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With Your

Loved One's

Brain Tumor



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COPING

With Your Loved One's Brain Tumor

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WHEN A FAMILY MEMBER has been diagnosed with a brain tumor, you are suddenly catapulted into a new and frightening world. Events evolve rapidly and you may feel overwhelmed trying to understand the current medical situation 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 this new situation.

“The stress was enormous and almost broke our family in half. After hearing the prognosis, I felt empty, inadequate, and emotionally flattened. My spiritual side rescued me and helped me to still have hope.”

—Carol, mother of a 20-year-old
brain tumor patient



I feel really anxious about everything and am having difficulty concentrating ever since my partner was diagnosed with a brain tumor. Is there something wrong with me? Should I see a doctor about this?

Coping with a diagnosis of a brain tumor causes increased levels of anxiety and stress. People react differently under extreme stress, but common reactions may include:

- Physical symptoms such as fatigue, nervousness, impaired sleep or appetite;
- Emotional reactions such as fear, shock, depression, anger, guilt, mood swings, or crying;
- Cognitive symptoms that may include difficulty concentrating or forgetfulness;
- Spiritual responses such as searching for meaning, or an increase or decrease in spirituality.

These reactions may be a normal and temporary response to stress. But it's 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.

My wife has had surgery for a brain tumor and is recovering well at home. But now I'm beginning to feel anxious and depressed. Is this normal?

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 may feel a new surge of emotion, which may relate to all you’ve experienced in such a short period of time. You will need time to heal emotionally—as an individual and as a family.

Understanding the Brain Tumor Survivor

Your loved one is adjusting to a life-altering illness, different treatments, rehabilitation, and possibly physical and cognitive impairments. It is important to assist him/her while providing emotional support in ways that strengthen his/her abilities and self-esteem.

Taking Care of Yourself

It is extremely important for you to take care of yourself during this time of stress and transition. Make sure that you get the support you need, as well as necessary time to rest and replenish yourself. Clarify what your care-giving responsibilities involve, but be realistic about your limitations. Identify other individuals who might share in assisting or supporting your loved one, and actively organize and delegate responsibilities. Family and friends often want to help, but may feel unsure about how to direct their energies. It’s up to you to take the first step and suggest ways they might help.

Changes in the Family System

Remember that each member of your family system and support network is adjusting to this situation in ways that are unique to each of them. Different coping styles may emerge, which may feel confusing or frustrating until better understood. For example, you might prefer being around people while others may choose to spend more time alone. Family roles and priorities may change given your family member's medical condition, financial concerns, and uncertain future. Open dialogue with family members about differences in needs and coping styles may help to avoid misunderstandings during this period of tremendous transition.

If your spouse or partner is the brain tumor survivor, there has no doubt been a significant shift in the dynamics of your relationship. The degree to which this person is available to continue with personal, family, and financial responsibilities will vary over time and in relation to medical treatments. Your spouse or partner also might not be able to support all of your emotional needs right now, which may leave you feeling frightened, alone, and shouldering all of the responsibilities you once shared. Allow other relatives and friends to help with some of these responsibilities until a new equilibrium can be established.

What you tell your children should take into account their age, cognitive and emotional maturity, and their proximity to the brain tumor survivor. A good rule of thumb is to let your children take the lead in terms of indicating how much or how little they want to know. Key into what is really concerning them and try



to avoid providing too much unnecessary detail or speculation. 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. Remember that your children's individual needs might differ depending on their age and personality style. 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 and inquiring approach in identifying those needs and how best to meet them.



Who and what is available out there to help me better understand and cope with this new situation?

Your *medical team and other health professionals* who specialize in working with brain tumor patients can address various needs of your family member. Try to identify a healthcare professional, such as a nurse specialist or social worker, who can serve as an “advocate” and run interference when you face bureaucratic barriers.

Family and friends are often available to provide individualized and unique emotional support in ways that others cannot. Don’t be shy communicating directly about ways they can help.

If you belong to a *religious community*, you may find many individuals interested in providing spiritual support as well as concrete assistance such as meals, transportation, or childcare.

Support groups for brain tumor survivors, their families, and caregivers 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 local group information.

Individual peer support from another caregiver can be accessed through your local caregiver community resource, through the facilitator of a local brain tumor support group, or through NBTF. Telephone support may be available if this feels more comfortable for you or if you are unable to attend a support group.

Internet support is available for on-line peer support as well as educational information. This is a convenient form of support if you have limited energy or time.

Specialists such as psychiatrists, psychologists, and individual and family counselors can provide additional emotional support to assist with adjustment and coping.

Consider putting your name on *mailing lists for local and national brain tumor and caregiver organizations* so you can receive their newsletters and information on services and events.

You may initially feel uncomfortable in acknowledging the need for and accepting outside support. It is important to adopt a pro-active approach in maintaining your emotional well-being, so you can successfully adjust to these many new experiences and continue to effectively support your family member. Try to be open to new and different ways of accessing support—you may be pleasantly surprised at what you find!

Are there specific things I can do to help me cope with this situation?

- Write things down! Rather than trying to keep track of all your concerns, make a list and then prioritize so you can better focus your energies.
- Consider developing a written log about your family member's medical experiences noting significant names, procedures, medications, and dates. This will make recall and communication with future healthcare professionals easier.
- Writing in a diary or journal can be an effective way to express and understand your feelings about your experiences. Your journal can also help you to appreciate how you've grown and changed over time.
- Reduce unnecessary stressors and try to maintain activities that relax and replenish you.
- Don't try to be superhuman! Recognize your limitations, accept help from others, and pace yourself.
- Try to establish a "normal" routine as much as possible while maintaining a flexible approach in responding to new issues.
- Create a schedule to actively organize caregiving responsibilities with persons who can help so that no one "burns out."
- Decide what you can and what you cannot control. Focus your energies on what you can control.
- Allow yourself to get adequate rest and nutrition (be your own caregiver!)

- Maintain open communication with your loved one as well as with other members of your support system. Check-in with others periodically so you are aware and sensitive to their needs and to minimizing misunderstandings.
- Keep long-term goals flexible while focusing energy on short-term goals and current achievements. Try to identify and appreciate the beauty in each day.
- Consider exploring stress management exercises such as deep breathing, imagery, or meditation.
- Share coping strategies with family and friends.
- Familiarize yourself with the numerous brain tumor, cancer, and caregiver resources available in your community and all they have to offer (educational information, emotional and social support, services, newsletters).

“Initially, I didn’t understand the disease or the treatment options. My coping strategy was to educate myself from the Internet and read the National Brain Tumor Foundation pamphlets, and I realized that there is the ability to prolong life.”

—George, father of a 25-year-old brain tumor survivor

“It was very helpful to have a friend or family member around to support me. Later, I began to attend a brain tumor support group so I could connect with people who could understand and relate to my experiences.”

—Lori, wife of a 33-year-old
brain tumor survivor



Living

It's 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 in 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 come 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!

Where do I go for more support?

- **Brain Tumor Mailing List**

A worldwide e-mail bulletin board.

To subscribe, send an e-mail message to listserv@mitvma.mit.edu. Leave the subject line empty and type Subscribe braintmr “your name” in the message.

- **Family Caregiver Alliance**

800.445.8106 (in CA only) or 415.434.3388
www.caregiver.org

- **National Family Caregivers Association**

800.896.3650 E-mail: info@nfcacares.org
www.nfcacares.org

- **National Parent to Parent Support and Information System**

800.651.1151 • www.nppsis.org

- **Well Spouse Foundation**

800.838.0879 • www.wellspouse.org

What specific programs does the National Brain Tumor Foundation offer to help caregivers?

The National Brain Tumor Foundation has a listing of **support groups** throughout the nation attended by both patients and caregivers. We also have a **telephone support network** where caregivers can talk with other caregivers. In addition, NBTF is developing a **special caregiver program** specifically designed for caregivers of brain tumor patients. Please call NBTF at 1.800.934.CURE (2873) for more information.

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