

Coping

*With Your Loved
One's Brain Tumor*



A Guide for
Family & Friends

*N***BT***F*
NATIONAL
BRAIN TUMOR
FOUNDATION

Coping

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When a Loved One has been diagnosed with a brain tumor, you are suddenly catapulted into a new and frightening world. Events unfold rapidly and you may feel overwhelmed trying to understand your loved one's current medical condition and treatment options. You are likely to have a variety of immediate as well as long-term fears and concerns, and may feel that nothing you have experienced previously has prepared you for these new experiences.

You are not alone. Many resources exist to provide you with information and support to help cope with your loved one's brain tumor diagnosis. We hope the information in this brochure will help you better navigate this challenging journey.

Riding the Emotional Rollercoaster

IT IS COMMON to experience a range of emotions when your loved one is faced with a brain tumor diagnosis. Although providing care to your loved one can be a rewarding opportunity to express your love and grow closer together, being a caregiver is challenging. The emotions and stress of the experience can interfere with “normal” functioning, such as your ability to concentrate or your ability to sleep.

These reactions may be a normal and temporary response to stress. However, it is important to recognize how stress is affecting you. If your response to stress feels extreme or persists over time, consider consulting your doctor or a counselor.



Feelings of depression, in particular, are extremely common among caregivers. Many caregivers find that working with a mental health professional, such as a psychiatrist or psychologist, can help alleviate depression and manage anxiety through counseling, medication, or other strategies.

Sometimes, feelings of anxiety and depression can persist even after your loved one has undergone treatment and is on the road to recovery. For example, it is quite common to feel a temporary return or increase in anxiety at certain treatment follow-ups, such as with post-surgery MRIs or lab tests following chemotherapy. Just as it is important to anticipate the physical recovery following treatment of a brain tumor, it is equally important to expect a process of “emotional recovery” following this family crisis. When things begin to slow down, you might feel a new surge of emotion, which may relate to all you have experienced in such a short period of time. You will need time to heal emotionally—as an individual and as a family.

Taking Care of Yourself

While you navigate your loved one’s diagnosis and treatment, it is extremely important for you to take care of yourself during this time of stress and transition. As you dedicate yourself to caring for your loved one, it is easy to overlook your own needs. The demands of caregiving can lead to sleep deprivation, poor eating habits and a lack of time to exercise. This can take a toll on your own health, making it harder to care for your loved one. Remember that the most effective way to care for your loved one is to first care for yourself.

Paying attention to your own needs is not selfish—it is an important part of caregiving. Make sure that you get the support you need, as well as necessary time to rest and replenish yourself. Clarify what your caregiving responsibilities involve, but be realistic about your limitations.

“It’s understandable that we carers feel we can’t cope. I try not to beat myself up about it. Watching your lifelong partner deteriorate is extraordinarily difficult. Some days I cry all day; other days I’m strong. That’s how it goes.”

—*Marcella from Canada*

You do not have to do everything by yourself. Identify other individuals who might share in assisting or supporting your loved one, and actively organize and delegate responsibilities. Make a list of specific tasks they could help with, such as childcare, running errands, household chores, or just staying with your loved one so that you can have a few hours of respite. If you have trouble thinking of items for your list, contact NBTf for a suggested needs list or for specific tips on working with others to manage different responsibilities. Family and friends often want to help, but may feel unsure about how to direct their energies. It is up to you to take the first step and suggest ways they might help.



Supporting Your Loved One

Now that you have taken care of yourself and sought help from those around you, you can better focus your attention on your primary concern: supporting and caring for your loved one.

Your loved one is adjusting to a life-altering illness, different treatments, rehabilitation, and possibly physical and cognitive impairments. Caregivers can provide emotional support and practical assistance in ways that strengthen their loved ones’ abilities and self-confidence. It is important for them to feel good about themselves at whatever capacity they may be functioning. Try to maximize independence when possible and build self-esteem by encouraging them to try tasks that they feel confident doing, such as helping with household chores.

People often wonder what to say to their loved ones to show support without making them feel uncomfortable or feeling uncomfortable themselves. Asking a question like, “What are you feeling?” can open the door for communication.

Sometimes patients may want to respond, but sometimes they may not. Let them know that you are available to talk, but that it is okay if they do not want to say anything. Simply being there is an important way of showing support.

When loved ones do begin to talk about their feelings, try to really listen to what they say. Although it may be difficult, it is important to discuss their preferences and treatment goals. At some point, you may be called upon to make quick decisions, and it can help to understand their wishes beforehand. Through your conversations, your loved one may express anger or sadness. These emotions are normal, and it is okay not to have a response. Not all questions have answers, and the act of listening is what truly matters.

Coping as a Family

Remember that each member of your family system and support network will adjust to this situation in unique ways. Each will have different coping styles, which may feel confusing or frustrating at first. For example, some people might prefer being around others to help them cope. Other people may choose to spend more time alone than before.

Open dialogue with family members about differences in needs and coping styles may help to avoid misunderstandings during this period of tremendous transition. For example, you may be showered with support from friends and relatives wanting to drop by for a visit. At the same time, your loved one may need time alone or feel too tired to receive visitors. You can help to guide others so that they can be supportive without

How Brain Tumors Affect the Mind, Emotions and Personality

Caregivers of brain tumor patients often note changes in their loved one's thinking, emotions and behavior. You may notice that your loved one is more forgetful, has slowed thinking, impaired speech, or difficulty functioning the way he or she used to. In many cases, these changes can be improved with cognitive rehabilitation (retraining for the mind), memory techniques (like using checklists), and other strategies.

Changes in your loved one's personality and behavior can be particularly devastating and difficult to cope with. Depression is especially common in people with brain tumors, but changes can also include irritability, anger, agitation and inappropriate behavior. Such uncharacteristic behaviors may emerge or escalate with the tumor and treatment, and are often overlooked by health professionals.

Trying to manage these abnormal behaviors can be very distressing, and you may feel like you are caring for a complete stranger at times. Be sure to bring up your concerns with your loved one's health team. They may be able to recommend medication, rehabilitation, or a counselor who can assist you and your family in coping with changes. Also, patient advocacy organizations like NBTF and ones that serve caregivers of people with traumatic brain injury and dementia, such as Family Caregive Alliance, can provide practical suggestions on coping with and managing difficult behaviors.



overwhelming your family. Through trial and error, you and your loved one may discover that certain times of the day are better than others. Try to find a balance and be flexible to accommodate changing energy levels and needs.

Family roles and priorities may change given your loved one's medical condition and uncertain future. If your spouse or partner is the brain tumor survivor, there has no doubt been a significant shift in the dynamics of your relationship. Your spouse may not be able to support all of your emotional needs as he or she did before. In addition, your spouse may be unable to fulfill traditional roles in the family, as with being the breadwinner, managing finances, or helping with childcare.

“There’s a lot of comfort in knowing others are going through exactly the same thing, and that they understand our fears and other emotions.”

—John from Wisconsin

These changes may leave you feeling frightened, alone, and overwhelmed with shouldering all of the responsibilities you once shared. The degree to which your loved one is able to continue with personal, family, and financial responsibilities will vary over time and in relation to medical treatments. Allow other relatives and friends to help with some of the responsibilities until a new equilibrium can be established. Seek support and look for ways to connect with others who have experienced a similar situation, such as through NBTF's Support Network or Caregiver Trainings.

Practical Issues for Caregivers

The impact of a brain tumor is not only emotional, but practical as well. Many families experience a change in their financial situation, due to a loss of income, medical bills and other expenses. Difficulty making home adaptations or arranging transportation and homecare (when the loved one cannot be left alone) are other common concerns. Also, the additional stress of spending hours on the phone dealing with the bureaucracy of health insurance, disability benefits and medical bills can leave the caregiver feeling even more depleted. Contact a social worker to learn about local resources, such as equipment lending libraries and caregiver respite programs. Organizations like NBTF and CancerCare can provide information about financial assistance and other services.

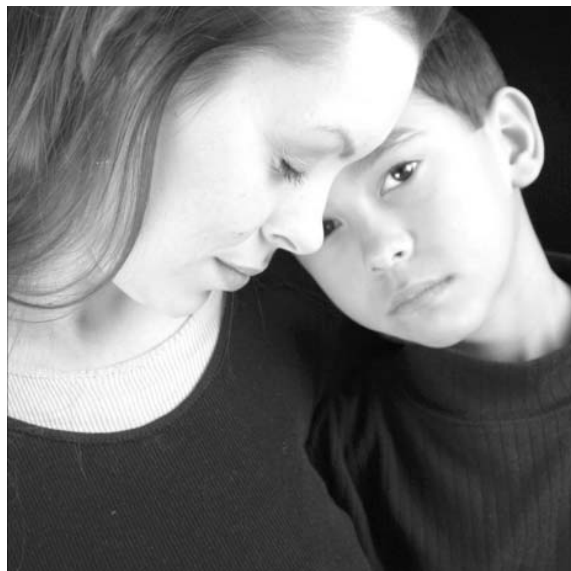
Talking with Your Children

Many times, parents wonder how to talk with their children about a brain tumor diagnosis. What you tell your children should take into account their age, cognitive and emotional maturity, and their relationship to the brain tumor survivor. Regardless of their age, all children should be reassured that they did nothing to cause the tumor.

The known is less scary than the unknown, so prepare your children for what to expect in an age-appropriate manner. Books, such as the NBTF publication *My Name is Buddy* about a dog with a brain tumor, are a good way to help children understand. It may be particularly difficult for children to understand side effects of the brain tumor, especially seizures, alterations in their loved one's appearance, and cognitive symptoms. Children may need extra support in coping with these changes.

“I was as open and honest with the kids as I could be. There was no hiding my fears and tears; they shared them along with me. I stressed to the kids that we were dealing with this disease and we must all support their dad and fight the battle together as a family.”

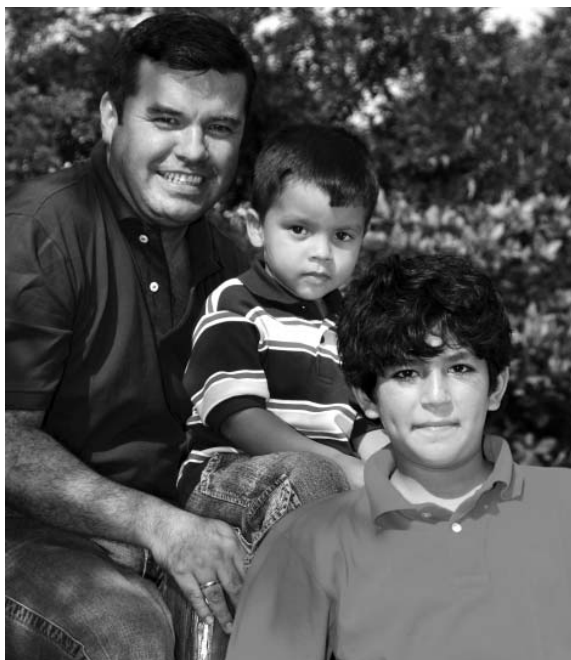
—Vicki from California



A good rule of thumb when talking with your children is to let them take the lead in terms of indicating how much or how little they want to know. Find out what is really concerning them. Avoid providing too much unnecessary detail or speculation, but be honest in your conversation. Generally, a simple and straightforward approach is best. Provide plenty of opportunities to talk with them about questions, concerns, and feelings; this can help reduce misinterpretations about the situation as well as reassure them. Children may imagine the worst, and it is important to be ready for questions about death. Many parents worry about crying in front of their children, but it is okay to cry sometimes. By crying or showing sadness, you are modeling that emotions are a part of the journey.

Remember that your children's individual needs might differ depending on their age and personality. It is not uncommon for children to temporarily demonstrate regressive behavior or act out when coping with a crisis. It is often helpful for children to maintain their regular routines as much as is realistically possible (e.g. continue with school and social activities with their friends) in order to provide them with a familiar structure during a time of stress and transition. The counselors at your children's school or the medical social worker at the hospital where your loved one is receiving treatment can offer further consultation and support for your children.

Expect that emotional needs and coping strategies will change over time just as the medical situation does. Try to adopt a flexible approach in identifying those needs and how best to meet them.



Getting Connected

There are a number of resources available to help you better understand and cope with your family's new situation. Being informed and surrounding yourself with a strong support system can help you feel less overwhelmed and alone, and strengthened to face each stage of your journey.

“The hospital told me about a brain tumor support group, and I’m going to join. I’m a bit of a loner normally, and very self-sufficient, but I know I can’t do this by myself. I know I won’t be able to help my husband at all if I fall apart.”

—Carla from Florida

YOUR MEDICAL TEAM AND OTHER HEALTH PROFESSIONALS who specialize in working with brain tumor patients can address various needs of your loved one and family as a whole. Try to identify a healthcare professional, such as a nurse specialist or social worker, who can serve as an advocate and provide assistance when you face bureaucratic obstacles or refer your family to local services.

FAMILY AND FRIENDS are often available to provide individualized and unique emotional support in ways that others cannot. Do not be shy about communicating directly about ways they can help.

Also, your religious community or other community organization may be an invaluable source of spiritual and emotional support, as well as practical assistance with meals, transportation or childcare.

SUPPORT GROUPS for brain tumor survivors, their families, and caregivers may exist in or near your community. They can provide ongoing support and an opportunity to share information and ideas with others who have had similar experiences. Contact NBTF for more information regarding brain tumor support groups in your area.

INDIVIDUAL PEER SUPPORT from another caregiver can be accessed through your local caregiver resource center, through the facilitator of a local brain tumor support group, or through NBTF. If you are unable to attend a support group or prefer a different form of communication, telephone support may also be an option. For example, NBTF has a telephone and email Support Network, which connects patients and caregivers to their peers for information, stories and an understanding ear.

INTERNET SUPPORT is available for online peer support and educational information. Message boards, online support groups, and survivors' personal websites can help you connect with others through virtual communities. You can also keep friends and family updated about your loved one by creating your own personal webpage on a free website like **CaringBridge.org**. With so many resources available, the internet is a convenient form of support if you have limited energy or time. The NBTF website at **www.brainumor.org** has brain tumor message boards and other support available online.

Tap into the **RESOURCES** offered by local and national brain tumor and caregiver organizations. Many offer helpful newsletters and information on services and events.

SPECIALISTS such as psychiatrists, psychologists, and individual and family counselors can provide additional emotional support to assist with adjustment and coping. Many people find that talking with a counselor is helpful in processing emotions and feeling better equipped to manage their loved one's diagnosis. Free professional telephone counseling is available from **CancerCare** by calling **800.813.4673**. For a referral to local counseling services, contact the **American Psychosocial Oncology Society hotline** at **866.276.7443**.

You may initially feel uncomfortable in acknowledging the need for and accepting outside support. It is important to adopt a proactive approach in maintaining your emotional wellbeing so that you can successfully adjust to the many new experiences and continue to effectively support your loved one. Try to be open to new and different ways of accessing support—you may be pleasantly surprised at what you find.

“I started seeing a counselor three months after my daughter was diagnosed. It helped me realize my feelings are real and normal. You can't keep everything inside. It's too hard.”

—Eileen from Michigan

Getting Informed

Learning everything you can about your loved one's condition and treatment is another important coping strategy. Being informed about the diagnosis, treatment options, symptom management and survivorship issues can help you feel more in control and equipped to manage the situation at hand.

“I did research on the latest treatments. Knowledge is power and can make you feel like you are in control of the situation.”

—*Suzanne from Massachusetts*

Contacting an organization like the National Brain Tumor Foundation is a good place to start learning more about brain tumors and resources to help. The NBTF website, www.braintumor.org, provides information about brain tumors and NBTF services. Call the hotline at **800.934.2873** to speak to a trained information specialist who can address your questions and provide guidance and referrals to help you through your journey. You can also speak with the NBTF Medical Information Nurse for answers to specific medical questions about treatment or medication. In addition, NBTF partners with local hospitals to conduct free trainings that provide practical tools specifically designed for caregivers of brain tumor patients. Contact NBTF at **800.934.2873** for more information.

Taking Action

As you get information and gather support, here are some specific strategies you can adopt to help you cope:

- Write things down! Rather than trying to keep track of all your concerns, make a list and then prioritize items so you can better focus your energy. Your list might include questions to ask the doctor or NBTF, as well as issues to discuss with your family.
- Consider developing a written log about your loved one's medical experiences noting significant names, procedures, medications, and dates. This will make recall and communication with future healthcare professionals easier and more productive.
- Keep long-term expectations flexible while focusing energy on short-term goals and current achievements. Try to identify and appreciate the beauty in each day.
- Writing in a diary or journal can be an effective way to express and understand your feelings about your experiences. It can also be a very effective stress management technique by helping relieve the daily build-up of worries and fears.
- Try to establish a “normal” routine as much as possible while maintaining a flexible approach in responding to new issues.
- Recognize your limitations, accept help from others, and pace yourself.

- Create a schedule to actively organize caregiving responsibilities with people who can help so that no one “burns out.”
- Familiarize yourself with the numerous brain tumor, cancer, and caregiver resources available in your community and everything they have to offer (services, educational information, emotional and social support, newsletters, etc.).
- Maintain open communication with your loved one, as well as with other members of your support system. Check in with others’ feelings periodically to be aware and sensitive to their needs and to minimize misunderstandings.
- Exchange ideas about coping strategies with family and friends.
- Consider exploring stress management exercises such as deep breathing, imagery, yoga or meditation.
- Distinguish between the things you can and cannot control. Focus your energies on what you can control.
- Allow yourself to get adequate rest and nutrition. Check in with yourself every week and ask yourself whether you are eating regularly and sleeping enough. If not, talk with your doctor. Remember to be your own caregiver!



Living

It is important to recognize the power of social support in positively affecting your loved one’s physical rehabilitation, your family’s emotional recovery process, and quality of life in general.

There is no easy recipe for coping, and only you can know what works best for your situation. Achieving a balance between caring for your family member as well as for yourself will initially be a daily effort, but it will become easier with continued practice. With your team of social support, you can begin to cope with this difficult situation. You are strong and capable—you can do it!

“I learned to take it one day at a time. You cannot foresee the future or know what it holds. Instead of spending my days worrying about what might happen, I try to do things with my mother that we both enjoy. We go take a walk, go somewhere new, or do things she has always wanted to do.”

—Patty from North Carolina

Resource List

Here is a partial list of resources that can assist you and your family. Check in your local area for other organizations that might be of assistance.

Brain Tumor and Support Organizations

National Brain Tumor Foundation

800.934.2873 • www.braintumor.org

The Brain Injury Association of America

800.444.6443 • www.biausa.org

Cancer Care

800.813.4673 • www.cancercare.org

Cancer Legal Resource Center

866.843.2572 • www.disabilityrightslegalcenter.org

Children's Brain Tumor Foundation

866.228.4673 • www.cbtf.org

Family Caregiver Alliance

800.445.8106 • www.caregiver.org

National Family Caregivers Association

800.896.3650 • www.nfcacares.org

Well Spouse Association

800.838.0879 • www.wellspouse.org

Internet Resources

- NBTF message boards and online peer support network: www.braintumor.org
- T.H.E. Brain Trust message boards: www.braintrust.org
- Online spouse caregiver support group: www.bradsupdates.com/care
- Personal webpages for families: www.caringbridge.org
www.carepages.com
www.lotsahelpinghands.com



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The National Brain Tumor Foundation

The National Brain Tumor Foundation is a nationwide non-profit organization that serves people whose lives are affected by brain tumors. We are dedicated to promoting a cure for brain tumors, improving the quality of life and giving hope to the brain tumor community by funding meaningful research and providing patient resources, timely information and education. Our services to patients, their loved ones, and health professionals include:

- Toll-free Patient Information Line at 800.934.2873
- Comprehensive website at www.braintumor.org
- Medical Information Nurse
- Quarterly newsletter and other publications
- Patient and Caregiver Support Network via phone and e-mail
- National caregiver training workshops
- Teleconferences and web conferences
- Patient Help Fund financial assistance program

The information in this brochure is subject to change. The reader is advised that information obtained from a physician should be considered more up-to-date and accurate than the information in the brochure and that this brochure does not and cannot purport to address facts and circumstances particular to any patient. This is something that can only be done by the patient's physician. Sponsorship of this brochure does not imply the National Brain Tumor Foundation's endorsement or recommendation of any particular form or forms of therapy, regimen, or behavior. The information in this brochure is not meant to be legal advice or replace the advice of an attorney.



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