

Caregiver Handbook



American
Brain Tumor
Association®

Providing and pursuing answers®

Acknowledgements

About the American Brain Tumor Association

Founded in 1973, the American Brain Tumor Association (ABTA) was the first national nonprofit organization dedicated solely to brain tumor research. The ABTA has since expanded our mission and now provides comprehensive resources to support the complex needs of brain tumor patients and caregivers, across all ages and tumor types, as well as the critical funding of research in the pursuit of breakthroughs in brain tumor diagnoses, treatments and care.

To learn more, visit **abta.org**.

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Caring for Your Loved One with a Brain Tumor

This handbook combines caregiver advice, professional experience and the outcomes of clinical research to provide you with an introduction to caring for someone close to you who has a brain tumor. The handbook will also provide tools and resources to help you navigate this journey.

“ I found myself in a life-altering situation. I had to adjust to the new normal. I learned to be more flexible, to laugh, and to remind myself that there was no ‘right’ way to be a caregiver. ”



Your Role as a Caregiver

Brain tumor patients, caregivers and their loved ones often need more support due to the neurological symptoms that can come with a brain tumor diagnosis. As a caregiver, you may find yourself taking on the role of a medical researcher, a financial manager, a patient advocate and a communicator. Caregiving can be a full-time job, even if you already have a full-time job. Each caregiver experience is different. This handbook will provide information to help you through your journey.

Your role changes over time

The patient's needs will change over the course of the disease and treatment, and so will the tasks you undertake. At first, you may find yourself in "crisis" mode as you attempt to understand the full breadth of coping with the disease.

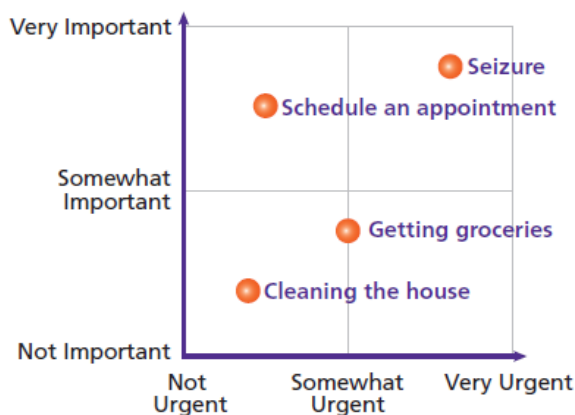
Many families find some relief after settling on a medical facility and plan of treatment. You can use this time for a number of tasks, such as getting organized, researching treatments, focusing on diet and nutrition for yourself and the patient, or finding a support group. Eventually, most people fall into a rhythm of care.

Prioritizing and solving problems

Some organize tasks by considering how urgent a task is and how important it is. For example, when a patient has a seizure, it is both urgent and important, so that task should be handled right away.

Making a doctor's appointment is important, but not as urgent, so it can be done later.

Things like getting groceries and cleaning the house are important, but may be lower on your priority list. Some of these items can be delegated to others or outsourced. You may even find that some items can simply be ignored.



Advocating for the patient

Treatment for a brain tumor is complex. As a caregiver, you will learn to be an advocate for the patient as you come into contact with a large, multidisciplinary medical team. You can advocate for the patient by:

- > **Understanding the medical team and their roles.** This can include hospital staff, clinic staff, specialists and other health care professionals.
- > **Involving the patient as much as possible.** You can be the patient's voice, making sure the patient has a thorough understanding of the choices he or she must make and ensuring his or her questions are answered.
- > **Learning about treatment options.** You can research treatment options as well as advocate for second opinions. The ABTA website features written information and videos to serve as a good starting point to understand treatment options.
- > **Communicating on the patient's behalf.** In your role as a caregiver, you can help communicate hard-to-discuss topics with others, whether that means with the medical care team or friends and family.



I focused on getting through each day,
breaking steps into manageable pieces.

— CAREGIVER



Day-to-day management

Day-to-day management means attempting to live as normal a life as possible for yourself and for the patient.

- > Many caregivers develop a **daily routine**, even scheduling everyday tasks. Routines can include managing medical appointments, taking care of the household, and assisting the patient with activities of daily living (ADL) like hygiene and taking medications.
- > Keeping a **master calendar** can help keep family and friends informed about your activities and needs. Free online tools include Google Calendar, Caring Bridge (caringbridge.org) and Lotsa Helping Hands (lotsahelpinghands.com).
- > **Recordkeeping** can include keeping track of tests, insurance information, medications, treatments, symptoms and side effects. There are several mobile apps that can help you manage medical information. Many people use binders with tabs to collect and organize this information.



Family Impact

A brain tumor diagnosis affects families in different ways. This section lists some of the changes that occur in the family and how to address them.

Changing relationships

Relationships with family, friends and the patient will most likely undergo changes during the course of the disease.

- > Many brain tumor patients experience mental and behavioral changes due to a brain tumor or treatment. A sweet and caring person may become angry and withdrawn. Another person may suddenly not enjoy the same activities as before. These changes may or may not be permanent, but regardless, they're difficult to accept. The patient may not even notice these changes.
- > You may find yourself in an unfamiliar role. For example, if your spouse handled the finances, the task may now be up to you. If you are caring for a parent, you may find the role reversal difficult to handle. Parents taking care of young children and teens may find that positive relationships with a co-parent and other children can suffer.
- > Many caregivers also experience positive changes. They have found emotional fulfillment from caring for the patient. Others are grateful for the support they receive from family and friends and have enjoyed seeing those relationships strengthened. Many other caregivers have found support and strength by connecting with others, both through online and in-person support groups.

Family expectations

Family and friends may have opinions on many aspects of the patient's care.

- > Family members have various ways of **communicating** with each other. Some families want regular updates. Others don't want as much information. Think about what might work for you. Do you enjoy updating family and friends by phone, or would social media or email updates be less draining? Can a family member or friend help you communicate?
- > They may have expectations on **how you should care for the patient**, including the type and the level of care. This can cause conflict as family members may expect you to do things differently or listen to their treatment

recommendations. Despite family opinions, as the primary caregiver you may need to evaluate and decide what kind of support you do or don't need. Some caregivers find it useful to make a list of "do's and don'ts" to share with family members to guide expectations.

- > Families may also have **expectations about your time**. Some family members may express disapproval when you do something for yourself. However, other caregivers have found that family members are willing to volunteer and chip in. And, they often find the experience uplifting.

Communicating with children

Sometimes, caregivers think it's best to shield children from knowing about the patient's brain tumor. However, rather than making them feel safe, children will most likely sense that something is going on, causing them to feel alone and excluded while their imaginations run wild with worst-case scenarios. Children may also find information online that is frightening or inaccurate. Talking to them about the diagnosis and keeping them informed during the disease process in an age-appropriate manner can help facilitate healthy coping and adjusting.

If a child has been diagnosed with a brain tumor, it is also important to keep communication open. Create an atmosphere where your child will want to ask questions or return to the topic whenever new questions or concerns arise. Some children will want lots of details, others will not. Follow your child's lead. Having conversations can help address misconceptions the child may have, such as believing their tumor is contagious or getting it was their fault. Most medical teams have a social worker or child life specialist who can help explain the diagnosis, tests and treatments in a way your child or teen will understand. The ABTA website also has information about how to speak with a child who has been diagnosed with a brain tumor as well as their siblings.



Overall, the best strategies for communicating with children and teens include:

- > Maintaining structure. Keep routines, schedules, etc.
- > Keeping children informed.
- > Letting children know that they'll be cared for, no matter what.

You can also determine how to tell and how much to tell your child based on their age and emotional development. Young children will need less information than older children. Finally, involving children in caring for the patient, but not overwhelming them, is challenging but possible. If the patient is a child, consider how siblings can get involved in the child's care or help with household chores and coming to medical appointments.

The ABTA website includes detailed information and specific examples about how to communicate with children about a brain tumor and how to include them in the care of a brain tumor patient.

Work vs. caregiving

Some patients may require around-the-clock care. Many have the difficult choice of continuing to work a full-time job or being a full-time caregiver. This is a personal decision each family must make based on their own situations, taking into account resources such as time and finances.

Some are able to afford leaving their current job to become full-time caregivers. Others must continue working during the day and care for their loved one at night. Here are some ways to help balance your new role as a caregiver with other responsibilities:

- > Enlist family and friends to help with daily tasks like shopping, meal preparation, cleaning, and taking the patient to appointments.
- > Check your employment benefits such as the Family Medical Leave Act (FMLA) which offers up to 12 weeks of unpaid, job-protected leave to patients and caregivers. Under FMLA, you will continue to receive benefits like health insurance.
- > Hire in-home nursing care for a few hours or a few days a week. This can be an expensive option, so see if it's right for you.
- > Ask your employer about flexible work options like working from home, adjusting hours or working part-time.
- > Look into disability benefits that your loved one may be eligible for, like short-term or long-term disability plans offered by an employer. There are also government disability benefit programs like Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI). There is usually a waiting period to be eligible for these benefits. Patients diagnosed with certain tumor types qualify for compassionate allowance, which reduces wait time for disability benefits.



Navigating the Health Care System

You are an essential part of the patient's health care team. You will be communicating with a wide range of health care providers from surgical specialists to social workers. Successfully navigating the health system will empower you to be a strong advocate for your loved one.

Preparing for appointments

Appointments are ideal times to gather information from the patient's medical team. Going through your notes and talking to the patient or other loved ones before the appointment can help you figure out what you want to discuss. Be sure to write down all questions before the appointment. In the beginning stages, you and the patient may have questions regarding:

- > The type of tumor and grade of the tumor
- > Medical tests and procedures needed, along with time frames
- > Contact information for the medical team
- > Which medical team members should be contacted in different situations
- > Treatment information: options, time frames and potential outcomes
- > Potential lifestyle changes
- > How to handle medical emergencies
- > Prognosis of the patient with or without treatment
- > Which health care provider to speak with about different topics

Later, once treatment has been determined, you may find it useful to track the patient's symptoms and side effects.

Managing a patient's medical records is also important. Medical records can help doctors make more effective decisions regarding treatment and care. This is especially true for survivors of childhood brain tumors, who may need to be monitored by doctors throughout their lives.

Be sure to ask for copies of medical records, including scans (e.g., MRI), lab test results, pathology reports and other information recorded by health care providers. Any records you receive should be kept for future reference, including if seeking a

second opinion. Many health care providers give patients access to electronic medical records, which can make the process of getting records easier and less time-consuming. Check with the provider to see if this is an option.

Hospital and clinic

It is also helpful to understand the institutions and people who are part of your loved one's health care team.

- > **The hospital** is where patient will go when they require higher-level care and monitoring, such as for surgery and for certain tests and procedures. If this is the first time that you have experienced a major hospital stay, you may be surprised at all the comings and goings of various professionals.
 - > Nurses, residents and attending physicians will make rounds and check on the patient.
 - > You will meet the patient's neurosurgeon, who will perform the surgery, as well as the neuro-oncology doctor, who will be the main coordinator for the patient's brain tumor care after the surgery.
- > **The clinic** is where most patients typically embark on a post-surgery treatment plan. The clinic may be part of a large hospital system, or it could be where your neuro-oncologist has office space.
 - > The patient will visit the clinic regularly for chemotherapy, radiation or other treatments.
 - > In addition to the physicians and nurses on staff, clinics typically have a wide variety of professionals to help you, including social workers, psychologists and physical, speech and occupational therapists.

Second Opinions

Getting a second opinion about a loved one's treatment options can offer many advantages, such as additional treatment options and viewpoints. While some situations are emergencies and require immediate treatment, in most cases there is time to seek a second opinion from another medical professional or institution. Call the ABTA or visit our website to find treatment centers that specialize in brain tumors.

Patient care team

During the course of the patient's illness, you may meet with many medical professionals. The patient's treatment team typically consists of the following:

- > **Neurosurgeon:** A physician trained in surgery of the nervous system.
- > **Neuro-oncologist:** A physician who specializes in treating patients with nervous system tumors, and/or their symptoms. The physician is often a trained neurologist, oncologist or neurosurgeon.
- > **Primary Care Physician (PCP):** The patient's local doctor. Although the PCP does not specialize in brain tumor care, he or she can be a resource for finding specialists and helping to coordinate overall care.
- > **Nurses:** Provide a number of services to patients, including performing physical exams, administering medications and educating about health and diseases. They also listen to patient concerns and share this information with the treatment team. There are different credentials and levels of nursing education, such as Registered Nurse (RN) and Licensed Practical Nurse (LPN).
- > **Medical Assistant:** Provides basic clinical services to patients, often in outpatient settings. Medical assistants are often cross-trained to manage administrative functions such as updating medical records and arranging for related medical services.
- > **Nurse Practitioner or Physician's Assistant:** These are health care professionals with advanced degrees who can either be your primary provider or may work alongside a physician to develop your treatment plan.
- > **Social Worker:** Provides valuable resources that can include assistance in making medical decisions, coordinating at-home care, locating financial resources and more. Social workers can help patients and their loved ones cope with a new diagnosis and any emotions you may be experiencing.
- > **Nurse Navigator:** Assists with appointment management, disease education, information on symptoms and side effects, finding resources and more. These nurses often specialize in the specific diagnosis for which they are providing navigation services.



The patient may also see specialists who can help with specific types of tumors or symptoms the patient experiences.

- > **Neuropathologist:** Analyzes brain tumor tissue removed during surgery and prepares a pathology report, which typically directs the type of treatment the patient receives.
- > **Neuropsychologist:** Helps assess and provide strategies for patients who are experiencing cognitive, behavioral and emotional side effects from the brain tumor or treatment.
- > **Psychiatrist:** A physician who diagnoses and treats mood and emotional issues that may arise from the brain tumor or treatment.
- > **Neuroradiologist:** A radiologist with training in reading images of the brain and central nervous system.
- > **Radiation Oncologist:** Oversees radiation treatment.
- > **Rehabilitative Specialists:** Health care professionals such as occupational, physical and speech therapists who can help improve a patient's strength, mobility, memory or communication.
- > **Endocrinologist:** May be consulted if the brain tumor or treatment affects one of the patient's endocrine organs, such as the pituitary gland.
- > **Child Life Specialist:** Works to reduce anxiety and distress for children during their hospital experience.

Health insurance

Understanding your insurance coverage and knowing how to find the answers you need from your insurance provider are essential during your caregiving journey.

- > The first thing most social workers recommend is to **have a printed or online copy of your policy available** when you're talking to administrators and social workers.
- > The **nurse navigator or social worker** assigned to the patient's case is often a good resource for health-insurance questions.
- > Some insurance companies provide a **dedicated patient representative**, such as a nurse care manager, to be a single point of contact. Ask your insurance company whether they provide this service.
- > Hospitals and medical facilities have trained specialists in their billing departments who may be able to connect you with financial resources relating to your medical care. Some billing departments offer financial assistance, which can lessen the financial burden of medical treatment.





Brain Tumor Symptoms & Side Effects

Symptoms are the result of a tumor affecting normal brain function. The types of symptoms and their severity differ for every individual, and can depend on the patient's brain tumor type, location, and other factors such as age and overall health. **Side effects** are symptoms caused by treatments, such as surgery, radiation or chemotherapy. The symptoms and side effects of a brain tumor can be physical, mental and emotional.

Side effects and symptoms are not something to be taken lightly and should be viewed as signals that the body needs help. As you log these with health care professionals, you may find that they can be treated, leading to a better quality of life.

Physical symptoms and side effects

Below is a list of common physical symptoms and side effects. Many patients experience at least some of these. All are described in more detail on the ABTA website.

- > A deep **fatigue** is more than simple tiredness. Medical professionals can help determine whether the fatigue can be treated with medication and/or energy-conserving strategies.
- > **Seizures** occur in about 39-60% of brain tumor patients at least once during their illness. Although frightening, most seizures can be medically managed. Speak with your loved one's doctor about treatment options. A health care professional should be notified about any new or worsening seizures. Share details such as how long the seizures last as well as any symptoms like arm movements or difficulty speaking. The ABTA has a Seizure First Aid wall cling, which provides instructions on how to handle a seizure, available at no charge. Call the ABTA or visit our website to place your order.
- > **Nausea and vomiting** can be a symptom of the tumor itself, or a side-effect of treatment. Medications may be available to relieve symptoms.
- > **Sensory and motor changes** can contribute to difficulty with activities, such as writing, eating, or controlling the arms or legs. While these symptoms may be lessened with the help of a rehabilitation specialist, sudden weakness or dizziness may be a sign of a stroke, in which case 911 should be called immediately.

- > **Deep venous thrombosis (DVT) and pulmonary embolism (PE)** occur in about 20% of brain tumor patients. DVT is a blood clot that usually develops in the legs or arms. Signs of DVT can include swelling, tenderness and pain in the leg, one leg appearing larger than the other one, or skin on the leg turning red. When the clot moves towards the pulmonary vein, it is then considered a pulmonary embolism (PE). Signs of a PE include shortness of breath and chest pain. If suspected, DVT or PE should be treated immediately. Call 911 or go to the emergency room. Fortunately, this condition is highly treatable if detected as soon as possible.
- > **Hearing and vision loss** can occur during the illness, but can also manifest after treatment is complete. While rarely an emergency, sudden blindness may indicate pressure from the tumor on the brain and may require emergency care.
- > **Pain** can be a major side effect of brain tumors and treatment. Pain affects many parts of a patient's life, such as sleep, diet and emotional state. Sometimes false perceptions about pain and pain medication can cause barriers to treatment. If you and the patient are worried about how to manage pain, relay your concerns to your health care team. Referrals can be made to pain clinics or palliative care programs. **Headaches** are a common form of pain, experienced by about 50% of brain tumor patients. When tracking headaches, note their severity, activities being done at the time that they start and any other accompanying symptoms. A doctor should be notified if headaches do not stop or are not relieved by over the counter medications.



Cognitive symptoms and side effects

Along with physical symptoms, brain tumors are often accompanied by cognitive symptoms and side effects. These are sometimes more difficult for patients and caregivers to manage than physical changes.

Cognitive symptoms and side effects can be mild or severe, and can change over time. Sometimes, these changes are so minor that only the patient recognizes them. Other times, the caregiver recognizes that something is different, even when the patient does not. You may see changes in:

- > Communication
- > Learning and memory
- > Attention and concentration
- > Planning and organizing
- > Personality

Just as with physical symptoms, there are many treatments available for patients to rebuild or strengthen cognitive functioning, including:

- > Cognitive rehabilitation therapy
- > Medication
- > Speech and language therapy

There are also many practical, everyday ways to help patients cope with cognitive changes. Some examples include listening to and validating what the patient is going through, minimizing distractions so the patient can focus, and developing and sticking to routines. Additionally, using organizational tools and keeping the brain active with reading, puzzles, writing, drawing and social activities with family and friends can help. Reduce television consumption. Try to focus on one thing at a time. Mindful meditation can also have positive effects on brain function.

Emotional symptoms and side effects

Patients can also experience emotional symptoms and side effects related to a brain tumor. These can be due to biochemical changes in the brain caused by the tumor or treatments. They can also be a reaction to the difficult news of a diagnosis and adjusting to a new way of living. Here are some of the emotional changes that can occur:

- > **Depression** is more than a low mood. It can include loss of interest or pleasure in usually enjoyable activities, changes in sleeping or eating patterns, and even thoughts of hopelessness or suicide.
- > **Mood swings** are sudden, unexplained changes in the way one feels. A patient can be content one moment, and very angry the next without any reason why.

- > In some cases, patients experience changes that resemble **psychiatric symptoms**, such as mania, aggression or hallucinations. A doctor should be notified of these symptoms as soon as possible, as they can lead to the patient causing harm to self or others.

Emotional symptoms are often eased by removing or treating the brain tumor. Other treatments for emotional symptoms include medications and psychotherapy.

The ABTA can provide additional information about brain tumor symptoms. Call or visit our website for more information.

Safety at home

Managing physical and cognitive changes may require you to make adjustments so the patient and loved ones are in a safe environment. It's best to work with a rehabilitation specialist to determine exactly what you will need for the patient. Adjustments will consider your size, physical strengths and level of ability. General tips include:

- > Protect yourself. If you tax your body too much you will not be able to help the patient.
- > Modify your home. This does not have to be permanent or expensive. A professional can help you identify potential issues and remove or install necessary items, such as rearranging furniture or adding a shower seat.
- > Learn to transfer the patient. If the patient requires help to move from one place to another, you can work with your care team to develop the best way to transfer the patient from bed to a chair, into a car, etc.
- > Evaluate injuries. With brain tumor patients, it can be difficult to evaluate the seriousness of a fall or injury. Symptoms can emerge hours or even days after an accident. Patients with sensory loss may be more injured than they realize. Because of all the unknowns, it is best to call a medical professional immediately if there is a chance that the patient fell or is hurt.





Caring for Yourself

The topic of caring for yourself is last in this handbook, but is first in importance. When you are healthy, both physically and emotionally, you are able to take much better care of the patient.

A mix of emotions

Most caregivers experience a wide range of emotions, including guilt, anger, grief and loss. Some people are able to experience joy and gratefulness during a patient's illness, even while they are experiencing sadness.

Coping strategies

Caregivers of patients with brain tumors have an incredible amount of resiliency. They must find ways to cope, and they do. If you find yourself struggling, you are not alone. Caregivers have found many ways to ease their burdens.

> **Share/talk about emotions.** Sharing and talking about the emotions you are experiencing – anxiety, sadness, anger – can be a great help. Even acknowledging these feelings to yourself can be important.

Resources include:

- > **Mental Health Care Professionals**, referred by the ABTA or your doctor or social worker.
- > **ABTA CareLine**, call 800-886-ABTA (2282) or email Info@abta.org, to connect with a CareLine staff member for personalized information and resources.
- > **ABTA Peer-to-Peer Support**
 - > **Brain Tumor Support Groups.** Visit abta.org to access a comprehensive directory of support groups listed by state.
 - > **ABTA Patient & Caregiver Mentor Support Program.** Connect with a trained brain tumor patient or caregiver mentor to help navigate a brain tumor diagnosis. Call the ABTA CareLine for more information at 800-886-ABTA (2282).
 - > **ABTA Connections Community.** An online support and discussion community of more than 35,000 members. To learn more, visit abta.org/connections.

- > Take care of your physical health. Consider getting a full physical. Tell your doctor about your role as a caregiver and any symptoms you are experiencing, whether emotional or physical. Taking time to plan and eat healthy, fulfilling meals, getting enough sleep and enjoying physical activities are other ways to boost your physical health. Learning how to move the patient without hurting yourself is also important. Check the Safety at Home section on page 16 for tips and advice.
- > Take care of your emotional and cognitive health. Between emotions and all you need to manage, it is helpful to find ways to ease your mind. You can keep a log or journal of emotions, physical symptoms and activities that are effective in helping you cope. Daily practices like expressing gratitude and setting positive intentions can also help foster a positive perspective and mood.



Sometimes I don't know how I did it. Cleaning him, going to all the appointments, massaging him, exercising him...and then doing it all again. I'd get angry at him for getting sick, and then feel guilty for getting angry.



— CAREGIVER

- > De-clutter your life. For some people, the upside of a brain tumor in the family is that it can be an opportunity to re-evaluate your priorities and simplify your life. Reflect on your obligations, routines and even relationships. Do they help, or are they a drain on your resources? Consider streamlining when possible. An ongoing list of tasks, with the focus on accomplishing at least one a day, no matter how minor, can help give you a greater sense of control over your environment.
- > Consider the spiritual. Whether you are religious or not, mindfulness practice, through prayer or non-religious means, is proven to reduce stress. Paying attention to your spiritual life can also lessen the effects of depression. In addition, connecting with others, whether as part of a religious-based community or through a support group, lifts the spirit and helps caregivers feel less alone. Many medical centers have spiritual counselors who can speak with you about your unique spiritual needs.

Asking for help

Many people feel uncomfortable asking for help. It can also be hard to answer non-specific offers of “What can I do?” or request something when someone asks “Is there anything you need?”

However, there are ways to transform non-specific offers of help into concrete assistance and find volunteers for day-to-day tasks. Some caregivers have done the following:

- > Make a list of people who have offered help and choose someone to act as a care coordinator. This person can help match the offers of help with the help needed on an ongoing basis.
- > Free websites such as Caring Bridge (www.caringbridge.org), Lotsa Helping Hands (www.lotsahelpinghands.com) and My Life Line (www.mylifeline.org) can help keep family and friends informed of a patient’s progress during illness. They may also have a calendar or volunteer feature. You can set up calendars and send updates through Facebook, Google Calendar and other social media.
- > Be specific about what you need. The more specific you are, the more likely you will be able to check something off your list.
- > Many health care institutions offer support services for caregivers. Nurses and social workers can share what is available to you.
- > Visit the ABTA’s Caregiver Resource Center at abta.org for a list of tips for asking for help from family and friends.

Finding additional resources

Many caregivers of brain tumor patients find that they need more help than their friends and family can provide. Sometimes they need additional assistance so they can go to work or have a small break. Other times, they lack the physical strength or skill needed, such as with moving the patient or wound care.

To begin your search for outside care you should understand your insurance coverage. Many policies specify the type of care that will be reimbursed and may require approval from the patient’s physician.

- > Your community may include services ranging from adult daycare to in-home care. The ABTA website describes different care options.
- > At some point, you may want to consider hospice care. The ABTA has much more information on this option on abta.org.
- > To discuss your options or any questions you may have, call the ABTA CareLine at 800-886-2282 or email Info@abta.org.

AMERICAN BRAIN TUMOR ASSOCIATION INFORMATION, RESOURCES AND SUPPORT

Educational brochures are available on our website or can be requested in hard copy format for free by calling the ABTA. Most brochures are available in Spanish, with exceptions marked with an asterisk.

General Information:

About Brain Tumors: A Primer for Patients and Caregivers

Brain Tumor Dictionary*

Brain Tumors Handbook for the Newly Diagnosed*

Caregiver Handbook*

Tumor Types:

Ependymoma

Glioblastoma and Anaplastic Astrocytoma

Medulloblastoma

Meningioma

Metastatic Brain Tumors

Oligodendroglioma and Oligoastrocytoma

Pituitary Tumors

Treatment:

Chemotherapy

Clinical Trials

Conventional Radiation Therapy

Proton Therapy

Stereotactic Radiosurgery*

Steroids

Surgery

AMERICAN BRAIN TUMOR ASSOCIATION INFORMATION, RESOURCES AND SUPPORT

Information

ABTA WEBSITE | [ABTA.ORG](https://abta.org)

Offers more than 200 pages of information, programs, support services and resources, including: brain tumor treatment center and support group locators, caregiver resources, research updates and tumor type and treatment information across all ages and tumor types.

Education and Support

- **ABTA Educational Meetings & Webinars**
In-person and virtual educational meetings led by nationally-recognized medical professionals.
- **ABTA Patient & Caregiver Mentor Support Program**
Connect with a trained patient or caregiver mentor to help navigate a brain tumor diagnosis.
- **ABTA Connections Community**
An online support and discussion community of more than 25,000 members.
- **ABTA CareLine**
For personalized information and resources, call 800-886-ABTA (2282) or email info@abta.org to connect with a CareLine staff member.

Get Involved

- Join an ABTA fundraising event.
- Donate by visiting abta.org/donate.

Contact The ABTA

CareLine: 800-886-ABTA (2282)

Email: info@abta.org

Website: abta.org

Connect with us on
Social Media



For more
information

800-886-ABTA (2282)

info@abta.org

abta.org



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