Fatigue is common among people with brain tumors and substantially affects their quality of life. People with malignant tumors and those with benign tumors experience fatigue, which can be defined as an overwhelming feeling of tiredness that is not relieved by sleep and interferes with usual functioning. Individuals describe fatigue as weakness, exhaustion, sleepiness, drowsiness, confusion, and lack of energy. The level of fatigue varies from person to person. Monitoring and reducing factors that trigger fatigue can help to cope with fatigue and improve quality of life.

What causes fatigue in people with brain tumors?
The exact cause of brain tumor fatigue is not well understood. Both the tumor and its treatment contribute to brain tumor fatigue. Some potential causes include treatment-related factors, cognitive changes, medications, other medical conditions, and psychosocial (or emotional) causes. Many of these factors are interrelated.

- **Treatment-related:** Surgery, radiation, and chemotherapy can all affect energy level. Surgery-related fatigue may occur for up to 1-2 years after most major surgeries, not just those involving the brain. Even when the tumor is removed, the "insult" caused by the abnormal growth may be slow to heal, and brain injury caused by the tumor and its treatment may be a factor. In addition, fatigue is frequently a side effect of radiation and patients often experience a delayed response that persists months after radiation is completed. Fatigue is also a common side effect of chemotherapy, and chemotherapy can induce anemia, which is a known cause of fatigue. In many cancers, chemotherapy is also linked to a loss of mental sharpness known as "chemo-brain."

- **Cognitive:** Short-term memory loss, overstimulation, and attention impairment can all contribute to fatigue. Many people experience something called "attentional fatigue," which refers to the tiredness that comes from having to think about behaviors that used to be easy. Routine tasks may require greater concentration and effort, and may even need to be relearned. Some patients struggle with slowed thinking, mental exhaustion, or difficulty focusing on several things at once.

- **Medication:** Medications commonly used by people with brain tumors can contribute to fatigue. For instance, seizure medications (antiepileptic drugs) are associated with fatigue. Decreasing the dose of steroid medication used to control swelling can lead to corticosteroid withdrawal, which also causes fatigue. The cumulative effect of antiepileptic drugs, chemotherapy, and other drug interactions is believed to affect energy levels.

- **Other medical conditions:** Generalized and complex partial seizures, low hormone levels, poor nutrition, dehydration, pain, one-sided hearing or vision loss, and problems with dizziness and balance are among the range of medical conditions patients may experience which can cause fatigue.

- **Psychosocial:** Depression, anxiety, stress, and other types of emotional distress affect patients' energy levels. Fatigue and quality of life are closely connected, and factors that affect quality of life, such as coping with cognitive changes and sleep disturbances, contribute to fatigue. Another factor is the tendency for people to overexert themselves on days when they feel well. The sense of urgency to get things done may lead people to push themselves too much.
Fact Sheet: Brain Tumors and Fatigue

What strategies can help manage fatigue?

Fatigue can be managed to some degree by identifying fatigue triggers and adopting strategies to reduce them. Different approaches work differently for different people, so find out which strategies work for you. If you continue to have problems with fatigue, do not hesitate to consult with your physician or nurse.

Identify treatable causes. Some of the factors that contribute to fatigue are treatable. Discuss your fatigue with your doctor and request a thorough evaluation to investigate what may be contributing. An evaluation of your medications and drug interactions may help identify medication-related sources of fatigue. Anemia, pain, and sleep disturbances may be improved with medication. Also, a very small number of studies suggest the psychostimulant drugs methylphenidate and modafinil may help reduce fatigue. In addition, a neuropsychological evaluation can help identify cognitive changes, pinpointing those most likely to respond to rehabilitation. The testing can also detect depression and anxiety, both of which respond to treatment.

Identify patterns in your energy levels. Keep a record of your energy levels and what seems to trigger fatigue. Learn the times of the day when you seem to have more energy and schedule activities accordingly. Pay attention to early signs of fatigue in yourself and stop activity before becoming overtired. Possible signals of mental fatigue include growing levels of disorganization, frustration, restlessness, irritability, tearfulness, slowed thinking, distractibility, worsening memory, or difficulty maintaining focus or concentration.

Adjust your environment and activities. Look for ways to simplify the environment around you. Limit distractions and reduce competing demands. Recognize that activities that used to be relaxing (socializing with friends, going out to eat, etc.) may now cause fatigue. Try shorter or lighter versions of activities you enjoy or activities that are less strenuous (like reading or listening to music).

Practice good daily habits. Drink plenty of fluids and eat as well as you can. Talk with your doctor or another health care professional about your nutrition and try to get enough calories and protein in your diet. Develop consistent sleep habits, like going to bed and getting up at the same time every day. Take short walks or exercise if possible (check with your physician first). Practice stress management and relaxation techniques, such as deep breathing and meditation.

Practice energy conservation. Pace yourself and prioritize your activities to save energy for the most important things. Schedule rest into your daily routine. Rather than planning one long rest period, take short naps or breaks. Allow yourself recovery time between activities and events to "recharge your battery." Before beginning an activity, take a moment to focus on the task, get organized, and plan out the steps. When others offer to help, let them. Make a list of chores, errands and other tasks that they could help with.

Develop realistic expectations. Avoid competing with the person you once were or holding yourself to former standards. You now operate without the energy reserves you once had. Resist the pull to keep running on empty. Give yourself permission to take a rest or a break without feeling that you are "giving in to the tumor." Long-term survivors who feel they have conquered fatigue say they did so by redefining "normal" and accepting the person they are now.

For more information and how to reach us:
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How Tumors Affect the Mind, Emotion, and Personality

Many brain tumor patients face changes in memory, thinking, or emotions since the diagnosis of a tumor or its treatment. In fact, studies have documented cognitive impairments in as many as sixty to ninety percent of patients with brain tumors. While the goal of survival remains a critical one, the post-treatment quality of survivors' brain functioning is gaining increased attention.

Often, people with brain tumors are quite aware of changes in the way they feel, think, remember, and act. These changes may be so subtle that patients themselves are more aware of their difficulties than those around them. Other times, it is the caregiver who first perceives differences. Occasionally, patients are rather unaware of their difficulties although changes are apparent to those around them. Some caregivers have said, "I took one person into surgery and came out with another."

What causes changes in brain functioning?
A number of factors contribute to changes in brain functioning. Factors associated with the tumor itself include the location, size, and how fast the tumor grows. There is a tendency for patients with brain tumors to develop particular difficulties related to the area of the brain affected by the tumor. However, the relationship between the tumor area and brain functions affected is much more complex. In part, this is because pathways from the tumor area to other areas of the brain may be disrupted as well. Also, treatments for the tumor can produce changes as severe as the tumor itself. For instance, radiation is known to place patients at greater risk for more severe and widespread cognitive problems. The combination of these factors can result in a very complex and individual pattern of neurobehavioral deficits. It is often impossible to separate or predict the effects of the tumor itself, the surgery, radiation treatment, immunotherapy, and chemotherapy.

What functions are affected after a brain tumor diagnosis?
There is no single pattern of neurobehavioral changes following a brain tumor diagnosis. Patients may experience any combination of changes, and even patients with similar tumors may have quite different experiences. Some common functions that are affected include:

- **Language**: Patients may demonstrate difficulty expressing themselves, understanding spoken language, or writing. The most common difficulties are word finding and word fluency problems. The word may be on the "tip of the tongue" but the patient is unable to retrieve the word on command.

- **Attention and Concentration**: Patients often complain of becoming distracted more easily or losing concentration, even when things are of interest.

- **Learning and Memory**: Most patients experience some short-term memory loss. While old memories are retained, new information is difficult to learn and remember.

- **General Cognitive Abilities**: Sometimes general intellectual abilities are affected. One frequent complaint is slower thinking speed. This may result in work and home projects taking much longer than before the onset of the tumor.

- **Executive Functioning**: Patients with frontal tumors and other large tumors often experience difficulty with problem solving, judgment, flexibility in thinking, and multi-tasking. Patients may maintain general intellectual abilities, but they may feel that thinking is effortful and less efficient.
Fact Sheet: How Tumors Affect the Mind, Emotion, and Personality

- Emotion and Personality: These are probably the most difficult changes for both the patient and family, and the ones most often overlooked by professionals even though they occur in approximately half of patients. While depression is particularly common, changes can also include irritability, anxiety, apathy, euphoria, and sudden mood changes. Behavioral and personality changes may also occur, ranging from exaggeration of previous characteristics to appearance of very different traits. Some patients and their families report new behaviors such as obsessive compulsive tendencies, disinhibition, withdrawal, or changes in sexual interest.

How are functions of the brain evaluated?

To evaluate changes in brain function, physicians and patients often consult with a clinical neuropsychologist, a licensed psychologist specializing in how the brain functions and the impact of brain trauma on a person’s abilities. Neuropsychologists often evaluate functioning of individuals who have suffered some type of injury to the brain, whether it be a result of a traumatic brain injury, a stroke, or a brain tumor. Neuropsychologists often work with brain tumor patients to determine how particular brain functions might have been affected as a result of the tumor and its treatments. Neuropsychologists also examine functions that have not been interrupted and cognitive strengths that may help the patient to adapt.

This assessment is referred to as a neuropsychological evaluation. During the assessment, a variety of pencil and paper, computer, and other noninvasive tests are used to evaluate functions of the brain. Many times, an initial (baseline) evaluation is done so that changes, both improvements and declines, can be monitored with follow-up evaluations. The assessment also helps to determine whether treatment, in the form of cognitive rehabilitation or psychotherapy, may be useful.

Are there treatments to improve brain functioning?

Cognitive rehabilitation is a treatment designed to help patients regain abilities or compensate for cognitive or behavioral changes. Sessions are often combined with counseling to help patients adjust to differences resulting from the tumor. In addition to receiving treatment for cognitive and memory difficulties, patients may also be disinhibition, frustration tolerance, and frequent mood changes. When abilities are difficult to recover, patients may learn compensation techniques (e.g. keeping a notebook with reminders to remember appointments, errands, and conversations). Sometimes, sessions are held to teach a patient’s family how to modify the environment to help their loved one work around deficits. Vocational rehabilitation (provided through various state agencies), job coaches in the work setting, and individual psychotherapy have also been shown to be helpful.

How can I get help?

Contact your physician for a referral to a neuropsychologist. Many university affiliated hospitals have neuropsychologists on their staff. Some neuropsychologists are trained in both evaluation and cognitive rehabilitation or psychotherapy, however most are only trained in evaluation. If possible, try to find a neuropsychologist who has experience in working specifically with brain tumor patients. People with brain tumors show different patterns and progressions than other patients affected by neurologic conditions such as stroke or head trauma.

Within every person, there exists a very unique mind with a special set of strengths and weaknesses. The goal of evaluation and treatment should be to identify these strengths and weaknesses and to monitor changes over the course of time. No evaluation is complete without a plan for treatment aimed at regaining as much function as possible and training in compensation techniques for those abilities which cannot be fully regained.

Adapted from a previous version by S. Portman.