



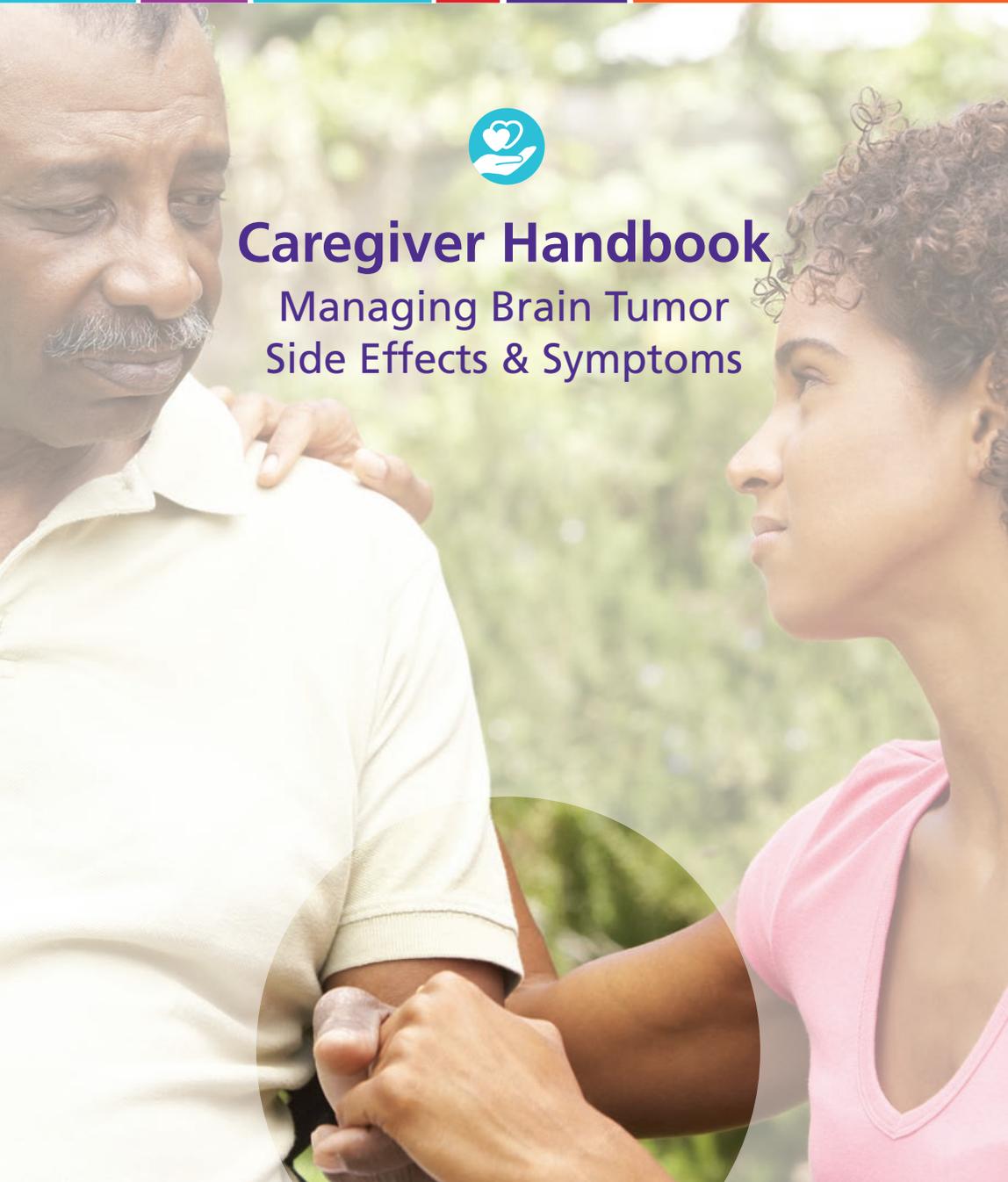
American
Brain Tumor
Association®

Providing and pursuing answers®



Caregiver Handbook

Managing Brain Tumor
Side Effects & Symptoms



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 you with 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."

— CAREGIVER

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Your Role as Caregiver

Studies have shown that due to the neurological symptoms that can come with a brain tumor diagnosis, brain tumor patients, caregivers and their relatives often need more support than do those living with other types of cancer. 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.

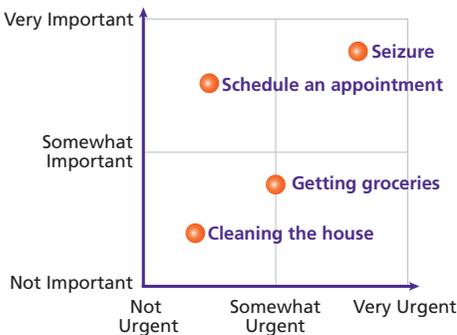
Eventually, most people fall into a rhythm of care, which can be a time to focus on the patient's quality of life. Once families settle on a medical facility and plan of treatment, it can be a time for caregivers to catch their breath. You can use that time for a number of tasks, such as getting organized, researching complementary therapies, focusing on diet and nutrition for yourself and the patient or finding a support group.

Prioritizing and solving problems

Some organize tasks by considering both 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.

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

— CAREGIVER



Making a doctor's appointment is important, but not as urgent, so 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. You may even find that some items that 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. There are many treatment resources on the ABTA website. The ABTA also offers a free, confidential, personalized clinical trial matching service called *ABTA TrialConnect™* that can help match the patient you are caring for with available clinical trials.
- **Communicating on the patient's behalf.** Although it can be difficult for some, 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.

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. Daily routines can include strategies to combat isolation, such as joining in on recreational activities with family and friends whenever possible.
- Keeping a **master calendar** can help keep family and friends informed about your activities and needs. Free online tools include Google calendar and calendars on websites such as Caring Bridge (www.caringbridge.org) and Lotsa Helping Hands (www.lotsahelpinghands.com).
- **Recordkeeping** includes keeping track of tests, insurance information, medications, treatments, symptoms and side effects. The ABTA website has multiple worksheets to help you track this information.



Family Impact

Every family reacts to a brain tumor diagnosis in its own way. It is important for the family to support one another through the journey.

Family expectations

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

- They may have expectations on **how you should care for the patient**, including the type and the level of care for the patient. This can sometimes cause conflict as family members may expect you to hire more help 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 need or don't need.
- 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. They often find the experience uplifting.
- Family members have various ways to **communicate** 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 Facebook or email updates be less draining? Can a family member or friend help you communicate?

Communicating with children

Sometimes, caregivers think that 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.¹ Talking to them about the diagnosis and keeping them informed during the disease in an age appropriate manner can help facilitate healthy coping and adjusting.

¹Rolland J. *Families, Illness and Disability: An Integrative Treatment Model*. New York, NY: Basic Books;1994:222



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.

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.



Changing relationships

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

- Many brain tumor patients undergo both **behavioral and cognitive changes**, resulting from the brain tumor itself as well as treatment. A sweet and caring person may become angry and withdrawn. Another person may suddenly not enjoy the same activities he or she used to. These changes may or may not be permanent, but regardless, they're difficult to accept. Complicating things, the patient may not even realize that he or she is different.
- You may find yourself in an **unfamiliar role**. For example, if your spouse handled the finances, then that task may be up to you now. 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. While other caregivers have found support and strength by connecting with others, both through online and in-person support groups.





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.

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.

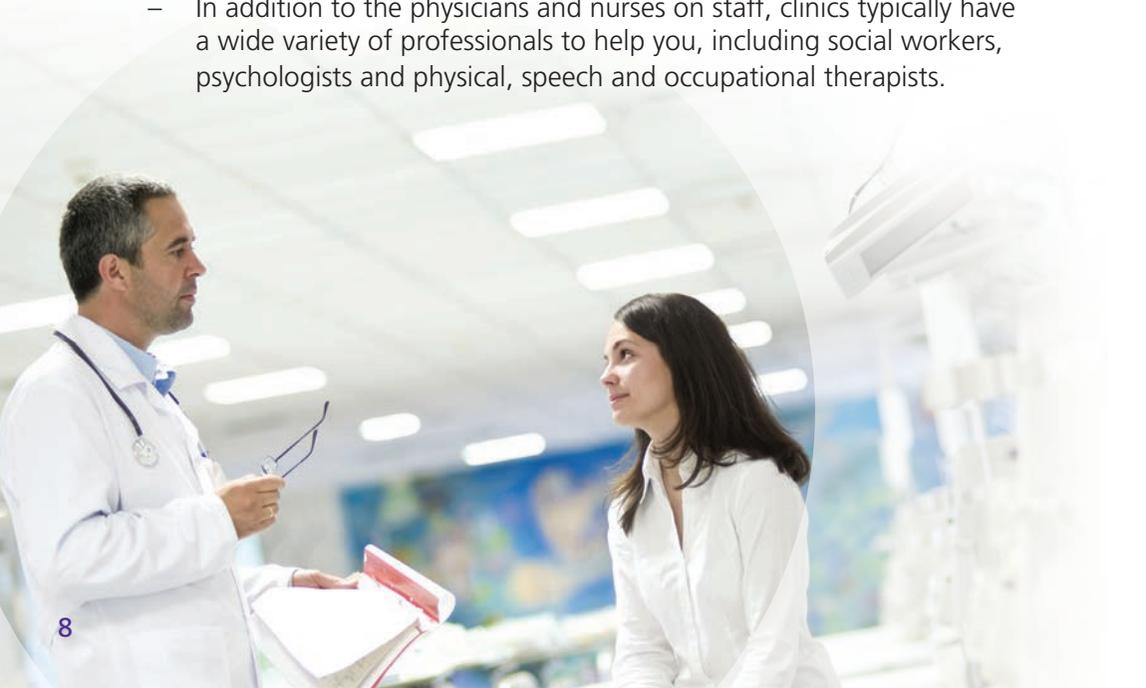
- The first thing that most social workers recommend is to **have a printed or online copy of your policy available** when you're talking to administrators and social workers.
- The **social worker** assigned to the patient's case is often a good resource for health-insurance questions. You can also contact the professionals at the *ABTA CareLine*, who can walk you through the process. Call 1-800-886-2282 or email abtacares@abta.org.
- Some insurance companies provide a **dedicated patient representative** to be a single point of contact. Ask your insurance company whether they provide this service.
- The ABTA provides information about **various types of insurance**, including resources if you are uninsured. A listing of financial and medical assistance resources is also available on the ABTA's website.



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 the patient undergoes surgery and tests. 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 all be making rounds and checking on the patient.
 - The patient's primary care physician may also visit the hospital. It is helpful to coordinate with him or her so you can prepare questions in advance.
 - 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.
 - Many patients and caregivers choose to get a second opinion before surgery or beginning treatment. Most doctors are not offended by this, and in fact, welcome another viewpoint.
- **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 a doctor's office 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.



Patient care team

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

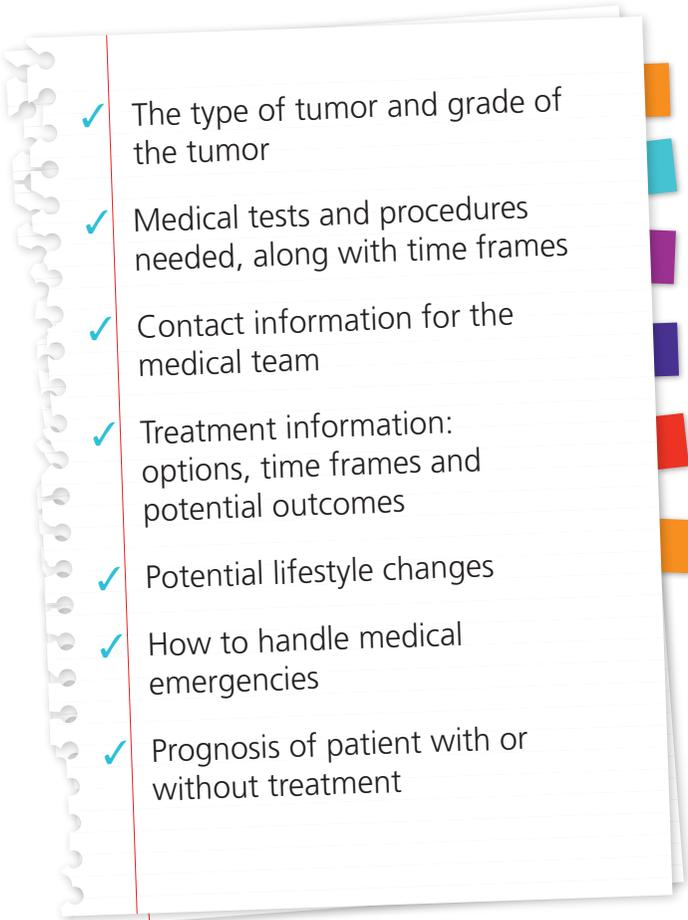
- **Neurosurgeon:** A physician trained in surgery of the nervous system.
- **Neuro-oncologist:** A physician who specializes in treating patients with brain tumors, and/or the consequences of cancer upon the nervous system. The physician is often a trained neurologist, oncologist or neurosurgeon.
- **Primary Care Physician (PCP):** 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.
- **Nurse Practitioner or Physician's Assistant:** Works with the doctors and will be able to answer many of the treatment questions.
- **Social Worker:** Assigned by the hospital or clinic to assist with patient and caregiver needs. Can also help you cope with the diagnosis and the many emotions you may be experiencing.
- **Nurse Navigators:** May be a primary point of contact to help navigate the health system and coordinate care.

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

- **Endocrinologist:** May be consulted if the brain tumor or treatment affects one of the patient's endocrine organs, such as the pituitary gland.
- **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:** Physician who diagnoses and treats mood and emotional issues that may arise from the brain tumor or treatment.
- **Neuroradiologist:** Oversees radiation therapy.
- **Rehabilitative Specialist/s:** Healthcare professionals such as occupational, physical and speech therapists who can help improve a patient's strength, mobility, memory or communication.

Preparing for appointments

Once you become more familiar with the individuals on the patient's care team, it may be easier to prepare for medical appointments. In the beginning stages, many patients and caregivers have questions such as:

- 
- ✓ The type of tumor and grade of the tumor
 - ✓ Medical tests and procedures needed, along with time frames
 - ✓ Contact information for the medical team
 - ✓ Treatment information: options, time frames and potential outcomes
 - ✓ Potential lifestyle changes
 - ✓ How to handle medical emergencies
 - ✓ Prognosis of patient with or without treatment

Later, once treatment has been determined, you may find it useful to track the patient's symptoms and side effects. Going through your notes and talking to the patient before the appointment can help you remember to bring up any questions or topics of concern.



The ABTA provides free downloadable worksheets and logs, for tracking side effects and symptoms to keeping track of food and sleep. If the patient is newly diagnosed, please visit the newly diagnosed section of the ABTA's website. Find all these resources at **www.abta.org**.



Brain Tumor Symptoms and Side Effects

As you already know, the symptoms and side effects of a brain tumor can be both physical and cognitive. 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 and symptoms are not something to be taken lightly and should be viewed as signals that the body needs help. As you log these symptoms and discuss them with health care professionals, you may find that they can be alleviated, leading to a better quality of life.

Physical symptoms

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

- A deep **fatigue** that is more than simple tiredness. Medical professionals can help determine whether the fatigue can be treated with medication and/or by energy-conserving strategies.
- **Headaches** are experienced by about 50% of brain tumor patients. When tracking headaches, note their severity, activities being done at the time and any other accompanying symptoms.
- **Seizures** occur in about 39-60% of brain tumor patients at least once during their illness. Although frightening, most can be managed at home. The ABTA has a Seizure First Aid wall cling, which provides instructions on how to handle a seizure, available at no charge. Visit the ABTA 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 loss** can contribute to difficulty with activities, such as writing and eating or gross motor activities, making it challenging to walk or control arms and 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. When the clot moves towards the pulmonary vein, it is then considered a pulmonary embolism (PE). Signs of DVT and PE can include swelling, tenderness and pain in the leg, one leg appears larger than the other one or skin on the leg turns red. If suspected, DVT or PE should be treated immediately. Call 911 or go to the emergency room. Fortunately, this condition is highly treatable with a timely diagnosis.
- **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 requires a trip to the emergency room.
- **Pain** can be a major side effect of brain tumors and treatment. Pain affects every part of the patient's life – sleeping, eating and the patient's 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.

Cognitive and behavioral symptoms

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



Psychological symptoms may include mood swings, forgetfulness or difficulty communicating. They may be mild or severe, and 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. Caregivers may see changes in:

- Emotion and personality
- Learning and memory
- Attention and concentration
- Executive functioning



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

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

There are also many practical, everyday ways to help patients cope with memory loss, mood swings and 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. And try to focus on one thing at a time. Mindful meditation can also have positive effects on brain function.

Safety at home

Managing physical and cognitive changes may require you to make adjustments so the patient is 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 for help if there is a chance the patient is hurt.

More detailed safety tips for you and the patient can be found at www.abta.org.





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.**

Even just acknowledging the emotions that you are experiencing – sadness, frustration, anger – can be a great help. Talking and sharing is also important.

Resources include:

- **Mental health care professionals**, referred by the ABTA or your case's social worker.
- **The ABTA CareLine.** Call 800-886-ABTA (2282) or email ABTACares@abta.org.
- **Peer-to-Peer Support.** The ABTA offers:
 - **ABTA Connections**, a private, online support community available for free, 24 hours a day.
 - A comprehensive directory of in-person support groups, listed by state at www.abta.org.
 - Opportunities for Peer-to-Peer support are available through **ABTA CommYOUity™ Connect**. If you are interested in participating, visit www.abta.org.

"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



- **Take care of your physical health.** Consider getting a full physical. You may want to share with your doctor your role as a caregiver and any symptoms, such as anxiety or depression, you are experiencing. Taking time to plan and eat healthy, fulfilling meals, get enough sleep and enjoy 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 13 for tips and advice.
- **Take care of your emotional and cognitive health.** Between emotions and all you need to manage, many caregivers recommend strategies to ease your mind. You can keep a log of emotions, physical symptoms and activities that are effective in helping you cope. An ongoing list of tasks, with the intent on accomplishing at least one a day, no matter how minor, can help give you a greater sense of control over your environment.
- **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.
- **Consider the spiritual.** Whether you are religious or not, mindfulness training, 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.



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 Calendars 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.
- Visit the ABTA’s *Caregiver Resource Center* at **www.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 more skilled care or they need care so they can go to work or have a small break. Other times, they physically cannot perform the tasks the patient needs, such as wound care, moving the patient or helping the patient with hygiene.

- 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 maintains a list of caregiving options on **www.abta.org**.
- At some point, you may want to consider hospice care. The ABTA has much more information on this option on **www.abta.org**.
- To discuss your options or any questions you may have call the *ABTA CareLine* at 800-886-2282 or email ABTACares@abta.org.



Remember...

...you are performing a critical job, but you do not have to do it alone. Remind yourself to take it one day at a time, and go easy on yourself. There is no one right way to care for someone with a brain tumor, and you will always do the best you can. Asking for help is both necessary and brave.





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For more information:

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