



Brain Tumors

A Handbook for the Newly Diagnosed



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**American
Brain Tumor
Association®**

No one is prepared to hear the words, “it’s a brain tumor,” and in that moment, everything changes. You need to process the diagnosis, master a new and difficult vocabulary, and make decisions about a course of treatment in a relatively short amount of time.

You are likely to feel frightened and overwhelmed. But you are not alone. The American Brain Tumor Association (ABTA) is here to assist you.

This handbook was written to help you, your family and your friends learn more about brain tumors. The first half of the handbook includes information about those critical first hours and days when you are struggling to process a brain tumor diagnosis while needing to make treatment decisions. The second half of the handbook provides general information about brain tumors, the different types and their effects. Additional resources available through the ABTA are also highlighted.

The information and suggestions offered are from experts and individuals and families who have been diagnosed with a brain tumor. Our team can provide additional information about your tumor, the treatment options you’ve been given, and resources for more information and support.

Please call our CareLine at
800-886-ABTA (2282) or send us
an email at **abta cares@abta.org**.

We also encourage you
to visit our website at **abta.org**.

PART ONE:

THE DIAGNOSIS

“You have a brain tumor.”

These words can evoke a wide range of emotions like fear, sadness and anger. While adjusting to these feelings, it may be hard to process the complex information your doctor is providing. An even greater challenge is to use this information to make important decisions about your course of treatment.

The following information will help you navigate the early days of a brain tumor diagnosis.





Where Do I Start?

It can take some time to come to terms with the diagnosis. Some newly diagnosed patients have difficulty absorbing all this information, while others desire more information right away. It is important to take time to process what is happening, to learn more about your specific brain tumor, and to consider the treatment options you have been presented so that you can make informed decisions.

- 1 The first thing to do is **educate yourself**. What type of brain tumor do you have, what is its grade, and what are the effects? This booklet contains a list of questions for your healthcare team, as well as information about the more common tumor types.
- 2 Treatment options will depend largely on your tumor type, grade, size and location. For some, “watch and wait” will be an option. For many others, a decision about surgery and follow-up treatment will need to be made promptly. After learning about your diagnosis, **evaluate your treatment options**. This will involve doing your own research as well as talking to various medical professionals and getting a second opinion.
- 3 **Call your insurance provider**. If you do not have health insurance, a social worker at the hospital can review your options. The insurance section in this booklet has specific information that can help you.

Types of treatment for brain tumors

The most common treatments for brain tumors are surgery, radiation therapy and chemotherapy. The decision about which treatments to use depends on the type and grade of brain tumor, its size and location in the brain, and other factors such as age and overall health.

The ABTA website, abta.org, has more information about medical centers that specialize in brain tumor treatment. Call 800-886-ABTA (2282) or send us an email at abtacares@abta.org to learn more.

Your healthcare team

You will have a team of professionals working with you from the point of diagnosis throughout your treatment. Physicians, nurses, surgeons, social workers, and even psychologists may be part of your team. All of these professionals specialize in different aspects of your brain tumor treatment.

Some of these professionals may be your point-person at different parts of the journey. For example, a neurosurgeon may oversee your surgery, a neuro-oncologist may be your main doctor during post-surgery treatment and a radiation oncologist may oversee your radiation therapy. Your doctors may also refer you to other specialists.

Questions to ask

Here are some important questions to ask when diagnosed with a brain tumor. The ABTA encourages you to take these questions to your healthcare team, who can provide personalized answers.

TUMOR-SPECIFIC QUESTIONS:

- > What can you tell me about my brain tumor?
- > How do you expect my brain tumor to progress?
- > What is my prognosis?
- > How likely is recurrence?

Some people — and some doctors — are reluctant to talk about serious and painful issues. However, an open, communicative relationship between patients and doctors will lead to the best outcome. You may need to advocate for yourself to get the answers you need.

QUESTIONS ABOUT TREATMENT OPTIONS:

- > What different treatment options are available?
- > What is the goal of treatment and what are the chances that we will reach this goal?
- > How did you decide on these treatment options?
- > Can treatment wait?
- > How long do I have to make decisions about my course of treatment?
- > How do you determine if the treatment is effective?
- > What is the expected time frame of my treatment?
- > What are common treatment side effects?
- > Can I work and/or resume activities, including driving, while in treatment?

QUESTIONS TO ASK PRIOR TO SURGERY:

- > Where is the tumor located and what is its size?
- > What are the risks of removing the tumor? In other words, will surgery impact my memory? My ability to think? My physical movement? My speech?

- > How can I ensure enough of the tumor is removed so that I have the option to have genotyping?
- > If the tumor is inoperable, what treatments do you recommend?
- > What happens after surgery?

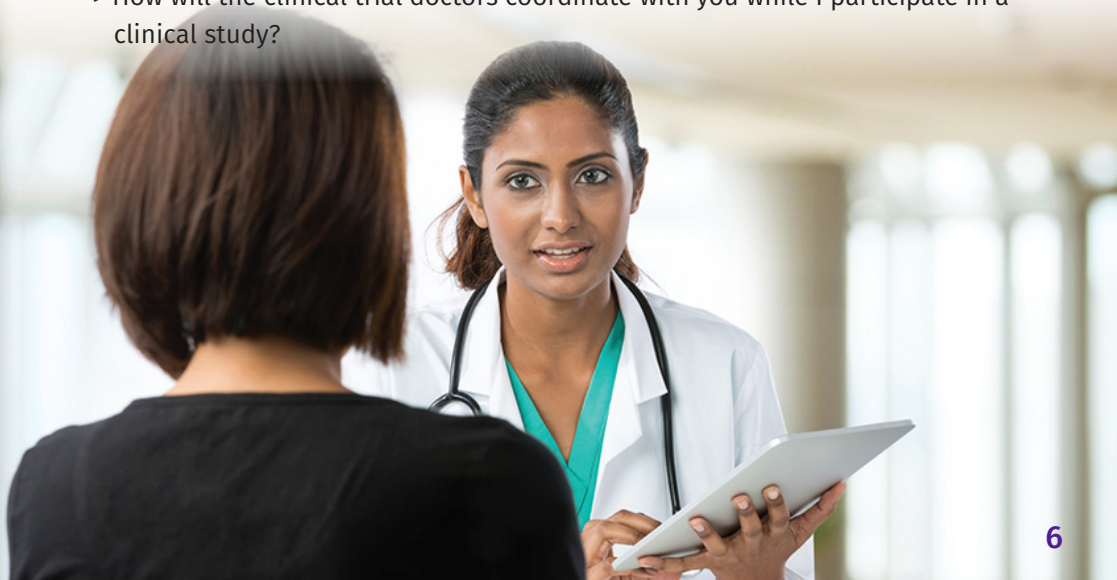
Genotyping: During surgery, tissue (part of the brain tumor) can be collected and sent for genetic testing. This can reveal the specific genetic mutations within your brain tumor. Genetic mutations can predict how your tumor will respond to certain treatments. This information is helpful in determining what kind of individualized treatment you should get and whether or not you may be eligible for a clinical trial. Therefore, it is important to gather this tissue because it can help you and your doctors during the treatment decision-making process.

QUESTIONS ABOUT DIAGNOSTIC TESTING:

- > Does the center/hospital offer genotyping?
- > When is the optimal time to have genotyping?
- > If your center doesn't provide genotyping, where do you refer patients who desire this testing?

QUESTIONS ABOUT CLINICAL TRIALS:

- > What clinical trials are available and when would I be eligible to participate?
- > Where can I find information about clinical trials?
- > What are the possible risks and benefits of participating in a clinical trial?
- > How will the clinical trial doctors coordinate with you while I participate in a clinical study?



GENERAL QUESTIONS FOR YOUR HEALTHCARE TEAM:

- > How many brain tumor patients with my tumor type do you treat each year?
- > What other specialists will be a part of my healthcare team (neuro-oncologist, neuro-surgeon, radiation oncologist, nurse, social worker, nutritionist, physical therapist)?
- > What do they do?
- > How will each of these specialists communicate with you about my treatment?
- > If I am hospitalized, will you be my doctor?
- > How frequently will I have appointments and for how long will they last?

HOW TO GET SUPPORT:

- > Where can I get more information about my diagnosis?
- > What support services are available to me and my family/caregiver?
- > How do I talk to my employer about my diagnosis?
- > How do I talk to my family and friends about my diagnosis?

LIFESTYLE QUESTIONS:

- > Do I have to change my diet?
- > How might this affect my quality of life and how long will these effects last?

QUESTIONS TO ASK YOURSELF:

- > Does the healthcare team seem interested in my questions?
- > Does my healthcare team spend enough time with me and address my concerns?
- > Do I feel comfortable with the doctor's recommendations?
- > Is everything being explained to me in a way I can understand?
- > Is the doctor open to me seeking a second opinion?
- > Do I feel like I have a say in my treatment plan?



Seeking a Second Opinion

A second opinion from a brain tumor specialist can offer an alternative perspective about your diagnosis and treatment. Don't be afraid to consult another doctor for a second opinion before starting treatment. In fact, a second opinion is quite normal for complex medical conditions and many doctors welcome it. Some insurance plans require a second opinion, while others may only cover a second opinion if the patient or doctor requests it.

Before you get a second opinion, here are a few tips:

- > **Gather all medical records from the time of diagnosis.** A new doctor will need to evaluate these records. They include all imaging tests, pathology report, blood work, operative and consultation reports, office visit records and any other testing that may have been done. You can request these records from your doctor's office or from the hospital's medical records department. There may be a charge for obtaining a copy.
- > **Check with your insurance company.** If you are seeking an opinion with a doctor outside of your network, ask about the costs and advocate for yourself to get the treatment and care that will be best for you. If the insurance company states they will not cover a medical procedure, ask about how to file an appeal for coverage. Oftentimes, exceptions can be made depending on the situation.
- > **Ask your doctor or a trusted source for a brain tumor specialist referral.** When surgery or long-term treatment is involved, most doctors welcome a colleague's opinion and can help by providing a recommendation.
- > **Go with the best assessment.** It's possible that the treatment plan from the doctors will be different. To weigh your options, ask yourself about the potential benefits of each. Talk over some of your concerns with the doctors. In some cases, a third opinion is warranted.

If your doctor is unable to recommend a brain tumor specialist for a second opinion, call the ABTA at 800-886-ABTA (2282) or visit abta.org to locate a brain tumor treatment center.

Insurance

If you have health insurance, working with your insurance provider is a necessary and sometimes difficult part of the journey. Insurance can often be complex and confusing. It is important to review your policy, noting key points such as deductibles, pre-authorizations needed, the formulary list of medications covered and limitations to your coverage.

If you don't have insurance, contact the social worker at the hospital. The social worker can outline insurance options, federal assistance programs, local and national funding organizations and other ways to help you find alternative forms of healthcare coverage.

When you or your loved one call your insurance provider to inform them of your condition, be sure to:



- > Review your policy prior to the call, noting any questions or concerns that you have.

- > Record the name of the person you speak with.

- > Get the case number assigned to your claim so you can refer to it in future calls.

Ask the following questions of the representative on the phone:

- > Can you assign me a single point-of-contact for my case? (Some providers do this)

- > Do I need to obtain pre-authorization for hospitalization or treatment? If so, whom do I call?

- > Do I need to obtain a second opinion before non-emergency surgery? If so, are there any limitations on who provides the second opinion?

- > Do I need to stay within a particular network of hospitals or doctors to receive insurance benefits? Where can I find a list of these providers? What will happen if I am treated “outside of network”?
- > Does my policy have a deductible? If so, how much have I paid for the year?
- > Does my out-of-pocket maximum include the deductible, coinsurance and copays or is it in addition?
- > Will my insurance cover my participation in a clinical trial if I choose it?

Keeping track of your communications with the insurance company can be important. Record with whom you spoke, when you talked, and what you discussed.

Additional Resources

Support for both the person with the brain tumor and that person’s loved ones is essential during this time. There are others who have knowledge and experience to share, and it will help to talk about your questions, concerns and emotions as you move forward.

- > The American Brain Tumor Association is here for you every step of the way. Contact us toll-free at (800) 886-ABTA (2282) or email ABTAcares@abta.org.
- > Doctors, nurses and other members of your healthcare team can offer answers and advice.
- > Social workers and counselors can provide support and resource referrals.
- > Friends and family can help with many aspects of your care. From having loved ones to listen to you, to accompanying you to appointments or helping around the home, it’s important for you to ask for help when you need it.
- > Support groups, either in person or online, can be a great outlet to share your feelings and learn about what other people are experiencing.

PART TWO:

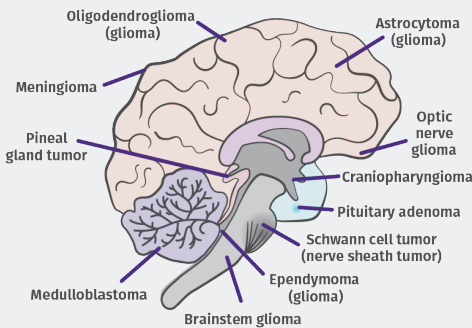
BRAIN TUMORS

Living creatures are made up of cells. The body normally forms new cells only when they are needed to replace old or damaged ones. A tumor develops if normal or abnormal cells multiply when they are not needed. A brain tumor is a mass of these unnecessary cells growing in the brain.

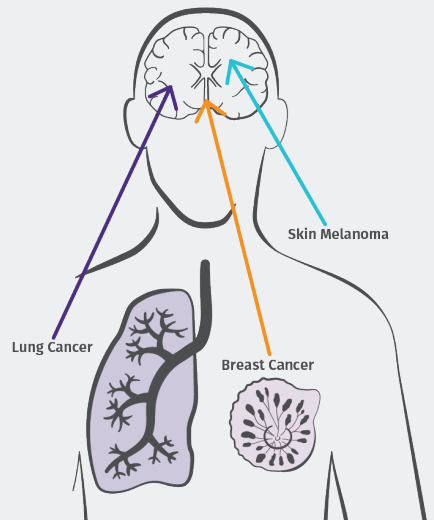
There are two kinds of brain tumors:

- 1 Primary brain tumors, which start and tend to stay in the brain.
- 2 Metastatic brain tumors, which begin as cancer elsewhere in the body and spread to the brain.

PRIMARY BRAIN TUMORS



METASTATIC BRAIN TUMORS





Types of Brain Tumors

PRIMARY BRAIN TUMORS

A tumor that starts in the brain is a primary brain tumor. Primary brain tumors can be grouped as non-malignant (benign) and malignant (cancerous). There are over 120 different types of primary brain tumors.

Non-malignant brain tumors

Non-malignant brain tumors consist of slow-growing cells. They usually have distinct borders and rarely spread. When viewed under a microscope, their cells have an almost normal appearance.

Non-malignant tumors are often referred to as “benign.” However, brain tumors made of benign cells can be in vital areas of the brain, making them life-threatening or difficult to treat.

Non-Malignant Tumors:

- *Slow-growing*
- *Distinct borders*
- *Rarely spread*

Malignant Tumors:

- *Usually rapid-growing*
- *Invasive*
- *Life-threatening*

Malignant brain tumors

Malignant brain tumors are fast-growing, invasive and life-threatening. They are sometimes called brain cancer. When viewed under a microscope, these tumors appear abnormal and lack distinct borders.

Malignant brain tumors can spread within the brain and spine due to their tendency to send “roots” into nearby normal tissue. They can also shed cells that travel to distant parts of the brain and spine through cerebrospinal fluid. These tumors rarely spread to other parts of the body.

METASTATIC BRAIN TUMORS

Cancer cells that begin growing elsewhere in the body and then travel to the brain form metastatic brain tumors. For example, cancers of the lung, breast, colon and skin (melanoma) may spread to the brain through the bloodstream or lymphatic system.

Brain Tumor Grades

Medical professionals assign tumors “grades” to help your healthcare team communicate better, plan treatment and predict outcomes. The grades (I, II, III or IV) assess how cancerous the tumor cells are. A grade I tumor is the slowest growing and easiest to treat. A grade IV tumor is the most cancerous and can be difficult to treat.

- > **Grade I** tumors are the least malignant tumors and are usually associated with long-term survival. They grow slowly and have an almost normal appearance when viewed through a microscope. Surgery alone might be an effective treatment for this grade of tumor. Pilocytic astrocytoma is an example of a grade I tumor.
- > **Grade II** tumors are slow-growing and look slightly abnormal under a microscope. Some can spread into nearby normal tissue and recur, sometimes as a higher-grade tumor. Examples are grade II oligodendroglioma and diffuse (grade II) astrocytoma.

Grade I Tumor

- *Slow-growing cells*
- *Almost normal appearance under a microscope*
- *Least malignant*
- *Usually associated with long-term survival*

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*

> **Grade III** tumors are malignant (cancerous). The cells of a grade III tumor are actively reproducing abnormal cells, which grow into nearby normal brain tissue. These tumors tend to recur, often as a grade IV. Examples include anaplastic astrocytoma and grade III oligodendroglioma.

> **Grade IV** tumors are the most malignant tumors. They reproduce rapidly, can have a bizarre appearance when viewed under the microscope, and easily grow into nearby normal brain tissue. These tumors form new blood vessels so they can maintain their rapid growth. Glioblastoma is the most common example of a grade IV tumor.

A single tumor may contain several grades of cells. The highest or most malignant grade of cell determines the tumor grade, even if most of the cells are a lower grade. Some tumors undergo changes. A lower-grade tumor might recur as a higher-grade tumor. Your doctor can tell you if your tumor might have this potential.



The Brain and Nervous System

The brain is a soft mass of supportive tissues and nerve cells connected to the spinal cord. Nerves in the brain and spinal cord transmit messages throughout the body. The brain and spinal cord together form the central nervous system (CNS).

The central nervous system is the core of our existence. It controls:

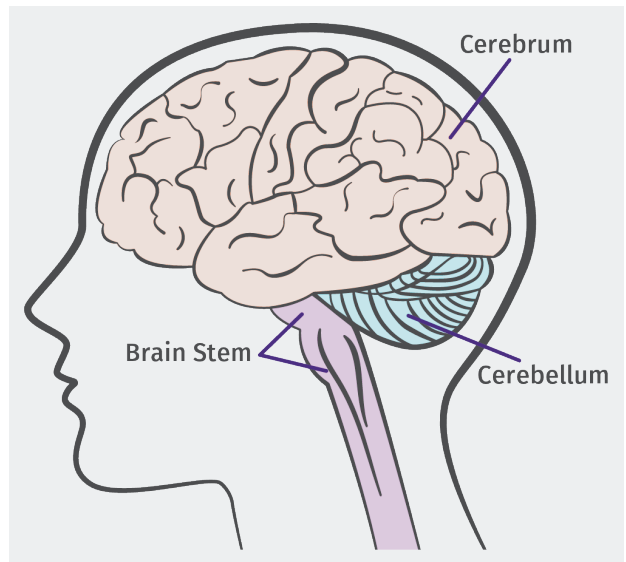
- > **Personality:** thoughts, memory, intelligence, speech, understanding and emotions
- > **Senses:** vision, hearing, taste, smell and touch
- > **Basic body functions:** breathing, heart beat and blood pressure
- > **How we function in our environment:** movement, balance and coordination

Learning about the normal workings of the brain and spine will help you understand the symptoms of brain tumors, how they are diagnosed and how they are treated.

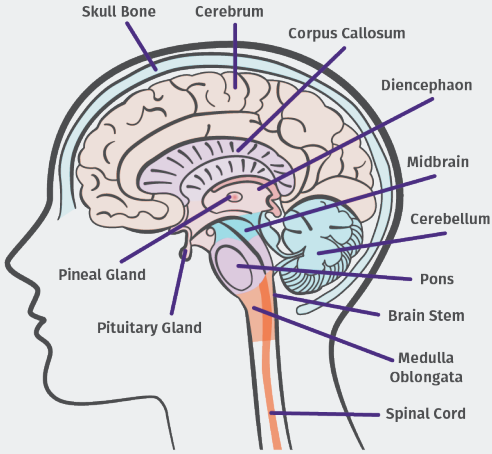
Major parts of the brain

There are three major parts of the brain.

- > **Cerebrum:** uses information from senses to tell our body how to respond. It controls reading, thinking, learning, speech and emotions.
- > **Cerebellum:** controls balance for standing, walking and other motion.
- > **Brain stem:** connects the brain with the spinal cord and controls basic body functions such as breathing, sleeping, body temperature and blood pressure.



CROSS SECTION



CENTRAL NERVOUS SYSTEM

Cervical Region (C1-C7)

Arm and hand functions

Thoracic Region (T1-T12)

Chest and abdominal functions

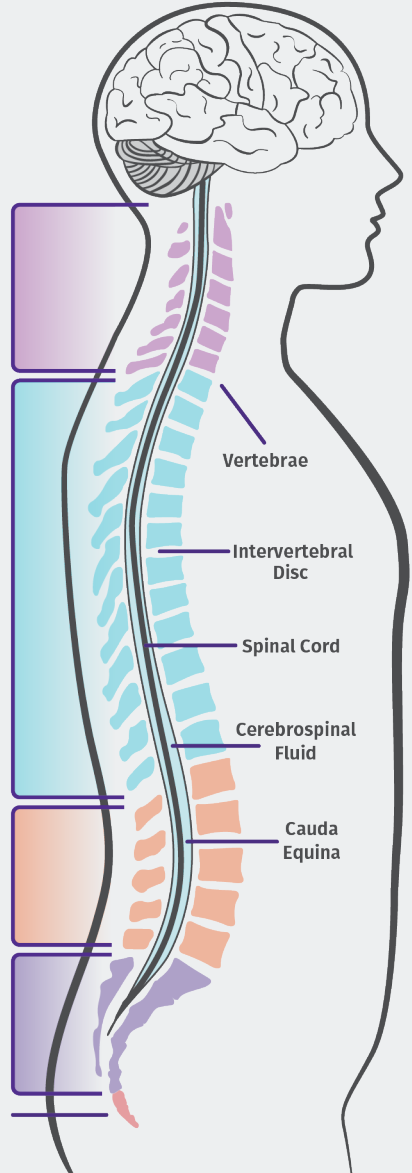
Lumbar Region (L1-L5)

Leg, knee and foot functions

Sacral Region (S1-S5)

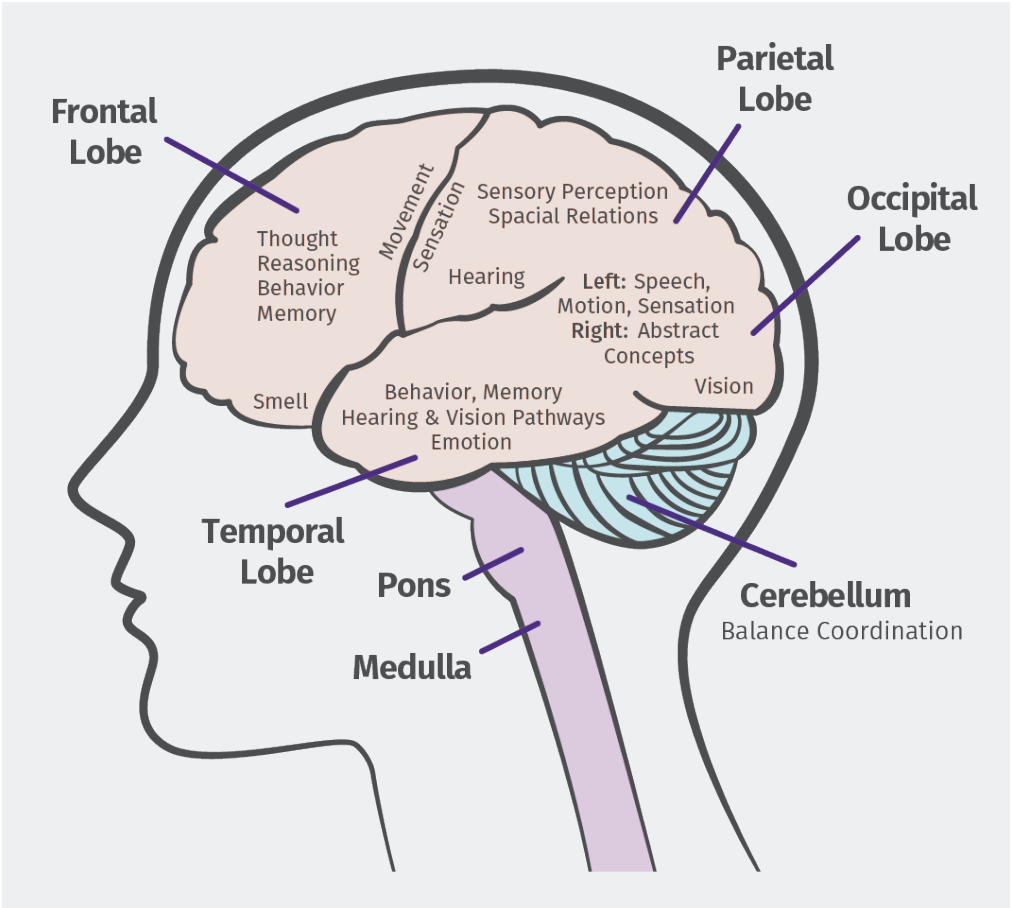
Leg, buttocks, foot, bowel, bladder and sexual functions

Coccyx



Lobes of the brain

Different lobes of the brain control different functions. As you can see in the diagram, the frontal lobe of the brain helps you think and reason. The temporal lobe contains the neural pathways for hearing and vision, as well as behavior and emotions. Having a tumor, or treatment, in one of these lobes could affect the lobe's specific functions. Additionally, since the brain has areas that connect, it is possible for a brain tumor to impact a function of the brain where the tumor is not specifically located.





Symptoms & Effects

Emotional effects

Emotional effects are natural for any major disease, brain tumor or not. When a brain tumor is diagnosed, it can take away your sense of security and control. Uncertainty is among the most challenging things that you may have to grapple with on a day-to-day basis. Depression is also very common.

In addition to the emotional reaction of receiving the diagnosis, the type, size and location may also affect your emotions. Some people with brain tumors experience intense emotions or personality changes because the tumor is located in an area that controls emotional functioning.

You do not have to feel guilty about emotional challenges. They are very common. A member of your healthcare team can refer you to a professional like a clinical social worker, clinical psychologist, or neuropsychologist. Support groups, which can be found on the ABTA website, may also help.

Cognitive effects

Cognitive effects are those that affect your ability to process information and communicate. For example, you may find it harder to find the words you need or calculate the tip at a restaurant. It may be difficult to concentrate or remember things. Your abilities may be better on some days and worse on others. Again, medical professionals and special types of therapy can help strengthen these abilities during and after treatment.

Physical effects

Physical effects are common, as treating a brain tumor can take a great toll on your body. While the effects are different for every person, a brain tumor and subsequent treatments may change your strength, balance, coordination and movement.

Additional common effects include seizures, fatigue, weakness, nausea, headaches and hair loss. Many people with brain tumors can handle these changes by adjusting daily activities. They set priorities and do only what needs to be done. They plan frequent rest and ask for help. In addition, medical services, such as physical and occupational therapy, can help improve body function. Make sure to speak with your doctor about any symptoms you may have, so they can be medically treated as best as possible.

More information about symptoms and effects, including seizures and fatigue, can be found at abta.org.



American Brain Tumor Association Resources

The American Brain Tumor Association (ABTA) was the first national nonprofit organization dedicated solely to brain tumors. For over 45 years, the ABTA has been providing comprehensive resources that support the complex needs of people with brain tumors and their caregivers, as well as the critical funding of research in the pursuit of breakthroughs in brain tumor diagnosis, treatment and care.

ABTA Resources

The ABTA offers support and information about brain tumors and their treatment and care.

The ABTA website, abta.org, is a comprehensive and trustworthy source of brain tumor information, including the following:

- > **Information about brain tumors**
 - > Symptoms and side effects
 - > Diagnosis
 - > Types of brain tumors
 - > Treatment options
 - > Support and resources
 - > Caregiving information
- > **Patient education brochures** related to tumor types and treatment options offered at no charge.
- > **Webinars** featuring nationally-recognized health, medical and scientific experts across a range of brain tumor topics.
- > **Local resources** including support groups and patient education conferences.
- > **CareLine** 1-800-886-ABTA (2282) and email (abta cares@abta.org) are staffed by caring professionals who are available Monday–Friday, 8:30 a.m.–5 p.m. CT.

- > **ABTA CommYOUUnity™ Connect** matches brain tumor patients or caregivers with someone who has been through a similar journey. Our trained volunteer mentors provide broad insight and support that ranges from a single phone call to lasting friendships. Visit abta.org/commYOUunity-connect for more information.
- > **Connections**, our online support community, connects those impacted by a brain tumor diagnosis with each other to share information, experiences, support and inspiration. Unlike other social media outlets, ABTA's Connections site (provided through Inspire.com) is a safe and more private setting where members can share their personal stories. Learn more at abta.inspire.com.
- > **Brain tumor educational conferences** The ABTA hosts a national conference annually in Chicago. Regional community meetings are also offered in select locations across the country. Renowned experts from top brain tumor centers present the latest advances in brain tumor research, treatment and care.

Our Mission

The mission of the American Brain Tumor Association is to advance the understanding and treatment of brain tumors with the goals of improving, extending and ultimately saving the lives of those impacted by a brain tumor diagnosis.

We do this through interactions and engagements with brain tumor patients and their families, collaborations with allied groups and organizations and the funding of brain tumor research.





Connect with us on
Social Media



For more
information

800-886-ABTA (2282)

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