



American
Brain Tumor
Association®

Providing and pursuing answers®



Brain Tumors

A HANDBOOK FOR THE NEWLY DIAGNOSED



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Introduction

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 help 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 just having a brain tumor while needing to make treatment decisions. The second half of the handbook provides more general information about brain tumors, the different types and their effects. Additional resources available through the ABTA are also provided.

The information and suggestions offered are from experts as well as from 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 abtacares@abta.org. We also encourage you to visit our website at www.abta.org.



PART ONE: THE DIAGNOSIS

"You have a brain tumor."

Those words can unleash a wide range of emotions, and it may be difficult 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 of 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 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, “wait, watch and see” will be an option. For many others, a decision about surgery and follow up treatment will need to be made early on. After learning about your diagnosis, **learn about your tumor type and 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 one, a social worker at the hospital can go over your options. What do you say, and what questions do you ask? The insurance section in this booklet has specific information that can help you.



Types of treatment for brain tumors

Brain tumor treatment decisions depend on the type and grade of brain tumor, its size and location in the brain, along with such other factors as age and overall health. In many cases, treatment includes surgery to remove the tumor followed by radiation therapy and/or chemotherapy.



Your healthcare team

You will have a team of professionals working with you at the point of diagnosis and 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* will 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?

QUESTIONS ABOUT TREATMENT OPTIONS:

- What treatment options are available?
- Can treatment wait?
- How long do I have to make decisions about my course of treatment?
- Are there alternative treatment options?
- How do you determine if the treatment is effective?
- 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?

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.



Genotyping: testing

that can reveal the specific genetic mutations within a patient's brain tumor from tissue that is collected at the time of surgery and then frozen and/or embedded in paraffin blocks. These mutations can help predict the response and sensitivity of your tumor cells to certain treatments. Doctors may be able to use this information to determine the optimal course of treatment for an individual patient. This information is also increasingly used to determine eligibility for a clinical trial.

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 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?
- Do I have to make any lifestyle changes?

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 the doctor open to me seeking a second opinion?





Seeking a second opinion

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. A second opinion from a brain tumor specialist can offer an alternative perspective about your diagnosis and treatment. 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 of your medical records from the time of diagnosis.

A new doctor will need to evaluate these records. They include all imaging tests, pathology slides, 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.



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 www.abta.org to help you locate a brain tumor treatment center.



Insurance

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

The ABTA website has more information about insurance and the ABTA staff can also help answer insurance questions. Call 800-886-ABTA (2282) or send us an email at abtacares@abta.org.



When you or your loved one calls 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.





You should also ask the following questions of the representative on the phone:

- Can you assign me a single point-of-contact for my case? (Some companies do this)
- Do I need to obtain pre-authorization for hospitalization or treatment? If so, who do I call?
- Do I need to obtain a second opinion before non-emergency surgery? If so, are there any limitations on whom 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?
- 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 caregiver and family is essential during this time. There are others who have knowledge and experience to share, and it will help to talk through your questions, concerns and emotions as you move forward.

-  The American Brain Tumor Association is here for you every step of the way. Our healthcare staff are available through our CareLine to answer any questions you may have and offer additional resources, often available locally. 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 to issues you are facing.
-  Social workers and counselors can provide support and resource referrals.
-  Friends and family can help with many aspects of your care. From having a person 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.
-  You can access additional resources on the ABTA's website, www.abta.org, including on-demand webinars on a variety of topics affecting brain tumor patients and their caregivers.

PART TWO: BRAIN TUMORS

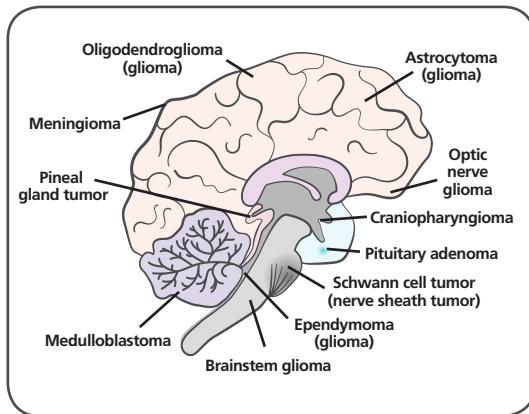
Living creatures are made up of cells. The adult body normally forms new cells only when they are needed to replace old or damaged ones. Infants and children create new cells to complete their development in addition to those needed for repair. A tumor develops if normal or abnormal cells multiply when they are not needed. A brain tumor is a mass of unnecessary cells growing in the brain.



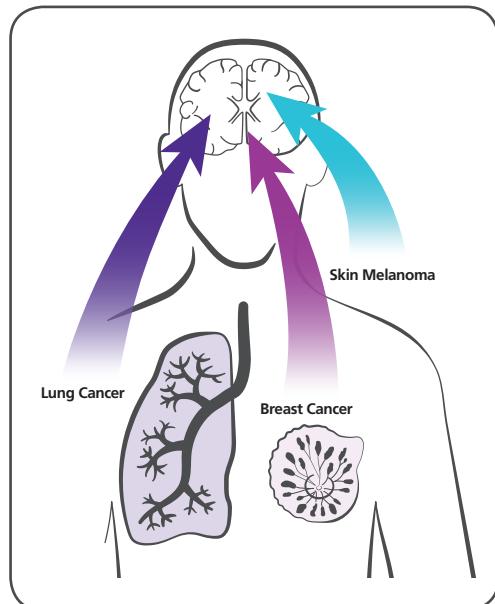
There are two kinds of brain tumors:

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

PRIMARY BRAIN TUMORS



METASTATIC BRAIN TUMORS





Primary Brain Tumors

A tumor that starts in the brain is a primary brain tumor. Gliomas for examples are primary brain tumors. Primary brain tumors are grouped into benign tumors and malignant tumors. There are over 120 different types of primary brain tumors.

BENIGN BRAIN TUMORS

A benign brain tumor consists of very slow-growing cells, usually has distinct borders and rarely spreads. When viewed under a microscope, these cells have an almost normal cellular appearance.

Surgery alone might be an effective treatment for this type of tumor. However, a brain tumor composed of benign cells, but located in a vital area of the brain impacting the way that the area of the brain works, can be life-threatening — although the tumor and its cells would not be classified as malignant.

MALIGNANT BRAIN TUMORS

A malignant brain tumor is usually rapidly-growing, invasive and life-threatening. Malignant brain tumors are sometimes called brain cancer.

Malignant brain tumors can spread within the brain and spine. They rarely spread to other parts of the body. They lack distinct borders 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, by way of the cerebrospinal fluid.

BENIGN TUMORS

- Slow growing
- Distinct borders
- Rarely spread
- Can usually be removed

MALIGNANT TUMORS

- Usually rapid growing
- Invade brain tissue
- Life threatening



Metastatic Brain Tumors

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

TUMOR NAMES

Tumors are diagnosed, and then named, based on a classification system. The World Health Organization (WHO) classification system is used for this purpose.

To learn more about your specific brain tumor, visit the brain tumor information section of ABTA's website at www.abta.org.



Tumor Grading

Medical professionals assign tumors “grades” to help your healthcare team communicate better, plan treatment, and predict outcomes. The grades (1–4) assess how cancerous the tumor cells are. A grade 1 tumor is the slowest growing and easiest to treat. A grade 4 tumor is the most cancerous and can be difficult to treat.

- **Grade 1** tumors are the least cancerous and are usually associated with long-term survival. The tumors grow slowly and have an almost normal cellular 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 1 tumor.
- **Grade 2** tumors are relatively slow-growing and have a slightly abnormal cellular microscopic appearance. Some can spread into nearby normal tissue and reproduce themselves, and can become a higher grade tumor. Examples are grade 2 oligodendrogloma and grade 2 astrocytoma.
- **Grade 3** tumor cells are actively reproducing abnormal cells which grow into nearby normal brain tissue. These tumors tend to recur, or reproduce themselves, and may recur as a grade 3 or change to a grade 4. A cancer recurrence is defined as a return of cancer after treatment and after a period of time during which the cancer cannot be detected.
- **Grade 4** are the most cancerous brain tumors. They reproduce rapidly, can have a bizarre cellular appearance when viewed under the microscope and easily grow into surrounding normal brain tissue. These tumors form new blood vessels so they can maintain their rapid growth. They also have areas of dead cells in their center. Glioblastoma is the most common example of a grade 4 tumor.

A single tumor may contain several grades of cells. The highest or most cancerous 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.

World Health ORGANIZATION (WHO) GRADING SYSTEM

GRADE 1 TUMOR

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

GRADE 2 TUMOR

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

GRADE 3 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 4 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



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).

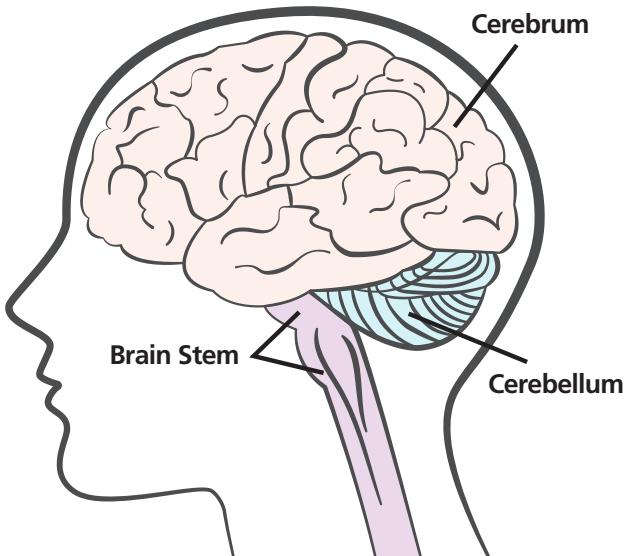
The central nervous system is the core of our existence. It controls our personality — thoughts, memory, intelligence, speech, understanding and emotions; our senses — vision, hearing, taste, smell and touch; our basic body functions — breathing, heart beat and blood pressure; and how we function in 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.

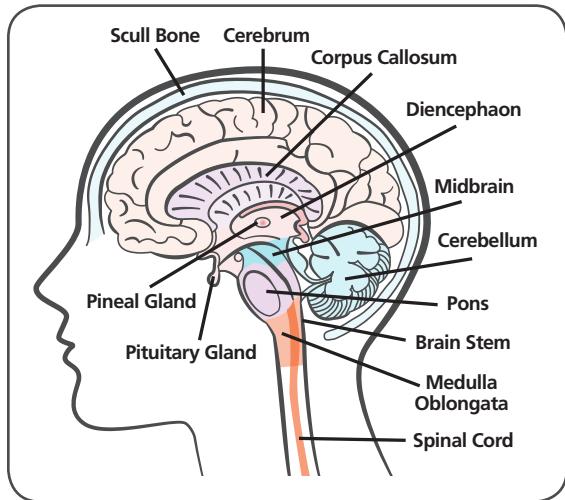
MAJOR PARTS OF THE BRAIN

There are three major parts of the brain.

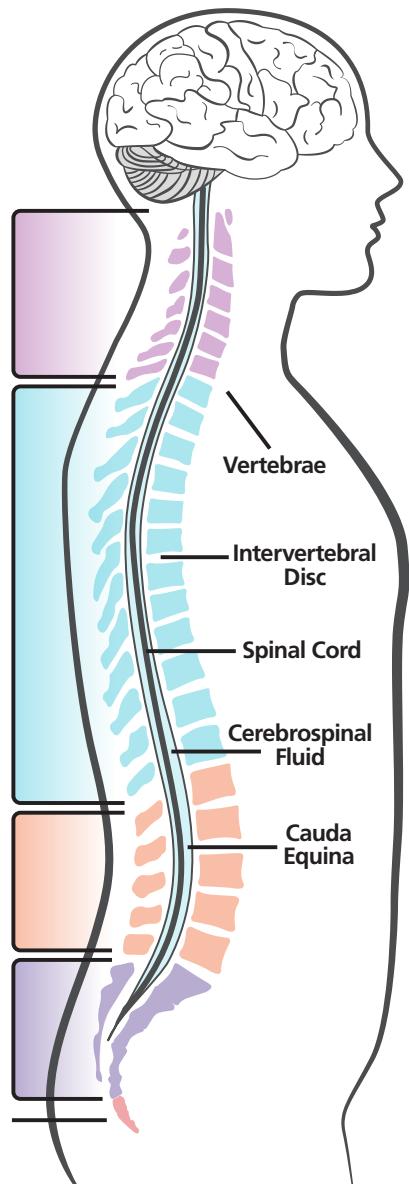
- **Cerebrum** — uses information from senses to tell our body how to respond. It controls reading, thinking, learning, speech and emotions.
- **Cerebellum** — controls balance for standing, walking and other motion.
- **Brain stem** — connects the brain with the spinal cord and controls basic body functions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

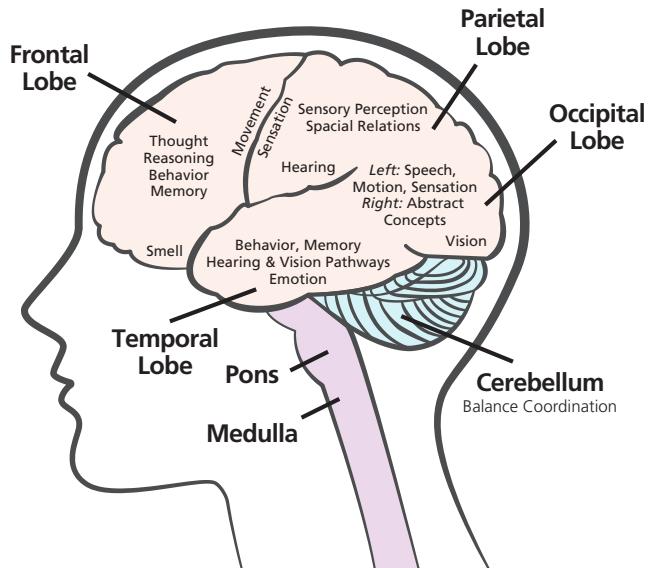
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LOBES OF THE BRAIN

Within the major parts of the brain, 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. You can

probably guess that a tumor in one of these lobes, or intervention to remove the tumor, could affect 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 and side effects of a brain tumor: emotional, cognitive, physical

- **Emotional side 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 side effects related to 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 side effects** are those that effect your ability to process information and communicate. 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** 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 appearance, strength and ability, as well as your ability to carry on a full, active day.

Additional common side effects include seizures, pain, fatigue, weakness, nausea, headaches and hair loss. Many people with brain tumors are able to handle these changes by being realistic. 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 make have, so that they can be medically treated as optimally as possible.

More information about how to manage symptoms and side effects, including seizures and fatigue, can be found at www.abta.org.

AMERICAN BRAIN TUMOR ASSOCIATION RESOURCES



American
Brain Tumor
Association®

The American Brain Tumor Association (ABTA) was the first national nonprofit organization dedicated solely to brain tumors. For over 40 years, the ABTA has been providing comprehensive resources that support the complex needs 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 treatments, side effects and the overall progression of the illness.

- The ABTA website, www.abta.org, is a comprehensive and trustworthy source of brain tumor information. Here you can find:

- **Information about brain tumors:**

- Causes and risk factors
- Symptoms and side effects
- Diagnosis
- Types of brain tumors
- Treatment options
- Support and resources
- Caregiving information

- **Patient Education Publications** related to tumor types and treatment options offered at no charge.



- **Webinars** featuring nationally recognized health, medical and scientific experts on a range of brain tumor topics.
- **Local resources** including support groups and patient education conferences.
- **CareLine** 1-800-886-ABTA (2282) and email (abtacares@abta.org) are staffed by licensed healthcare professionals who are available Monday–Friday, 8:30 a.m.–5 p.m. CT.

- **Peer to peer mentoring** program 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/volunteer 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 www.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 across the country present the latest advances in brain tumor research, treatment and care. Visit www.braintumorconference.org for more information.

Sign up for email updates from the ABTA at www.abta.org.

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.



Notes



American
Brain Tumor
Association®

Providing and pursuing answers®

For more information:

-  **Call:** **800-886-ABTA (2282)**
-  **Email:** **info@abta.org**
-  **Visit:** **www.abta.org**