

Brain Tumors and Fatigue

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Introduction – why this guide is needed

Fatigue is a common complaint among people who have been diagnosed and treated for different varieties of brain tumors. Unlike the usual physical and emotional sensations of “being tired” that a healthy person might experience, fatigue is a debilitating, persistent loss of energy that is not relieved or improved by sleep. This unusual, whole body weariness can have a profound effect on a person’s quality of life. Fatigue can vary in intensity from day to day, or at different times of the day. Its effects are unpredictable and may last for years following brain tumor treatment. Patients affected by fatigue describe overwhelming feelings of exhaustion that interfere with their ability to carry out daily activities.

The purpose of this patient education guide is to provide an overview of brain tumors and fatigue, along with suggestions for coping techniques that can be used by individuals who are affected by this condition. As with any health concern, please consult your personal physician and other members of your healthcare team for specific guidance regarding which of these techniques might be useful for your unique circumstances.

What are some possible effects of brain tumor related fatigue?

Fatigue can be manifested in a variety of ways. Here are some examples of physical, social, attentional, spiritual or emotional changes that may accompany brain tumors and their treatments:

Physical

- ◆ Reduced energy level
- ◆ Diminished strength or endurance
- ◆ Difficulty sleeping

Social

- ◆ Changes in roles or relationships
- ◆ Altered responsibilities within family
- ◆ Reduced ability to perform job responsibilities
- ◆ Changes in sexual relationships or sexual response
- ◆ Reduced interest in affection

Attentional

- ◆ Difficulty concentrating
- ◆ Inability to understand new information
- ◆ Being distracted by sensory input (i.e., noise, activity, etc.)
- ◆ Feeling overwhelmed by daily tasks
- ◆ Finding that typical activities of daily living are more difficult to do

Spiritual

- ◆ Questioning one’s purpose
- ◆ Disinterest in previous religious or spiritual practices
- ◆ Feelings of “why me” related to brain tumor diagnosis
- ◆ Indifference about prayer, meditation or other mindfulness

Emotional

- ◆ Changes in mood
- ◆ Reduced feelings of self-esteem or confidence
- ◆ Diminished sense of control about daily life
- ◆ Fears or anxiety about the future
- ◆ Concerns about body image changes (i.e., facial differences, hair loss, etc.)

When discussing any of these symptoms or feelings with your healthcare team, it is important to identify the factors in your life that might be related to fatigue. Some physicians and nurses encourage patients to categorize their levels of fatigue using a numerical scale (0 to 10), similar to the one commonly used to describe levels of pain. In this instance, 0 would be “no fatigue” and 10 would be “the worst fatigue you could imagine.” Using this type of numerical scale and keeping notes about your perceptions of fatigue also allows fatigue levels to be more easily monitored over time.

Why does fatigue develop?

A variety of medical conditions and other factors can cause fatigue, including anemia, side effects from medications, insomnia, depression, dehydration, poor nutrition, and chronic pain. For this reason, anyone experiencing symptoms of fatigue should first have a thorough medical evaluation to identify possible reasons for their symptoms, which might be unrelated to their brain tumor. Sometimes addressing other medical issues can reduce or even eliminate fatigue.

Once other factors have been identified and possibly treated, it's time to approach the effects of fatigue on an individual basis. By learning about coping techniques for each specific symptom of fatigue and applying them one at a time, the overall impact of fatigue might be lessened. Although fatigue can affect every aspect of a person's life, many of these effects may be improved by the use of coping techniques.

What are some self-care techniques that can improve fatigue?

The first and most important step toward coping with fatigue is to recognize and accept this as a valid medical condition. Talking to your doctors and nurses will help you define how fatigue impacts your life, including identifying the specific circumstances that contribute to your fatigue. Once you have focused on the individual factors related to your fatigue, it is easier to apply distinct coping techniques. Here are some common circumstances that can intensify fatigue and suggestions for improving those conditions.

NUTRITION AND HYDRATION

Even for healthy people who are unaffected by brain tumor issues, getting adequate nutrition and staying hydrated can be a challenge. For anyone with a chronic health concern -- including people diagnosed with brain tumors -- this can be even more challenging.

Many people find it easier to meet their nutritional needs by planning five or six small meals throughout the day, rather than eating larger amounts less often. Suggestions for healthy eating including utilizing all food groups, with an emphasis on lean protein and complex carbohydrates, combined with small amounts of healthy fats. By filling most of your plate with vegetables, and using the remaining space for protein and whole grains, it's easier to maintain a healthy nutritional balance. Many nutritionists emphasize choosing fruits and vegetables in a rainbow of colors, to maximize the nutrients in your food choices. Incorporating healthy snacks when needed can be another source of extra nutrition for people with diminished appetite.

For people affected by nausea (from chemotherapy, radiation or other causes), palatable meals and snacks are especially important. Dietary choices like yogurt, milkshakes, dried fruit, whole grain muffins, pudding, cut up vegetables and dip, fresh fruit or other well tolerated foods might be more easily consumed. Ironically, sometimes an empty stomach can promote increased feelings of nausea. Keeping “portable” snacks like cereal bars or peanut butter crackers available at all times can be especially helpful in these circumstances.

Drinking enough water throughout the day is also important for many bodily functions. Many healthcare professionals suggest drinking six to eight glasses (about two liters) of water daily. Choosing water as a beverage with meals, while avoiding dehydrating beverages with caffeine (i.e., coffee, tea, cola drinks, etc.) can help you consume adequate fluids. Keeping bottled water handy or taking breaks every half-hour or so for a glass of water can also help prevent dehydration.

EXERCISE

To some people who are challenged by fatigue, the idea that exercise can be helpful seems impossible. However, inactivity actually increases levels of fatigue. This can be seen during hospitalization or other periods of prolonged bed rest when people lose physical conditioning. Talk to your medical team about which types of gentle exercise might be useful for your individual circumstances. Many people find walking easy to incorporate in their daily schedule. Others may choose yoga, Tai Chi, circuit training, fitness classes, swimming or water exercise, bicycle riding or weight training. Even people with physical limitations can find some way to incorporate exercise into their daily lives. Consulting with a physical therapist can be helpful when factors like altered balance, weakness, or partial paralysis are involved.

SLEEP AND REST

Getting adequate sleep is an important part of managing fatigue. While daytime naps can be helpful as well, it's best to limit naps to 45-60 minutes daily so they do not reduce nighttime sleepiness. Going to bed and waking up at the same time each day helps your body develop a regular sleep routine. Keeping your bedroom at a comfortable temperature (neither too hot nor too cold) can also be helpful. Many sleep professionals suggest limiting bedroom activities to sleep and sexual intimacy. This promotes a restful, relaxed atmosphere in the bedroom, which can help prevent insomnia. Avoiding beverages containing caffeine, and eliminating any mentally or physically stimulating activities before bedtime can also promote restful sleep. Sometimes the effects of watching a suspenseful movie or exercising in the evening can make it difficult to relax and fall asleep. Some people enjoy a hot bath or shower before bedtime, or a light snack. If these or other choices make it easier for you to sleep soundly, then make them part of your nightly routine. Talk to your doctor if you have difficulty falling asleep or sleeping through the night on a regular basis. There may be other medical conditions involved, which might be managed with the use of medications or certain adaptive techniques.

ENERGY CONSERVATION

For people experiencing fatigue, one of the most important coping techniques is learning to conserve and manage their limited amount of energy. Energy conservation includes using practical techniques to carefully plan activities and prioritize. By making lists and deciding what is most meaningful on an individual basis, you can actively decide to do those activities that are most important to you. Learning to use your "free time" wisely and performing those tasks that must be done will allow you to feel a sense of accomplishment, even with a limited schedule. Being efficient and combining similar tasks, or those in the same geographical area, will also conserve time and energy. In addition, the telephone and email can be beneficial tools to find information, to make appointments, and to communicate with family and friends.

One of the most important parts of energy conservation is learning to pace yourself. Regardless of how long ago your brain tumor diagnosis and treatment occurred, it's important to remember that healing is not a competition. Some people resume their pretreatment level of activity within a matter of weeks. Other people never return to their prior level of activity and functioning. Whatever your personal condition, be patient with yourself, and allow yourself to take one step at a time. Each accomplishment in your daily life – large or small – is significant.

Another very important part of energy conservation is learning to delegate. By asking for help from family and friends -- and being willing to accept help from others -- you can use available energy for those tasks which are most meaningful to you. When asking for help, being specific about concrete responsibilities will make the process easier for both you and your helper. Some examples:

- ◆ "Can you please stop at the market and pick up the items on my grocery list?"
- ◆ "When you come over to visit, could you please fold a load of laundry?"
- ◆ "Thanks for your offer to help. Can you bring lunch for me on Tuesday?"

- ◆ “I need a ride to physical therapy on Wednesday. Can you please take me there?”
- ◆ “When you go to the post office, can you please pick up stamps for me?”

For many people, the idea of asking for help is very difficult to accept. One way to have a more positive outlook about this is to imagine switching places with the friend or family member whose help you are requesting. If they were depending on you, how would you feel? Remember that people who care about you will want to do what they can to help. Letting other people provide help makes everyone feel good.

RESTORING ATTENTION

Simple coping techniques can be helpful for attentional fatigue, as well as for the spiritual manifestations of fatigue. Some of the most effective techniques for restoring attention include activities that increase contact with the natural environment. Practical examples of these and other techniques to restore attention would be activities such as:

- ◆ walking or sitting outdoors
- ◆ gardening or tending indoor plants
- ◆ spending time with pets
- ◆ watching birds or other wildlife
- ◆ knitting, needlework or other crafts
- ◆ meditation or relaxation exercises
- ◆ any activity where you “lose track of time” and relax

By making these relaxing activities part of each day’s schedule, the symptoms of attentional fatigue can be diminished. These activities also promote an increased quality of life for many people.

STRESS MANAGEMENT

A variety of techniques can be beneficial in reducing stress by helping to relax the body and mind. Here are some of the best known ways to cope with stress overload:

- ◆ Breathing Exercises: simple patterns of breathing, in combination with taking deep breaths, help increase oxygen levels throughout the body
- ◆ Imagery: learning to visualize relaxing scenes can help mentally transport you to a place where you feel calm and comfortable
- ◆ Relaxation Exercises: specific techniques such as progressive relaxation (systematically relaxing each part of the body from head to toes) can relieve the physical and emotional effects of increased stress
- ◆ Journal Writing: keeping notes about your feelings and your fatigue symptoms will help you have a better understanding of how this condition affects your health. By noticing patterns in the time of day or activities that seem to be associated with increased fatigue, you can choose to alter some behaviors as a way of reducing fatigue symptoms. Consider writing your response to questions about how illness has affected your life in different ways.
- ◆ Intellectual stimulation: reading good books, exploring the Internet, playing games which require thinking (i.e., bridge, Scrabble, rummy, etc.), doing puzzles, listening to music and other similar pastimes can keep your mind active while helping your body to relax.

Of course, all of the self-care suggestions mentioned earlier (i.e., improved nutrition and hydration, gentle exercise, adequate sleep and rest, etc.) will also have a beneficial effect on managing stress.

SUGGESTIONS FOR CAREGIVERS

While the focus of this guide is on helping brain tumor patients (currently being treated) and brain tumor survivors (those who have had brain tumor treatments in the past), many of the health promoting suggestions will also be applicable for family members or caregivers. In addition to emphasizing positive

self-care, it is also important that family members are supportive to the person who is coping with brain tumor related symptoms. Although the effects of brain tumor related fatigue often have an impact on family members, it is meaningful to remember that the person coping with these health issues faces the greatest challenge.

In conclusion

If you are coping with the effects of brain tumor related fatigue, please remember that you are not alone! Many other people who have survived various types of brain tumors and different treatments are also affected by chronic fatigue. By using the coping techniques described in this guide, applying positive self-care, and working closely with your healthcare team to develop a personalized coping plan for your own fatigue, the effects of this common health issue can often be reduced and an improved quality of life can be restored. Notice the blessings that each day brings and let them be part of your celebration of survival.

About the authors

Nancy Conn-Levin, M. A., Health Educator, has written patient education materials and resource guides for healthcare professionals. She is a member of the Advisory Board of the Brain Science Foundation, a board member of The Healing Exchange BRAIN TRUST, and co-founder of the Monmouth and Ocean County Brain Tumor Support Group, Inc. She is also a brain tumor survivor.

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<http://www.brainsciencefoundation.org>

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Additional copies of this booklet are available by contacting:

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For more information about brain tumors, contact these charitable organizations:

American Brain Tumor Association

2720 River Road
Des Plaines, IL 60018

Toll free: 800-886-2282
Telephone: 847-827-9910
Fax: 847-827-9918
<http://www.abta.org>

Brain Tumor Foundation of Canada

620 Colborne St., Suite 301
London, Ontario, Canada N6B 3R9

Telephone: 519-642-7725
Fax: 519- 642-7192
<http://www.braintumour.ca>

The Brain Tumor Society

124 Watertown Street, Suite 3-H
Watertown, MA 02472

Toll free: 800-770-8287
Telephone: 617- 924-9997
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<http://www.tbts.org>

Central Brain Tumor Registry of the U.S.

244 East Ogden Ave
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Hinsdale, IL 60521

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T.H.E. BRAIN TRUST
186 Hampshire Street
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22 Battery Street, Suite 612
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Disclaimer

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Telephone numbers and other contact information for organizations listed above may be subject to change.

Online Support and Information

Free online groups are provided by The Healing Exchange BRAIN TRUST, a charitable organization that helps people affected by brain tumors and related conditions. More than two thousand brain tumor survivors, family members and others who are interested in this topic exchange email messages, sharing support and information with each other. To learn about the BRAINTMR list, The Meningioma List, TOPS (teens of parent survivors) or other online groups, contact:

info@braintrust.org

Additional information about these groups is also available at this web site:

<http://www.braintrust.org/support.htm>