

Fact Sheet



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Revised 2004

How Tumors Affect the Mind, Emotion, and Personality

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Many brain tumor patients face changes in memory, thinking, or emotions since the diagnosis of a tumor or its treatment. It is estimated that more than half of all patients with malignant brain tumors experience some cognitive or behavioral change. With some treatments such as radiation, this figure increases further. While the goal of survival remains a critical one, patients, caregivers and health professionals are also becoming more aware of the importance of post-treatment issues such as the quality of brain functioning for survivors.

Often, following treatment for a brain tumor, patients 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 are those around them. Other times, it is the caregiver rather than the patient who first sees 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 cause changes in brain functioning. Factors associated with the tumor itself include the location, size, and how fast the tumor grows. Although there is a tendency for patients with brain tumors to develop particular difficulties related to the area of the brain affected by the tumor, the relationship between the tumor area and brain functions is not so clear. In part, this is because pathways from the tumor area to other areas of the brain may be disrupted as well. Also, interventions to treat these tumors in some cases produce problems as severe as the tumor itself. For instance, it is known that radiation (especially in children treated before the age of 6 and in the elderly) places 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.

Following complex treatment of a brain tumor, it is often impossible to separate or predict the effects of the tumor itself, the surgery,

radiation treatment, immunotherapy, and chemotherapy. The pattern of difficulties varies considerably from patient to patient.



What functions are affected after a brain tumor diagnosis?

There is no single pattern of neurobehavioral changes following a brain tumor diagnosis. Any combination of the following changes may present, and patients with similar tumors may look quite different. Some common difficulties include:

- ◆ **Language:** Patients may demonstrate difficulty expressing themselves, understanding spoken language, or writing. The most common difficulty is 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 decline in 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, particularly after recurrence of aggressive tumors. More frequently, patients complain of slowing in 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, judgement, flexibility in thinking, and "multi-tasking." Patients may maintain general intellectual abilities, but they may feel that thinking is effortful and less efficient.

◆ **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 the most common is depression, changes can also include irritability, anxiety, apathy, euphoria, and sudden mood changes. Behavioral and personality changes may occur as well, ranging from exaggeration of previous characteristics to 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 clinical psychologist with advanced training in consequences of neurological disorders. 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 such as an accident, a stroke, or a brain tumor.

Neuropsychologists often work with patients who have had a brain tumor in determining whether particular brain functions have been involved as a result of the tumor and its treatments. Also determined are functions that have not been interrupted and cognitive strengths that may help the patient adapt following treatment.

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 global and specific 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. An 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 seen for emotional and personality changes, including disinhibition, frustration tolerance, and frequent mood changes. When abilities are difficult to recover, compensation techniques are taught (i.e.,

keeping calendars and organizers to remember appointments, errands, and conversations). For patients who have lost much ability, sessions are held with the family to teach members how to modify the environment to help their loved one compensate (work around the deficits). Vocational rehabilitation (provided through your State Department), job coaches in the work setting, and individual psychotherapy have also been shown to be helpful.

How can I get help?

Contact your physician who may work closely with a neuropsychologist specializing in brain tumors. Many university affiliated hospitals have neuropsychologists on their staff. In choosing a neuropsychologist, be aware that while some are trained in both evaluation and cognitive rehabilitation or psychotherapy, most are only trained in evaluation. If possible, try to find a neuropsychologist who has experience in working specifically with brain tumor patients because brain tumor patients 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. ■

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The National Brain Tumor Foundation (NBTF) was founded in 1981 as a non-profit organization by people whose lives were affected by brain tumor disease. NBTF provides support services for patients and their families and raises funds for research to treat and cure brain tumors. For more information call 800.934.CURE.

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