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

— Archie, patient
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Understanding Brain Tumors

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

THINGS TO REMEMBER

- There are over 120 types of brain and central nervous system tumors. When diagnosed, it is important to understand:
  1. The type and grade (how aggressive it is)
  2. Whether it is a primary or a secondary tumor
  3. If it is cancerous (malignant) or not (benign)
  4. Where in the brain the tumor is located

- It helps to get a second or even third opinion to confirm your diagnosis and treatment plan.

- Keep a list with phone numbers for all of the doctors, specialists, nurses, etc. on your team (collect business cards).

- You can bring someone to doctors’ appointments to help you sort through information, ask questions, remember next steps, and keep notes.

- Keep copies of your medical records, current medication list, and diagnostic test results. This can help you as you meet new doctors and work with insurance.

- Take one step at a time. You can learn about your diagnosis, treatment options, and what to expect after treatment, then decide the best next-steps for you and your family.
Brain and Spinal Cord

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

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

For more information about the brain, view the National Cancer Institute’s brain tumor PDQ, www.cancer.gov/cancertopics/pdq/treatment/adultbrain/Patient
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.
Approximately 20-40% of all other cancers later develop a brain metastases.

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

In 2012, new primary brain tumor diagnoses included:

<table>
<thead>
<tr>
<th>Tumor Type</th>
<th>Percentage</th>
<th>Number of Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Benign Tumors</td>
<td>63%</td>
<td>41,980</td>
</tr>
<tr>
<td>Malignant Tumors</td>
<td>37%</td>
<td>24,300</td>
</tr>
</tbody>
</table>

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

Primary brain tumor types:

- Glioblastoma: 16%
- Astrocytoma: 7%
- Meningioma: 35%
- Pituitary: 14%
- Nerve Sheath: 9%
- Lymphoma: 2%
- Other: 33%

(Other includes Ependymoma, Oligodendroglioma, Embryonal, etc.)

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

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

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

**Neurological Examination**

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

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

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*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)
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)
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)
THE TREATMENT TEAM

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

TO PARTNER WITH YOUR TREATMENT TEAM

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

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

— Deanna Glass-Macenka, nurse
Specialists

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

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

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

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

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

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

**CLINICAL PSYCHOLOGIST**
A licensed professional who can help patients and families adjust to the effects of illness on their lives. Neuropsychologists specialize in brain functions and how brain damage can affect a person’s abilities.

**REGISTERED DIETICIAN OR NUTRITIONIST**
A trained specialist with knowledge about how a person’s diet and daily nutrition will impact their health. The Academy of Nutrition and Dietetics lists professionals with oncology experience: [www.eatright.org/programs/rdfinder](http://www.eatright.org/programs/rdfinder)

It is ideal to find a neurosurgeon with experience. Ask if at least 50% of their practice is with brain tumor patients.
CANCER SUPPORT COMMUNITY’S FRANKLY SPEAKING ABOUT CANCER SERIES

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

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

For more information about this program, the Frankly Speaking About Cancer series or Cancer Support Community, please visit our website at www.cancersupportcommunity.org or call us toll-free at 1-888-793-9355.
Cancer Support Community and the National Brain Tumor Society together with our partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or another health care professional to answer questions and learn more.

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