgery is completed.

Shunt Placement (VP, LP, VA)

Hydro means water and cephalus means head. Hydrocephalus is a term that refers to too much water in the brain. The water, also known as cerebral spinal fluid (CSF), is stored in a small space in the brain's center called the ventricles. One common treatment for hydrocephalus is a shunt. The shunt is a thin (thinner than a pencil), flexible tubing with holes at the two ends. This tubing provides an alternative route for water to pass through and drain from the brain to another location in the body.

VP Shunt

A ventriculoperitoneal (VP) shunt travels from the ventricles (center of the brain) to the peritoneal cavity (abdomen). Specifically, it travels from the ventricles in the center of the brain to the surface of the skull bone, then behind the ear, down the neck, down the chest, into the abdomen (all under the skin). The water that passes into the abdomen is little enough that the body is able to absorb it no problem.

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VA Shunt

A ventriculoatrial (VA) shunt travels from the ventricles (center of the brain) to the blood vessel next to the heart. Specifically, it travels from the ventricles in the center of the brain to the surface of the skull bone, then behind the ear, down the neck, into the vein next to the heart (all under the skin). The water that passes into the heart is little enough that it mixes in with the blood with no negative effects.

LP Shunt

A lumboperitoneal (LP) shunt travels from the spinal canal to the peritoneal cavity (abdomen). Specifically, it travels from the space around your nerves in your spine (which is surrounded by CSF), around the flank (the side of your body below your ribs), to the abdomen (all under your skin). The water that passes into the abdomen is little enough that the body is able to absorb it no problem.

Subdural Peritoneal Shunt

This surgical procedure involves placing a drain into the subdural space (space situated above the brain and under the skull) and redirected to the peritoneal space in the abdomen where it can be absorbed. These shunts are placed in the subdural space to address abnormal fluid buildup such as cerebral spinal fluid or blood. The shunt has a valve that is connected to the drain tubing that can be adjusted to drain more or less using a magnet. The shunt tubing is tunneled under the skin and is not visible to the eye.

Stereotactic Biopsy

In cases where there is a lesion in the brain or spine with an unclear diagnosis, the surgeon may recommend a biopsy. A biopsy is taking a small piece of tissue to send to the lab for testing. This testing, which involves microscopic examination, staining with different dyes, and molecular sequencing, will help determine a diagnosis. The steps of the biopsy procedure are explained next. The patient is put to sleep and then positioned on an operating table with their head fixed in a head rest. Once positioned, the surgeon will use a stereotactic navigation probe on the surface of your skin to find the lesion. This navigation probe (shaped like a pencil) is like GPS for your brain. By moving the probe on your skin surface, the surgeon is able to see on a screen the brain under the probe's tip. Once the ideal path is confirmed with the navigation probe, a mark is made on your skin. The skin where the incision will take place is washed to be sterile (little to no hair is shaved at the incision site). An incision is then made on the skin about half the width of a fingernail. After the skin cut, a thin drill (thinner than a pencil) is used to put a hole in the bone. Then through this hole, a long needle is passed to the center of the lesion. The needle tip grabs a few pieces of the lesion which will be sent to the lab for testing. The needle is then removed and one stitch with absorbable suture is used to close the skin.

LITT (Laser Interstitial Thermal Therapy)

This is a surgical procedure that uses a laser to destroy unhealthy brain tissue including brain tumors, and radiation necrosis that are deep in the brain. The procedure is performed by your surgeon and involves implanting a laser catheter into the unhealthy tissue and heating it to a temperature high enough to kill the unhealthy tissue. Most patients will go home the following day after the procedure.

Gleolan

Gleolan is known as a imaging agent. Patients drink the medicine two to four hours before surgery and the gleolan helps the neurosurgeon see certain brain tumors, known as high grade gliomas during surgery. Your neurosurgeon may ask you to take this medication prior to surgery. Side effects are increase risk of sun sensitivity or sun burn with sun exposure. Please avoid direct sunlight for five days after surgery.

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Radiation

Radiation therapy uses x-rays and other sources to kill tumor cells. Radiation therapy is delivered by a machine called a linear accelerator (external beam radiation), or, in very rare cases, by implanted "seeds" that release radiation after being placed inside your body close to the brain tumor (brachytherapy).

External beam radiation is given from outside the body and aims only at the area of your brain that contains the tumor. It can include your whole brain or just part of it, depending on the tumor type. Sometimes radiation is used after surgery to kill tumor cells that might have been left behind.

Radiation therapy is planned on an individual basis, depending on the tumor type.

Side effects of radiation therapy depend on the type and dose. In general, side effects are fatigue, patchy hair loss, and scalp redness and itching.

Radiation therapy is usually an outpatient procedure, so you can go home the same day.

Radiosurgery (Gamma Knife, Cyberknife and Zap)

Radiosurgery is not a traditional form of surgery. Instead, it uses multiple beams of radiation to deliver a highly focused form of radiation treatment to kill the tumor cells in a small area. Each beam of radiation is not particularly powerful alone, but where all the beams meet—the brain tumor—a very large dose is delivered, killing the tumor cells.

Radiosurgery is usually an outpatient procedure, as it is not invasive and requires no incision. Side effects may include fatigue, headache, and nausea. Steroids may be prescribed for a short time to help with these side effects. Patients usually go home the same day but may be admitted to the hospital for closer observation if necessary.

BNI offers three forms of stereotactic radiosurgery, Gamma Knife, CyberKnife and Zap. Each form is usually referred to by its specific name.

Chemotherapy

Depending on your tumor type, chemotherapy may be recommended as part of your treatment plan. Chemotherapy is medicine that kills tumor cells.

For patients with a newly diagnosed glioblastoma (GBM) standard therapy (treatment) starts two to four weeks after surgery for tumor biopsy or resection. Treatment is given over six weeks, and is a combination of daily oral chemotherapy pills (temozolomide) with radiation treatments. This is followed by 12 monthly cycles of temozolomide. A shortened course of three to four weeks of treatment is considered in some instances for older patients and is at the discretion of your treating doctors.

Temozolomide is a chemotherapy pill, which is taken at home for 42 days, starting the night before or the same day as your brain radiation. Radiation treatments are given daily Monday through Friday at the Radiation Oncology Department, except for holidays. However, temozolomide is taken continuously for 42 days, even on weekends and holidays. Typically, standard radiation therapy is given in 30 fractions (30 days) of treatment over a period of six weeks. Weekly blood tests are done during this time to be sure that you are safely tolerating the treatment. A follow-up MRI brain scan is done three weeks after completion of your radiation and chemotherapy. This scan is used to monitor your tumor

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for any growth or changes, since the start of radiation therapy. Ideally, the MRI is done the same day as a follow-up appointment with your neuro-oncologist. At this follow-up visit, the plan for monthly chemotherapy will be discussed. Temozolomide is taken for 12 cycles for 5 days once every 28 days (12 monthly cycles). The dose of the temozolomide increases during these cycles. Blood tests are done once or twice monthly at this time.

Possible Side Effects of Temozolomide
Fatigue, nausea, constipation or diarrhea, rash, decreased appetite, changes to your blood tests (low platelets or low white blood cells). If blood cells are reduced, your chemotherapy dose may be decreased or your next cycle delayed to allow further recovery of your blood counts.

To prevent nausea, ondansetron or similar medicine will be prescribed and is to be taken 30 to 60 minutes prior to each dose of chemotherapy and can be taken again eight to 12 hours later if you have nausea. If you have nausea or vomiting, please contact your neuro-oncologist, as a new medication can be ordered to help with your nausea.

To prevent constipation related to your chemotherapy, you will be instructed to take polyethylene glycol (MiraLAX) daily on days when you are taking your chemotherapy. You should contact your neuro-oncologist if you are unable to have a bowel movement for more than three days or if you develop abdominal discomfort or diarrhea. Additional medications can be ordered, if needed.

Similar treatment has been routinely applied to patients with anaplastic astrocytoma (AA) and is often used for low grade gliomas (grade II) following surgery or if the tumor progresses.

For more information on Temozolomide, visit the ABTA website at ABTA.org or ChemoCare.com

Most chemotherapy medicine are cytotoxic medicine and work by destroying tumor cells. These chemotherapies disrupt the tumor cells ability to reproduce themselves to slow or stop tumor growth. Examples of cytotoxic medicine include: Carmustine (BCNU), Lomustine (Gleostine) (CCNU), Gliadel wafer (BCNU discs that can be placed in the tumor cavity at the time of surgery), Temozolomide (Temodar), Cisplatin, Carboplatin, Etoposide and Irinotecan. They may be given as a single agent (alone) or in combination.

Of note, BCNU/CCNU, Gliadel wafer and Temodar have been approved by the Food and Drug Administration (FDA) for the treatment of high-grade brain tumors. The others listed have been approved for treatment of other cancers, and thus must be prescribed “off-label” for brain tumor use.

Tumor Treating Fields (Optune)

Tumor Treating Fields (TTFields) are low intensity, alternating electrical fields that interfere with cancer cell division which slows or stops cancer cells from dividing and may destroy them. Optune® is the name of the device that delivers TTFields.

Optune is a wearable and portable device that can be incorporated into daily life. Optune is FDA-approved for adults with glioblastoma multiforme (GBM). Optune is prescribed by certified physicians as part of a treatment plan for the appropriate GBM patients. For newly diagnosed GBM, Optune is used together with the chemotherapy Temozolomide (TMZ) after surgery and radiation with TMZ. For recurrent GBM patients, Optune can be used alone once treatment options like surgery and radiation have been exhausted.

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How does it work?
When the device is turned on, it creates low-intensity, wave-like electric fields called Tumor Treating Fields (TTFields). These TTFields are delivered by transducer arrays to the location of the GBM tumor. TTFields interfere with GBM cancer cell division. This action slows or stops GBM cancer cells from dividing and may destroy them.

In clinical trials, Optune has not been proven to cure GBM. However, in a large clinical trial of patients with newly diagnosed GBM, using Optune with chemotherapy was proven to extend survival and maintain quality of life compared to TMZ alone. Approximately half of the patients who used Optune with TMZ were alive at two years compared to 31% who were on TMZ alone. Adding Optune to the chemotherapy temozolomide (TMZ) more than doubled survival for newly diagnosed GBM patients at five years compared to TMZ alone (13% vs 5%).

Side Effects
When Optune is used with TMZ side effects can be: low blood platelet count, nausea, vomiting, constipation, fatigue, scalp irritation, convulsions, and depression. When using Optune alone side effects include scalp irritation and headache from device use. For more information discuss this device with your healthcare professional or visit the website Optune.com.

Targeted Drug Therapy

Targeted drug treatments focus on certain defects within tumor cells. By blocking these defects, targeted drug treatments can cause tumor cells to die. Many targeted therapies are still being studied in clinical trials.

One targeted drug therapy used at BNI to treat brain tumors is called bevacizumab (Avastin). This drug is injected into the vein about every 14 days and may be ordered by your neuro-oncologist. It is given with chemo or alone as a part of your treatment.

Brain Metastasis Treatment

Brain Metastasis Clinic, Neuro Oncology Program, Barrow Neurological Institute

Brain metastases are the most common type of intracranial tumor. In the United States, an estimated 98,000 to 170,000 cases occur each year. The incidence of brain metastases is increasing likely as a result of several factors. Patients with a systemic metastatic disease have a longer survival with new systemic therapies (including immunotherapy) that have recently seen more widespread use. Furthermore, the growing use of sensitive MRI techniques has contributed to better detection of small asymptomatic brain metastases. This provides new and challenging approaches for treatment and management of these group of patients and it requires appropriate management strategies from multidisciplinary teams.

Traditionally, brain metastases were treated and managed by the primary Oncologist who treated the patient's original cancer. For example, a breast cancer oncologist would provide medical treatment for the breast cancer patient who developed brain metastasis. Historically, this approach presented challenges, as brain disease shows different Molecular profiling and management has many challenges that are critical to the understanding of optimal treatment.

Patients with brain metastasis have unique and complex needs that require input from several aspects including treatment for the primary disease and also focused treatment for brain disease and neurologic complications of CNS involvement. We view the development of the Brain Metastasis Clinic

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as a model for coordinated care within the BNI Neuro-Oncology Division that will improve the standard of care for patients with challenging and complex disease.

Our goals in creating Brain Metastasis Program is to improve the care of patients with secondary brain tumors using a multidisciplinary approach with Neurosurgical and radiation therapy evaluation and systemic treatment including immunotherapy and other novel treatments.

Tumor Molecular Profiling

Molecular profiling is a way to test tumor cells to look for mutations (changes) in the tumor's genetic makeup. These changes may help tailor treatment with chemo, targeted treatment, or clinical trial options. This is a promising area of brain tumor research to identify targets to treat in a tumor. Your oncology team and neurosurgeon can talk with you about the details of the testing when you are in their office.

Ketogenic Diet

Advances in science about understanding of glioma biology has led to an increase in targeted therapy in clinical trials. Scientist have found virtually all tumor cells have altered metabolism. It is thought that tumor cells have an increased reliance on glucose, suggesting that treatments affecting cellular metabolism may be effective way to improve current brain tumor treatments. The ketogenic diet has been shown in animal models to help anti tumor effects of chemo and radiation treatments. Some patients with gliomas have chosen to follow the ketogenic diet. The Barrow has no published clinical trial information the diet helps the anti tumor effect of chemo and radiation but our treatment doctors do feel it is safe and an option for add on therapy if patients wish to do so.

The ketogenic diet is high fat, moderate protein and low carbohydrate (glucose) diet. Scientists hypothesize the decrease in carbohydrates (glucose) causes ketosis in the body which is the metabolic environment that may have an antitumor effect. If you are interested in the ketogenic diet there are dieticians in the hospital that are able to give education in the hospital only and once you go home there are some useful websites. Please also discuss your interest with your treating oncology team and they can help you.

Resources:

Mathews Friends: matthewsfriends.org

Ketodiet blog: ketodietapp.com/blog

Charlie Foundation: charliefoundation.org

KetoResource: ketoresource.org

Ruled.me: ruled.me

MyKeto: Low carb counter mobile app

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Barrow Brain Tumor Research

Doctors, scientists, nurses, and coordinators at the Ivy Brain Tumor Center carry out research studies in special research labs and also in clinical trials involving patients. Research studies help us to better understand how brain tumors grow and behave with certain treatments. Clinical trials help us to discover better ways to diagnose and treat patients with brain tumors. The main goal is to find a cure for brain tumors. We may offer you participation in a clinical trial as part of your treatment.

Standard Treatment versus Clinical Trials

Standard treatment is the best agreed upon treatment at the time of your surgery. Standard treatment changes over time as doctors learn from research, and the type of standard treatment depends on the kind of tumor you have.

Clinical trials test new drugs, equipment, and treatments that the US Food and Drug Administration (FDA) has not yet approved, and new surgery techniques. Clinical trials also may test a new drug with standard treatment that is already FDA approved. We may offer a clinical trial to people who have new tumors as well as to those whose tumor has returned. For the most up-to-date information on clinical trials being conducted around the country, please visit ClinicalTrials.gov.

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The Ivy Brain Tumor Center at Barrow Neurological Institute – Clinical Trials

Barrow Neurological Institute is home to the Ivy Brain Tumor Center, the largest Phase 0 clinical trials program in the world and the first of its kind in neuro-oncology. This precision medicine program reflects our commitment to always push the envelope for brain tumor patients around the world. At the Ivy Center, we understand that time is the most important commodity for our patients. Therefore, Ivy Phase 0 clinical trials match patients to first-in-class drug combinations, confirm drug effects within days of exposure and only treat patients when therapies are active in their tumor.

SAVES VALUABLE TIME | PERSONALIZES THE TREATMENT | TESTS NEW DRUGS

How an Ivy Phase 0 Clinical Trial Works

Once enrolled in this study, the patient will receive a very small exposure to the investigational drug combination days before a planned operation to remove their brain tumor.

This exposure is enough that when we remove the tumor, our team of experts can ask two important questions:

1. **Did the treatment penetrate the tumor?**
2. **Did the treatment have its intended effect?**

If the answer to both questions is yes, the patient will move forward with receiving a full dose of the treatment – advancing to a Phase 2 clinical trial.

Alternatively, if the treatment has no effect on the tumor, the patient can enroll in another clinical trial without losing time or receiving an ineffective treatment.

For brain tumor patients facing the fight of their lives, no stone should be left unturned. Our team treats more brain tumor patients than any other hospital in the nation and the Ivy Center's portfolio of early-phase clinical trials serves as a resource for the world's brain tumor community.

Free trial screenings are available upon request. If a patient is determined to be eligible, the Ivy Center covers all costs associated with study participation outside of the standard of care.

To learn more and view all open Phase 0 clinical trials, please visit **IvyBrainTumorCenter.org** or contact an Ivy Navigator at **(602) 406-8605**.

Ivy Brain Tumor Center
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Community Support and Resources

Arizona Brain Tumor Support Groups

Many people find that talking with others in a similar situation can help with the stress. It can also provide useful insight and refreshing perspectives.

Barrow Brain Tumor Support Group
Our Brain Tumor Support Group provides a supportive setting for open discussion. Each group is led by a peer facilitator (a survivor or a family caregiver) who understands the challenges you may be facing. Some meetings feature a guest speaker.

Meets the 4th Tuesday each month (6:00-7:30 p.m.)
(Does not meet during May, November, or December)
Sonntag Pavilion at Barrow Neurological Institute
2910 N. 3rd Ave, Phoenix, AZ 85013
Contact: Lanette Veres at (623) 205-6446 or email GrayMattersFoundation@gmail.com for first time attendees or if you have any questions.

Brain Tumor Patient and Caregiver Education
The Ivy Brain Tumor Center and Barrow Neurological Institute created the Brain Tumor Patient & Caregiver Symposium to provide patients and their families with educational information to help them navigate a brain tumor diagnosis.

Each symposium video covers a practical topic, such as latest treatments, coping mechanisms and symptom management.

Follow the Ivy Brain Tumor Center on Instagram and Facebook for general updates and community activities.

Barrow Pituitary Center Support
Cushing's Support Group
Meets on the 3rd Wednesday of each month from 4-5 p.m. (AZ time) via zoom.

Acromegaly Support Group
Meets on the 4th Wednesday of each month from 4-5 p.m. (AZ time) via zoom.

The registration link for the zoom meeting is available on the BarrowNeuro.org/Pituitary website for both suppport groups.

Questions? Contact: Terry Maxwell, BSN, RN
Office: (602) 406-5954
E-mail: Terry.Maxwell@CommonSpirit.org
BarrowNeuro.org/Pituitary

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Cancer Support Community Arizona
The cancer support community provides a range of support programs at no cost for people and loved ones. Visit the website CSCAZ.org to register for a free virtual program.

360 East Palm Lane
Phoenix, AZ 85004
Phone: (602) 712-1006
CSCAZ.org

Barrow Connection Outreach Program
Barrow Connection is committed to enriching the lives of children and adults with neurological disabilities by facilitating: health, sports, education, resources, wellness, recreation and conferences.

BarrowNeuro.org/Connection
(602) 406-6280

Individual Support

Editha House
Provides lodging for adult cancer patients from out of state or outside the Phoenix area while they receive treatment in Phoenix. Patients and caregivers alike find comfort and support in one another.

336 East Willetta Street
Phoenix, AZ 85004
Phone: (602) 388-4920
Website: EdithaHouse.org
Email: Info@EdithaHouse.org

Arizona Palliative Home Care
Home health services for adult patients who are mainly homebound.
Program benefits include:

- Coordination of care
- Rehabilitation therapy and services
- Education and family caregiver support
- Community resource referrals
- Support from a nurse 24/7 by phone

1510 E. Flower Street
Phoenix, AZ 85014
Phone: (602) 212-3000

Gray Matters Foundation
The Gray Matters Foundation is dedicated to love, kindness, and the celebration of life. This foundation supports each patient as an individual.

GrayMattersFoundation.org/Contact
Contact: Lanette Veres (623) 205-6446 or GrayMattersFoundation@gmail.com

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Brain Tumor Organizations

American Brain Tumor Association
This nonprofit association is dedicated to support, research, and education of patients and caregivers across the U.S. Educational material is available for free on their website.

ABTA.org
Care Line: 1-800-886-2282

National Brain Tumor Society
National Brain Tumor Society is the largest, most influential nonprofit that is fiercely committed to finding better treatments and driving rapid progress toward a cure for brain tumors. They drive a multifaceted approach to aggressively influence and fund strategic and collaborative research, and advocate for public policies in order to achieve the greatest impact, results and progress. Education material can be downloaded from their website free of charge.

BrainTumor.org

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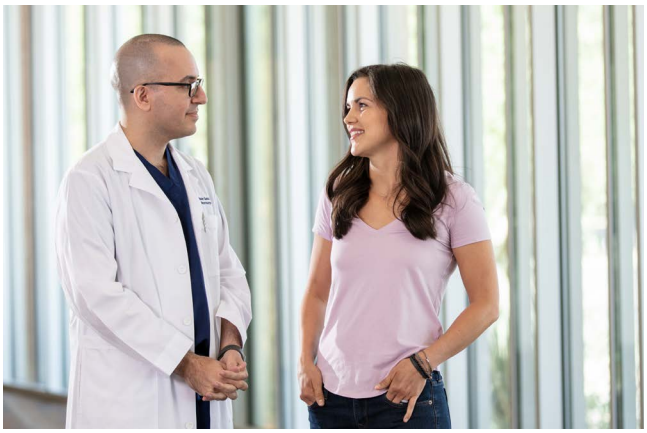
Supporting the Work of the Barrow Brain Tumor Research Center

Why Giving Matters



Support from individuals and families allows the Ivy Brain Tumor Center to fund programs and services that advance research, improve treatments and ultimately work to find a cure for brain tumors. Additionally, gifts also provide patient education and enhanced patient care. As a donor, you will join a unique and incredible community of people who not only vary in age but in nationality and economic background. Some donors are former patients of Barrow Neurological Institute, some may have had a friend or family member who received exceptional care, and some are simply people that want the very best for their community. While unique in their own ways, every donor shares a common and commendable trait of generosity that allows Barrow to stay at the leading edge of neuroscience.

Ways to Give

There are many ways that a person can become a Barrow supporter. Making a donation of any amount is a valuable way to assist in funding research and innovation. Another option is to honor someone by making a tribute gift in celebration of an event, such as a birth, anniversary, or another occasion. Planned giving is another alternative, and involves someone committing to donate a predetermined gift amount upon his or her passing. Lastly, hosting fundraisers is a great way to not only raise money for research and medical care but also to create awareness of current needs and issues that require attention in order to continue advancements in progress.

How to Help

For information on how you can become a supporter of the Ivy Brain Tumor Center, please contact the Barrow Neurological Foundation by calling (602) 406-1018. You may also visit SupportBarrow.org to make a gift online.

Molly Mychaels
Manager of Philanthropy
Barrow Neurological Foundation
Dignity Health | St. Joseph's Hospital and Medical Center
2910 North 3rd Avenue, Suite 450
Phoenix, AZ 85013

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Checklist

1. Make an appointment with your Primary Care Physician.

   ❏ Completed

2. Make an appointment with your Neurosurgeon.

   ❏ Completed

3. Make an appointment with the Radiation Oncologist.

   ❏ Completed

4. Make an appointment with the Neuro Oncologist.

   ❏ Completed

5. Make an appointment with your Ophthalmologist if recommended by your Doctor.

   ❏ Completed

6. Find an outpatient rehab facility for Physical Therapy, Occupational Therapy, and/or Speech Therapy if needed.

   ❏ Completed

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My Diagnosis

Tumor type: _____

Grade: _____

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Possible Side Effects of My Treatment

1. _____

2. _____

3. _____

4. _____

5. _____

6. _____

My Follow-up Visit

Doctor's Name	Specialty	Date

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Questions for My Appointment

1. _____

2. _____

3. _____

4. _____

5. _____

6. _____

7. _____

8. _____

9. _____

10. _____

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My Medications

Name of Drug	Dose	When to Take	Start Date	Ordering Provider

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Notes

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Ivy Brain Tumor Center

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Discovering Tomorrow's Treatments Today

The Ivy Brain Tumor Center, led by Dr. Nader Sanai, was founded with a singular goal: to discover new treatments for glioblastoma and other incurable brain tumors. Patients enrolled in Ivy Center trials gain access to new therapies unavailable anywhere else in the world. It's a faster, smarter path to lifesaving breakthroughs, fueled by philanthropy and designed to change the future of brain cancer.

IvyBrainTumorCenter.org

Barrow Neurological Institute | *Minding What Matters Most®*