

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

Table of Contents

Intro Letter	ii
Introduction	1
Meet Our Team	2
My Barrow Treatment Team	4
Finding Your Barrow Treatment Clinics	5
At Home After Surgery	6
Medicines	7
Symptoms and Conditions Associated with Brain Tumors	9
Symptoms Based on Brain Tumor Location	13
The Barrow Tumor Board	15
Tumor Diagnosis	16
Brain Tumor Overview	17
Brain Tumor Treatment	19
Barrow Brain Tumor Research	22
The Ivy Brain Tumor Center at Barrow Neurological Institute	23
Community Support and Resources	24
More Information on “Frankly Speaking About Cancer: Brain Tumors”	27
Supporting the Work of the Barrow Brain Tumor Research Center	28
Checklist	29
My Diagnosis / Treatments	30
Possible Side Effects / My Follow-up Visit	31
Questions for My Appointment	32
My Medications	33
Notes	34
Frankly Speaking About Cancer: Brain Tumors	37



Nader Sanai, MD
*Director, Division of
Neurosurgical Oncology*
*Director, Ivy Brain Tumor
Center*
*Barrow Neurological Institute
Phoenix, Arizona*
Office: (602) 406-3770
Nader.Sanai@bnaneuro.net

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 www.ivybraintumorcenter.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,

A handwritten signature in black ink, appearing to read "Nader Sanai".

Nader Sanai, MD

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.

Medical Oncologist: A doctor with special training who treats cancers and tumors from other places in the body (such as the lung or breast). Medical oncologists also care for people with primary brain tumors if a neuro-oncologist is not available. If you are diagnosed with a metastatic brain tumor, you will be treated by a medical oncologist.

Nurse Practitioners (NPs): The NPs at Barrow have special training in the neuroscience field. Their role is to work with doctors and serve as the main contact person on your care team while you are in the hospital. An NP works closely with your neurosurgeon to direct your plan of care and teach you about your disease.

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.

Brain Tumor Team

Division of Neurosurgery Oncology



Nader Sanai, MD
Director of
Neurosurgery Oncology



Mark Garrett, MD



Michael T. Lawton, MD



Andrew Little, MD



Peter Nakaji, MD



Randall W. Porter, MD



Kris Smith, MD



Robert F. Spetzler, MD



John E. Wanebo, MD



Kaith Almefty, MD



F. David Barranco, MD



Steve Chang, MD



David Fusco, MD

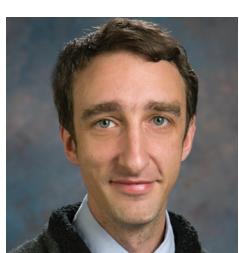
Division of Neuro-Oncology



Surasak Phuphanich MD
Director of Neuro Oncology



Kelly Braun, MD



Christopher Dardis, MD

Division of Neuro-Radiation Oncology



Igor Barani, MD
Director of Neuro-Radiation
Oncology



Charles Leland Rogers MD



Emad Youssef, MD

Division of Neuropathology



Jennifer Eschbacher, MD
Director of Neuropathology



Michelle Felicella, MD

Division of Neuropsychology



Leslie Baxter, PhD

Division of Neurosurgery Oncology Nurse Practitioners



Estelle Doris FNP-C, CNRN



Jasmin Stefani FNP-C,
CNRN

Nurse Navigator



Jaclyn Garcia, RN, CNRN

Division of Neuro-Oncology Nursing Research



Lindsay Higgenbotham, RN,
BSN, CNRN



Norrissa Honea, PhD, RN,
CNRN

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: _____

Finding Your Barrow Treatment Team Clinics

Your neurosurgeon has a clinic within St. Joseph's Hospital and Medical Center 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.

Barrow Neuro Oncology and Stroke Center

240 West Thomas Road, Suite 403

Phoenix, Arizona 85013

Office number: (602) 406-6262

<https://www.barrownuro.org/>

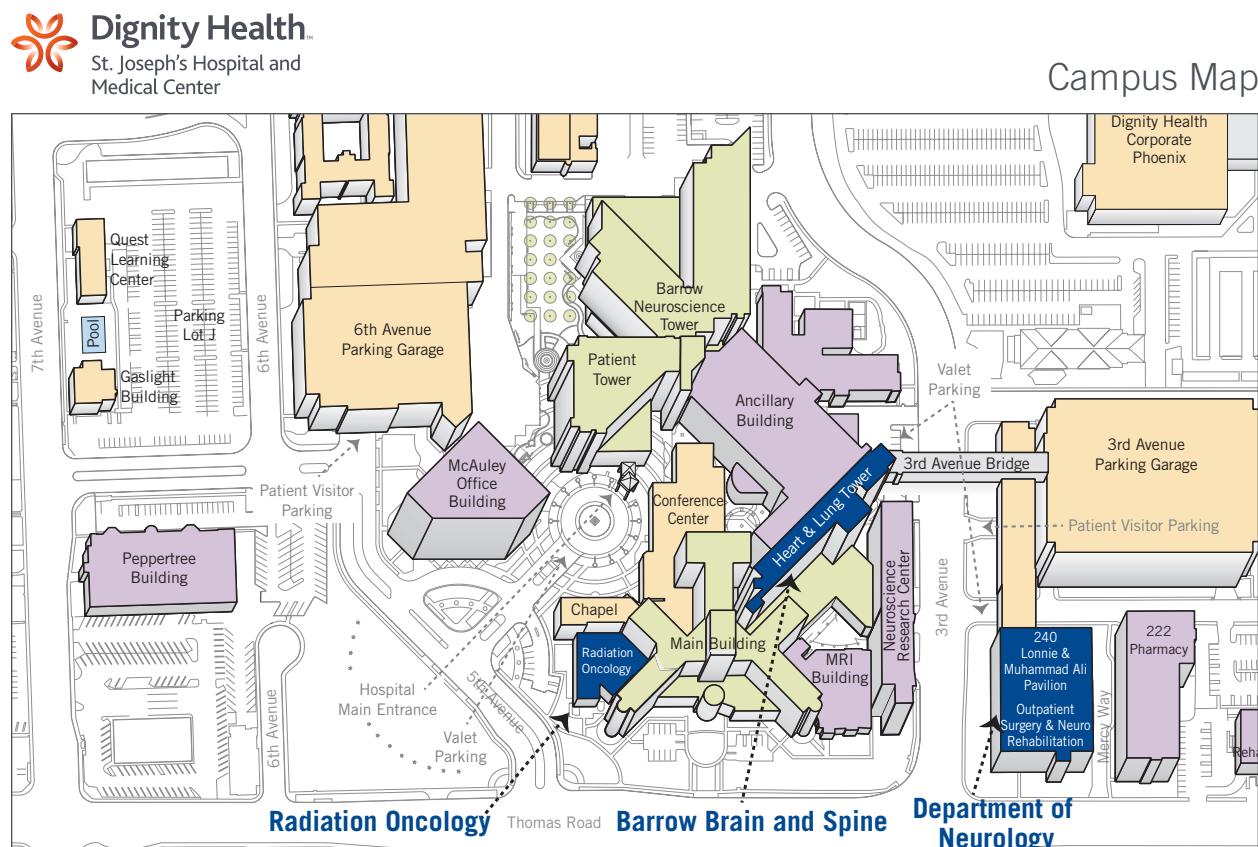
If you had a visit in the hospital with a radiation oncologist, you will have follow up at the clinic located within St. Joseph's Hospital and Medical Center.

Radiation Oncology & CyberKnife Department

350 West Thomas Road

Phoenix, Arizona 85013

Office number: (602) 406-6761



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 7 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 to the area every 30 minutes, as needed.

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 4 to 6 weeks after surgery.

Activity

It is important to get out of bed and move about as soon as possible after surgery to avoid the risk of problems such as blood clots or pneumonia. If you feel unsteady on your feet, use help to walk. Get plenty of rest. Avoid any exhausting activity for 4 weeks. Walking for exercise is okay.

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 1 to 2 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 6 to 8 weeks for bone to heal.

Do not try to lift, push, or pull more than 10 pounds for 4 weeks after surgery.



Nutrition

Eat plenty of fruits and vegetables to prevent constipation. Drink 6 to 8 cups of water each day, which will also help prevent constipation.

Medicines

Pain Control

You will receive a prescription (Rx) of pills for pain when you go home from the hospital. Here are some facts you need to know about pain pills:

- Pain pills are strong medicine and you need a prescription (Rx) by a doctor or NP to obtain strong medicines.
- Some pain pills also have acetaminophen (Tylenol) mixed in them.



oxycodone/acetaminophen (Percocet, Endocet)

hydrocodone/acetaminophen (Vicodin, Norco)

**DO NOT TAKE EXTRA
acetaminophen with these 2 types
of pain pills. (Tylenol®)**

oxycodone

hydrocodone

hydromorphone (Dilaudid)

codeine

tramadol

You can also take 650 mg of acetaminophen (Tylenol®) every 4 to 6 hours, if needed, with these 5 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 4 to 6 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 pills.

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 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

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
Myoclonic <ul style="list-style-type: none">Single limb on one side or muscle twitching, jerking, shaking	During Seizure: <ul style="list-style-type: none">Be sure loved one is breathingProtect head from hitting floorDo not try to put anything in persons mouthDo not restrain limbs After Seizure: <ul style="list-style-type: none">After seizure attempt to place person on their sideStay with loved one until you reach physician for directions	<ul style="list-style-type: none">Seizure may not be an emergency if person is not in distress and has a known seizure disorderCall 911 if not breathing or having difficulty breathingCall 911 if seizure last longer than 5 minutes or multiple seizures happenCall 911 if person is not awakeCall your treating neuro oncologist or treating doctor to describe seizure and for directions
Tonic Clonic (Grand Mal) <ul style="list-style-type: none">Loss of consciousness followed by twitching and jerking type rhythmic movementsMay lose control of bladderMay bite tongueAfter affects are sleepiness, confusion, body aches		
Absence seizure <ul style="list-style-type: none">A type of seizure that involves brief and sudden loss of attention, as if the person is staring off into nowhere		

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
<ul style="list-style-type: none">• 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	<ul style="list-style-type: none">• 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	<ul style="list-style-type: none">• 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
<ul style="list-style-type: none">• 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	<ul style="list-style-type: none">• 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	<ul style="list-style-type: none">• 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

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
<ul style="list-style-type: none">• Swelling or pain in the leg or arm	<ul style="list-style-type: none">• 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	<ul style="list-style-type: none">• 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
<ul style="list-style-type: none">• Chest pain• Shortness of breath• Fast heart beat	<ul style="list-style-type: none">• Call 911, Pulmonary embolism is a an emergency	<ul style="list-style-type: none">• Call 911

Nausea and Vomiting

Description	What to do	Who to call
<ul style="list-style-type: none">• 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	<ul style="list-style-type: none">• Take prescribed anti nausea medicine• Eat a bland diet• Do not take opiate pain medicine on an empty stomach	<ul style="list-style-type: none">• Call treating doctor during business hours

Vision Loss or Vision Disturbances

Description	What to do	Who to call
<ul style="list-style-type: none">• Double vision or blind spots	<ul style="list-style-type: none">• Certain compensatory therapies such as occupational therapy is helpful• Alert treating Doctor	<ul style="list-style-type: none">• Call treating Doctor during business hours for discussion

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	<ul style="list-style-type: none">• Depression and anxiety• Irritability. Some medications such as steroids can cause irritability and agitation	<ul style="list-style-type: none">• Discuss symptoms with treating Doctor during business hours• Psychotherapy• Medication therapy• Support groups
Memory and learning difficulties	<ul style="list-style-type: none">• Short term memory difficulties• Difficulty processing information• Difficulty following directions	<ul style="list-style-type: none">• Cognitive therapy• Avoid giving multistep directions
Attention and Concentration	<ul style="list-style-type: none">• Easily distracted• Confusion	<ul style="list-style-type: none">• Cognitive therapy• Medication therapy
Executive Functioning	<ul style="list-style-type: none">• Difficulty with day to day planning such as paying bills or organizing a schedule• Impaired judgement	<ul style="list-style-type: none">• 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
<ul style="list-style-type: none">• Feeling extremely tired after simple activities such as walking or therapies	<ul style="list-style-type: none">• Resting in between periods of activity• Light activity such as walking	<ul style="list-style-type: none">• Discuss symptoms with treating Doctor during business hours• Medication therapy

Symptoms Based on Brain Tumor Location

Frontal Lobe

Weakness, Paralysis on one side of body, Mood disturbances, Difficulty thinking , Confusion , Disorientation , Mood swings

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)

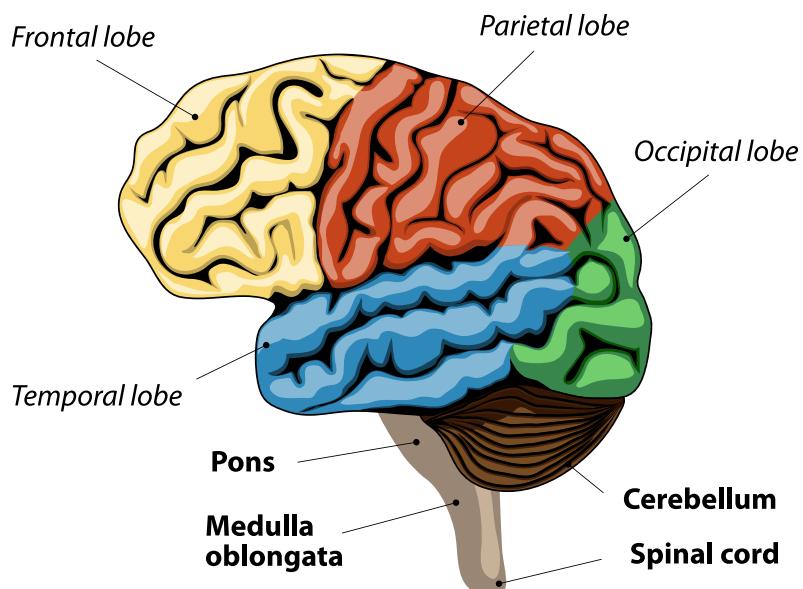
Cerebellum

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

Hypothalamus

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

HUMAN BRAIN





**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 higher than 100 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 3 days that is not helped by over-the-counter pills

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.



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 7 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: _____



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** (grades III and IV) grow from the cells that make up the brain. They are called astrocytoma (“astro”), oligodendrogloma (“oligo”), and glioblastoma (“GBM”), also known as grade IV astrocytoma. GBM is the most common type of adult primary brain tumor. The usual treatment after surgery is radiation and chemotherapy. Treatment in a clinical trial may also be offered.
- **Low-grade gliomas** (grade II) include astrocytomas and oligodendroglomas. 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 are aggressive therefore radiation is recommended.

- **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.
- **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.

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.

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 a brain tumor carries risks, such as infection and bleeding. Other risks may depend on where the tumor is located in the brain. For example, surgery on a tumor near the part of the brain that controls movement may cause weakness after surgery.

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 and CyberKnife)

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 two forms of stereotactic radiosurgery, Gamma Knife and CyberKnife. 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 2 to 4 weeks after surgery for tumor biopsy or resection. Treatment is given over 6 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 3 to 4 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 6 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 3 weeks after completion of your radiation and chemotherapy. This scan is used to monitor your tumor 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 8 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 3 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 www.abta.org or <http://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.

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 2 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.

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.

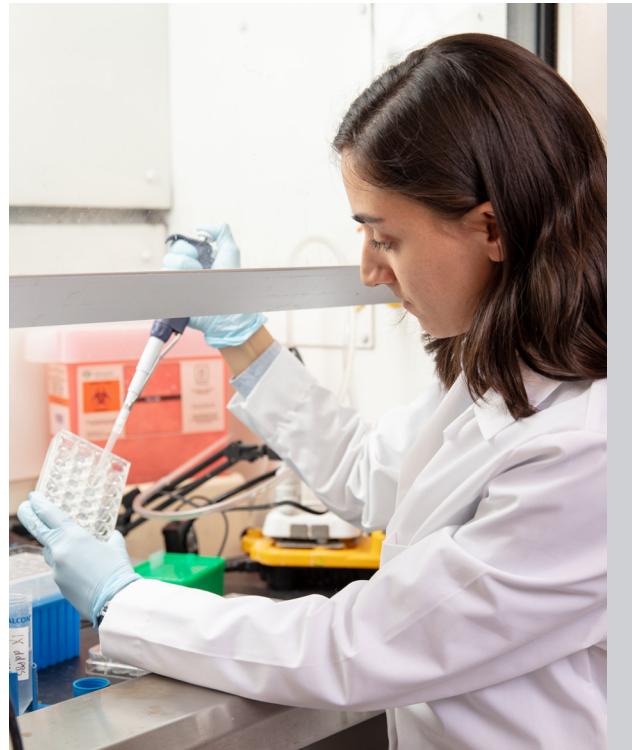
Barrow Brain Tumor Research

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 www.clinicaltrials.gov.



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

The Ivy Brain Tumor Center at Barrow Neurological institute is home to the largest Phase 0 clinical trials program in the world.

The Phase 0 trial's goal is to see if a study drug or drugs; new or already approved for other tumor types, is taken up by your tumor. When you are told you will require surgery to remove a growing tumor, a Phase 0 trial may be offered to you.

The process starts by identifying what study drug may work in your individual tumor. This is done by looking at the tumor from your last surgery and verifying that you have specific tumor genes for the study drug to target. If we find a drug match to your individual tumor, you would take a study drug for a short amount of time before surgery.

After surgery, the Ivy Brain Tumor Center scientists will verify if there was drug in your tumor, cerebral spinal fluid (CSF) and blood. They will also look for a change in your tumor cells. If so, you would be offered a treatment trial phase of the drug, in hopes to stop the tumor from growing back.

The benefits of the Phase 0 trial include:

- Personalized treatment for your unique tumor.
- Because you are given a “micro-dose” of the drug or drugs, there is a lower chance of side effects
- You will have results within a few weeks after surgery. If the Phase 0 study does not have the desired effect, you won't lose time on other 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 hospital in the nation and the Ivy Brain Tumor Center's portfolio of early-phase clinical trials serves as a resource for the world's brain tumor community. Within 36 hours of a Trial Screening Request, our team assesses a patient's suitability for our clinical trials program, as well as provides additional support to the physicians managing these cases. Patients enrolled in our studies are not required to transfer their care to our Center, as our philosophy is to partner with, not replace, their treatment team.

Trial Screening Requests are provided at no cost and, for patients we determine to be eligible for a clinical trial, the Ivy Brain Tumor Center covers all costs associated with study participation.



www.ivybraintumorcenter.org

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.

St. Joseph's Hospital and Medical Center
Main Hospital Building
350 West Thomas Road
Phoenix, AZ 85013
Conference room 1 and 2 on first floor
Meets the 4th Tuesday each month (6:00 PM to 7:30 PM)
(DOES NOT MEET: May, November, December)
Contact: Lanette Veres, group facilitator at (623) 205-6446 or
email at graymattersfoundation@gmail.com



Brain Tumor Survivor/Caregiver Education Day

This is a day dedicated to bringing brain tumor survivors and their caregivers together to learn about the latest treatments, coping mechanisms, and symptoms management after brain tumor diagnosis. Attending these events is also a great way to connect with other survivors and caregivers. Topics vary from each event, which we host twice a year, once in the spring and once in the fall, on the St. Joseph's Hospital and Medical Center campus. If you are interested in learning more about this program, please contact Jaclyn Garcia at 602-406-4429.

Barrow Pituitary Center Support Group

This National support group provides education and support to people affected by pituitary tumors including patients, caregivers and friends. Group members have a chance to meet others with similar issues, discuss problems, ask questions and learn more information about topics related to pituitary tumors. Support group meetings are held throughout the year in addition to a bi annual all day patient education conference. Education materials are available for free on the web site.

Contact: Maggie Bobrowitz, RN, MBA
Office: (602) 406-7585
E-mail: Margaret.bobrowitz@dignityhealth.org
Website: BarrowNeuro.org/pituitary

Southern Arizona Brain Tumor Support Group

This support group is open to people with brain tumors, their family members, and their friends. Group members have the chance to meet others with similar issues to discuss problems, ask questions, and learn new information about topics related to brain tumors.

University Medical Center

University Campus, Room 4978

1515 North Campbell Avenue, Tucson, Arizona

Date: Meets the 2nd Wednesday each month (10:30 AM to 12:00 PM)

Contact: Marsha Drozdoff, LCSW, ACSW at (520) 694-4605 or mash.drozdoff@auhealth.com

Caregivers Support Group at Barrow

This support group provides information, resources, and help for those who care for others with illnesses or disabilities such as stroke, brain or spine injury, or brain tumor.

Outpatient Rehabilitation Building near St. Joseph's Hospital and Medical Center

114 West Thomas Road

Phoenix, AZ 85013

Meets the 2nd Monday each month

Call (602) 406-6688 for more information

Grief Support Group

St. Joseph's hosts a grief support group every other Wednesday in the Mercy Conference Room.

The group is led by a chaplain. Please call (602) 406-3275 for times and dates.

Cancer Support Community Arizona

(Formerly The Wellness Community of Arizona)

The Cancer Support Community provides a full range of support programs at no cost for people with cancer and their loved ones in a comfortable home-like setting. It offers drop-in and ongoing support groups led by professionals. It also offers networking groups for people with specific types of cancer, educational workshops, exercise activities, stress-management sessions, lectures by experts in the field of oncology, and social gatherings—all while helping people maintain a sense of humor, joy, and hope.

360 East Palm Lane

Phoenix, AZ 85004

Phone: (602) 712-1006

www.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.

2018 Resource Guide for Work, Recreation/Sports, Support, Driving, Etc.

<https://indd.adobe.com/view/228ad89d-20df-4818-92dd-68afc8e69854>

www.Barrownuro.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.

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

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.

www.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.

www.braintumor.org

More Information on “Frankly Speaking About Cancer: Brain Tumors”

The rest of this handbook is a 7-chapter booklet about brain tumors that contains valuable information for people with a newly diagnosed brain tumor, long-term brain tumor survivors, and family members. Various sections discuss emotional aspects of the diagnosis, fertility issues, financial concerns, long-term care planning, and much more. ***Frankly Speaking About Cancer: Brain Tumors**** is given to you on behalf of BNI, and reprinted with permission from the Cancer Support Community and the National Brain Tumor Society. We hope you will turn to this handbook time and again for helpful additional information.

We encourage you to find out all you can about your brain tumor. Write down your questions and bring them to your doctor visits. As you collect answers from your treatment team, take notes or ask a family member to come along with you on the visits. The more you and your family know and understand about each part of your care, the more confident you will feel when it comes time to make treatment decisions.

*©2013 Cancer Support Community, all rights reserved.

Supporting the Work of the Barrow Brain Tumor Research Center

Oscar Garcia was diagnosed with a high grade glioma in March of 2016. After two surgeries, he is doing well and works to support and inspire other patients. He is pictured here with his neurosurgeon, Dr. Kris Smith.

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) 406-3041. You may also visit SupportBarrow.org to make a gift online.

Robyn Duda
Robyn.Duda@BarrowNeuro.org
124 West Thomas Road, Suite 250
Phoenix, AZ 85013

The Barrow portion of this handbook was prepared by many staff members from Barrow Neurological Institute and Barrow Brain and Spine. Special thanks to Estelle Doris, FNP-C, CNRN; Norissa Honea, PhD, RN, AOCN, CNRN; Jaclyn Garcia, BSN; Lindsay Higginbotham RN, CNRN, Rima Woo and Charlotte Myers MS, ANP-C.

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

My Diagnosis

Tumor type: _____

Grade: _____

Location: _____

My Treatments

Surgery: _____

Date: _____

Radiation: _____

Dates: _____

Systemic Therapy/
Chemotherapy: _____

Dates: _____

Other: _____

Dates: _____

Possible Side Effects of My Treatment

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____

My Follow-up Visit

Doctor's Name	Specialty	Date

Questions for My Appointment

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____

My Medications

Notes

Notes

Notes

Brain Tumors



People with cancer who actively participate in their recovery along with their health care team will improve the quality of their lives and may enhance the possibility of their recovery. People with cancer who actively participate in their recovery along with their health care team will improve the quality of their lives and may enhance the possibility of their recovery.



National
Brain Tumor
Society



CANCER SUPPORT
COMMUNITY
A Global Network of Education and Hope

*I won't let a brain tumor defeat me or the people I love.
It's a scary diagnosis but now I know the facts.*

— Brain Tumor Survivor

Table of Contents

CHAPTER 1 / THE EMPOWERMENT APPROACH	1
You are not alone	3
Gaining control	3
10 actions you can take	4
CHAPTER 2 / UNDERSTANDING BRAIN TUMORS	5
What is a brain tumor?.....	7
Defining brain tumors.....	7
Diagnosing a brain tumor.....	9
The treatment team.....	14
CHAPTER 3 / TREATMENT OPTIONS.....	17
Empowered communication.....	18
Basic treatments & medications used for brain tumors	19
Long-term planning.....	29
Managing late effects	30
Hospice	30
CHAPTER 4 / MANAGING COMMON SIDE EFFECTS.....	31
Location matters	32
Learn what to expect after your treatment.....	34
Rehabilitating physical symptoms	35
Headaches	36
Seizures	36

Blood counts	38
Gastrointestinal (GI) problems.....	38
Fatigue.....	39
Cognitive and behavioral changes.....	40
Anxiety and depression.....	42
Hormonal changes, fertility and sexuality.....	43
Complementary or alternative medicine (CAM).....	44
CHAPTER 5 / QUALITY OF LIFE.....	47
Coping with your diagnosis	48
The value of support	49
Relationships.....	51
Spirituality.....	53
CHAPTER 6 / PRACTICAL CONSIDERATIONS	55
Going back to work	56
Employment laws and financial support	58
Managing medical costs.....	59
Practical, legal, and estate planning.....	61
Death and dying.....	62
CHAPTER 7 / CARE FOR THE CAREGIVER	63
Care for yourself.....	64
Making important decisions	65
Moving forward	67
CHAPTER 8 / RESOURCES	69

PROLOGUE

No one is ready to receive a brain tumor diagnosis, yet the National Cancer Institute estimates that 66,300 people will be diagnosed for the first time this year alone. In fact, there are over 688,000 people in the United States who are currently managing life with a brain or central nervous system tumor.

In this book, we've collected valuable resources, facts, and tips about the medical, practical, and emotional effects of brain tumors to help you (or an advocate) gain control and learn how to cope with the diagnosis.

You may find that when you feel empowered to make choices you're comfortable with, you can develop a renewed perspective on hope. This book can help guide you. Flip through the pages to find information that seems most helpful now, and refer back to other sections later.

This book was created by the Cancer Support Community and the National Brain Tumor Society, in partnership with neuro-oncology and psychosocial experts and the advocacy groups, Accelerate Brain Cancer Cure and Musella Foundation. It is also based on research with 407 patients and caregivers in a national survey and personal interviews with several thoughtful, honest and inspiring individuals.

Throughout this book you will see symbols that can help you identify useful information:

 Look for this symbol to find helpful tips.

 Look for this symbol to find questions for your doctor, or yourself.

 Look for this symbol to find "Things to Remember" from each chapter.

 Look for this symbol to find useful organizations and resources for more in-depth information.

The brain is an elaborate, elegant, and sophisticated mass of tissue and nerve cells. It seamlessly controls our *personality*, our *senses*, helps regulate *vital body functions*, and controls *how we move* in our environment.

When abnormal cells grow in the brain to develop a tumor, it can disrupt how we function and will require treatment considerations that balance how the tumor is treated with how well our brain operates.

THE BRAIN

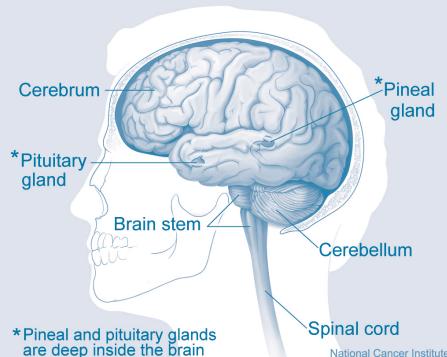
The brain controls our:

Personality: thoughts, memory, intelligence, speech, judgment, and emotions

Senses: sight, hearing, taste, smell, and touch

Vital body functions: heart rate, breathing, and blood pressure

Movement: coordination, balance, and negotiating space



Source: National Institutes of Health, National Cancer Institute



*I'm a huge believer
that we have the
capacity to do great
things, even recover
from extraordinary
happenings. It is
within us. And with
some help along the
way, we can tap into
our inner "Superman."*

— Tony, patient

The Empowerment Approach

CHAPTER 1 / THE EMPOWERMENT APPROACH	1
You are not alone	3
Gaining control	3
10 actions you can take	4

The Empowerment Approach

Everyone's experience with a brain tumor is different – yet a similar sense of fear is felt by anyone who receives a diagnosis. Many people learn to manage the fear, insecurity and anger. You can take actions that give you more control over the experience every step of the way. You can take an empowerment approach.



THINGS TO REMEMBER

- It's normal to feel scared, insecure, and angry about a brain tumor diagnosis – and it is possible to deal with these feelings.
- You can take an **empowerment approach** to gain a sense of control over this disease.
- Consider the 10 Actions You Can Take (See p. 4)
- You are not alone.
- No question is wrong to ask.
- Take time to process the information you're given. You probably have enough time to take a deep breath and think about your next steps.
- Talking openly can become a priority for your family and with your doctors (see Chapter 5 for tips).
- Remember what's important to you and think about your goals and values. Aim to enjoy the things that make your life special.

Over the last ten years I was diagnosed with five hemangiopericytoma tumors. I have had one craniotomy and three Gamma Knife surgeries. Since my first surgery I've hiked to the top of Mt. Whitney and Half Dome, gone white water rafting and hang gliding, learned to rock climb and ride a motorcycle, got married, and had a beautiful son that I never thought I could have. I am not sure what the future has in store for me, but I will not give up!

— Tiffany (from the National Brain Tumor Society's Story Corner)

Being empowered is about choosing to adopt a series of actions, behaviors, and attitudes that can help improve your quality of life.

The Patient Empowerment Concept states: *People who actively participate in their fight for recovery along with their health care team will improve the quality of their life and may enhance the possibility of their recovery.*



BE EMPOWERED

- Access resources for practical information and support
- Partner with your doctor through good communication
- Make active choices in your treatment
- Make changes in your life that are important to you

Don't let this disease off the hook without a major fight.

— Richard (from the National Brain Tumor Society's Story Corner)

YOU ARE NOT ALONE

When confronted with a brain tumor it is common for people to feel alone, confused, and fearful of the unknown. This time is challenging, but can be managed. No one coping with a brain tumor has to do it alone.

Regardless of your diagnosis, most people (patients and caregivers alike) find it helpful to talk about their situation and sort through information with others who have a personal experience with brain tumors. You can talk to people with experience through support groups, counselors, online chat groups, or organizations that offer over-the-phone expert and practical support.

Throughout this book, especially in Chapters 5-8, you will find information about how to access services and trained experts.

GAINING CONTROL

Your involvement in the choices you make with your medical team can make a big difference in your experience and your quality of life.

This includes acknowledging your physical, social, and emotional needs. Most importantly, it includes partnering

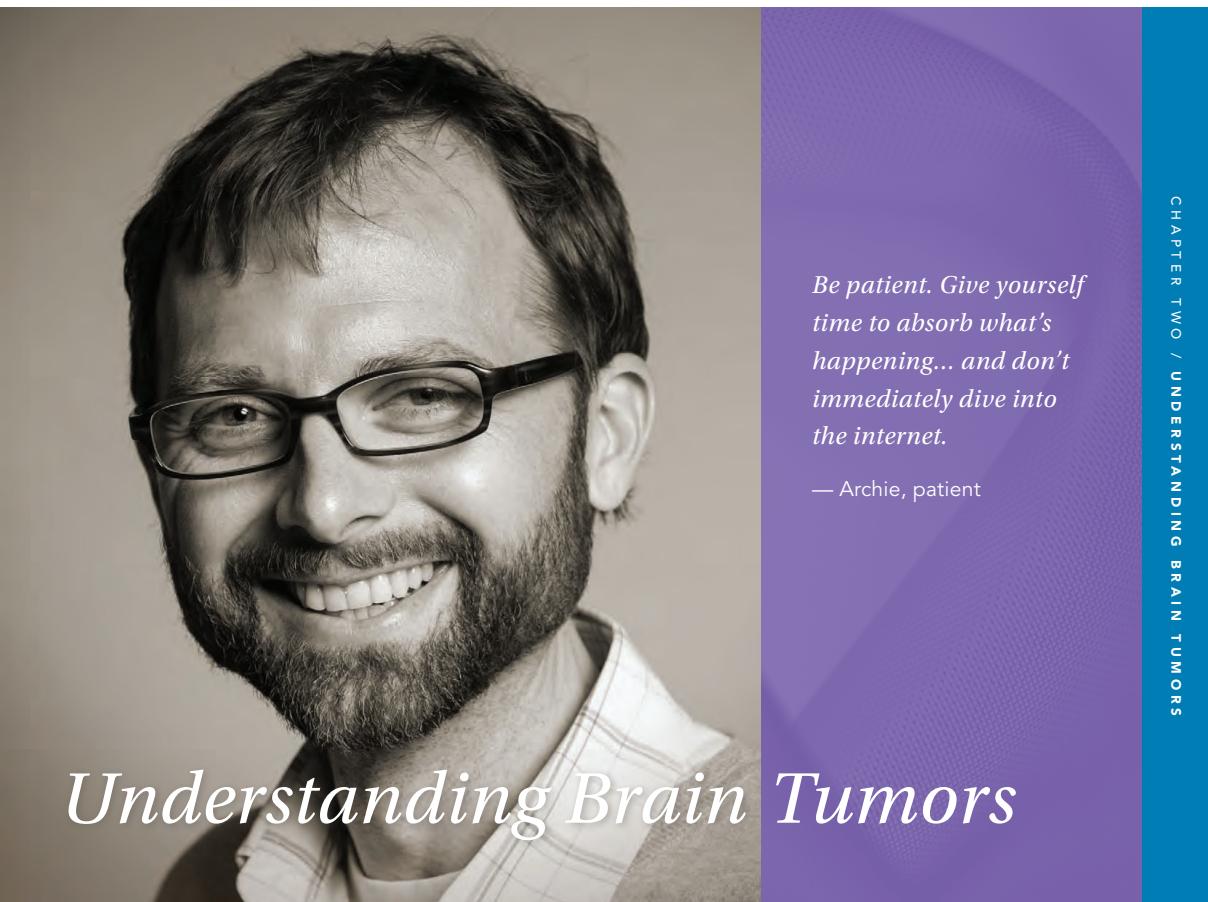
with your health care team to get answers to your questions. (Look for sample questions throughout this book to help you frame your own questions.) You may feel more confident about what to do next if you take part in making plans and finding a network of people to help you.

*No one coping
with a brain tumor
has to do it alone.*



10 Actions You Can Take

1. **Take one day at a time, and make one decision at a time.** Try to resolve only today's problems. The future is always unknown – for everyone. Life with a brain tumor can feel overwhelming but taking one small step at a time can help.
2. **Partner with your health care team.** Having an honest relationship with your medical team can help you feel a greater sense of trust and control. Consider a second or third opinion from experts, ideally at a brain tumor center. Carry a notebook with you or ask someone to write down the things you'd like to ask your doctor. Refer back to your notebook to help you remember what your doctor said.
3. **Ask your family and friends to help.** Family and friends often want to help but don't know how. Offer specific examples, such as: driving to appointments, researching financial support, making phone calls, or just talking. Reach out to your nurse or social worker to learn about available support services when you need extra help.
4. **Reach out to other brain tumor survivors.** It's often comforting to talk with others who can understand what you're experiencing, because they've also been there. See p. 69 to find organizations that can help you connect.
5. **Acknowledge and express your feelings.** Take time to listen to yourself. Find ways to express your feelings through journaling, physical activity, or creative pursuits, or consider talking to a social worker or psychologist.
6. **Establish a reasonable amount of control over your life.** Having a brain tumor can make it difficult to feel in charge of your life and your care. At times you may feel too exhausted or are unable to think clearly. Work with your medical team to develop a plan that gives you as much control over your life as you can comfortably handle.
7. **Learn to relax.** It can help to feel calm. Try relaxation or meditation programs to reduce stress. Relaxation is something that you might have to learn, or build it into your day, but it is important.
8. **Make healthy lifestyle choices.** It's never too late to make changes that will improve your well-being. Every small step you take to eat better, get more exercise, and find more humor in life can make you feel better.
9. **Find a new perspective.** A brain tumor diagnosis is life changing. It can be difficult, but also an opportunity to reprioritize goals and reframe your self-image.
10. **You can find hope in many things.** When you find something that gives you hope, you may feel better equipped to handle challenges. Draw upon family connections, cultural customs, and spiritual beliefs. If a cure is unlikely, one can always hope for small things that make each new day better in some way.



Be patient. Give yourself time to absorb what's happening... and don't immediately dive into the internet.

— Archie, patient

Understanding Brain Tumors

CHAPTER 2 / UNDERSTANDING BRAIN TUMORS	5
What is a brain tumor?.....	7
Defining brain tumors.....	7
Diagnosing a brain tumor	9
Scans and imaging techniques	10
Tumor grading.....	11
Tumor types	12
Diagnostic surgery	13
Pathology report.....	13
The treatment team.....	14
Specialists.....	15

Understanding Brain Tumors

The brain, its structure, and the role that each part plays in our everyday thoughts and behaviors is remarkable. These are only some of the reasons why a tumor in the brain is so complex.



THINGS TO REMEMBER

- There are over 120 types of brain and central nervous system tumors. When diagnosed, it is important to understand:
 1. The **type** and **grade** (how aggressive it is)
 2. Whether it is a **primary** or a **secondary** tumor
 3. If it is cancerous (**malignant**) or not (**benign**)
 4. **Where** in the brain the tumor is located
- It helps to get a second or even third opinion to confirm your diagnosis and treatment plan.
- Keep a list with phone numbers for all of the doctors, specialists, nurses, etc. on your team (collect business cards).
- You can bring someone to doctors' appointments to help you sort through information, ask questions, remember next steps, and keep notes.
- Keep copies of your medical records, current medication list, and diagnostic test results. This can help you as you meet new doctors and work with insurance.
- Take one step at a time. You can learn about your diagnosis, treatment options, and what to expect after treatment, then decide the best next-steps for you and your family.

Brain and Spinal Cord

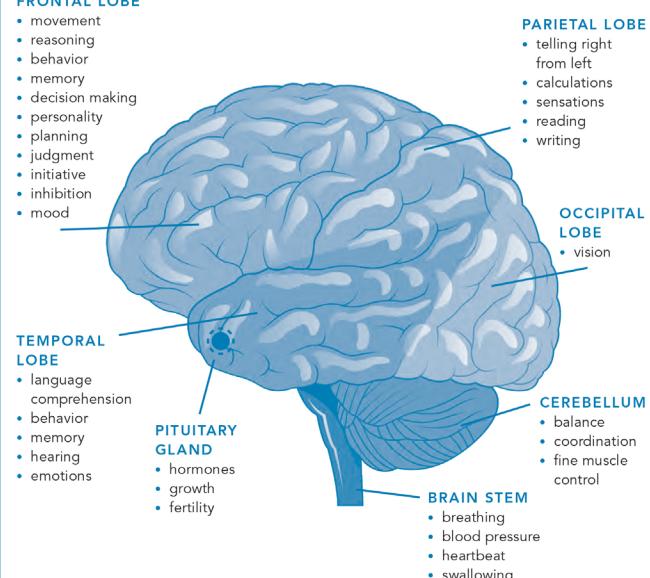
Together, the brain and spinal cord (the central nervous system (CNS)) control the physiological and psychological functions of our body. Generally our brain includes three major parts:

- The **cerebrum** controls thinking, learning, problem solving, emotions, speech, reading, writing, and voluntary movement.
- The **cerebellum** controls movement, balance, and posture.
- The **brain stem** connects the brain to the spinal cord, and controls breathing, heart rate, and the nerves and muscles that we use to see, hear, walk, talk, and eat.



For more information about the brain, view the National Cancer Institute's brain tumor PDQ, www.cancer.gov/cancertopics/pdq/treatment/adultbrain/Patient

BRAIN STRUCTURES AND THEIR FUNCTIONS



Based on an illustration from National Brain Tumor Society's *The Essential Guide to Brain Tumors*

WHAT IS A BRAIN TUMOR?

A brain tumor is an abnormal growth of tissue in the brain or central spine that can disrupt proper brain function. Doctors refer to a tumor based on where the tumor cells began, and whether they are cancerous (*malignant*) or not (*benign*).

All brain tumors can grow to damage areas of normal brain tissue if left untreated, which could be disabling and possibly fatal.

Brain and spinal cord tumors are different for everyone. They form in different areas, develop from different cell types, and may have different treatment options. In this book, we try to offer general guidance for both low grade (benign) and high grade (malignant) primary brain tumors for adults.

DEFINING BRAIN TUMORS

Benign

The least aggressive type of brain tumor is often called a **benign brain tumor**. They originate from cells within or surrounding the brain, do not contain cancer cells, grow slowly, and typically have clear borders that do not spread into other tissue. They may become quite large before causing any symptoms. If these tumors can be removed entirely, they tend not to return. Still, they can cause significant neurological symptoms depending on their size, and location near other structures in the brain. Some benign tumors can progress to become malignant.

Malignant

Malignant brain tumors contain cancer cells and often do not have clear borders. They are considered to be life-threatening because they grow rapidly and invade surrounding brain tissue. Although malignant brain tumors very rarely

spread to other areas of the body, they can spread throughout the brain or to the spine. These tumors can be treated with surgery, chemotherapy and radiation, but they may recur after treatment.

Primary

Whether cancerous or benign, tumors that start in cells of the brain are called **primary brain tumors**. Primary brain tumors may spread to other parts of the brain or to the spine, but rarely to other organs.

Metastatic or Secondary

Metastatic or secondary brain tumors begin in another part of the body and then spread to the brain. These tumors are more common than primary brain tumors and are named by the location in which they begin. They are treated based on where they originate, such as the lung, breast, colon or skin.

FACTS ABOUT BRAIN TUMORS IN THE UNITED STATES

An estimated **688,000+ PEOPLE** in the U.S. are living with a primary brain or central nervous system (CNS) tumor diagnosis:

138,000 WITH MALIGNANT TUMORS
550,000 WITH BENIGN TUMORS

APPROXIMATELY
20-40%
OF ALL OTHER CANCERS LATER
DEVELOP A BRAIN METASTASES

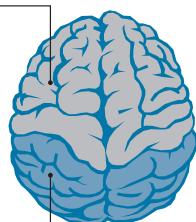


This accounts for 98,000 to 170,000 new metastatic brain tumor cases each year.

IN 2012, NEW PRIMARY BRAIN TUMOR DIAGNOSES INCLUDED:

63%
BENIGN
TUMORS
(41,980 Cases)

37%
MALIGNANT
TUMORS
(24,300 Cases)



PRIMARY BRAIN TUMOR TYPES



- 16% Glioblastoma
- 7% Astrocytoma
- 35% Meningioma
- 14% Pituitary
- 9% Nerve Sheath
- 2% Lymphoma
- 33% Other
(Ependymoma, Oligodendroglioma, Embryonal, etc.)

Source: CBTRUS Statistical Report (2012)

DIAGNOSING A BRAIN TUMOR

What a crazy ride this has been. I went to bed after watching a movie and woke up in an ambulance on the way to the hospital.

I didn't know my name, didn't recognize my wife or kids and couldn't understand why I was in the back of this ambulance.

— Mike (from the National Brain Tumor Society's Story Corner)

Some people may have symptoms that suggest there is a brain tumor, others have no obvious symptoms.

Commonly, people experience long-term headaches, seizures or convulsions, difficulty thinking and speaking/finding words, personality changes, tingling or stiffness in one side of the body, a loss of balance, vision changes, nausea, and/or disorientation (see Chapter 4).

If these symptoms are occurring, a doctor will ask questions about a person's medical history and overall health, and prescribe a variety of diagnostic tests to determine what is causing these problems, and then seek remedies.

Neurological Examination

As part of the diagnostic testing, a doctor will measure nervous system functions, physical and mental alertness, and include the examination of normal brain functions from reflexes to judgment, smell and taste.

If responses are not normal, a brain scan will be ordered, or a patient will be referred to a neurologist or neurosurgical oncologist for more tests.

SCANS AND IMAGING TECHNIQUES

A scan is the first step to identify if a brain tumor is present, and to locate exactly where it is growing. A scan creates computerized images of the brain and spinal cord by examining it from different angles. Some scans use a contrast agent (or a dye) to allow the doctor to see the difference between normal and abnormal tissue.

A patient may need more than one type of scan to diagnose a tumor, depending on its type and location.

Commonly used scanning and imaging techniques:

- **Computed Axial Tomography (CAT or CT Scan)** is a computerized x-ray that can show a combination of soft tissue, bone, and blood vessels. This is often the first test a person will receive in an emergency room (i.e. after a seizure).
- **Magnetic Resonance Imaging (MRI)** can create clear and detailed three-dimensional images of a brain tumor. An MRI is not often used with people who have a pace maker or other metal device.

- **Magnetic Resonance Spectroscopy (MRI Spect or MRS)**, measures the levels of metabolites in the body. An MRS can detect irregular patterns of activity to help diagnose the type of tumor, evaluate its response to therapies, or determine aggressiveness of a tumor.

- **Perfusion MRI** examines the flow of blood into the tissues to help assess the grade/aggressiveness of tumors and differentiate a recurrent tumor from dead tumor tissue.

- **Functional MRI (fMRI)** tracks the use of oxygen and blood flow in the brain as patients perform tasks. An fMRI can identify the motor, sensory, visual and language centers of the brain which helps your doctor carefully plan for surgery.

- **Positron Emission Tomography (PET)** scan uses a radioactive substance to visualize hypermetabolic activity such as with malignant cells, or abnormalities from a tumor or scar

tissue. PET is also used during brain mapping procedures.

- **Spinal tap (also called a lumbar puncture)**, uses a special needle placed into the lower back to measure pressure in the spinal canal and brain and determine if there is an infection or tumor cells.

Things to Know about Scans

Ask your neurosurgeon or nurse what you have to do for a scan, where to go and how the scan works, so you can feel prepared. Keep a record of your scan and x-ray history. This information can help doctors make informed treatment decisions and minimize your over-exposure to radiation.

Be prepared to receive multiple scans over time: first to detect the tumor; then to observe the site after surgery; later, with follow-up care, to see if the tumor returns.

TUMOR GRADING

The World Health Organization (WHO) has created a standard by which all tumors are classified. There are over 120 brain tumor classifications defined by the WHO, based on the tumor cell type and location, making this a very complex diagnosis. Tumors are given a name based on the cells where they arise, and a number ranging from 1-4, usually represented by Roman numerals I-IV. This number is called the "grade" and it represents how fast the cells can grow and are likely to spread. This is critical information for planning treatment and predicting outcomes.

Lower grade tumors (grades I & II) are not very aggressive and are usually associated with long-term survival.

Higher grade tumors (grade III & IV) grow more quickly, can cause more damage, and are often more difficult to treat. These are considered malignant or cancerous.

Grade I Tumor

- Slow-growing cells
- Almost normal appearance under a microscope
- Usually not cancer
- Associated with long-term survival
- Can potentially be cured with surgery

Grade IV Tumor

- Abnormal cells which reproduce rapidly
- Very abnormal appearance under a microscope
- Form new blood vessels to maintain rapid growth
- Areas of dead cells (necrosis) in center

Grade II Tumor

- Relatively slow-growing cells
- Slightly abnormal appearance under a microscope
- Can invade adjacent normal tissue
- Can recur as a higher grade tumor

Tumors can contain several grades of cells; however, the most malignant cell determines the grade for the entire tumor (even if most of the tumor is a lower grade). Some tumors can change the way they grow and may become malignant over time. Your doctor can tell you if your tumor might have this potential.

Grade III Tumor

- Actively reproducing abnormal cells
- Abnormal appearance under a microscope
- Infiltrate adjacent normal brain tissue
- Tumor tends to recur, often as a higher grade

Tumor Types

With over 120 tumor types, it's challenging to diagnose and treat brain tumors. The most common primary tumor types found in adults are:

GLIOMAS

Gliomas begin from glial cells found in the supportive tissue of the brain. There are several types of gliomas, categorized by where they are found, and where the tumor begins.

The following are gliomas:

- **Astrocytomas** begin in the supporting tissue cells (astrocytes). In adults, they are most commonly found in the cerebrum where they cause pressure, seizures and personality changes. Astrocytomas are generally subdivided into low (grade I & II) or high grade (grade III & IV). High grade (grade IV) are the most malignant of all brain tumors, known as glioblastoma.
- **Oligodendrogliomas** also start in the supporting cells of the brain, often found in the cerebral hemispheres (cerebrum), causing seizures, headaches, weakness, sleepiness, or changes in behavior. Oligodendrogliomas tend to respond better to therapies and have a better prognosis than most other gliomas. They are grade II or III.

MENINGIOMAS

Meningiomas are usually slow-growing, benign tumors that come from the outer coverings of the brain just under the skull. This type of tumor accounts for about one third of brain tumors in adults. They may exist for many years before being detected and are commonly found in the cerebral hemispheres just under the skull.

SCHWANNOMAS

Schwannomas are usually benign tumors that arise from the supporting nerve cells called vestibular schwannomas or acoustic neuromas. Vestibular schwannomas often cause hearing loss, or problems with balance or weakness on one side of the face. Surgery can be difficult because of where they are located. Sometimes radiation (or a combination of surgery and radiation) is used to treat these tumors.

PITUITARY TUMORS

The pituitary gland is located at the base of the brain and it produces hormones that control other glands in the body; specifically the thyroid, adrenal glands, ovaries and testes, glands for milk

production in pregnant women, and the kidneys. Tumors in or around the pituitary gland can lead to problems with how these glands function. Also, patients may have vision problems. Pituitary tumors are frequently benign, and surgical removal is often the cure. Some are treated with medication to shrink or stop the tumor from growing.

CENTRAL NERVOUS SYSTEM (CNS) LYMPHOMA

CNS Lymphoma is a malignant primary brain tumor that originates from the lymphocytes found in the brain, spinal cord, or eyes. It typically remains confined to the CNS. Treatment commonly includes chemotherapy and/or radiation.



For more information, visit the National Cancer Institute's website (www.cancer.gov); the National Brain Tumor Society's website (www.braintumor.org); the American Brain Tumor Association's website (www.abta.org)

DIAGNOSTIC SURGERY

Surgery

Surgery is used to diagnose and treat brain tumors. Ideally, the brain surgeon (neurosurgeon) can completely remove a brain tumor with surgery. If complete removal is not possible, the surgeon will remove as much as possible (called a **resection** or **debulking**) without negatively affecting the brain's neurologic functions. If a resection is not possible, then a biopsy will be done (removing a small piece of tumor tissue) to diagnose the tumor type and grade so treatment recommendations can be made.

- **Craniotomy.** A surgical procedure that involves removing a piece of the skull to access the brain. After the tumor is resected and tested, the bone is usually put back and held in place with plates and screws. All tissue obtained during the procedure is evaluated by a **pathologist**, the doctor who examines the tissue to identify the tumor type and grade.

- **Biopsy.** A surgical procedure to remove a small sample of tissue from the tumor so the cells can be examined under a microscope.

There are two kinds of biopsy procedures:

- **Open Biopsy:** done during a craniotomy.
- **Closed Biopsy** (also called stereotactic or needle biopsy): when a needle is used to access and remove a small selection of tumor tissue from an area that is difficult to reach.

PATHOLOGY REPORT

A pathology report contains the analysis of brain tissue taken from a biopsy. Sometimes the pathologist can't make an exact diagnosis, so the tissue may be sent to another pathologist for a second opinion.

The day I was told I had a 4.3 cm tumor in my head it was as if someone tossed a hundred lead blankets on top of me. After it was removed, and the diagnosis was anaplastic ependymoma grade III, that's when it rained boulders. But I'm still here.

— Mark (from the National Brain Tumor Society's Story Corner)

THE TREATMENT TEAM

It's likely that you will work with a large team of medical professionals for treatment. Keep in mind that you can be in charge of this process – and you can aim to like and trust the doctors you work with. You have time to find a good team.



A very special patient of mine once told me "Feed your faith and your fears will starve to death."

— Deanna Glass-Macenka, nurse



TO PARTNER WITH YOUR TREATMENT TEAM

- Be involved in decisions.
- Learn about your diagnosis and your treatment options by asking as many questions as you need to, and by learning how to access resources that may be helpful.
- Talk to your treatment team about your worries and concerns.
- Try to keep all medical appointments and be on time.
- Know how to contact your treatment team between appointments, so you can ask questions that need quick answers.
- Ask for access to your medical records: either get copies or access your electronic file. This can help when you meet a new specialist or if you'd like another opinion.

Specialists

NEUROLOGIST

A doctor specializing in disorders and diseases affecting the brain and spinal cord (the central nervous system or CNS). Some neurologists have oncology training.

NEURO-ONCOLOGIST

An oncologist (cancer doctor) specializing in the treatment of cancers and tumors affecting the CNS.

NEUROSURGEON (IDEALLY A NEUROSURGICAL ONCOLOGIST)

A surgeon specializing in the surgical management of CNS disorders. If possible, talk to a neurosurgeon who works with brain tumor patients 50% of the time, or more.

NEURO-RADIOLOGIST

A radiologist (an expert in imaging techniques) specializing in the interpretation of scans and images of the CNS. Some are specialists in brain tumors.

NEURO-PATHOLOGIST

A doctor specializing in the diagnosis of CNS disorders through microscopic examination of biopsied tissues (tumor cells).



It is ideal to find a neurosurgeon with experience. Ask if at least:

50% OF THEIR PRACTICE IS WITH BRAIN TUMOR PATIENTS

NEURO-ONCOLOGY NURSE

A registered nurse specializing in patient education (including symptom management) and support services for brain tumor patients.

At any point before, during or after treatment, the services of the following professionals can be valuable:

SOCIAL WORKER

Medical social workers specialize in counseling and crisis intervention, and help locate appropriate care, legal resources, and financial aid.

CLINICAL PSYCHOLOGIST

A licensed professional who can help patients and families adjust to the effects of illness on their lives. Neuro-psychologists specialize in brain functions and how brain damage can affect a person's abilities.

REGISTERED DIETICIAN OR NUTRITIONIST

A trained specialist with knowledge about how a person's diet and daily nutrition will impact their health. The Academy of Nutrition and Dietetics lists professionals with oncology experience:
www.eatright.org/programs/rdfinder



WHAT A GIFT!

— Dolores (from the National Brain Tumor Society's Story Corner)

I know that it sounds crazy, but if I hadn't been blessed with a brain tumor, I would not know the things that I know today. I would not have the courage to live every day as if it were my last. I now know what really matters in life. Today is a gift, and that is why it is called the present! I have so much to be grateful for but I never realized it before, until it was almost taken away from me.

My journey began in the summer of 2008, after months of enduring excruciating pain in my head and finally deciding to go to the doctor. On April 13, 2009, I was diagnosed with a meningioma tumor the size of a baseball that was located behind my left ear. I was stunned, this was the last thing that I expected and all I could think of was... "How was I ever going to fit this into my busy schedule?" This is the kind of diagnosis that allows fear to set in no matter how strong one thinks they are.

Thus, my search began to find my purpose in life, to discover my inner self, and to further understand that everything happens for a reason. Since then, I no longer fear death. Fear of death causes fear of life. Where once I lived my life going 100 mph each day, stressed out and angry, I have now found an inner peace that I have never known before. Now I pray for the wisdom and inspiration to help others find the peace I feel.



There are no clear answers for me, so I had to learn that emotionally and medically, my brain tumor care is something we'd have to manage for a long time. That's why it was so important for me, us, to interview and find the best doctors for us.

— Darren, patient

CHAPTER 3 / TREATMENT OPTIONS.....	17
Empowered communication.....	18
Basic treatments & medications used for brain tumors	19
Treatment for low grade tumors	21
Treatment planning for high grade tumors	21
Treatment questions	22
More treatment options for high grade tumors	23
Treatment after recurrence	28
Long-term planning	29
Managing late effects	30
Hospice	30

Treatment Options

Once you have a medical team in place, talk to them about your questions, fears, and concerns. You and your loved ones are the only people who know everything about your care and what you need. It's critical to speak up and learn about all of your treatment options before you decide what care you need.



THINGS TO REMEMBER

- Talk openly and honestly with your medical team. It may seem difficult, but it will help you get better care.
- Keep a notebook and schedule planner to track daily questions, side effects, notes, and appointment information.
- Learn about your treatment options over the short and long term.
- All questions are valuable.
 - Ask about the risks and benefits of each treatment option presented.
 - Ask about what to expect at the time of treatment, just after treatment, over the course of recovery, and in the long-term.
- Ask about clinical trials. This is the only way to access some promising new treatments.
- Ask about how to maintain a high quality of life over time.
- Ask about palliative care or other options to help manage your symptoms.
- If you feel overwhelmed: contact the Cancer Support Community's "Open to Options" treatment decision counseling program.
(See p. 27)

EMPOWERED COMMUNICATION

To talk more effectively with your health care team:

1. **Keep a notebook.** A notebook can help you keep track of questions and issues that you'd like to discuss at appointments. If you're not feeling well enough to write everything down, ask someone to help. This notebook can include:
 - a. *Questions*
 - b. *Side effects or symptom tracking*
 - c. *Supplements*
 - d. *Other medications*
 - e. *Your "to do" list*

2. **Know how to get your questions answered.** Will there be enough time during appointments to talk through your questions? Is email better? Do you need to schedule an extra appointment just to talk through everything? Is it better to schedule a

time with the nurse? Ask these types of questions up-front so you and your doctor can maintain a productive relationship.

3. **Bring someone with you to appointments.** It is hard to manage all of the information and emotions. A family member or friend can be very helpful as an extra set of ears, to help take notes, and to discuss what you heard or remember things you might forget.
4. **Use a schedule-planner to organize help.** In addition to a regular calendar, consider an online resource (like www.rci.lotsahelpinghands.com or www.mylifeline.org) to help you stay organized and recruit help when you need it. You can plan for things like a ride to medical appointments, or help with dinner or childcare.



QUESTIONS ABOUT TREATMENT OPTIONS

1. What is the goal of treatment for me?
2. What are my treatment options?
3. Am I eligible for any clinical trials and when? What is the goal of the trial(s)?
4. What are the possible side effects of each treatment option?
5. What can I do to prepare for treatment?
6. What will my recovery look like?
7. What is the likelihood this tumor will return after treatment?
8. What additional treatments might I need?
9. Will I need rehabilitation services, like speech therapy or physical therapy?
10. How can I reach you if I have questions after today?
11. Who would you recommend that I see for a second opinion?

BASIC TREATMENTS & MEDICATIONS USED FOR BRAIN TUMORS



WHEN TO CONSIDER A SECOND OPINION

- If you feel uncertain about your initial diagnosis, recurrence, or response to treatment.
- If you wish to have access to additional experts in the treatment of brain tumors, or wish to have access to clinical trials.
- If you feel that your physician is limiting your treatment options or has told you that no further treatment can help you – but you want more information or believe there may be other options.
- If you just want to be sure that you're on the right course.

Treatment for brain tumors is based on:

- Your age, overall health, and medical history
- The type, location, and size of the tumor
- How likely the tumor is to spread or recur
- Your tolerance for specific medications, procedures, or therapies
- Your opinion or preference

The first step is to address symptoms:

- **Seizures** – range from visual problems, to sensations such as numbness or tingling, to feelings of being disconnected and unable to speak, to uncontrollable body movements. (See p. 36).
- **Brain tissue swelling /edema** – causes problems like memory loss, personality change, confusion, speech problems, visual problems, muscle weakness, sensory alterations, and decreased levels of consciousness.
- **Headaches** – are very common.

- **Hydrocephalus** – causes pressure in the brain from cerebrospinal fluid. If removing all or part of the tumor cannot resolve this problem, a shunt to re-direct the path of fluid may be required.

- **Other common symptoms** – can include muscle weakness, or changes in sensation, cognitive functions, and personality.

Treatment for these symptoms may include:

Antiseizure/Antiepileptic Drugs (AEDs)

Antiseizure drugs treat and prevent seizures associated with pressure in the brain from a tumor, from surgery, or from an irritating treatment. In general, AEDs are recommended around the time of surgery, or for a longer period of time for people with a history of seizures. Some people experience sleepiness, unsteadiness, or confusion when taking AEDs. If a rash occurs, your doctor must be contacted immediately and AED use must stop.

Steroids

Steroids are used to treat and prevent swelling and pressure in the brain. They are very helpful, but they also cause side effects such as weight gain, "moon face," mood changes, difficulty sleeping, muscle weakness, osteoporosis, or joint pain, increased risk for infections and bruising, an increase in blood sugar, and possibly gastrointestinal bleeding. It is important to take steroids to reduce swelling, but it is equally important to manage their side effects. If you experience these types of side effects, talk with your doctor or nurse so they can help you with strategies for relief, including changes to the dose and type of steroid used. This can take some time. (More in Chapter 4)

Surgery

The ultimate goal of surgery is to remove as much of the brain tumor as possible. Removing the tumor often relieves the symptoms caused by it. Surgery is only possible if the tumor is in a location that can be reached without damaging important brain functions. It is critical to balance the possible impacts of surgery with the benefits.

Sophisticated **neurosurgical navigation** equipment is used in nearly all brain surgery centers to map around the brain to the tumor. The best comparison is like a GPS map for the brain. Brain mapping for surgery involves a special scan that is synchronized with operating equipment before surgery so the surgeon can identify abnormal brain tissue and provide the most complete and safest surgery possible.



SOME PLACES TO CONTACT FOR REFERRALS

- You can ask your primary physician to recommend a neuro-oncology expert
- The National Brain Tumor Society website can provide links to information and locations of treatment facilities near you. 1-800-934-2873 or www.braintumor.org
- The National Cancer Institute can locate a Comprehensive Cancer Center near you. 1-800-422-6237 or www.cancer.gov/researchandfunding/extramural/cancercenters

TREATMENT FOR LOW GRADE TUMORS

Often, low grade tumors (grade I and II) are treated with watchful monitoring or surgery alone. Though all tumors are monitored with repeat scans, grade II tumors are watched more closely after surgery and over time to make sure there is no recurrence.

Try to talk openly about how you're doing with your family, close friends, and your employer so that you can make plans with them as you strive to return to more regular routines and responsibilities.

TREATMENT PLANNING FOR HIGH GRADE TUMORS

Higher-grade tumors are more difficult to remove and require additional treatments beyond surgery, such as radiation, chemotherapy, or a clinical trial if one is available. Microscopic tumor cells can remain after surgery and will eventually grow back. All treatments, therefore, are intended to prolong and improve life for as long as possible.

Try to ask straight-forward questions that consider your quality of life during and after treatment. There may not be clear answers, but it's important to ask your questions anyway.



The doctor didn't speak plainly to us. I think it's important to learn as much as you can about what to expect over time, so you can feel more prepared.

— Candice, caregiver

BOOK RECOMMENDATIONS FOR MORE INFORMATION

Johns Hopkins Patient's Guide to Brain Cancer by Deanna Glass-Macenza and Alessandro Olivi

Navigating Life with a Brain Tumor by Lynne P. Taylor, Alyx B. Porter Umphrey and Diane Richard

Treatment Questions



TREATMENT QUESTIONS FOR ALL BRAIN TUMORS

1. What are the risks and benefits of surgery for me?
2. What can I do to manage symptoms or side effects?
3. Will my symptoms go away?
4. Will I experience different symptoms or cognitive problems after surgery?
5. Where and how big will the incision be? Will you have to shave my head?
6. How long will I be hospitalized after surgery?
7. Who will be involved with care for my recovery? How long?
8. Will I need rehabilitative care such as speech, physical, or occupational therapy? How long?
9. Will I have to see a neuro-oncologist for chemotherapy or radiation oncologist for radiation therapy?
10. Who is responsible for my follow-up care?
11. Do you anticipate a recurrence of this type of tumor?
12. Can I donate my tumor tissue to research?



TREATMENT QUESTIONS FOR HIGH GRADE TUMORS

1. How can I tell the difference between treatment side effects and brain tumor symptoms?
2. What are the standard guidelines to treat my tumor vs. what you recommend? Why?
3. Can you recommend a clinical trial for my care?
4. What will my life be like after treatment?
5. What is the likelihood that radiation and chemotherapy will help? What are the pros and cons of my options?
6. If I decide not to undergo further treatment, what will my progression look like?
7. Can you recommend a social worker or support group to help me and my family cope with my future life?
8. What else can I do to improve my quality of life, and the quality of life of those who care for me?



The National Comprehensive Cancer Network (NCCN) guidelines set the standard for treating brain tumors. The way that different institutions and physicians approach treatment starts with these guidelines, but may differ with institutional or personal opinions. It is worth looking at the NCCN guideline for your tumor type as you consider treatment opinions. www.nccn.org/professionals/physician_gls/f_guidelines.asp#cns

MORE TREATMENT OPTIONS FOR HIGH GRADE TUMORS

Radiation Therapy

When surgery is not enough, radiation treatment uses x-rays and other forms of radiation to destroy tumor cells, or delay tumor growth. This can also be used when tumor cells are found in hard-to-reach areas.

By planning treatment carefully with brain mapping techniques, radiation oncologists try to avoid killing healthy cells, thereby reducing side effects. You may wear a special mask that fits around your head to hold your head in place during radiation treatment.

For higher grade gliomas, radiation treatment is often given with low daily doses of chemotherapy (such as temozolomide (*Temozol*®)) to help delay a recurrence and allow patients to live longer.

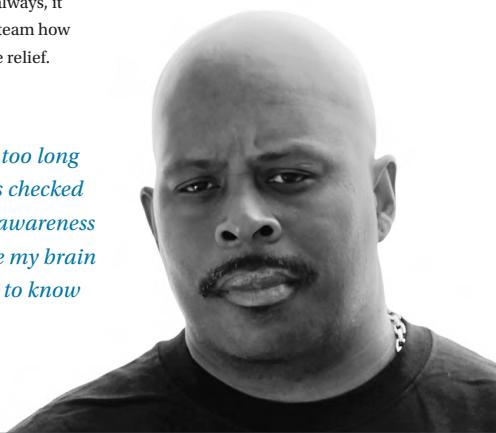
Side effects from radiation may include swelling, fatigue, headaches, nausea, possible hair loss, and changes in your sensations or movement. Damage to normal brain cells is often subtle, but it can affect mental sharpness and the ability to think clearly. Cognitive impairment can worsen to become a long-term problem for some people.

There are ways to reduce the side effects from radiation treatment, so as always, it is important to tell your medical team how you feel so they can help provide relief.

Radiation therapy options:

- **External beam fractionated radiation**

is the standard treatment used for all patients with high grade malignant gliomas, typically given in an outpatient clinic. If you need help with transportation to a radiation appointment, you can ask if transportation benefits are available through your hospital or insurance.



I know now that I waited too long before I got my headaches checked out. Now I want to bring awareness to this disease. I overcame my brain tumor, and I want people to know they can overcome it, too.

— Anthony, patient

- **Stereotactic radiosurgery** is a technique that focuses high doses of radiation at the tumor from many different angles. This form of radiation, often performed with the Gamma Knife® unit or the newer CyberKnife® unit, can be used to treat both benign and malignant tumors, but is most appropriate for tumors with well-defined edges.
- **Proton beam radiation therapy** is a type of high-energy, external radiation therapy that kills tumor cells with little damage to nearby tissues. It is most appropriate for tumors located at the base of the skull or behind the eyes.

Chemotherapy

Chemotherapy is the use of drugs to kill cells that rapidly divide, such as cancer cells. It is prescribed when surgery is not enough to remove a tumor – most often for higher-grade tumors. Low doses may reduce the impact of chemotherapy-related side effects, such as hair loss,

nausea, fatigue, weight loss, and gastrointestinal problems. Patients are monitored closely to manage problems that may occur.

Chemotherapy is provided in three forms:

- **Chemotherapy wafers** containing drug called carmustine or BCNU are inserted directly into a high grade glioma during surgery. The wafer, named Gliadel®, slowly dissolves over 2-3 weeks to kill tumor cells.
- **Intravenous chemotherapy** is when the chemotherapy is given through a vein, in a clinic setting. Examples for high grade gliomas include:
 - Nitrosourea: BCNU
 - Vinca alkaloids: vincristine
 - Platinum Analogues: carboplatin, cisplatin
- **Oral Chemotherapy** is when chemotherapy is given in a pill, by mouth. Examples include: TMZ or temozolomide (*Temozol*®),

temozolomide (*Temozol*®), or procarbazine (Matulane®). TMZ plus radiation is the standard treatment for high grade gliomas. Some doctors treat anaplastic oligodendrogiomas with procarbazine, vincristine, and CCNU (known as PVC chemotherapy).

Oral chemotherapy is not always effective on brain tumors. This is because of the body's naturally protective system in the brain and cerebro-spinal fluid. This protective mechanism is known as the **blood-brain barrier** and it prevents harmful substances from entering the CNS.

You can ask your doctors which chemotherapy they think would be appropriate for your treatment and why. You can also ask your insurance company what drugs are covered. The decision of whether or how much chemotherapy you'd like to use is ultimately up to you.

Clinical Trials

Clinical trials are studies designed to test the most promising new treatments. People participate in a clinical trial for a variety of reasons: to try a new and promising treatment method, to contribute to the development of future treatments, or to help find a cure. Most clinical trials require a patient to qualify with certain medical criteria. Some trials can be joined before your first surgery, others during radiation, others at the point of recurrence. You can ask your doctor if you are eligible for a trial, or get a second opinion at any time.

Though participants may be among the first people to benefit from a new treatment, there can be unexpected side effects, or the new treatment may not be better than or even as effective as the standard treatment. Patients are provided with very clear information about the treatment under investigation before they decide to participate. If they do wish to participate, they are monitored closely.

Clinical Trial Phases:

- **Phase I:** Determine maximum tolerated dose...how much, how safe, how often?
- **Phase II:** Evaluate effectiveness...does it do any good?
- **Phase III:** Compares a new treatment to the standard treatment to determine which is more effective...is the new treatment better?



QUESTIONS TO ASK ABOUT CLINICAL TRIALS

1. Do I qualify for any available clinical trial(s)?
2. What is the purpose of the study?
3. How do the possible risks and benefits of the new treatment compare with my other treatment options?
4. Does the study sponsor pay for my treatment in the clinical trial?
5. Will there be any travel, housing, or childcare costs that I need to consider while I'm in the trial?
6. If the new treatment has negative effects, what will be done for me and who will cover the cost?
7. When and where will the clinical trial's findings be reported?
8. If I use Gliadel, will it restrict me from entering a trial?
9. Can I have a sample of my tumor tissue frozen, so I can be a candidate for a vaccine in the future, or genetic tests?

MORE ABOUT CLINICAL TRIALS

National Brain Tumor Society's Clinical Trials Matching Service
1-877-769-4812
www.emergingmed.com/networks/NBTS

Cancer Support Community's Clinical Trials Matching Service
1-800-841-8927
www.cancersupportcommunity.org
search: Clinical Trials

National Cancer Institute
1-800-422-6237
www.cancer.gov/clinicaltrials

Targeted Therapy

Targeted therapies focus on specific elements of a cell, such as molecules or pathways required for cancer cell growth (i.e., cell proteins) and use them as a target. When a targeted therapy attaches itself to a designated protein in a cancer cell, it can stop certain functions in the cell. For example:

- Bevacizumab (Avastin®) is an FDA approved targeted therapy that affects a tumor's ability to make new blood vessels. It can be helpful for recurrent glioblastomas in adults.

Other targeted and biologic therapies continue to be tested in clinical trials. Examples include tyrosine kinase inhibitor (TKI) therapy and anti-vascular endothelial growth factor (VEGF) therapy.

Electric Field Treatments

Electric field treatments are a new strategy to kill brain tumor cells, utilizing a device called NovoTTF™ (by Novocure), that is placed along the scalp. It provides a mild electric current (electrodes) that may stop the growth of tumor cells without harming normal brain cells. There is some controversy about the efficacy of this therapy.

Other promising treatments still in development are:

Vaccine Therapy

Vaccine therapy uses the patient's immune system to recognize and then attack cancer cells. Substances made with brain tissue or made in a laboratory are used to boost, direct, or restore the body's natural defenses against cancer - similar to the way a flu vaccine helps the body fight the flu.



ADVANCES BEING MADE IN BIOMARKER RESEARCH

Advances are being made in the area of biomarker research, where specific proteins (biomarkers) found in the RNA and DNA of brain tumor cells can be used for cancer detection and treatment. Biomarker research is a foundation for personalized medicine and provides hope for cancer cures. Research is ongoing and very promising, but more time is needed.

When a patient donates tissue samples for biomarker research, it helps bring researchers one step closer to finding a cure. To learn more about donating tissue samples: www.cancer.gov/cancer-topics/factsheet/Information/donating-tissue-research, or look online for information about The Cancer Genome Atlas project.

For information about innovative new research and treatments, visit Accelerate Brain Cancer Cure's website (www.abc2.org).

Immunostimulatory Molecules

Clinical trials are planned to begin in 2014 for the use of Ipilimumab in the treatment of glioblastoma. Ipilimumab (Yervoy™) is a monoclonal antibody (a lab-made antibody used for targeted therapy) that has been found to be beneficial in the treatment of melanoma, and is now being tested on glioblastoma. It stimulates the immune system to help destroy unwanted tumor cells.

Gene Therapy

Gene therapy uses engineered genes that can selectively kill cancer cells, stop their growth, or stimulate the immune system to fight them. This is done with the introduction of engineered genes that can enter into cells for treatment because they affect the way cancer cells behave. Gene therapy can be introduced to cancer cells by inserting them into viruses, stem cells, liposomes, or other immune cells. Gene therapy has been very promising in pre-clinical trials.

IF YOU NEED HELP WITH MAKING TREATMENT DECISIONS

Open to Options™ is a free telephone or in-person counseling program provided by trained professionals at the Cancer Support Community. It empowers you to:

- Communicate your concerns clearly
- Create a list of questions for your doctor or health care team that will help you address your specific needs
- Organize your questions for specialists to help you get the most helpful answers from the right people

It works! Patients who participated in this program:

- Were less anxious about their medical appointments
- Felt that their appointments went more smoothly
- Felt better about the care decisions they made



Open-to-Options™
call: 1-888-793-9355
www.cancersupportcommunity.org

TREATMENT AFTER RECURRENCE

If you are diagnosed with a recurrent brain tumor, you will want to consider how additional treatment can impact your quality of life. Options available for retreatment include surgery with or without chemotherapy wafers, chemotherapy (intravenous or orally), possibly radiation, and/or clinical trials.

Supportive care is most helpful when there is a cancer recurrence – regardless of additional treatment. Supportive or palliative care refers to strategies that ease pain and other symptoms. (See p. 29)

Most patients with high grade glioma receive a lifetime dose of radiation shortly after diagnosis. It is important to be aware of your risk to normal brain tissue if additional radiation treatment is offered. In rare cases, when a good period of time has passed since initial treatment, special techniques, such as stereotactic radiosurgery or brachytherapy, may allow additional radiation to be directed to the tumor safely. However, there is no proof that these radiation treatments improve survival or provide any benefit to the patient compared to supportive care alone.

It's also helpful to ask if you are eligible for a clinical trial and to learn how it may benefit you.

You may benefit from retreatment if you have:

- Good overall health
- A smaller amount of tumor present
- A longer interval (i.e., more than one year versus less than one year) between your original treatment and the recurrence



If you are diagnosed with a recurrent brain tumor, you may want to consider how additional treatment can impact your quality of life.

LONG-TERM PLANNING

I had brain surgery and the aftermath left me partially paralyzed. I endured intense physical and occupational therapy. Being partially paralyzed everyone thought dancing would be over for me, but I was determined to start dancing again. Eight years later, I have regained a sense of movement which was imperative. Dance is my life.

— Zazel-Chavah (from the National Brain Tumor Society's Story Corner)

All brain tumor patients can develop a plan with their treatment team, not just for immediate treatment, but also for recovery and long-term management. This may include follow-up scans, follow-up treatment, rehabilitative care, psychiatric care, and/or estate planning. Talk with family and your medical team about what you need.

During and after treatment, all patients can receive a plan for:

- **Continuous follow-up care** to manage recovery from treatment, to detect if the tumor returns, and to manage late effects of treatment. Your medical team can tell you how often you should receive follow-up care over time.

- **Rehabilitation care** for post-surgical or other treatment to help you regain lost motor skills and muscle strength. Speech, physical, and occupational therapists may be involved in this aspect of care, based on rehabilitative needs.

- **Supportive care/Palliative care** to minimize the side effects of the tumor or treatment and provide maximum support for the caregiver. Palliative care maximizes quality (as well as quantity) of life for the patient and those who care for them—not just at the end of life but throughout the course of disease.



THE GOALS OF PALLIATIVE CARE

- To treat symptoms that impact a person's quality of life, such as pain, nausea, insomnia, cognitive changes, and other physical symptoms caused by brain cancer or its treatment
- To treat a patient's emotional and social needs, including symptoms such as anxiety or helping with difficult family relationships
- To address a patient's spiritual needs or concerns
- To address a patient's practical needs, such as transportation and financial concerns
- To provide support for the patient's family, friends, and caregivers

MANAGING LATE EFFECTS

Treatment, and managing a brain tumor, can feel like a long haul. "Late effects" happen well after treatment is over, and they can vary for people based on age, general health, tumor type, and location.

Late effects to manage with help from your medical or palliative care team can include:

- Physical disabilities
- Learning and cognitive disabilities
- Behavioral changes and emotional issues
- Hormonal problems including diabetes and infertility
- Damage to internal organs or other body systems from treatment

Your medical team has strategies to help. Palliative care options can also relieve discomfort and provide extra assistance to families as they manage day-to-day stressors. When a caregiver needs help, sometimes family, friends, or paid professionals can also step in (See Chapter 4 and 7).

HOSPICE

High grade brain cancer typically cannot be cured and deciding when to stop aggressive treatment is difficult. Caregivers don't have to manage this decision alone.

When a person is unlikely to live longer than six months, hospice care is often recommended. It involves the care of all aspects of a patient and family's needs, including the physical (i.e., pain relief), psychological, social, and spiritual aspects of suffering. It does not typically involve "heroic measures" to keep a patient alive (for example, it may not provide fluids or nutrition).

Hospice is about comfort. This care may be given at home, in a nursing home or at a hospice facility. Usually multiple care providers are involved, including a physician, registered nurse, nursing aide, a chaplain or religious leader, a social worker, and volunteers.

Hospice providers work together to support the caregiver, meet the patient and family's needs, and significantly reduce suffering for everyone. Hospice care doesn't end when a patient dies – it remains as a service for the family members left behind, to aid in their grieving and to help them get back on their feet.



For more information about hospice, go to www.hospicenet.org.

I appreciate knowing that I can call someplace like the Cancer Support Community's hotline to talk to someone – People around you love you so much, but they can't fix it.

— Candice, caregiver



It is important to explore what a patient hopes for. Is it: freedom from pain or other physical symptoms, independence for as long as possible, participating in a family event or gathering, making peace in a troubled relationship, dying with dignity? What people hope for frequently changes throughout life, but rarely does anyone stop hoping.

— Deanna Glass-Macenka, RN

Managing Common Side Effects

CHAPTER 4 / MANAGING COMMON SIDE EFFECTS	31
Location matters	32
Learn what to expect after your treatment.....	34
Rehabilitating physical symptoms	35
Headaches.....	36
Seizures	36
Blood counts	38
Gastrointestinal (GI) problems	38
Fatigue.....	39
Cognitive and behavioral changes	40
Anxiety and depression.....	42
Hormonal changes, fertility and sexuality	43
Complementary or alternative medicine (CAM)	44

Managing Common Side Effects

Not everyone experiences the same side effects, but this information is here to help if you experience any of these more common problems. You can keep notes about how you feel and work closely with your doctors and nurses to find the best ways to feel better.



THINGS TO REMEMBER

- Your symptoms are linked to the location of the tumor in your brain, and result from your treatments.
- There are ways to relieve symptoms and side effects, but this process is not perfect and it requires time and patience.
- Rehabilitation specialists (physical, speech and occupational therapists) can be terrific help. Try to find a team that is experienced in working with brain tumor patients.
- Keep track of how you feel (or ask someone to keep notes for you.) Aim to bring your notes to appointments to help you remember what you'd like to discuss.
- Many cognitive symptoms (memory loss, anger, anxiety or depression) not only affect you, but also people close to you.
- Try to be patient with yourself and with others as you strive for a higher quality of life.
- Licensed social workers and support groups can help as you cope with depression, anxiety, or other changes in your life. (See Chapter 5 for more.)
- Complementary or alternative medical techniques, such as diet changes, exercise, or relaxation techniques, may also help you feel better.

LOCATION MATTERS

As a brain tumor grows, it presses on the surrounding brain tissue, which affects the function controlled by that part of the brain. This chart shows symptoms that can be caused by tumors in different parts of the brain and the spinal cord.

LOCATION OF THE TUMOR	SYMPTOMS
Frontal lobe	<ul style="list-style-type: none">• Changes in personality• Loss of inhibitions, behaving aggressively• Losing interest in life (apathy)• Difficulty with planning and organizing• Being irritable• Weakness in part of the face, or on one side of the body• Difficulty walking• Loss of sense of smell• Problems with vision or speech
Temporal lobe	<ul style="list-style-type: none">• Forgetting words• Short term memory loss• Seizures associated with strange feelings, smells
Parietal lobe	<ul style="list-style-type: none">• Difficulty speaking or understanding what is said to you• Problems with reading or writing• Loss of feeling in part of the body
Occipital lobe	<ul style="list-style-type: none">• Sight problems or loss of vision on one side
Hindbrain (cerebellum)	<ul style="list-style-type: none">• Poor coordination• Uncontrolled movement of the eyes• Nausea and vomiting• Neck stiffness• Dizziness

LOCATION OF THE TUMOR	SYMPTOMS
Brain stem	<ul style="list-style-type: none"> Poor coordination Drooping eyelid or mouth on one side Difficulty swallowing Difficulty speaking Seeing double
Spinal cord	<ul style="list-style-type: none"> Pain Numbness in part of the body Weakness in the legs or arms Loss of control of the bladder or bowel Difficulty walking
Pituitary gland	<ul style="list-style-type: none"> Irregular or infrequent periods Infertility in men and women, impotence Lack of energy Weight gain Mood swings High blood pressure Diabetes Enlarged hands and feet
Nerves controlling sight or hearing	<ul style="list-style-type: none"> Blurry vision Hearing loss
Meninges	<ul style="list-style-type: none"> Headache Nausea and vomiting Sight problems Neck pain

Adapted from Cancer Research UK. www.cancerresearchuk.org



QUESTIONS TO ASK ABOUT SIDE EFFECTS

- What side effects should I expect?
- When should I call you for immediate help? (With which side effects?)
- What can I do to manage my side effects? Can you help me create a management plan?
- How do you recommend I keep track of how I feel, and what do you need to know?
- What can I do to feel better?

LEARN WHAT TO EXPECT AFTER YOUR TREATMENT

After any surgery or cancer treatment, it is not unusual to feel worse than you did before. Though this is temporary, it can be depressing. Brain surgery is a lot for your body to cope with. Swelling in the brain after an operation means it will take some time before you feel the benefit from having your tumor removed.

You may experience dizzy spells or get confused about where you are and what's happening. These episodes can come and go. This is normal and part of the recovery period.

For some people, recovery may be complete after a few weeks or months; for others, you may have to learn to adjust and manage permanent changes in your life including not being able to work or accomplish all of the tasks you did before. Your surgeon can give you some idea, *but ask as many questions as you can about what to expect for your recovery.*

It was hard to see Archie's heart break when he couldn't express himself. It was hard for me to receive text messages that made no sense. Practice is critical. Archie is a published author, but he had to relearn so much. I just wanted him to be patient with himself. So he would practice, and say words over and over again until he got it right.

— Sarah, caregiver



REHABILITATING PHYSICAL SYMPTOMS

People who experience a variety of physical symptoms including weakness, difficulty speaking, stiffness, problems with movement, etc. can benefit from various forms of rehabilitative treatment. Every person with a brain tumor deserves to function as optimally as possible, so patients should be evaluated for successful rehabilitation treatment.

Physical, occupational, and speech therapists are experts in this area – and ideally, you can work with professionals who are experienced in working with brain tumor patients and/or neurological disorders (rather than sports injuries, for example):

- **Physical therapists** help patients improve their walking, balance and strength. Some people experience permanent mobility problems. Physical or occupational therapists will offer exercises to support your range of motion and make sure your body has proper positioning to help decrease pain and freezing of the limb(s) as much as possible.

- **Occupational therapists** teach patients how to manage their side effects so that they can go about their lives and perform daily activities, such as cooking, writing, and driving.

- **Speech therapists** help people overcome problems understanding and producing language. Speech therapists also help with eating and swallowing caused when there are oral motor problems. They teach patients how to improve their speech process and adjust how they verbalize or otherwise express themselves.

If you need them, there are assistive devices and exercises that can be prescribed by rehabilitation specialists. Handrails and grab bars, and bath or shower chairs are some. There are also tools and tips to help with eating and dressing, and to help a person maintain computer access and independence. Keeping track of issues and talking regularly with rehabilitation specialists can help you get the support you need.

It is also useful to know about the federal and state programs that link people with services, technology, and funding. For example, the Americans with Disabilities Act helps people who experience a disability due to illness, like a brain tumor, but want to go back to work with reasonable accommodations. (Chapter 6 offers more information, or visit www.govbenefits.gov, or www.abledata.com.)



QUESTIONS ABOUT REHABILITATION SERVICES

1. How long do you estimate that I will need rehabilitation services?
2. Do I have insurance benefits for rehabilitation? If so, what will it cover?
3. If I haven't met my rehabilitation goals before my insurance benefit runs out, how will that be handled?

HEADACHES

Headaches are most often caused by edema (swelling of the brain caused by the tumor or treatment). Steroids may be prescribed to reduce edema. Unfortunately, steroids can cause their own set of problems (difficulty sleeping, sweating, over-eating, agitation). If you take steroids, be clear with your medical team and tell them if you experience sleeplessness or other new symptoms so they can adjust the dose.

Some headaches are connected with symptoms such as dizziness, nausea, or vomiting, often because of where the tumor is located in the brain. The surgical removal of the tumor will often relieve those headaches; and post-operative headaches often go away after a short period of time.

If headaches persist, you should be evaluated. If headaches return, it could be a sign of recurrent edema or a new tumor and should be addressed by your treatment team.

SEIZURES

A seizure is a sudden attack or convulsion caused by an abnormal burst of electrical activity in the brain. It can cause a range of reactions, from muscle contractions, to staring, to loss of consciousness.

Some people only experience one seizure while others suffer from reoccurring seizures, or epilepsy. Seizures are common with slow-growing gliomas, meningiomas, and metastatic brain tumors.

- **Simple Partial Seizures** can cause involuntary jerking, tingling or numbness in one part of the body, buzzing in the ears, lip smacking, and dilated pupils.

- **Complex Partial Seizures** cause altered consciousness. A patient may be aware of his or her surroundings but unable to speak, or may feel confused and hallucinate (imagining sights, odors, and sounds).

- **Generalized Seizures** are also called grand mal seizures. They begin with a sudden loss of physical control with flailing arms and legs, unconsciousness, twitching muscles, and incontinence, or shallow breathing. Afterward, the patient may be limp or confused.

Patients who suffer from multiple seizures can keep a journal of when and for how long the seizures occur. The doctor can then find a pattern and adjust antiepileptic drugs to help.

A patient may be put on an antiepileptic or antiseizure drug if he or she experiences a seizure or to prevent seizures. The type and amount of medication is based on the level of seizure control needed and how well you react to the medication.

Some AEDs react badly with certain chemotherapy drugs and should not be used together. If side effects are a serious problem, a doctor can change the medication.

If you are aware of AED medications, or other medications that you should not take or react badly to, it is helpful to consider wearing a [medical alert bracelet](#) with this information.



Patients who suffer from multiple seizures can keep a journal of when and for how long the seizures occur. The doctor can then find a pattern and adjust **antiepileptic drugs** to help.



HELPING SOMEONE WHEN THEY HAVE A SEIZURE

If someone is experiencing a seizure, stay with them and allow the seizure to pass. This can take a few seconds to a few minutes. Loosen any tight clothing if possible, and make sure they are breathing. Try to remove or cushion harmful objects to prevent injury, and do not put anything in their mouth.

Call for emergency help if the seizure lasts longer than five minutes, if a second seizure immediately follows, or if the person has trouble breathing or is injured.

BLOOD COUNTS

Anemia is when red blood cell (RBCs) levels are unusually low. RBCs are important because they contain hemoglobin which allows the oxygen exchange to occur as blood circulates through our bodies. Low RBC levels lead to fatigue or symptoms like dizziness, or shortness of breath. If anemia becomes severe, it can be treated with medications or with a blood transfusion.

Leukopenia is when white blood cells (WBCs) are unusually low. WBCs are important because they help to fight infection. Chemotherapy can affect your ability to maintain adequate amounts of WBCs. Steroids can also lower certain WBCs, called lymphocytes. Your doctor may prescribe antibiotics to help protect you.

Thrombocytopenia is when the level of thrombocytes or platelets is unusually low. Platelets are important for our blood to clot. Chemotherapy can decrease the production of these cells, and when they fall too low we are at risk for spontaneous

bleeding. If thrombocytopenia becomes too severe, platelet transfusions may be necessary.

Thrombosis is the formation of blood clots as a result of increased clotting factors in the blood. With deep vein thrombosis, blood clots form in the legs and disrupt the flow of blood, causing pain or swelling in the calf, behind the knee, or in the thigh. If blood clots break loose and block blood vessels in the lung, it is called pulmonary embolus (PE), which requires immediate medical attention. DVT and PE may occur at any time after brain tumor surgery, especially when a patient is not physically active. Patients and caregivers need to be aware of DVT symptoms and call the doctor immediately if they have concerns.

Staying active and walking as much as possible is the best way to prevent DVT. Compression stockings and medication to thin the blood are also used for prevention.

GASTROINTESTINAL (GI) PROBLEMS

GI problems can include any difficulty with digestion or stomach discomfort. Chemotherapy is well known for causing GI problems.



TIPS TO RELIEVE CONSTIPATION

- Eat more fiber-rich foods (whole grains, fruits and vegetables)
- Increase physical activity
- Consider laxatives
- Drink more water

FATIGUE



TIPS TO RELIEVE NAUSEA AND VOMITING

- Antinausea medications called antiemetics may help
- Diet changes are useful. For example, when you don't feel like eating, try frequent healthy snacks rather than large meals
- Bland foods, crackers, and clear liquids between meals may be better tolerated
- Avoid foods with strong odors, heavy spice, alcohol, and greasy or fried foods
- Suck on a lemon drop candy to relieve nausea

Feeling exhausted or extremely tired is the most common side effect reported by patients.

Fatigue is not relieved by a good night's sleep; it can last for a short time or for many years. It is caused by many things, from tumor treatments to the tumor itself, to the healing process, to poor sleep, stress, or anemia. Fatigue is considered to be one of the most debilitating symptoms and side effects of a brain tumor because it limits a person's ability to function.

No matter what the cause, fatigue can be managed. The goal is to conserve energy so you can focus on doing the things that are important to you.



TIPS TO MANAGE FATIGUE

- Try to establish a daily routine
- Listen to your body. Rest when you need to
- Mild exercise will help give you more energy
- Make lists of things you need to do and recruit help
- Make plans to get things done during the time of day when you have the most energy
- If one reason for your fatigue is anemia (a low level of red-blood cells), seek medication to increase the level of your red blood cells
- Ask if drugs, like Provigil, may help reduce fatigue

COGNITIVE AND BEHAVIORAL CHANGES

A brain tumor and its treatment(s) can cause changes in a person's behavior and ability to think. Patients may experience difficulties with their communication, concentration, memory, and their personality may change.

These difficulties may affect a patient's ability to work or go about his/her daily life, and they do not always go away. This can cause stress for both the patient and his or her family.

Medication may be prescribed to reduce problems with cognitive and behavioral changes, and counseling may help a patient recognize when they are experiencing cognitive problems.

More tools to cope with cognitive and behavioral changes include:

Cognitive Rehabilitation

Cognitive rehabilitation is designed to help people regain as much of their mental, physical and emotional abilities as possible.

• **Compensation techniques** are methods to develop alternate skills to make up for those that have been lost, such as exercises to strengthen sight, speech, and movement. When full recovery is not possible, treatment includes compensation techniques like learning to live with memory loss by keeping calendars, reminder systems, and organizers. Neuropsychologists are cognitive experts that can help identify compensation solutions or offer medications to enhance mental functioning (for example, Ritalin).

• **Anger management training, counseling or medication** can help a patient who experiences behavioral and personality changes such as impulsiveness, frustration, or moodiness.

Caregivers and/or family members also benefit from compensation techniques. Often, a caregiver feels frustrated ("Why can't [the patient] do a simple task?") and angry ("He/She's driving me nuts!"). Mixed emotions towards a loved one are common. These feelings make home life very complicated – especially as people with brain tumors live longer in a cognitively impaired state. It is important that a caregiver has help or compensation strategies that he/she can use to maintain the high level of patience that is required. (See Chapter 7)

EXERCISE YOUR BRAIN

PLAY TO YOUR STRENGTHS.

Use memory tools to help you remember. Sticky notes, lists, and always putting your keys in the same place help take the burden off your memory systems. Tools (notebooks, calendars) can also help you remember.

CHALLENGE YOURSELF IF YOU CAN.

Puzzles, games, playing an instrument, and reading all help to improve your memory and thinking abilities. Be patient with yourself.

GET ENOUGH SLEEP.

Your body needs 7-9 hours of sleep per day. When you're recovering from brain surgery, you will want even more sleep. Take cat-naps during the day if you're having trouble with sleep during the night.

PRACTICE RELAXATION.

Remember that stress plays a large role in memory. Relax using yoga, meditation, exercise, and other techniques.



EXERCISE YOUR BODY.

Even light exercise greatly improves mental performance by bringing oxygen and nutrients to your brain.

EAT RIGHT.

Focus on eating fruits and vegetables. Keeping your blood sugar normal improves mental performance. Adding essential fatty acids (Omega 3s from fish and flax seed), B-Vitamins, and Amino acids will also help.

ADJUST MEDICATIONS.

If you think that your memory problems may be worsened by something you're taking, ask your doctor.



At first I didn't realize how much self-esteem I'd lost. I'm in cognitive therapy now and it's like psychotherapy.

Three weeks in and I feel better mentally at work, and I've noticed a difference in myself.

— Darren, patient

ANXIETY AND DEPRESSION

Anxiety is a normal response to new and stressful situations. Feeling anxious from the diagnosis or from medications that increase agitation may make every situation feel even more intense. Common symptoms of anxiety include: rapid heartbeat, fear, restlessness, nervousness, and sweaty palms.

If you are feeling anxious it is important to talk about your feelings and concerns, and to find ways to regain a sense of control in your life.

Often, depression and anxiety go together. Depression is common in people with brain tumors. People who feel depressed experience a sense of irritability, hopelessness, an inability to concentrate, apathy, withdrawal, and mood swings – sometimes a desire to harm themselves. While many of these symptoms can be attributed to a tumor, depression can and should be treated on its own.



TIPS TO COPE WITH EMOTIONAL DISTRESS

- Talk with friends, family, or spiritual advisors about your feelings and fears
- Make an appointment with a counselor, therapist, or psychiatrist for help
- Join a support group or call a cancer outreach program
- Ask your doctor about medications that can help
- Try to solve only one problem at a time
- Use relaxation techniques to reduce your body's sensation of stress or anxiety
- Focus on living in the moment

Treatments include antidepressant medication and counseling. Just talking about how you feel with someone skilled in relieving emotional problems can help make you feel better.

Most people note that their mood improves as the symptoms of a brain tumor or side effects from treatment are managed and go away.



WAYS TO FIND A TRAINED COUNSELOR

- Ask your doctor for an oncology social worker referral (a counselor who specializes in cancer)
- Request to talk with the psychiatric liaison nurse in your treatment center
- Contact the Cancer Support Community or other cancer support organizations poised to help (see resources section)
- Contact your insurance company's mental health service for a referral

HORMONAL CHANGES, FERTILITY AND SEXUALITY

Hormonal Changes

Changes in hormones and endocrine function may result from a tumor found in or near the hypothalamus, pituitary or pineal glands, or as a delayed effect of radiation therapy. If left untreated, hormone disruptions can become a disturbing, chronic problem that causes mood and personality changes, as well as sexual dysfunction. These conditions require specialized treatment and monitoring by an endocrinologist.



TIPS TO RESTORE INTIMACY

- Communication is essential. To feel connected with your partner, consider how he/she "hears" what you want to say
- Find ways to feel more attractive to yourself, and in turn, to your partner
- Be open to discovering new ways that you and your partner can connect and feel close
- Remember to make small, intimate gestures, like a smile, a touch, or a hug
- Look online for the American Cancer Society's booklet on sexuality and intimacy after cancer (www.cancer.org)

Fertility

Many of the treatments used for brain tumors can impact a person's fertility either temporarily or permanently. Options are available for people who wish to get pregnant after treatment, but you must speak up before treatment begins to consider sperm or egg banking, or tissue freezing. Insurance coverage is not consistent for these things, so ask your insurance company what's covered before you begin.

Sexuality

Changes in sexuality from treatment or a tumor can result from a decreased libido, fatigue, changes in self-image (from the surgery and treatment). Many people don't feel comfortable talking about this problem with their doctor, although it might be important to do so. Consider that your doctor or nurse may have helpful suggestions and advice.

Complementary or Alternative Medicine (CAM)

The medical community is increasingly recommending complementary medical techniques to relieve symptoms for brain tumor patients. CAM is primarily used to relieve side effects and stress.

The most common CAM techniques are: eating a plant-based diet, relaxation, exercise, acupuncture, chiropractic, guided imagery or meditation, healing touch (such as Reiki), herbal medicine, and massage therapy. If you choose to use a CAM approach, then it is important to inform your medical team. In some cases, CAM practices could impact the way traditional cancer treatment is provided, so it's a good idea to keep your medical team informed about your entire system of care.



To learn more about CAM, look for information on the National Center for Complementary and Alternative Medicine's website: nccam.nih.gov.

DIET AND NUTRITION

The purpose of a nutritious diet is to provide energy and to improve immune functioning. Most often, people are asked to eat more plant-based foods (vegetables, fruits, beans and whole grains) – while avoiding or minimizing processed foods, refined sugars, meat and cheese. A plant-based diet has been shown to improve our body's ability to fight disease, reduce blood pressure, reduce cholesterol, and improve overall health. Avoiding cured food (like deli meat or salted chips) and eating more whole foods high in antioxidant vitamins may lessen the risk of developing additional cancer – and over time – improve your body's ability to fight the cancer you have.

There are some worthy diet recommendations available, such as in *Eat to Live* by Joel Fuhrman, MD, or *Eating Hints: Before, During, and After Cancer Treatment* by the National Cancer Institute. Under all circumstances, it is best to eat whatever food you can tolerate. Talk to a dietician educated in working with cancer patients, and ask your neurologist if a diet you'd like to use is safe for you.

EXERCISE

The goal of exercise is to enhance—rather than deplete—energy, strength, and vitality. It helps you breathe properly and increases your lung capacity, which in turn benefits the immune system. It also improves muscle strength and heart health. Patients who must take steroids for long periods of time minimize damage to muscle strength with exercise. Several studies have shown that exercise can help people have better treatment outcomes, as well as secondary psychological benefits.

Exercise can be simple, or more intense, depending on your ability. You can start with walking, light weightlifting, or practices such as Tai Chi, yoga, or Pilates. It is helpful to start slowly with a goal to build up your energy level and abilities.

HEALTHY EATING TIPS

30-60% Vegetables
1/2 Raw, 1/2 Cooked

10-40% Fruits

10-40% Beans/Legumes

10-20% Seeds, Nuts, Whole Grains

5-10% Fish, Eggs, Poultry, Dairy

1-5% Beef, Sweets, Cheese, Processed Foods

GREAT FOODS TO EAT

- raw and cooked colorful vegetables: dark green, deep yellow, orange, red, or purple
- raw and cooked lightly colored vegetables: cauliflower, mushrooms, onions, cucumber, lettuce
- raw and cooked starchy vegetables: squash, potatoes, corn
- fresh and dried fruits, avocado
- nuts, seeds and oats
- tofu and beans

STAY HYDRATED

- water
- fruit juice
- coconut, almond, or rice milk
- decaffeinated tea
- fruit smoothies

FOODS TO LIMIT

- cured meats
- red meat
- alcohol
- sugary sweets
- processed foods with food coloring and saturated fats
- fried foods
- cheese

Our dietician was so helpful. She gave Darren tips to feel more energy, tips to get more liquid into his diet when he was dehydrated, tips to address lots of side effects. And it works. ...It's funny, we thought we ate healthy before, but the dietician showed us how we really ate! Now we do better.

— Carrmen and Darren, caregiver and patient





*I hate that phrase,
“live like you’re dying” -
I say: Live like you’re
alive, and re-think
what your definition
of alive is.*

— Tony, patient

Quality of Life

CHAPTER 5 / QUALITY OF LIFE.....	47
Coping with your diagnosis	48
The value of support	49
Relationships.....	51
Spirituality.....	53
Making plans for the future.....	54

Quality of Life

Generally, people who are well informed about their illness, treatment, and resources for support are more able to make decisions that take into account their quality of life and overall wellbeing.



THINGS TO REMEMBER

- You and your loved ones can learn to adjust to a new perspective on life.
- When problems arise, consider active coping strategies (see p. 48), to identify solutions that you can live with.
- Value support from others with experience.
- Take the time you need to experience your grief.
- Think about how to get help for your immediate caregivers, to avoid them from "burning-out."
- Find a sense of peace and meaning in your life by tapping into your spirituality and/or other things that bring you comfort.
- Make plans for the future, with realistic intentions and without regret.

COPING WITH YOUR DIAGNOSIS

When you feel overwhelmed about your diagnosis (or any problem for that matter), it's useful to think about how you react in difficult situations. Many people find that an "active" coping style reduces stress and improves their focus when they try to solve serious problems.

When you are making treatment decisions and learning how to manage your diagnosis, consider your quality of life. You have to define what "quality" means to you, then take reasonable steps to bring you closer to your quality of life goals.

It helps to recognize that you don't have to sort everything out at once. It may take some time to deal with each issue that you face, so ask for help if you need it. It is likely that your doctor or nurse will know who you can contact for additional support.



ACTIVE COPING

- Define the problem: break it into smaller parts
- Decide which elements of the problem you can control, and which you can't
- Look for advice and information to address the problem
- Make a plan and take action to deal with the problem
- If the problem cannot be solved, try to adopt a new perspective to make it an issue you can live with
- Acknowledge your feelings
- Find a support group or counselor
- Build relaxation into your schedule (Yoga, exercise, music, reading)

Coping with the Fear of Recurrence

The risk of recurrence is one issue that people diagnosed with a brain tumor genuinely fear. The goal of treatment is, most often, to prevent recurrence for as long as possible, but for how long is unknown.

One of the best safeguards for your quality of life is to be familiar with and follow the post-treatment monitoring plan set by your medical team. The earlier a problem is detected, the more options you may have for re-treatment. If additional treatment is suggested, consider the possible risks and benefits of treatment, and it's often helpful to get a second or even third opinion before deciding what to do.

One of the hardest realities for most of us is the unknown. When you allow thoughts of tumor recurrence to disturb your ability to enjoy life, or to depress you, then it's time to get help.

THE VALUE OF SUPPORT

By developing a new perspective on life, no matter how awkward or foreign it may initially feel, it has helped many people come to terms with the unknowns in their lives. They may find peace and new meaning. They realize they may need to shift priorities and focus on ways to enjoy life, and each moment in it, differently.

It sounds cliché, but if you can focus on keeping a healthy lifestyle and spending more time doing things that make you and others in your life feel happy, it makes a difference, and can push the fear of recurrence away. It's valuable to focus on what you can control, such as your highest quality of life, rather than to focus on what you can't control, such as cancer recurrence.

How you feel can have implications on your quality of life and the way you experience your diagnosis. It's important to stay in touch with your feelings and seek support when you need it.



EXPRESSING YOUR EMOTIONS CAN

- Decrease anger or feelings of hostility
- Improve self-confidence and assertiveness
- Improve feelings of empathy, interest, and humor
- Improve energy (reduce fatigue)
- Improve overall quality of life

Get the Support you Need

There are many ways to get the support you need. Part of the challenge is accepting that you'd like support, and that it's okay. If you already have people you can talk with and lean on, use them. If you'd like to find people who understand, seek them out. Knowing that you have people to talk with about difficult emotions is essential when coping with a brain tumor.

Support Groups

No one understands the experience of someone affected by a brain tumor more completely than somebody else in the same situation. That is the basis of support groups.

Support groups serve several functions. They give patients and families opportunities to talk with knowledgeable people, including health care professionals, who can educate them and provide information about their disease.

They offer emotional support and practical insight to help cope with the crisis of a brain tumor diagnosis. And they can smooth the transitions that patients and families must make as they deal with unfamiliar environments, such as hospitals and outpatient clinics.

Professional Counseling

Many people benefit from personalized help in dealing with emotional stressors. To find a counselor or psychiatrist with experience in helping people with cancer, specifically brain cancer, again ask your doctor or nurse. Often, the treatment center's social worker or a spiritual leader can offer guidance at no additional cost.

GREAT RESOURCES FOR SUPPORT GROUPS

For more information on support groups, talk with the social worker or nurse at your treatment center or ask:

- **National Brain Tumor Society**
www.brainumor.org
NBTS offers information about one-on-one and online support specifically for brain tumor patients with links to several other organizations that can help.
- **T.H.E. Brain Trust**
www.braintrust.org
T.H.E. Brain Trust offers a large variety of online support groups for specific brain tumor types and caregivers.
- **Imerman Angels One-On-One Cancer Support**
1-877-274-5529
www.imermanangels.org
Imerman Angels carefully matches a person touched by cancer with someone who has fought and survived the same type of cancer. Personalized matches are also provided for cancer caregivers.
- **Cancer Support Community**
1-888-793-9355
www.cancersupportcommunity.org
CSC offers on-site or online support groups for a variety of cancer types and caregivers.
- **American Cancer Society**
www.cancer.org/treatment/supportprogramsservices/index
ACS offers a search tool to find cancer support groups located in or near your zip code area.
- **American Brain Tumor Association**
www.abta.org
ABTA offers a list of brain tumor support groups by state, with a zip code search.
- **Musella Foundation**
www.virtualtrials.com/lists.cfm
Musella Foundation offers online support groups for people affected by brain tumors.

RELATIONSHIPS

Talking about your Diagnosis

Many people, understandably, find it difficult to talk about their diagnosis with others. First you'll have to decide who you need to tell – and what you want to tell. You may decide that you have different groups of people that you'll talk with about different things. It can help you feel better, and the people you talk with will also feel good as they find ways to help and support you.

There are people who will be directly affected by your experience (family members, close friends, your boss). These people should know what you're going through so they understand the stressors that you must face, and the schedule changes that you'll experience.

Children sense and know more than adults often give them credit for. Children will overhear telephone conversations, pick up their parents' anxiety, blame themselves, and fear the worst if they are given no information. When a parent has a brain tumor, the natural desire is to protect the children through silence – but that usually backfires and makes things worse.

Young children up to the age of eight will not need a great deal of detailed information; older children and adolescents will need to know more. In a two-parent household, try to talk to each other first, to determine the best way to talk to your children. If single parents are feeling a bit anxious about the conversation, they may want to ask a relative or friend to be present.

Although no one wants to alarm children, there is nothing wrong with crying when a crisis happens. Crying is normal and healthy.



QUESTIONS ABOUT HEREDITY

Only 5-10% of brain cancers are hereditary. If you have questions about your family history, we suggest the following:

- If you have multiple family members diagnosed with brain tumors or have concerns about starting a family after having a brain tumor yourself, consider a consultation with a genetic counselor. He or she can access the latest genetic information related to the specific tumor type in your family and advise you accordingly.
- Share your family's medical history with your kids and help them become good medical historians as their own future health is monitored.

How your Diagnosis Impacts Others

Different people will react differently to your news; some will be eager to help, while others will withdraw and not know what to do.

It is not uncommon for a serious diagnosis to produce changes in personal relationships. This is because it is stressful, because brain tumors can change a person's personality, and because they can leave people unable to function the way they used to. Relatives and close friends may find behavioral changes hard to deal with.

On the other hand, many feel that their marriage or relationship is strengthened through the process of dealing with a crisis together. They are grateful to have each other's support.

When friends and family want to help, it can be useful to put together a list of tasks that are easy to delegate. Be specific about what you need: a drive, help with shopping, help making phone calls.

Keep in mind that most people offering help are eager to do something—and by allowing them to be supportive, they will feel appreciated. Similarly, it's important not to over-use supportive people; take note of when they need a break.

As a caregiver, it's important to know that your loved one may not be aware of how their behavior impacts you. You must be able to find the support you need to take care of yourself. You will need all the strength you can get.

— Candice, caregiver



SPIRITUALITY

Humor

Is a brain tumor humorous? No, but learning to laugh at life's challenges has been shown to help people cope better with difficult situations. Being able to find humor in life can be calming when dealing with a brain tumor diagnosis.

Humor therapy is an actual science. It is used to improve quality of life, provide pain relief, encourage relaxation, and reduce stress. The physical effects of laughter include increased breathing, increased oxygen use, short-term changes in hormones and certain neurotransmitters, and increased heart rate.

Most often, finding the humor in life is something you and your friends can focus on anywhere, anytime.

The crisis of a brain tumor diagnosis often helps people gain insight into their beliefs and spirituality. Each of us holds beliefs about life, its meaning, and its value, whether we participate in a religious tradition or not. Prayer may be comforting and help you feel less alone.

Some people find comfort in their spiritual beliefs while others question their faith, possibly feeling distressed by the idea that the illness might be a punishment for some past sin or lack of faith. Having doubts and being angry are normal responses.

It can be helpful to talk to your pastor, rabbi, imam, or a spiritual counselor in your community. Members of religious and spiritual communities also may provide practical help, such as assistance with transportation, meals, and visitation services.

MAKING PLANS FOR THE FUTURE

Hope is a powerful concept and coping strategy that empowers people to look beyond the moment and into the future. Your sense of "hope" can change over time. It's not about being positive all of the time, but about trying to view things from a positive perspective as much as possible.

When you make plans for the future, keep hope in mind. Make reasonable plans based on your well-being at the time. Patience is important. Simple plans can be appreciated just as much as larger goals for the future.



GAIN A NEW PERSPECTIVE...

- Remember to do things that make you happy
- Spend more positive time with family, friends, and loved ones
- Seek a more meaningful job
- Volunteer to help others (like becoming a brain tumor advocate)
- Focus on your health: quit smoking, eat better, exercise more
- Become more spiritual, whatever that looks like for you

If has been six years since my diagnosis and treatment. I have dedicated my life to helping those going through cancer or caring for someone going through cancer. There is so much that a person like myself can do to help.

— Greg (from the National Brain Tumor Society's Story Corner)



GET INVOLVED TO HELP OTHERS

National Brain Tumor Society, www.braintumor.org
Accelerate Brain Cancer Cure, www.abc2.org
Imerman Angels, www.imermanangels.org



There's a lot we can do, so I'm ready to fight and keep fighting with Darren. We're in this together.

— Carmen, caregiver

Practical Considerations

CHAPTER 6 / PRACTICAL CONSIDERATIONS.....	55
Going back to work	56
Talking with your employer	57
Employment laws and financial support	58
Managing medical costs.....	59
Considering private home care and long term care	60
Practical, legal, and estate planning.....	61
Death and dying.....	62
Your caregivers.....	62

Practical Considerations

There's so much more to consider than treatment and recovery. There's work, finances, family, and the future. What's really important to you and what isn't? What do you need to do now and what can you do later?



THINGS TO REMEMBER

- Going back to work is a practical and personal decision.
- Review your goals, perspective or abilities after a brain tumor diagnosis.
- There are federal laws and supports that can protect someone with cancer from losing their job due to new disabilities.
- Aim to manage medical costs in an organized and informed way.
- Making practical end-of-life plans helps everyone, whether healthy or ill. If you don't already have a will and advanced directives in place, consider making these plans now.
- You can gain control over the future and make plans that give everyone involved a sense of peace.
- Caregiving is a difficult job. People who need help should be aware of how their caregiver is coping and aim to find balance with everyone's changing role.

GOING BACK TO WORK

There is not one "right" answer about working full-time, part-time, or not at all during or after treatment. This is a practical decision, based on your needs, abilities, and personal preferences. Some people make a complete recovery from their brain tumor while others have lasting effects. It isn't always possible to know how things will turn out.

Your health care team can suggest how your treatment and prognosis might affect your ability to work, so it can help to talk with them about your job and your work-based priorities through treatment and recovery. Consider what's best for you at each point in your experience.

If you hold a job where your mental skills are important, or where your strength is needed for heavy machinery, you may not be able to continue at the same level. This can feel devastating.

Sometimes an employer can arrange for you to take on another role until you are fully better, or you may ask to go back to work part-time until you regain your strength.

It will take time to come to terms with career changes, and to determine what you would like to do next. If you think you'll need to choose a different type of work or need financial guidance, then it may be useful to see a social worker or counselor for help.



THINGS TO CONSIDER ABOUT WORK

- Do I enjoy my work and/or find it a welcome distraction?
- Have my career priorities changed?
- What does my health care team recommend?
- Can I complete my work functions while in treatment?
- What should I expect about my abilities and side effects after treatment?
- How much sick leave do I have?
- Am I eligible for the Family Medical Leave Act if I need to take time off?
- Does my state offer short-term disability insurance? Or can I receive disability insurance payments through my employer or private insurance?
- Will I qualify for long-term Social Security Disability Insurance (SSDI)? If so, do I have savings to carry me through the 5-6 month waiting period?
- If I decide to stop work temporarily, how will this affect me and others?
- If I decide to stop work, what will I need to do to keep health insurance?

TALKING WITH YOUR EMPLOYER

How much you tell an employer about your health is an individual decision. Some people find it helpful to tell their employers about their diagnosis, while others wish to keep it private. Do whatever feels right to you.

An advantage to letting your boss know is that it may be less stressful when you need to rearrange your work schedule or miss a substantial amount of time at work. As long as you can do your work, there are laws to protect you from discrimination due to a brain tumor diagnosis.

No matter what type of relationship you have with your boss, it's good practice to keep records of your conversations regarding your diagnosis. If you request accommodations for your work, ask for this in writing. You may also want to make a copy of any recent performance reviews and any positive statements about your work.

Make note of anything that could indicate discrimination. In the unlikely event that you have problems with your employer in the future, careful records can prove invaluable in your defense. Your state's fair employment agency can help you with additional questions.



If you go back to work with a scar on your head, people are going to question not only how you're doing, but also your work product. You have the burden of proving that you're healthy and proving that you're competent. I think that takes a toll on you... especially because things aren't exactly the same.

— Archie, patient

Employment Laws and Financial Support

AMERICANS WITH DISABILITIES ACT (ADA)

The ADA is a federal law that protects workers with a disability (including a brain tumor and/or effects of treatment) against discrimination as long as a worker can complete his/her job. The law requires that employers make **reasonable accommodations** so people with disabilities can function. This might include modifying a work schedule or making the physical workplace accessible with things like hand rails or tools for hearing loss. You can ask your medical team about accommodations if you need them.

FAMILY AND MEDICAL LEAVE ACT (FMLA)

The FMLA entitles eligible employees to take up to 12 workweeks of unpaid, job and benefit-protected leave in a 12-month period for specified family and medical reasons. FMLA covers time to care for a spouse, parent or minor child with a serious health condition, or to take personal medical leave. This law only applies when an employer has 50 or more people employed within 75 miles, and when a worker has worked for at least 1,250 hours during the past year.

The law does say that when leave is needed for planned medical treatment, the employee must make a reasonable effort to schedule treatment in a way that won't disrupt the employer's operation.

If you have questions about these and other benefits, such as **Employer Sponsored Insurance** provided by your employer, you should discuss this specifically with your boss and/or your human resources department.

SOCIAL SECURITY DISABILITY INSURANCE (SSDI)

SSDI is a federal program through the Social Security Administration that provides a monthly payment to people who have worked for a sufficient period of time, paid Social Security taxes, and are deemed "disabled" by Social Security. In addition to the monthly check (paid after a waiting period), after two years of receiving this monthly benefit, SSDI recipients are also entitled to Medicare.

Many people diagnosed with mid to late-stage brain cancer qualify for SSDI. If you are not working and you think you might want to apply, it is helpful to start sooner rather than later. The Social Security

Disability application process can take more than 100 days; and a year or longer if you have to appeal.

SUPPLEMENTAL SECURITY INSURANCE (SSI)

If you have a very low income and minimal savings and assets you may qualify for benefits. These would begin immediately. You would be able to receive monthly payments during the SSDI waiting period, if you qualify.

You may also qualify for the **Supplemental Nutrition Assistance Program (SNAP)**, formerly Food Stamps and Medicaid. Medicaid can be a welcome relief, if you are struggling to pay for private medical insurance and qualify. The social worker or financial counselor at your treatment facility can provide more information.



For more information about co-pay assistance programs, see p. 70.

To apply for SSDI or SSI: call 1-800-772-1213; go online to www.socialsecurity.gov/disability.

MANAGING MEDICAL COSTS

The very first question you may ask yourself about managing the financial aspects of your diagnosis is: *"Am I able to coordinate the financial piece of my medical care right now?"* If you answer "No," perhaps you can ask a friend or family member to do this for you. Insurance companies can sometimes assign a caseworker to help you navigate insurance benefits and costs. Often, people can use some help.

Try to anticipate and plan for the many costs that can accompany a brain tumor diagnosis. These costs can include special medications and supplements not covered by insurance, child care, elder care, transportation, parking, food delivery – in some cases, even oral chemotherapy. Though this can seem overwhelming (especially with concerns about your health), it's helpful to feel like you have a plan in place to manage the costs of care.



PRACTICAL TIPS FOR COPING WITH THE COST OF CARE

- Get a notebook to record your expenses, conversations with the insurance company, medical appointments, and other pertinent information (date, time and who helped with what).
- Pick a certain day to be 'health care bill day.' Use this allotted time to work on the task of keeping things organized. This will prevent it from becoming overwhelming.
- Get an accordion folder to help you file papers so you can find them easily, or ask for electronic billing information so you can create electronic files you can access.
- Identify one spot where you and someone you trust can easily access bills, paperwork, and notes.



COPING WITH THE COST OF CARE

Frankly Speaking About Cancer: Coping with the Cost of Care is a free publication by the Cancer Support Community that can help guide you through the financial impact of medical care.

Order this booklet through www.cancersupportcommunity.org or by calling 1-888-793-9355

CONSIDERING PRIVATE HOME CARE AND LONG TERM CARE

Private duty or custodial care includes services such as having someone drive to your home to fix meals or drive you to medical appointments. When this type of help is needed, it's good to know what costs are involved. Unlike home health care with skilled nurses, private duty or companion care are usually not covered by health insurance.

Similarly, long-term care is not typically covered by health insurance. Long-term care involves extended care at a nursing home or other specialized facility for a longer period of time than rehabilitation care.



QUESTIONS FOR YOUR HEALTH CARE TEAM

- What local organizations provide low-cost or free private duty care or other services?
- Should I plan financially for long-term medical care such as a nursing home or hospice care?
- Who can help me understand my state's Medicaid rules (www.medicaid.gov) for long-term care and my eligibility?



QUESTIONS ABOUT LONG-TERM CARE

- Are private duty care and long-term care covered under my health insurance policy? If not, can I purchase this additional coverage now?
- Do you have a special rate for people paying out-of-pocket?

PRACTICAL, LEGAL, AND ESTATE PLANNING

It's helpful for all adults, regardless of their current health status, to prepare for the future by having their affairs in order. Ensuring that legal documents exist, including a will, living will, and advanced directives, will help maintain your sense of control and provide you and your family with guidance.

It helps to talk with those closest to you about questions like: *"At what point is it time to stop active treatment?"* and *"How does what I leave behind affect my family's future?"* These are difficult discussions, but it's important to provide direction for those closest to you, and prevent problems later.

There are several important documents to consider for advanced care planning. If you have questions, please speak with your doctor, nurse, or social worker.

Living Will

The living will is a legal document that states whether or not we would like to be placed on life support if our bodies cannot survive without such "heroic" intervention. This information should be given to doctors and family members when we are still actively making our own decisions. Most doctors have a standardized state form available. Once completed, all people involved should have a copy.

Health Care Proxy or Medical Power of Attorney

This is a legal document that allows us to appoint a trusted person to make medical decisions for us if we cannot make them for ourselves. In many states, the person you appoint (your Medical Power of Attorney) is able to speak on your behalf if you are not able. It is important that this person knows your wishes and is willing to take responsibility.

Financial Power of Attorney

A trusted person is legally named Financial Power of Attorney to make financial decisions on our behalf when we are incapable or otherwise desire assistance with money and finances. If you have to manage multiple bank accounts, know that each bank or financial institution may require you to file separate forms of proof.

Will

The Will is a legal document that defines what we want to do with our property, money, and other possessions (including children) after we die. Guardianship may be a key element of a Will. If a person has no written Will, the laws of the state can determine how wealth and children are passed along to family members.

These documents can be created independently (you can look online to find sample forms for you and your family to fill-out and keep on record), or formally with a lawyer.

DEATH AND DYING

When you are diagnosed with a potentially life-threatening illness, it's common to think about death. It's normal for people diagnosed with a serious brain tumor to want to discuss the possibility of death and to anticipate what they might want or need in the weeks, months or years ahead.

On the other hand, individuals might not want to discuss this, because it's difficult or sad. These discussions can be important and powerful parts of the coping process.

Talking openly about your feelings and desires can help you and your family to maintain control over this time, and provide you the opportunity to accomplish certain goals or put closure to matters. It's valuable to feel prepared for whatever lies ahead. Remember that a social worker or professional counselor is always someone who can help ease and enlighten these discussions.

YOUR CAREGIVERS

As a person receiving help, you may resent the need after being able bodied, or feel terrible guilt for being a burden on someone you love. Perhaps you don't even realize that you are using a loved one's time. It's valuable to look at how caring for you is affecting your loved one, from their eyes. Living with someone who has a serious disease is not easy.

Most caregivers are happy to help and don't want you to feel guilty about what they can provide. It's important to talk

honestly with your caregiver, and get a sense of when and how they could use a break. Try to express your appreciation when you can. There are many things that can help your caregiver cope with their new role — Chapter 7 offers some guidance.

*When I was diagnosed, I wanted to know "what did I do wrong?"
I realize the answer is "Nothing"...
but still, that's infuriating!*

— Tony, patient





Don't lose sight of yourself. It's easy to get wrapped-up in the process of appointments and waiting. Don't get caught up. Take even 5 minutes to find out what you need for yourself. It's not easy, but you have to take care of yourself too.

— Sarah, caregiver

Care for the Caregiver

CHAPTER 7 / CARE FOR THE CAREGIVER.....	63
Care for yourself.....	64
Making important decisions	65
Finding support and help	66
Moving forward	67
Bereavement	68

Care for the Caregiver

A **caregiver** is anybody who provides unpaid help, or arranges for help, to a relative or friend because they have an illness or disability. Help can be physical, emotional, spiritual, financial, or logistical.



THINGS TO REMEMBER

- You can be a tremendous resource to help your loved one think through treatment options, goals and priorities during this difficult period.
- Reach out to others who are also caring for someone with a brain tumor. These individuals are often helpful.
- Say YES! Remember that it's vital to ask for and accept help.
- Be mindful of your own needs and feelings. There are many ways to support your loved one without neglecting your own physical, economic, spiritual and emotional well-being.
- Talk with the doctors about what to expect and how to plan. Recovery after treatment can take a long time, it helps to feel prepared.
- End-of-life care plans can be helpful. Make sure that all family members are on the same page, and that the doctor is aware of your loved one's preferences.
- Enjoying life is about how you and your loved one focus on the things that really matter.
- If you are grieving the loss of the life you knew, give yourself time to grieve.

CARE FOR YOURSELF

People who are forced to adopt a new role as "caregiver" have shared that as they gain information about the disease, options for treatment, expectations for recovery, and resources for support, they begin to feel more confident about managing the task before them, and their fear, anger, and frustration begin to dissipate.

When a Loved One's Personality Changes

Depression, anger, confusion and mood swings are common symptoms for individuals with brain tumors. These symptoms can be caused by the tumor, the treatment, or may have been present before. Regardless of the source, personality changes in someone you care for can be very challenging. These changes can be subtle or drastic. Speak with your doctor if you notice these types of changes. The symptoms may be treatable.

People who care for someone with a serious illness can forget to take care of themselves and can neglect their own needs. It becomes hard to focus on work, household responsibilities and other demands, yet those pressures continue. There are many ways to build-in time for your own care, and this is essential for your physical and mental wellbeing. Take time for yourself – this is not selfish.

Aim to find a balance between caring for your loved one, caring for yourself, and caring for others in your life. The patient will benefit most from being with you when your own life is in balance—and you will be less likely to feel exhausted or resentful about caregiving.



TIPS TO MANAGE DIFFICULT MOMENTS

- Recognize feelings such as guilt, resentment and anger. Admit them if it will help you address the problem rather than ignore it or let anger grow.
- Be compassionate with yourself. There's no one way a caregiver should feel. Give yourself permission to separate your feelings from your actions.
- Reach out to your own support network for some coping ideas. Call a family meeting and say, "Let's figure out how we can help each other."
- Set limits. Take time on a regular basis to care for yourself. Your batteries must be recharged so you can be a better caregiver over the long haul.
- Remember that you do not need to have all the answers or fix all the problems.
- Often, just "being there" and quietly listening is all that's needed.

Making Important Decisions

Many people with a brain tumor diagnosis experience changes in their ability to think clearly and process information. This may be due to the tumor, treatment or simply feeling overwhelmed by the diagnosis. Whatever the cause, a loved one is often responsible for setting the course for a patient's care as their advocate. If you must be the treatment decision-maker, know that you can take some time to ask questions, research options, and find support.

Before you can know what's needed and what you can do to help, you must understand the situation.

1. **Learn about the brain tumor** including its location, grade, treatment options, anticipated treatment side effects, and expectations for recovery.
2. **Try to identify the top medical centers and experts** in your loved one's (or your) area for a second opinion or additional services, as needed.
3. **Research information** on credible websites, like through the National Cancer Institute, and the National Brain Tumor Society.
4. **Weigh the pros and cons** of each treatment option with your loved one, including elements like time, where treatment will be given and cost.
5. **Create a "to do" list** with your loved one of immediate versus long-term needs. Decide what your loved one can address independently, what you or someone else can address from a distance (via phone or internet) and what requires hands-on support.
6. **Recognize and respect** the unique capabilities of your loved one and their wishes and desires, in addition to the roles played by others involved.
7. **Set limits.** Define what you can and can't reasonably do for your loved one.
8. **Organize a care-plan** featuring coordination and open communication among all participants (who is doing what, when?). This plan will help reduce family stress and bring needed relief.
9. **Remember that each stage of care requires different levels of support,** and everyone's roles will change along the way. Brain tumors are not the same as other major life events; they can be ongoing and often unpredictable. Try to think through reasonable short- and long-term expectations.
10. **Secure proper authorization** that allows you to gather copies of medical and treatment records (including operation reports and x-rays). By obtaining legal "Power of Attorney" you will be granted this authorization. This will help with follow-up care plans and future medical needs.
11. **Utilize an oncology social worker** at the cancer center or affiliated with the oncologist. They offer a wealth of information and can answer many logistical and financial questions.
12. **Enjoy your relationship.** Try to value the time you spend with your loved one, because every moment is special.

FINDING SUPPORT AND HELP

Above and beyond the specific advice that the doctor, nurse, and social worker can give you, there are several organizations and websites designed to help family caregivers and volunteers get help and get organized. Look through the resources at the end of the book, and consider:

- **National Brain Tumor Society**
www.braintumor.org
Offers information, connection, and advocacy for people affected by brain tumors. NBTS has excellent resources listed throughout their webpages.
- **American Brain Tumor Association's Connections Online Support Community**
www.abta.inspire.com
ABTA connects patients, families, friends, and caregivers for support and inspiration.

- **Cancer Support Community**
www.cancersupportcommunity.org
Provides education, free online support groups, and discussion boards for people affected by cancer and their caregivers.
- **My Lifeline**
www.MyLifeline.org
Those with cancer can create their own personal webpage to communicate with family and friends. Pages include online calendar tools, scheduling timelines, and information about ways friends and family can offer support.
- **Musella Foundation for Brain Tumor Research & Information**
www.virtualtrials.com
Offers education, support (emotional and financial), advocacy and guidance to brain tumor patients. Online support groups and opportunities to participate in fundraisers for brain tumor research are also available.

Evaluating your Needs

If your loved one is not receiving the help you hoped for or need, it may be time to regroup. Are your expectations realistic? If you're not sure, have an honest conversation with the medical team. If your expectations are realistic but not being met, you may need to secure a different type of support. Try to brainstorm creative ways to address each issue by breaking problems into smaller parts and tapping into additional resources.

Respite Care and Palliative Care

Respite care is short-term, temporary relief to caregivers who are providing full-time support to an ill loved one. Respite offers intensive care for the patient in their home so a caregiver can take a break. It often provides a positive experience for everyone involved. You can contact a respite care organization when you need time away.

MOVING FORWARD

Palliative care is a service used at any point in a patient's experience to help a caregiver with the management of pain and other symptoms. Palliative care has the goal of achieving comfort, managing symptoms, and improving a patient's quality of life. Palliative care professionals may come to a person's home to deliver care and to teach caregivers how to manage problems. Check with your insurance, and you can ask your hospital or doctor for a referral.

TO ACCESS RESPITE CARE SERVICES IN YOUR AREA FOR YOU OR ANOTHER CAREGIVER, TRY:

- **Arch National Respite Organization**
archrespite.org/respitelocator
- **Caregiver Action Network**
202-772-5050
caregiveraction.org
- **Family Caregiver Alliance**
1-800-445-8106
www.caregiver.org

A diagnosis of advanced brain cancer can make you wonder how long your loved one has to live. It's frightening to envision a different future than you originally planned for yourself. It can also be difficult to talk about such painful topics.

Finding ways to talk about what is happening makes most people feel relieved. The conversation often leads to hopes about living the life you have together now. Often, people want to make the most of their time together with family, as they make peace with the circumstances. Perhaps these can be uplifting conversations that give you both a sense of peace.



One day Gary turned to me and said, "will you marry me?" and I said, "we're already married." And he said, "no, the first time I asked you was for who I thought you'd be, now it's for who I know you are."

— Candice, caregiver

BEREAVEMENT

If you try to discuss the subject but your loved one isn't ready, know that we all have our own timing. Finding someone else you can talk to about your concerns when you're ready is important. Research shows that caring for someone with a brain tumor is just as stressful (but in a different way) as having the diagnosis.

As with other difficult emotional issues, you can contact a social worker or counselor skilled in working with people with a brain tumor, or talk to a spiritual leader that you trust.

Losing someone you love to cancer is one of the most difficult and profound experiences in life.

In the weeks and months after a death, people feel an enormous mixture of emotions. It is important to know that practically any emotion you experience is normal. Sadness can also involve physical symptoms, such as sleeplessness, muscle tension, and decreased energy.

Be assured that you will feel a sense of calm eventually. You must give yourself time to grieve.

Some people move quickly through grief; others move slowly. No matter how you grieve, it is important to become aware of the normal aspects of grief, feel it, then be okay to move on.



My dad was diagnosed when I was eleven and he passed when I was 14. When my dad worked, he was on the road a lot. So when he got sick, we joked that we were really lucky to have a stay-at-home dad for three years. We got to know him really well those years – and if he died any other way, that would not have been the case.

— Natalie, caregiver



When my husband was diagnosed, I wanted to stay in touch with others but didn't have a lot of time, so I made a group on Facebook. I posted every couple of days and I got so much in return. For example, I'd ask: could somebody help me with research? I'd get lots of answers. It's an amazing tool. My community even set up this caravan of dinners. This gave me the love and support that I needed to stay strong.

— Candice, caregiver

Resources

CHAPTER 8 / RESOURCES	69
Cancer Support Community's resources for support	72

Resources

Brain Tumor Specific Support

Accelerate Brain Cancer Cure

202-419-3140

www.abc2.org

ABC² aggressively invests in bold and innovative research and drives collaboration to speed the development of new and effective treatments for brain cancer patients.

American Brain Tumor Association

800-886-2282

www.abta.org

ABTA raises funds for brain tumor research and education; their website offers information, education, and support.

American Cancer Society

800-227-2345

www.cancer.org

ACS offers information about brain tumors, treatments, and managing life with the disease; a search tool helps locate support groups; ACS offers the Health Insurance Assistance Service.

American Society of Clinical Oncology / Cancer.Net

888-651-3038

www.cancer.net

Cancer.net is a resource for direct and accurate information about cancer treatment based on the expertise of clinical oncologists.

CancerCare

800-813-4673

www.cancercare.org

CancerCare provides free, professional counseling and support groups to individuals, families, caregivers, and the bereaved. CancerCare's Co-Payment Assistance Foundation: www.cancercarecopay.org.

Cancer Support Community

888-793-9355

www.cancersupportcommunity.org

CSC provides support, education and hope to all people affected by cancer including personalized services at no cost.

The Healing Exchange

Brain Trust

877-252-8480

www.braintrust.org

T.H.E. Brain Trust runs online support groups and forums for discussion on all brain tumors for patients, providers, researchers, educators and caregivers.

Imerman Angels

312-274-5529

www.imermanangels.org

Imerman Angels matches anyone seeking cancer support with someone just like you – a "Mentor Angel" who is the same age, gender, and has beaten the same type of cancer.

LIVESTRONG Foundation

855-220-7777

www.livestrong.org/

cancersupport

The LIVESTRONG Foundation provides information and tools to help people affected by cancer. LIVESTRONG Navigation Services offers free referrals to counseling and other resources in your area.

Musella Foundation for Brain Tumor Research and Information

888-295-4740

www.virtualtrials.com

Musella Foundation offers education, support (emotional and financial), advocacy and guidance to brain tumor patients. Videos, articles, online support groups, and information about fundraisers for brain tumor research are also available.

National Brain Tumor Society

800-770-8287

www.braintumor.org

NBTS drives strategic research to find new treatments and advocates for policies to meet the critical needs of this community.

National Center for Comprehensive and Alternative Medicine

888-644-6226

www.nccam.nih.gov

NCCAM is the Federal government's lead agency for scientific research on the practices known as comprehensive and alternative medicine (CAM). NCCAM offers information on the value and legitimacy of CAM practices.

National Cancer Institute

800-422-6237

www.cancer.gov

NCI is the premier agency for cancer research, training and information in the US Federal Government. Their website has valuable information for all people affected by cancer – including search tools for clinical trials.

Financial and Legal Assistance

Brain Tumor Copayment Assistance Program, Musella Foundation

855-426-2672

<https://braintumorcopays.org>

This program provides up to \$5,000 in financial assistance per year to families who qualify and use certain drugs to treat brain tumors.

Cancer and Careers

646-929-8032

www.cancerandcareers.org

CAC educates people with cancer to thrive in their workplace. Look online for free publications, career coaching, and support groups for employees with cancer.

Cancer Legal Resource Center

866-843-2572

www.disabilityrightslegalcenter.org/cancer-legal-resource-center

The CLRC provides free and confidential information and resources on cancer-related legal issues for anyone coping with cancer.

Co-Pay Relief Program

866-512-3861

www.copays.org

The CPR program provides financial support to insured patients who qualify to access pharmaceutical co-pay assistance. The program offers call counselors who guide patients through the enrollment process.

Corporate Angel Network

866-328-1313

www.corpangelnetwork.org

Corporate Angel Network is a non-profit organization that arranges free air transportation for cancer patients traveling to treatment using the empty seats on corporate jets.

Healthcare.gov

The new Federal website offering customized information about the various health insurance options for which you may be eligible, including comprehensive information about Medicare and Medicare Services through CMS (www.cms.gov).

LawHelp.org

www.LawHelp.org

LawHelp helps low and moderate income people find free legal aid programs in their communities, answers questions about legal rights, and helps with their legal problems.

National Cancer Legal Services Network

www.NCLSN.org

NCLSN is a coalition of legal service providers who offer some free legal services programs to people affected by cancer.

National Coalition for Cancer Survivorship

877-622-7937

www.canceradvocacy.org

NCCS offers free publications on insurance and employment issues for people coping with cancer. The Cancer Survival Toolbox is an audio-program that includes a section on Finding Ways to Pay for Care.

NeedyMeds
www.needymeds.org
NeedyMeds is a free, online clearinghouse to help people who cannot afford medicine or health care costs. This website includes information about services such as Discount Drug Cards, Medicaid websites, Federal Poverty Guidelines, and other useful information.

Partnership for Prescription Assistance
888-477-2669
www.pparx.org
The PPA is a coalition of pharmaceutical companies, doctors, other health care providers, and community groups that help qualifying patients get the medicines they need. The website offers access to more than 475 public and private patient assistance programs, including more than 180 programs offered by pharmaceutical companies.

Patient Access Network Foundation
866-316-7263
www.panfoundation.org
PAN Foundation provides assistance to underinsured patients. Patients or a member of their medical team can apply online or over the phone; a determination for assistance is generally made within one business day.

Patient Advocate Foundation
800-532-5274
www.patientadvocate.org
PAF offers information about financial resources and mediation services to assure access to care, maintenance of employment, and financial stability. Look for the Underinsured, Uninsured, and Financial Resource Directories, with information about alternative coverage options (www.patientadvocate.org/resources).

Survivorship A-Z
www.survivorshipatoz.org/cancer
Survivorship A-Z is a web-based resource providing practical, legal and financial information. The site includes the ability to make a computer-generated profile, personalized to your legal, financial, and social situation.

Cancer Support Community's Resources for Support

Cancer Support Community's resources and programs below are available at no charge.

CANCER SUPPORT HELPLINE®

 Whether you are newly diagnosed with cancer, a long-time cancer survivor, or caring for someone with cancer, CSC's TOLL-FREE Cancer Support Helpline (1-888-793-9355) is staffed by licensed CSC Call Counselors available to assist you Mon-Fri 9 am-8 pm ET. Our Call Counselors have been specially trained to answer your questions and link you to valuable information.

AFFILIATE NETWORK SERVICES

Almost 60 locations plus more than 100 satellites around the country offer on-site support groups, educational workshops, yoga, nutrition, and mind-body programs specifically designed for people affected by cancer. For a full list of affiliate locations, visit the Cancer Support Community website or call us at 1-888-793-9355.

OPEN TO OPTIONS™

 Free one-on-one decision counseling is available with licensed mental health professionals who can help you process information about your situation, and formulate a list of specific questions for the oncologist. Appointments can be made by calling 1-888-793-9355 and by visiting the CSC website to contact an affiliate providing the Open to Options service.

CANCER EXPERIENCE REGISTRY

 The Cancer Experience Registry is a movement designed to help CSC better understand the social and emotional needs of people living with cancer so that we and others can develop new resources to support the millions of people living with cancer every day. The Cancer Experience Registry collects information about the experiences of people who have volunteered to share their cancer journey in a survey, and connects them to a network of resources. Join today at CancerExperienceRegistry.org.

THE LIVING ROOM, ONLINE

Cancer Support Community's "The Living Room" offers much of the same programming available at each CSC affiliate. On CSC's website you will find online support groups, discussion boards and social networking, "build your own website" services, and education materials.



To access these services, visit
www.cancersupportcommunity.org

These services are made available with generous contributions from CSC supporters.

Cancer Support Community and the National Brain Tumor Society would like to recognize and thank all of those who contributed to the success of this book.

CONTRIBUTORS & EDITORS

Deanna Glass-Macenka, RN, BSN, CNRN

Johns Hopkins Hospital

Lora Hays, L.M.F.T., R.P.T.

Cancer Support Community Central Indiana

Ashley Varner, MSW, MBA, LCSW-C

Anne Arundel Medical Center

Johns Hopkins Brain Tumor

Education Group

Erica Weiss, MPH, MSUP

Writer/Editor

Patrick Y. Wen, MD

Dana-Farber Cancer Institute

CONTRIBUTING PARTNERS

Accelerate Brain Cancer Cure

Nicola Beddow

Cancer Support Community

Allison Harvey, MPH, CHES

Musella Foundation

Al Musella, DPM

National Brain Tumor Society

Kristina Knight

Michele Rhee, MBA, MPH

DESIGN & PHOTOGRAPHY

Suzanne Kleinwaks Design, LLC

Design

Ralph Alswang

Photography

We'd like to extend a special thanks to focus group, interview, and survey participants who shape the information provided in this booklet.

CANCER SUPPORT COMMUNITY'S FRANKLY SPEAKING ABOUT CANCER SERIES

Cancer Support Community's Frankly Speaking About Cancer: Brain Tumors program is part of a national education program that provides support, education, and hope to people affected by cancer and their loved ones.

Frankly Speaking About Cancer booklets feature information about treatment options, how to manage side effects, the social and emotional challenges of the diagnosis, and survivorship issues.

For more information about this program, the Frankly Speaking About Cancer series or Cancer Support Community, please visit our website at www.cancersupportcommunity.org or call us toll-free at 1-888-793-9355.

WWW.CANCERSUPPORTCOMMUNITY.ORG 1.888.793.9355



Cancer Support Community and the National Brain Tumor Society together with our partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or another health care professional to answer questions and learn more.

©2013 Cancer Support Community. All rights reserved.



**National
Brain Tumor
Society**

**CANCER SUPPORT COMMUNITY AND THE NATIONAL BRAIN TUMOR SOCIETY
THANK OUR PROGRAM PARTNERS:**



People with cancer who actively participate in their recovery along with their health care team will improve the quality of their lives and may enhance the possibility of their recovery. People with cancer who actively participate in their recovery along with their health care team will improve the quality of their lives and may enhance the possibility of their recovery.



Ivy Brain Tumor Center

AT THE BARROW NEUROLOGICAL INSTITUTE

Discovering Hope. Every Day.

Our research program is singularly focused on discovering new therapies for brain tumor patients through a broad portfolio of pharmacodynamic- and pharmacokinetic-driven clinical trials, combining industry-partnered drug development with the nation's largest operative brain tumor volume.

www.IvyBrainTumorCenter.org

 **Ivy Brain Tumor Center**
AT THE BARROW NEUROLOGICAL INSTITUTE

BARROW
Neurological Institute

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