

FRANKLY
SPEAKING
ABOUT CANCER

Brain Tumors



National
Brain Tumor
Society


CANCER SUPPORT
COMMUNITY.





*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

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PROLOGUE

No one is ready to receive a brain tumor diagnosis, yet researchers estimate that 86,970 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 (CNS) tumor.

In this book, we've collected resources, facts, and tips about the medical, practical, and emotional effects of primary brain and spinal cord tumors to help you (or an advocate) 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 in 2013 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 was also based on research with 407 patients and caregivers in a national survey and personal interviews with several thoughtful, honest and inspiring individuals. Cancer Support Community updated this book in 2019.*



This book deals with primary tumors (those that start in the brain or spinal cord). It does not cover treatment of secondary tumors or brain metastases (tumors that began in another organ and spread to the brain or spinal cord). To learn more about brain metastases, read about the specific type of cancer at www.CancerSupportCommunity.org or www.Cancer.org.

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.

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.

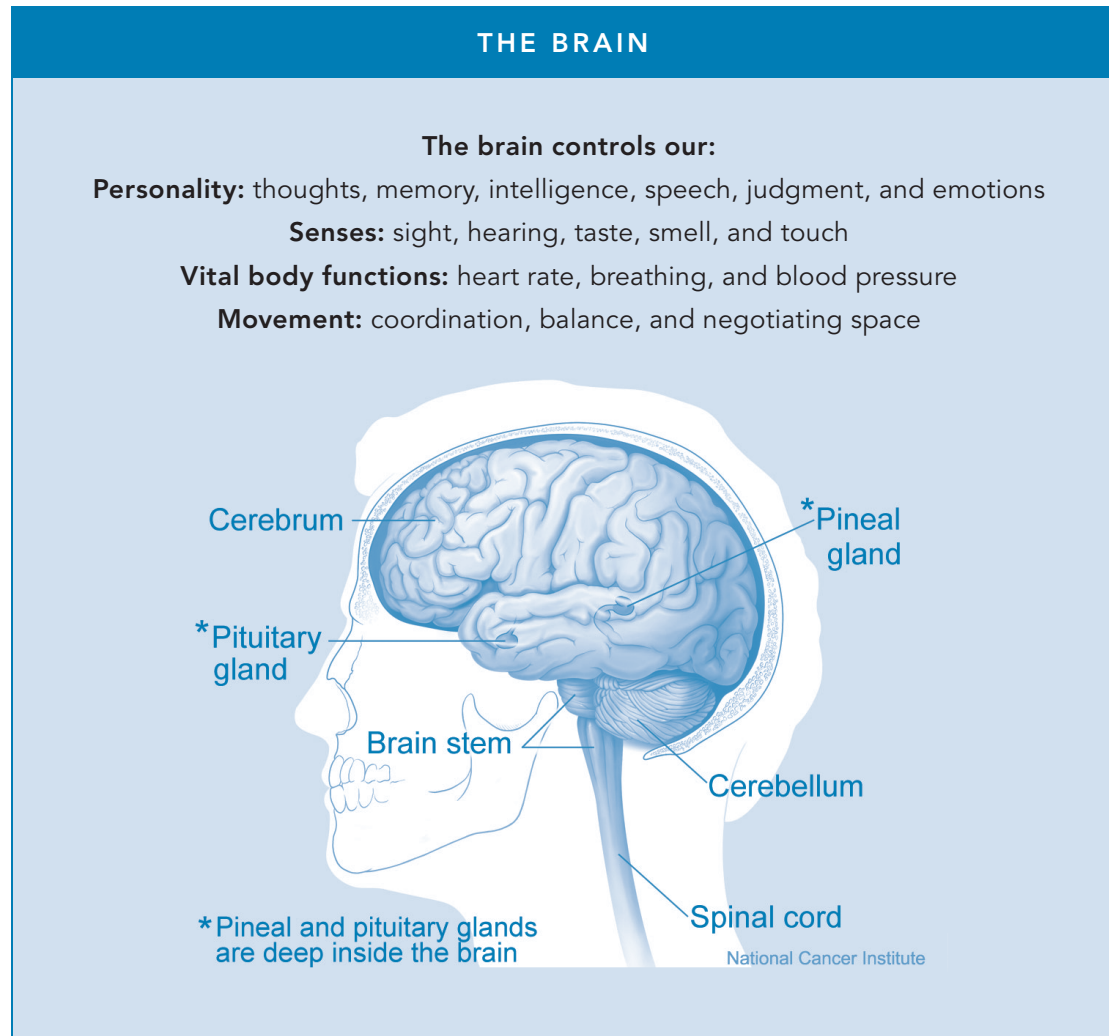
My journey began in the summer of 2008, after months of enduring excruciating pain in my head and finally deciding to go to the doctor. On April 13, 2009, I was diagnosed with a meningioma tumor the size of a baseball that was located behind my left ear. I was stunned, this was the last thing that I 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.



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.



Source: National Institutes of Health, National Cancer Institute

1 *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. Your goals, hopes, and preferences can be included throughout your care plan. 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 (see Chapter 3, p. 18) and with your doctors (see Chapter 6, p. 55, 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

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 6-9, you will find information about how to access services and trained experts.

KNOWLEDGE, ACTION, & COMMUNITY

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.*



Ten 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.

2 *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
 5. If your tissue was sent for **biomarker testing**.
- 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.

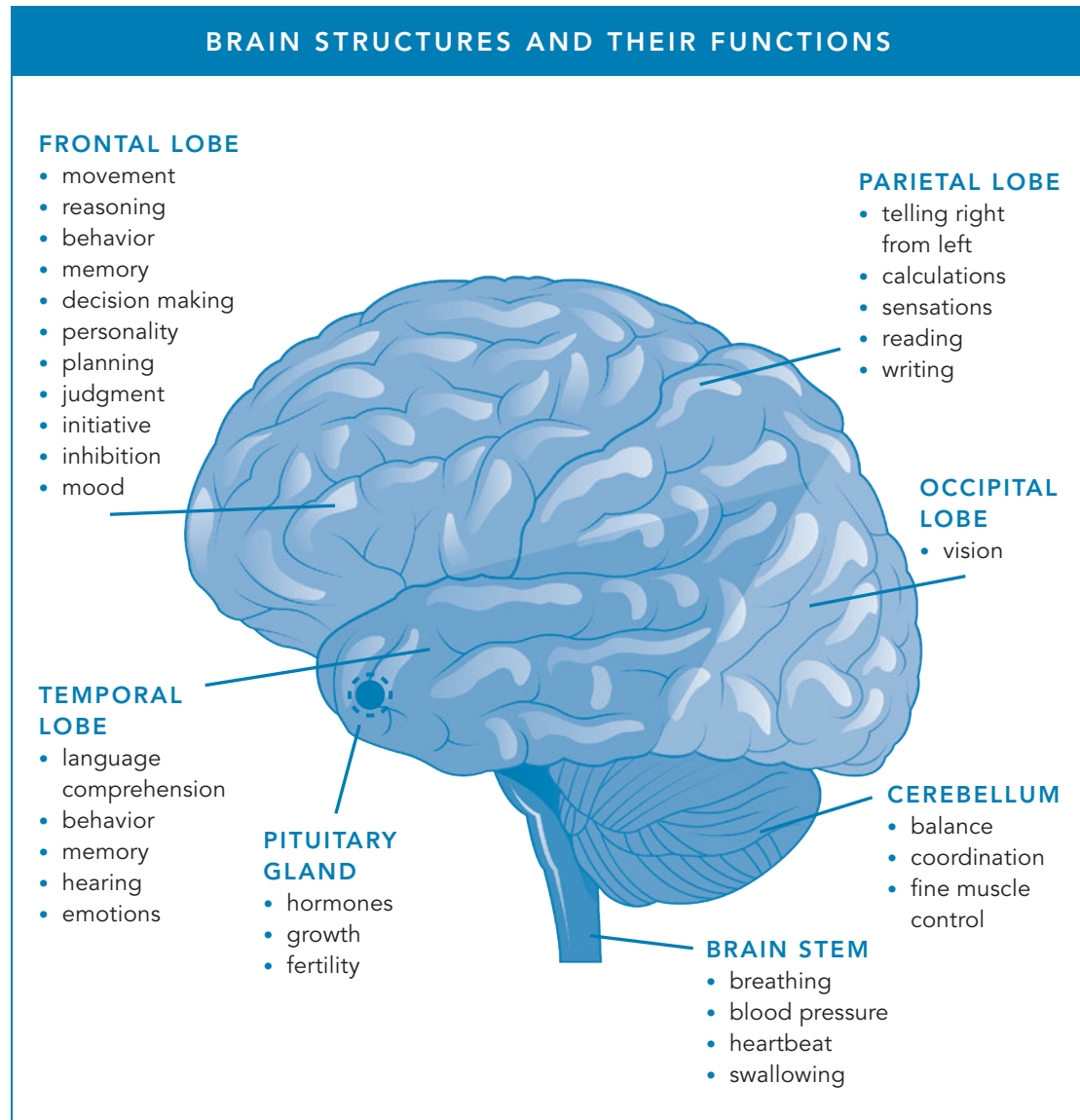
Brain and Spinal Cord

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/types/brain/patient/adult-brain-treatment-pdq



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
10-35%
OF PRIMARY TUMORS
(OTHER THAN BRAIN) LATER
DEVELOP A BRAIN METASTASES



This accounts for 150,000 to 200,000 new metastatic brain tumor cases each year.

IN 2019, NEW PRIMARY BRAIN TUMOR
DIAGNOSES INCLUDED:

70%

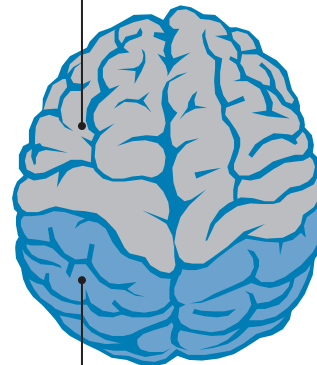
**BENIGN
TUMORS**

(60,800 Cases)

30%

**MALIGNANT
TUMORS**

(26,170 Cases)



PRIMARY BRAIN TUMOR TYPES



- **15%** Glioblastoma
- **11%** Glioma
- **37%** Meningioma
- **17%** Pituitary
- **9%** Nerve Sheath
- **12%** Other
(Astrocytoma,
Ependymoma,
Oligodendroglioma,
Embryonal, etc.)

Sources: Nayak, Lee, and Wen (2012); Porter, McCarthy, Freels, Kim, and Davis (2010); Gavrilovic and Posner (2005); CBTRUS Statistical Report (2018)

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, p. 21).

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 II Tumor

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

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

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

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.

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.

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)

PATHOLOGY REPORT AND BIOMARKERS

After the surgeon removes tumor tissue, a pathologist will look at the cells under a microscope, grade the tumor, and decide whether the cells are cancerous. If the pathologist cannot make an exact diagnosis, the tissue may be sent to another pathologist for a second opinion.

The tissue should also be tested for biomarkers. (Biomarker testing is also known as molecular or genomic testing.) These features of the tumor help your doctors decide what treatments may be best for you. This step is important because tissue from tumors of the same type might look alike under the microscope but be different at the molecular level and respond differently to treatment.

For instance, to learn what kind of glioma a person has, pathologists look for biomarkers such as proteins called IDH1, IDH2, and MGMT. If these tests are not done when the tissue biopsy is done, it can delay you getting the treatment that is best for you.

Biomarker testing is not done at all hospitals. Ask your neuro-oncologist about having your tissue sent out for testing. You will need to check with your insurance provider to find out whether your cost of testing is covered.

When planning your surgery, request that your surgeon get a large enough tissue sample for biomarker testing. Some of it should be stored for future use. As new biomarkers or new treatments are discovered, having stored tissue samples may be helpful to decide whether a new treatment might work for you.

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

— Deanna Glass-Macenka, nurse

If your tumor was sampled before 2016 and the tissue was stored, ask your doctor to have it tested again. The World Health Organization reclassified tumors in 2016 to include biomarker information. Having biomarker information about your tumor could change your doctors’ treatment plan.



QUESTIONS ABOUT YOUR DIAGNOSIS

1. What type of tumor do I have?
2. Where is the tumor located?
3. What grade is the tumor?
4. Can you recommend another pathologist’s review?
5. Did you test for biomarkers like IDH1, IDH2, MGMT, or 1p/19q?
6. Can you explain my test results?
7. How do the cancer grade and test results affect my treatment choices?
8. How often do you and this center treat patients with my type and grade of tumor?
9. Should I see any other experts to review my tumor type, and other treatment options, including clinical trials?

3 *Your 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. When possible, take the time to find an experienced team.

You want to find a care team with a great deal of experience in treating your kind of brain cancer and that keeps up with the latest treatment advances. Consider getting treatment or at least a second opinion at an NCI-designated comprehensive cancer center or other brain tumor center.

HELP FINDING YOUR TREATMENT TEAM

- Ask your primary doctor to suggest a brain tumor center or neuro-oncologist.
- 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
- NCI can locate a Comprehensive Cancer Center near you. 1-800-422-6237 or www.cancer.gov/cancer-centers

BE AN ACTIVE PARTNER WITH YOUR CARE TEAM

- Find a care team you are comfortable talking with and who answer your questions.
- Ask as many questions as you need to. Let your team know if you need information in a different language or format.
- Talk to your care team about your worries, concerns, and goals for treatment.
- Is there a symptom or side effect you want to be sure you avoid?
- Ask how to contact your care team between appointments and after hours, if you need quick answers or to report new side effects.

KNOW YOUR TREATMENT TEAM

Your team should include many experts, who each work on a different part of your care. Together they can make sure you get everything you need.

The **neurologist** specializes in brain and spinal cord diseases. Some patients get help from an **epileptologist**, a neurologist with extra training in seizures and epilepsy.

Your **neuro-oncologist** treats brain and spinal cord tumors and cancers and will be the lead doctor on your team.

The **neurosurgeon** takes out brain and spinal cord tumors when possible. They also get samples of cells from tumors (biopsies) so they can be checked for cancer and biomarkers.

You will still see your **primary care physician** for checkups and for care of chronic conditions like asthma, high blood pressure, and diabetes.

Oncology nurse practitioners (NP) and **oncology physician assistants** diagnose and treat medical problems, prescribe medicine, and serve as your contact for urgent questions.

Neuro-oncology nurses are registered nurses (RNs) who specialize in symptom management and support for brain and spinal cord tumor patients.

Radiation oncologists use radiation therapy (high energy rays, like X-rays) to cure or slow the growth of cancer or to ease symptoms.

Neuroradiologists read scans and interpret tests of the brain or spinal cord. They evaluate tests like MRI scans, CT scans, and PET scans.

Neuropathologists look at tissues that surgeons remove under the microscope to diagnose cancer. They also do biomarker (molecular) tests to further understand the cancer subtype.

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

Palliative care specialists manage pain and other side effects. In the past, these specialists focused on end-of-life or hospice care. Today, they also help patients feel better during treatment.

Oncology social workers provide counseling and crisis intervention. They may be able to help you find answers to questions about home care, transportation, and the cost of care.

Psychologists and **psychiatrists** provide counseling and address anxiety and depression. Although both are trained in mental health, only the psychiatrist can prescribe medicine. A **neuropsychologist** specializes in brain functions and how brain damage can affect a person's abilities.

SECOND AND THIRD OPINIONS

A **registered dietitian** (RD or RDN) helps people find ways to take in healthy food when treatments make it hard to eat. They use their knowledge about diet and nutrition to help you recover.

A **patient navigator** can help you talk with your health care team, set up visits and tests, and find financial, legal, and social support.

Physical therapists and **occupational therapists** treat discomfort and problems with moving that get in the way of your daily life.

Speech therapists may treat certain speech and language problems.

Oncology pharmacists can teach you about the drugs being used in your care and their side effects.

Chaplains can offer emotional support to patients and their families regardless of religion.

You should feel comfortable enough with your doctor to ask about getting second and third opinions. Your doctor, in fact, may be able to suggest brain tumor centers with expertise in the exact subtype of tumor you have.

Many people find that it helps to get a second or even third opinion from another brain tumor center with an active research program, such as an NCI-designated cancer center. (Visit www.cancer.gov/cancer-centers or call 800-422-6237 to find an NCI-designated cancer center.)

Seeking other opinions can help you make a decision or confirm your current treatment plan. Newer treatments that

are showing success are sometimes only available through clinical trials. Not every brain tumor center offers clinical trials. And each center may offer different trials. Ask your doctor if there is a clinical trial that is right for you. You may want to check with your insurance company first to find out if a specific doctor or brain tumor center will be covered by your policy.

Talking to other brain tumor specialists can be the best way for you to make informed decisions about your care options. If a treatment you are trying stops working, or you need new options for managing side effects, these discussions can help you adjust your plans.



It is ideal to find a neurosurgeon with experience. Ask if their practice is focused primarily on brain tumor surgery.



TIPS FOR TALKING WITH YOUR HEALTH CARE TEAM

- **Talk openly** and honestly with your health care team. It may be hard to start some conversations, but it will help you get better care. Tell them about your worries and concerns.
- **Let your team know how you feel.** They need to know how your symptoms, treatments, and any side effects are impacting your every day life, physically and emotionally.
- **Tell your team your goals for treatment.**
 - Do you have a family event or gathering you want to participate in?
 - Is there a symptom or side effect you want to be sure you avoid?
 - Do you want to be independent for as long as possible?
 - What is going on in your life that will help your team decide how aggressively they should be treating you and what side effects will least effect your everyday life?
- **Learn about your diagnosis and treatment options.** This will help you make treatment decisions and can help you better understand how to be a partner in your care.
- **Ask any questions you have.**
 - Write down your questions and concerns before each doctor's visit.
 - Tell your doctor if you prefer more simple or scientific information.
 - Keep asking questions until you understand what is being said.
 - Ask for information in a different language or format if you need it. For example, you can ask your doctor to draw you a picture or compare it to something you already know.
- **Keep a notebook** to track questions to ask your care team, side effects, medication, notes, and appointments.
- **Bring a relative or friend to appointments** to take notes and be an extra set of eyes and ears. You can also ask to include a loved one with a video call or phone call.
- **Ask if you can record your conversation** so you can listen to it again to better understand what your provider is saying.
- **Ask how to contact your care team** between appointments, so you can ask questions that need quick answers or report new side effects.
- **Request copies of your medical records.** Keep them for your files. They may be helpful if you need to seek additional opinions in the future.
- **Use a schedule-planner to organize help.** An online planner like www.MyLifeline.org can help you keep in touch with friends and family and let them know how they can help.
- **Ask about ways to manage treatment costs.** If your provider doesn't know the answers, talk to a social worker or financial navigator or contact the Cancer Support Community toll-free Helpline, 888-793-9355.

4 *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

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 by treatment decisions: contact the Cancer Support Community's "Open to Options" treatment decision counseling program. (See p. 20)

The **National Comprehensive Cancer Network (NCCN)** guidelines set the standard for treating brain tumors. The way that different brain centers and doctors 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/patients/guidelines/cancers.aspx



QUESTIONS ABOUT TREATMENT OPTIONS

1. Given the type, grade, and location of my tumor, what are my treatment choices?
2. What treatment(s) do you suggest? Why?
3. Are there any clinical trials that are right for me? How do I find out more about them?
4. What is the goal of each treatment? Is it to get rid of the cancer, help me feel better, or both?
5. Who will be part of my treatment team, and what does each member do?
6. How often do you and this center do this treatment?
7. Should I see any other experts before deciding on treatment?
8. Do you have suggestions for where to go or who to see for other opinions?
9. After treatment, will I return to my normal self? Will I be able to think, walk, and talk?
10. Will the changes last a few months or for the rest of my life?
11. Will I need physical and speech therapy to walk and talk?
12. Will I need occupational therapy to relearn tasks I have to do all the time?
13. Will I have neuropsychological testing?
14. Can a cognitive therapist help me with memory, planning, or organizing thoughts or activities?
15. Will I need any changes at work so I can stay in my job?
16. Who can help me learn how to pay for my cancer care?
17. Where can I find emotional support for me and my loved ones?



WANT MORE HELP TALKING TO YOUR HEALTH CARE TEAM ABOUT TREATMENT OPTIONS?



If you are facing a cancer treatment decision, CSC's

Open to Options® research-proven program can help. Our Open to Options® team can help you create a list of questions for your doctor in English or Spanish. Call 888-793-9355 to make an appointment or to find a local CSC or Gilda's Club near you.

SYMPTOMS

Symptoms your health care team needs to know about

Because the brain and spine have so many functions, the symptoms that develop with tumors and the side effects that result from surgery or other treatments can vary a lot. You may have some of them or none of them.

Keep track of your symptoms, and tell your care team about anything unusual that you experience. Your team will want to know if you have:

- **Headaches** - Headaches affect about half of all people who have had a brain tumor. For some people, headaches happen in the morning and get worse when they do their activities.
- **Seizures** - Seizures can give you visual problems, numbness, a tingling sensation, feelings of being disconnected, the inability to speak, uncontrolled body movements, or loss

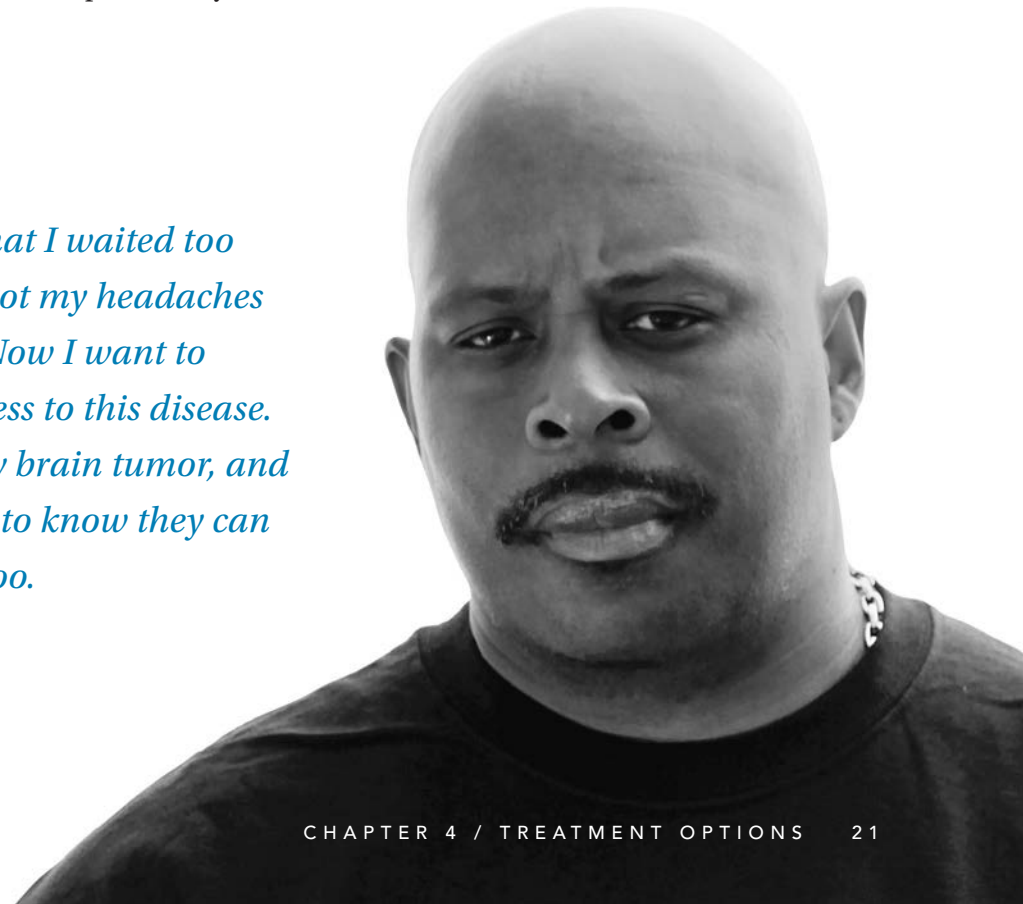
of consciousness. (See Chapter 4, p. 40 for more information about seizures.)

- Problems with balance and movement or muscle weakness
- Memory problems
- Problems thinking clearly or problems making decisions
- Unexplained shifts in personality or mood

- Problems with speech, vision, or hearing
- Nausea
- Disorientation (not being sure where you are)
- Anxiety or depression.

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



These symptoms can be the result of seizures or of:

- Pressure the tumor puts on sensitive parts of the brain or spinal cord.
- **Brain swelling (edema)** - This increases pressure in the skull and can keep blood from reaching the brain.
- **Hydrocephalus** - Tumors can stop the usual movement of fluid in your brain (cerebrospinal fluid). Normally, the brain clears extra fluid out. When the brain cannot do this, pressure in the brain increases, making it hard for the brain to work.

Brain tumors' ability to interfere with your everyday life might surprise or even scare you. Ask your care team to help you find therapists or social workers to help you with any emotions that come up.

Even before they are certain that the cells from tumors are benign (not cancer) or malignant (cancer), your medical team will want to treat your symptoms. They do this to keep you safe and able to function as well as possible in your daily life.



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

TREATING SYMPTOMS

Palliative (supportive) care should be part of your treatment from the moment you are diagnosed. The goal of palliative care is to relieve symptoms and make you feel better, not to treat the cancer. You may have a palliative care specialist on your care team. Palliative care is not the same as hospice or end-of-life care.

Steroids are one of the ways that doctors treat brain swelling (edema). Prednisone and dexamethasone (Decadron®) are commonly prescribed. When the swelling goes down, some symptoms get better. But the steroids do not destroy or remove tumors.

Your health care team will monitor you for side effects from steroids. Weight gain, mood changes, difficulty sleeping, and joint pain can happen with steroid use. They can also increase the risk for osteoporosis (weak bones) and stomach bleeding. If you get any of these side effects, tell your health care team. They may change your dose or the type of drug. (See the next chapter for more.)

Antiseizure / antiepileptic drugs

(AEDs) are given to prevent seizures. They are often prescribed before and after any surgery. You may be given these for a long period of time.

Shunts, which redirect cerebrospinal fluid, are used to treat hydrocephalus.

Surgery to remove brain tumors is done when possible to ease the symptoms they cause. For example, surgery may reduce seizures. We will talk more about surgery that removes tumors beginning on page 25.

Radiation therapy and chemotherapy, which are normally used to limit or destroy cancer cells, are sometimes used to treat symptoms. These treatments are described in more detail beginning on page 25.

Treatment for symptoms may cause additional side effects. In particular, cognition might be affected. That is your ability to think, learn, pay attention, and make decisions. Ask about possible side effects when discussing any treatment.

Other types of palliative care

Among the things palliative care specialists do is look for ways to ease symptoms such as pain, nausea, and insomnia. They help people cope with cognitive changes and issues such as anxiety or depression. Palliative care also addresses fatigue, diet, and exercise. Alternative medicine, yoga, meditation, and spiritual and social support may be part of the palliative care plan.

Another important part of palliative care is rehabilitative treatment. This can mean working with physical, occupational, speech, and cognitive therapists. They help people with mobility, the tasks of everyday life, thinking and memory, and emotional skills. These therapists help people return to work and maintain as much independence as possible, if they have lost function after tumor removal or other treatments. (Chapter 5, p. 39 has more information about the ways rehabilitative services can help people dealing with the problems caused by brain and spinal cord tumors.)

For more on treating symptoms and side effects, and what kinds of symptoms to expect based on the location of your tumor, see Chapter 5.



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

TREATING TUMORS

Treating brain and spinal cord tumors is difficult for several reasons.

- The immune system behaves differently in the brain than elsewhere in the body.
- The blood-brain barrier protects the brain from viruses and toxins. However, that barrier also prevents cancer drugs from getting in to do their work. It is hard to develop drugs that can both get through and that can beat cancer.
- Local antitumor treatments (like surgery or radiation) have to be used in ways that don't kill brain tissue you need to control your body.

Because brain and spinal tumors are complicated, many factors go into deciding how to treat them. The treatments your doctors recommend are based on:

- Your age and overall health
- Whether the tumor is cancer or not
- The size and location of the tumor

- The tumor grade (low- and high-grade tumors may get different treatments)
- How likely the tumor is to spread or come back

- Your tolerance for specific drugs, procedures, or therapies
- Your values, goals, and preferences.

TREATMENT BY TUMOR GRADE

Low Grade

Grade I and grade II tumors (low grade tumors) can be treated several ways. Because they are not aggressive, sometimes doctors suggest watchful monitoring. Sometimes they recommend surgery. If all of a grade I tumor can be removed, that may be all the treatment a person needs.

Treatment outcomes are best when the whole tumor can be taken out. When the surgeon is unable to remove all of a low-grade tumor, treatment could include radiation and chemotherapy. These treatments are becoming more common for patients who are over 40 years old.

Grade II tumors can come back and be a higher grade. Your doctors will want to watch closely to make sure there is no recurrence.

High Grade

Grade III and grade IV tumors (high grade tumors) are more difficult to remove than low-grade tumors. They need treatments beyond surgery. Radiation and chemotherapy are standard; sometimes tumor treating fields are used. However, clinical trials may provide the best options for high-grade tumors, which grow faster than low-grade tumors.

All treatments are intended to prolong and improve your life for as long as possible. However, treatments often have side effects. When discussing options, ask your doctor how a treatment will affect the quality of your life during and after treatment.

SURGERY

Whether you get treatment through a clinical trial or not, your care may include one or several of the following treatments:

- Surgery
- Radiation Therapy
- Chemotherapy (chemo)
- Targeted therapy
- Tumor treating fields (also known as alternating electric field therapy)

These treatments and others might be offered alone or in combination through a clinical trial.

With brain tumors, surgery is used during diagnosis (see Chapter 2) to find your tumor type and grade. The surgery used for diagnosis can also be the first treatment of your brain tumor. Sometimes surgery can also be used as a follow-up treatment.

The goal of the initial surgery is to remove as much of the brain tumor as possible without damaging other parts of the brain. A “total resection” is when the surgeon gets the entire tumor. This is an ideal outcome. (Still, some cells can remain behind.) In a “subtotal resection,” the surgeon is only able take out part of the tumor, which means other treatment approaches will be needed.

When a tumor appears to be difficult to remove because of its size or location, the neurosurgeon may want to only do a biopsy to get tumor tissue for testing. If possible, get a second opinion to see whether another surgeon could remove the tumor.

Tumor removal and surgical procedures to remove tissue for a biopsy do pose risks, just as all surgeries do. When procedures are to be done on the brain, people sometimes are reluctant to have them done. Discuss any concerns you have about brain surgery with your doctor.

Neurosurgeons use brain mapping (neurosurgical navigation) to reduce damage to parts of the brain responsible for important functions. When looking for a neurosurgeon, ask how much experience she or he has. Ideally, your neurosurgeon should have performed this same surgery on your tumor type many times.

Side Effects from Surgery

After your surgery, it is common to not feel well. You might experience:

- changes in personality
- seizures
- confusion and difficulty thinking clearly
- speech problems
- a loss of balance
- brain swelling
- headaches

The changes could be brief or last a few weeks or months. Sometimes they are longer term or even permanent. Your palliative care team will help you find ways to manage any changes that happen after surgery. (For more on coping with side effects, see Chapter 5.)

RADIATION THERAPY

Radiation therapy uses high-energy rays like X-rays to kill cancer cells. Sometimes these treatments are called radiotherapy or radiation surgery.

All of the treatments use high doses of tightly controlled radiation to shrink tumors, slow tumor growth, and kill cancer cells. That radiation can be in the form of X-rays, photons, or protons.

Radiation therapy (also called radiotherapy or radiation surgery), can be offered in several different ways:

In **external beam radiation therapy** (EBRT), the radiation oncologist delivers radiation using a large machine that can move around you. It is a standard treatment for brain tumors and can be used on the whole brain or part of it. There is more cognitive decline (problems thinking) with whole brain treatments than with some other options.

EBRT treatments are painless, and each lasts only a few minutes. Treatments may run every weekday for five or six weeks.

Three-dimensional conformal radiation therapy (3D-CRT) is a specialized type of EBRT that limits damage to healthy cells. It uses brain scans to locate the tumor and a computer to adjust the radiation so it matches (conforms to) the tumor's shape. This therapy is used on gliomas.

Proton radiation therapy uses beams of protons to deliver radiation from the outside. This therapy delivers a high dose of radiation to cancer cells without affecting nearby healthy tissue. It has been used to treat meningiomas and gliomas.

Proton radiation therapy is not available at every cancer center. Each treatment lasts only a few minutes, but you will get it every weekday for several weeks at a time.

In **brachytherapy**, radiation is delivered from an “implant” or “seed” inside the body. Those implants could stay in the body a few days to a few months. Some are permanent. Brachytherapy is given as a booster before or after external beam radiation therapy.

Stereotactic radiosurgery uses focused, high-energy beams to treat small brain and spinal cord tumors. The radiation is focused at the tumor from many different angles, allowing a large dose to go to the tumor and much smaller doses to surrounding tissues. This treatment can be given in one session (stereotactic radiosurgery) or more than one session (stereotactic radiotherapy). This is not surgery in the traditional sense because there is no cutting, just highly-focused radiation. Sometimes it is the best choice when brain surgery is not a safe option. You may hear it called Gamma Knife®, CyberKnife®, X-knife, or Clinac “surgery.”

Radiation side effects

Side effects can occur following radiation. Those effects will differ depending on the type of radiation therapy you receive. The most common side effect is fatigue, but people also experience hair loss, nausea, skin irritation, and nausea.

The damage to normal cells caused by radiation can cause mild to serious changes in cognition, movement, and other neurological activities. Palliative care in the form of cognitive, speech, occupational, and physical therapy might be needed to address these side effects.

The neurological side effects can develop right after radiation, or they sometimes appear years after treatment is finished (late effects). Late effects can affect learning, hearing, behavior, hormones, vision, and sexual functioning.

For more on coping with side effects, see Chapter 5.

CHEMOTHERAPY

Chemotherapy drugs are used after surgery and sometimes with radiation therapy. These drugs attack and kill fast-growing cells like cancer. But they can also harm healthy cells like those that grow hair or those that line the digestive tract. As a result, chemo can cause side effects like hair loss, nausea, and low white blood cell counts.

Chemotherapy drugs are most often given by IV (into a vein) and as pills. You may get one drug or a combination of chemotherapy drugs. Chemotherapy may also be combined with other therapies, such as radiation and tumor-treatment fields.

Ideally, chemotherapy will destroy all the cancer cells and produce a cure. When a cure is not possible, the aim might be to control the cancer by shrinking the tumor or keeping it from spreading.

Sometimes chemotherapy is used to ease symptoms and make a person more comfortable. Ask your doctor what the goal of chemotherapy is in your case.

Some of the chemotherapy drugs used most often to treat brain tumors are:

- temozolimide (Temodar®)
- lomustine (CCNU, Gleostine®)
- carboplatin (Paraplatin®)
- carmustine (BiCNU® or Gliadel® wafers that are placed in the space that opens up after a tumor is removed)
- cisplatin (Platinol®)

Chemotherapy Side Effects

When people receive chemotherapy drugs, they are given breaks between cycles in order to cope with side effects.

These can range from hair loss to lack of appetite to mouth sores. Fatigue is common. So are low blood counts.

Occasionally, medications or transfusions may be given to increase blood counts.

(Find more on common side effects and how to cope with them in Chapter 5.)

Some chemotherapy drugs destroy white blood cells, which are used by your body to fight infection. Any infection during cancer treatments is serious and needs prompt attention. Call your doctor, if you have:

- a fever (100.4 degrees F or 38 degrees C)
- cough
- sore throat
- nasal congestion
- redness or swelling in any area
- diarrhea
- vomiting
- increased urination

The period of greatest risk is often a few weeks after a chemotherapy cycle when your white blood cell count is lowest. If your white blood cell count gets very low (leukopenia), your doctor may give you

filgrastim (Neupogen®) or a drug like it (Zarxio®, Nivestym®). These drugs help your body make white blood cells.

While you are getting chemotherapy, you can reduce your risk of infection by:

- Washing your hands often—before eating, after using the bathroom or changing diapers, after handling trash, before and after treating a wound, and after coughing and sneezing.
- Asking people who care for you to wash their hands.
- Avoiding contact with sick people.
- Using lotion after bathing to prevent cracks in your skin.
- Using gloves when cleaning up after pets or have someone else do the job.
- Thoroughly cooking meat and eggs.
- Keeping your household surfaces clean.
- Brushing your teeth twice daily with a soft toothbrush.

- Not sharing food, drink cups, utensils, or other personal items.
- Getting your flu shot.
- Wearing gloves and a mask while gardening and washing your hands when you finish.



For more information about preventing infection, go to www.cdc.gov/cancer/preventinfections/patients.htm or www.CancerSupportCommunity.org/SideEffects.

TUMOR-TREATING FIELDS (ALTERNATING ELECTRIC FIELD THERAPY)

Another treatment option is alternating electric field therapy (Optune®, also known as tumor-treating fields or TTFields). Worn on the head, this portable device uses alternating electric fields to block cancer cells from dividing and slow tumor growth.

TTFields are FDA-approved for people with glioblastoma. For patients with newly-diagnosed glioblastoma, TTFields are used after surgery and with the chemotherapy drug temozolomide. In recurrent glioblastoma, TTFields are sometimes used alone, after surgery, chemo, and radiation treatment.

Tumor-treating Fields Side Effects

When used alone, TTFields do not cause side effects like those caused by chemotherapy and radiation. However, some people do develop skin irritation. Mild rashes are most often treated with steroid cream. Skin infections or blisters can be treated with antibiotic cream or by a break in treatment.

TARGETED THERAPY

Targeted therapy is a type of cancer treatment that targets a specific change in some cancers that help them grow, divide, and spread. Targeted drugs are designed to block cancer growth “driven” by these changes. With some targeted therapies, doctors decide to use it based on the findings of biomarker tests, including mutation testing of your tumor. The two targeted therapies that are currently approved for treating brain tumors do not need biomarker testing before their use.

Bevacizumab (Avastin®, Mvasi®) and everolimus (Afinitor®) are two targeted therapy drugs approved by FDA for brain tumors. Bevacizumab has been used to treat people who have had glioblastoma return after treatment with standard radiation therapy and temozolomide chemotherapy. It prevents tumors from forming new blood vessels and growing.

GETTING TREATMENT THROUGH A CLINICAL TRIAL

Everolimus treats a type of brain tumor called subependymal giant cell astrocytoma. It works by keeping cancer cells from growing and dividing.

In addition to the targeted therapy drugs that have been approved by FDA, there are other treatments being studied in clinical trials.

Targeted Therapy Side Effects

Because targeted therapies are so precise, normal cells are not damaged as they are with chemotherapy. However, targeted therapies can have side effects such as:

- fatigue
- low blood cell counts
- loss of appetite
- diarrhea
- rash
- mouth sores
- increased risk of infection

Find more on common side effects and how to cope with them in Chapter 5.

Clinical trials are research studies with patients. Their goal is to find better ways to treat diseases like brain and spinal cord tumors. They can test new drugs or treatments or find ways to use existing treatments better. Many people with brain and spinal cord tumors get treatment in a clinical trial. Often, the most promising new approaches to treatment are only available through clinical trials.

Key Things to Know About Clinical Trials

- People who receive their treatment through a clinical trial receive high quality care.
- There are rules about who can join each trial, so they are not open to every patient.
- There are laws to protect the safety of people who participate.
- No one receives a placebo or “sugar pill” in place of appropriate treatment.

- People who join clinical trials can leave at any time, and for any reason.
- Some clinical trials may require travel; others may be close by. They are NOT only available at major cancer centers. Locations vary with each trial.
- Most often, the trial pays the costs of the drug or approach being studied. Usually, your health insurance and your copay cover “standard” treatment costs. Be sure to ask what costs you may incur.

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. Does your treatment center offer a clinical trial for my tumor subtype?
2. What will the researchers be studying in this trial? Safety? Efficacy (how well it works)?
3. Will I need to have extra tests or doctors' visits for this clinical trial?
4. What side effects or risks are likely?
5. Should I expect any short-term, long-term, or late effects?
6. Is this experimental treatment likely to be better than the standard treatment?
7. How will the researchers protect my health information?
8. Which treatment costs would be covered by my health insurance? What would be my out-of-pocket costs?
9. Will I need to travel to be treated in a clinical trial?
10. If I have to travel, what organizations might be able to help with travel and housing?



MORE ABOUT CLINICAL TRIALS

Brain Tumor Network

844-286-6110

www.braintumornetwork.org

Cancer Support Community's Clinical Trials Resources

800-814-8927

[www.CancerSupportCommunity.org/
ClinicalTrials](http://www.CancerSupportCommunity.org/ClinicalTrials) and

[www.CancerSupportCommunity.org/
Finding-Clinical-Trial](http://www.CancerSupportCommunity.org/Finding-Clinical-Trial)

National Brain Tumor Society

617-924-9997

<http://trials.braintumor.org>

National Cancer Institute

800-422-6237

www.cancer.gov/clinicaltrials

If you are not eligible for a clinical trial, you may still be able to get what is known as an “investigational drug therapy.” The US FDA has guidelines for expanded access or “compassionate use.” This is a route that very sick patients, who are not part of a clinical trial, can take to request drugs that are under study. More information can be found at www.fda.gov/NewsEvents/PublicHealthFocus/ExpandedAccessCompassionateUse

Treatments being studied for brain cancer

CHECKPOINT INHIBITORS are immunotherapy drugs that make it harder for cancer cells to hide from your immune system. When used to treat glioblastoma in clinical trials, checkpoint inhibitors have had mixed success. They are now being studied in clinical trials where they are combined with other therapies.

In **CAR T CELL THERAPY**, T cells are taken from the patient and then modified in a lab. Once returned to the person, these modified T cells find and kill cancer cells. CAR T cell therapy has been approved for some blood cancers, and it is being studied in clinical trials for brain tumors.

THERAPEUTIC VACCINES are vaccines that are given after a person has been diagnosed with an illness. In cancer treatment, they are designed to “teach” your T cells to find and kill tumor cells. A therapeutic vaccine now under study in people with glioblastoma is showing promise in clinical trials. The vaccine uses a combination of dendritic cells (that’s a kind of immune system cell) and tumor cells to “train” the immune system to fight the cancer.

GENE THERAPIES are techniques that use engineered genes to treat or prevent diseases. One approach is to activate a person’s immune system by introducing genetic material using engineered viruses that will change the way cancer cells behave. Clinical trials are underway for a

gene therapy treatment for recurrent high-grade gliomas. The therapy, which relies on a modified virus, helps brain tumors become producers of an anti-cancer drug that works against the tumor cells, but not against healthy cells.

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

WHEN TUMORS COME BACK (RECURRENCE)

Sometimes tumors come back. This is called a recurrence.

There is no single way to treat a recurrence. Treatment might include some combination of surgery, chemotherapy, radiation therapy, targeted therapy, or other approaches available in clinical trials. Two drugs used when there is a recurrence are temozolomide and bevacizumab. Your doctor may also suggest a clinical trial to access new treatments. See page 31 for ways to search for a clinical trial that may be right for you.

You will want to consider how additional treatment will impact your quality of life. For example, 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.

You may benefit from treating your recurrence if you have:

- Good overall health
- A smaller amount of tumor present
- More than one year between your original treatment and the recurrence.

Advocate for yourself. As you progress through treatment, ask your doctors to be honest about your future. Is the goal for your treatment a cure? It is to stop tumor growth and make you feel better? There may come a time when you will decide that stopping treatment of a high-grade brain cancer will give you more days of feeling better than continuing treatment. The conversations about that decision will be hard, especially for your loved ones.

Whether you are receiving antitumor treatment or not, palliative care can always help you with symptoms and side effects.

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, location, and other factors.

Late effects to manage with help from your health 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
- Ongoing seizure
- New tumor development many years after radiation therapy.

HOSPICE

Your health care 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 8).

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)

High-grade brain cancer often cannot be cured. Deciding when to stop aggressive treatment is difficult. Patients and 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. However, not all doctors will raise the topic. If you already have a palliative care specialist on your health care team, you and your family may benefit from talking to them about when hospice may be appropriate.

Hospice involves the care of all aspects of a patient and family's needs, including the physical, psychological, social, and spiritual aspects of suffering. It focuses on pain relief and does not typically involve "heroic measures" to keep a patient alive.

The goal of hospice care is to provide comfort for the patient and rest and help for their caregivers. That care can be delivered at home, in a nursing home, or in a hospice facility. The group providing the care may include a physician, nurses,

social workers, volunteers, and a chaplain. Compassion guides their work. For more information about hospice, go to <https://moments.nhpco.org> or www.nhpco.org.



For more information about hospice, go to <https://moments.nhpco.org> or www.nhpco.org.



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

— Candice, caregiver

5 *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 6 for more.)
- Complementary or integrative 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

1. What side effects should I expect?
2. When should I call you for immediate help? (With which side effects?)
3. What can I do to manage my side effects? Can you help me create a management plan?
4. How do you recommend I keep track of how I feel, and what do you need to know?
5. 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 7 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.



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.

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.



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.



Caregivers should learn what to do in the event of a seizure. First aid information about seizures can be found at the US Centers for Disease Control (www.cdc.gov/epilepsy/about/first-aid.htm) and at the Epilepsy Foundation (www.epilepsy.com/learn/seizure-first-aid-and-safety).

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. (See page Chapter 4, p. 28 for more information on reducing your risk of infection.)

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. For more on relieving GI problems, visit www.CancerSupportCommunity.org/TreatmentNutrition.



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.

For more on coping with fatigue, visit www.CancerSupportCommunity.org/Fatigue.



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 8).

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.

For more information on this and other side effects of cancer treatment, visit www.CancerSupportCommunity.org/SideEffects.



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 and integrative medicine (CIM)

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

The most common CIM 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 CIM approach, then it is important to inform your medical team. In some cases, CIM 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 CIM, look for information on the *National Center for Complementary and Integrative Health's* website: nccih.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

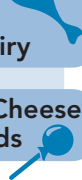
5-10%

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

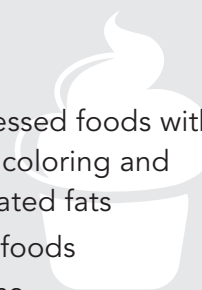
STAY HYDRATED

- 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



6 *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. 46), 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:

- **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.
- **National Brain Tumor Society**
www.braintumor.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.
- **CancerCare**
800-813-4673
www.cancercare.org
CancerCare provides free telephone and online support groups for brain tumor patients and caregivers.
- **Musella Foundation**
<http://virtualtrials.com/lists.cfm>
Musella Foundation offers online support groups for people affected by brain tumors.
- **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.
- **American Brain Tumor Association**
www.abta.org
ABTA offers a list of brain tumor support groups by state, with a zip code search.

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. See more about this topic at: www.CancerSupportCommunity.org/Kids.



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.

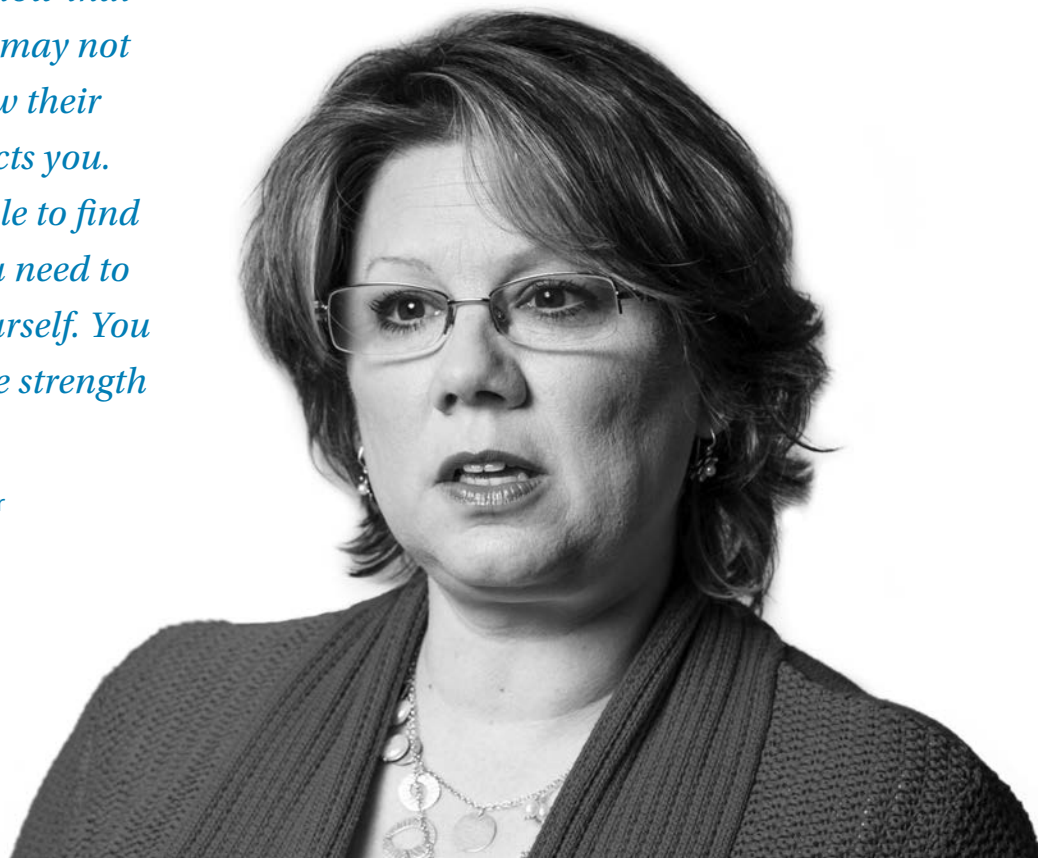
On the other hand, many feel that their marriage or relationship is strengthened through the process of dealing with a crisis together. They are grateful to have each other's support.

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.

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

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.



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

It 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

7 *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: Managing the Cost of Cancer Treatment (www.CancerSupportCommunity.org/cost) is a free Cancer Support Community program that can help you manage and cope with the costs of your care.

You may also call the Cancer Support Helpline at 888-793-9355 for help navigating financial challenges.

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 8 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

8 *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.”
- Create a digital network of friends and family and set up a helping calendar to support you and your loved one on Cancer Support Community’s www.MyLifeLine.org
- 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**
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.inspire.com/groups/american-brain-tumor-association/
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.

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**
<https://archrespite.org/arch-membership>
- **Caregiver Action Network**
202-454-3970
www.caregiveraction.org
- **Family Caregiver Alliance**
1-800-445-8106
www.caregiver.org

MOVING FORWARD

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

Resources

Brain Tumor Specific Support

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.

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.

Brain Tumor Network

844-286-6110

<https://braintumornetwork.org>

The Brain Tumor Network (BTN) is a navigation resource for adult patients and caregivers in the USA seeking information about brain tumor treatment options including clinical trials. This unbiased resource is provided at no cost to patients, caregivers, or healthcare professionals.

CancerCare

800-813-4673

www.cancercare.org

CancerCare provides free, professional support services and information to help people manage the emotional, practical, and financial challenges of cancer. CancerCare's Co-Payment Assistance Foundation: www.cancercarecopay.org.

Cancer Support Community

888-793-9355

www.CancerSupportCommunity.org

CSC is a global non-profit network of 175 locations, including CSC and Gilda's Club centers, that deliver more than \$50 million in free support services to patients and families. In addition, CSC administers a toll-free helpline, an online community www.MyLifeLine.org and produces award-winning educational resources.

Imerman Angels

866-463-7626

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.

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

617-924-9997

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
Complementary and
Integrative Health**

888-644-6226

www.nccih.nih.gov

NCCIH is the Federal government's lead agency for scientific research on the practices that are not generally considered part of conventional medicine. NCCIH was formerly known as the National Center for Complementary and Alternative Medicine.

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.CancerLegalResourceCenter.org

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

Corporate Angel Network

914-328-1313

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 private and corporate jets.

Healthcare.gov

800-218-2596

The 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 the Cancer Survival Toolbox. This audio-program includes information on advocating for yourself, employment rights, and talking with your care team.

NeedyMeds

978-281-6666

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.

Patient Access Network (PAN) 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.

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 assistance options (www.patientadvocate.org/resources).

Patient Advocate Foundation 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.

PhRMA's Medicine Assistance Tool (MAT)

888-477-2669

www.medicineassistancetool.org

PhRMA's Medicine Assistance Tool (MAT) is a search engine designed to help patients, caregivers, and health care providers learn more about the resources available through the various biopharmaceutical industry programs. MAT is not its own patient assistance program, but rather a search engine for many of the patient assistance resources that the biopharmaceutical industry offers.

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.

Triage Cancer

www.TriageCancer.org

Education on the practical and legal issues that may impact people living with cancer.

Cancer Support Community's Resources for Support

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

CANCER SUPPORT HELPLINE®

**CANCER SUPPORT
HELPLINE
888-793-9355** Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon - Fri 9am - 9pm ET.



OPEN TO OPTIONS®

Need help making a cancer treatment decision? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

FRANKLY SPEAKING ABOUT CANCER®

**FRANKLY
SPEAKING
ABOUT CANCER** Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

SERVICES AT LOCAL CSCs AND GILDA'S CLUBS

With the help of 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. www.CancerSupportCommunity.org/FindLocation

CANCER EXPERIENCE REGISTRY



CANCER EXPERIENCE REGISTRY

Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org.

MYLIFELINE

CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up at www.MyLifeLine.org.

GRASSROOTS NETWORK

Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/become-advocate.



To access these services, visit www.CancerSupportCommunity.org

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

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



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. This book is available to download and print yourself at www.CancerSupportCommunity.org/brain.



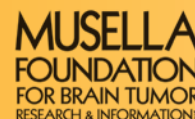
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**National
Brain Tumor
Society**

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