



Care for the Caregiver

Don't lose sight of yourself. It's easy to get wrapped-up in the process of appointments and waiting. Don't get caught up. Take even 5 minutes to find out what you need for yourself. It's not easy, but you have to take care of yourself too.

— Sarah, caregiver

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Care for the Caregiver

A **caregiver** is anybody who provides unpaid help, or arranges for help, to a relative or friend because they have an illness or disability. Help can be physical, emotional, spiritual, financial, or logistical.



THINGS TO REMEMBER

- You can be a tremendous resource to help your loved one think through treatment options, goals and priorities during this difficult period.
- Reach out to others who are also caring for someone with a brain tumor. These individuals are often helpful.
- Say YES! Remember that it's vital to ask for and accept help.
- Be mindful of your own needs and feelings. There are many ways to support your loved one without neglecting your own physical, economic, spiritual and emotional well-being.
- Talk with the doctors about what to expect and how to plan. Recovery after treatment can take a long time, it helps to feel prepared.
- End-of-life care plans can be helpful. Make sure that all family members are on the same page, and that the doctor is aware of your loved one's preferences.
- Enjoying life is about how you and your loved one focus on the things that really matter.
- If you are grieving the loss of the life you knew, give yourself time to grieve.

People who are forced to adopt a new role as “caregiver” have shared that as they gain information about the disease, options for treatment, expectations for recovery, and resources for support, they begin to feel more confident about managing the task before them, and their fear, anger, and frustration begin to dissipate.

When a Loved One's Personality Changes

Depression, anger, confusion and mood swings are common symptoms for individuals with brain tumors. These symptoms can be caused by the tumor, the treatment, or may have been present before. Regardless of the source, personality changes in someone you care for can be very challenging. These changes can be subtle or drastic. Speak with your doctor if you notice these types of changes. The symptoms may be treatable.

CARE FOR YOURSELF

People who care for someone with a serious illness can forget to take care of themselves and can neglect their own needs. It becomes hard to focus on work, household responsibilities and other demands, yet those pressures continue. There are many ways to build-in time for your own care, and this is essential for your physical and mental wellbeing. Take time for yourself – this is not selfish.

Aim to find a balance between caring for your loved one, caring for yourself, and caring for others in your life. The patient will benefit most from being with you when your own life is in balance—and you will be less likely to feel exhausted or resentful about caregiving.



TIPS TO MANAGE DIFFICULT MOMENTS

- Recognize feelings such as guilt, resentment and anger. Admit them if it will help you address the problem rather than ignore it or let anger grow.
- Be compassionate with yourself. There's no one way a caregiver should feel. Give yourself permission to separate your feelings from your actions.
- Reach out to your own support network for some coping ideas. Call a family meeting and say, "Let's figure out how we can help each other."
- Set limits. Take time on a regular basis to care for yourself. Your batteries must be recharged so you can be a better caregiver over the long haul.
- Remember that you do not need to have all the answers or fix all the problems.
- Often, just “being there” and quietly listening is all that's needed.

Making Important Decisions

Many people with a brain tumor diagnosis experience changes in their ability to think clearly and process information. This may be due to the tumor, treatment or simply feeling overwhelmed by the diagnosis. Whatever the cause, a loved one is often responsible for setting the course for a patient's care as their advocate. If you must be the treatment decision-maker, know that you can take some time to ask questions, research options, and find support.

Before you can know what's needed and what you can do to help, you must understand the situation.

1. **Learn about the brain tumor** including its location, grade, treatment options, anticipated treatment side effects, and expectations for recovery.
2. **Try to identify the top medical centers and experts** in your loved one's (or your) area for a second opinion or additional services, as needed.
3. **Research information** on credible websites, like through the National Cancer Institute, and the National Brain Tumor Society.
4. **Weigh the pros and cons** of each treatment option with your loved one, including elements like time, where treatment will be given and cost.
5. **Create a "to do" list** with your loved one of immediate versus long-term needs. Decide what your loved one can address independently, what you or someone else can address from a distance (via phone or internet) and what requires hands-on support.
6. **Recognize and respect** the unique capabilities of your loved one and their wishes and desires, in addition to the roles played by others involved.
7. **Set limits.** Define what you can and can't reasonably do for your loved one.
8. **Organize a care-plan** featuring coordination and open communication among all participants (who is doing what, when?). This plan will help reduce family stress and bring needed relief.
9. **Remember that each stage of care requires different levels of support,** and everyone's roles will change along the way. Brain tumors are not the same as other major life events; they can be ongoing and often unpredictable. Try to think through reasonable short- and long-term expectations.
10. **Secure proper authorization** that allows you to gather copies of medical and treatment records (including operation reports and x-rays). By obtaining legal "Power of Attorney" you will be granted this authorization. This will help with follow-up care plans and future medical needs.
11. **Utilize an oncology social worker** at the cancer center or affiliated with the oncologist. They offer a wealth of information and can answer many logistical and financial questions.
12. **Enjoy your relationship.** Try to value the time you spend with your loved one, because every moment is special.

FINDING SUPPORT AND HELP

Above and beyond the specific advice that the doctor, nurse, and social worker can give you, there are several organizations and websites designed to help family caregivers and volunteers get help and get organized. Look through the resources at the end of the book, and consider:

- **National Brain Tumor Society**
www.braintumor.org
Offers information, connection, and advocacy for people affected by brain tumors. NBTS has excellent resources listed throughout their webpages.
- **American Brain Tumor Association's Connections Online Support Community**
www.abta.inspire.com
ABTA connects patients, families, friends, and caregivers for support and inspiration.

- **Cancer Support Community**
www.cancersupportcommunity.org
Provides education, free online support groups, and discussion boards for people affected by cancer and their caregivers.
- **My Lifeline**
www.MyLifeline.org
Those with cancer can create their own personal webpage to communicate with family and friends. Pages include online calendar tools, scheduling timelines, and information about ways friends and family can offer support.
- **Musella Foundation for Brain Tumor Research & Information**
www.virtualtrials.com
Offers education, support (emotional and financial), advocacy and guidance to brain tumor patients. Online support groups and opportunities to participate in fundraisers for brain tumor research are also available.

Evaluating your Needs

If your loved one is not receiving the help you hoped for or need, it may be time to regroup. Are your expectations realistic? If you're not sure, have an honest conversation with the medical team. If your expectations are realistic but not being met, you may need to secure a different type of support. Try to brainstorm creative ways to address each issue by breaking problems into smaller parts and tapping into additional resources.

Respite Care and Palliative Care

Respite care is short-term, temporary relief to caregivers who are providing full-time support to an ill loved one. Respite offers intensive care for the patient in their home so a caregiver can take a break. It often provides a positive experience for everyone involved. You can contact a respite care organization when you need time away.

Palliative care is a service used at any point in a patient's experience to help a caregiver with the management of pain and other symptoms. Palliative care has the goal of achieving comfort, managing symptoms, and improving a patient's quality of life. Palliative care professionals may come to a person's home to deliver care and to teach caregivers how to manage problems. Check with your insurance, and you can ask your hospital or doctor for a referral.



TO ACCESS RESPITE CARE SERVICES IN YOUR AREA FOR YOU OR ANOTHER CAREGIVER, TRY:

- **Arch National Respite Organization**
[www.archrespite.org/
arch-membership](http://www.archrespite.org/arch-membership)
- **National Family Caregivers Association**
1-800-896-3650
www.nfcacares.org
- **Family Caregiver Alliance**
1-800-445-8106
www.caregiver.org

MOVING FORWARD

A diagnosis of advanced brain cancer can make you wonder how long your loved one has to live. It's frightening to envision a different future than you originally planned for yourself. It can also be difficult to talk about such painful topics.

Finding ways to talk about what is happening makes most people feel relieved. The conversation often leads to hopes about living the life you have together now. Often, people want to make the most of their time together with family, as they make peace with the circumstances. Perhaps these can be uplifting conversations that give you both a sense of peace.



One day Gary turned to me and said, "will you marry me?" and I said, "we're already married." And he said, "no, the first time I asked you was for who I thought you'd be, now it's for who I know you are."

— Candice, caregiver

BEREAVEMENT

If you try to discuss the subject but your loved one isn't ready, know that we all have our own timing. Finding someone else you can talk to about your concerns when you're ready is important. Research shows that caring for someone with a brain tumor is just as stressful (but in a different way) as having the diagnosis.

As with other difficult emotional issues, you can contact a social worker or counselor skilled in working with people with a brain tumor, or talk to a spiritual leader that you trust.

Losing someone you love to cancer is one of the most difficult and profound experiences in life.

In the weeks and months after a death, people feel an enormous mixture of emotions. It is important to know that practically any emotion you experience is normal. Sadness can also involve physical symptoms, such as sleeplessness, muscle tension, and decreased energy.

Be assured that you will feel a sense of calm eventually. You must give yourself time to grieve.

Some people move quickly through grief; others move slowly. No matter how you grieve, it is important to become aware of the normal aspects of grief, feel it, then be okay to move on.



My dad was diagnosed when I was eleven and he passed when I was 14. When my dad worked, he was on the road a lot. So when he got sick, we joked that we were really lucky to have a stay-at-home dad for three years. We got to know him really well those years – and if he died any other way, that would not have been the case.

— Natalie, caregiver



Cancer Support Community and the National Brain Tumor Society together with our partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or another health care professional to answer questions and learn more.

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National
Brain Tumor
Society

CANCER SUPPORT COMMUNITY AND THE NATIONAL BRAIN TUMOR SOCIETY
THANK OUR PROGRAM PARTNERS:



People with cancer who actively participate in their recovery along with their health care team will improve the quality of their lives and may enhance the possibility of their recovery. People with cancer who actively participate in their recovery along with their health care team will improve the quality of their lives and may enhance the possibility of their recovery.