



# Life after Brain Tumor

You've survived cancer and cancer treatment. Now what?

BY STEPHANIE CAJIGAL

**I**n March 2003, 44-year-old Gary Smith started experiencing severe headaches. They became so intense that this brawny paper-mill worker from Tacoma, WA, was taking six to eight aspirin at a pop to make the pain bearable. When the aspirin stopped helping, Smith began taking pain meds given to him by a co-worker, who had been prescribed the pills while recovering from knee surgery. These kept the headaches at bay for at least eight hours, but they were no solution.

Then one day that April, Smith woke up with the most excruciating pain he had ever felt. He called his parents and asked them to take him to the nearest emergency room. "All I could do was slip a t-shirt over my head, put on sweatpants, and walk to my front window. I stood there and bawled, it hurt so badly. I worked in a paper mill, so I've had knife cuts, large objects dropped on me, an 800-pound roll of paper go over my foot, but I could always stop myself crying. This time I couldn't."

At the ER, Smith learned the cause for his headaches: a brain tumor. A neurosurgeon removed the tumor the next day, but Smith's prognosis was grim. A biopsy showed that the lump was actually a glioblastoma.

Smith was given between 10 months and one year to live. Average survival with glioblastoma is 12-15 months, according to David Schiff, M.D., co-director of the Neuro-Oncology Center at the University of Virginia Health System in Charlottesville, VA. Age is an important predictor of survival, as is the patient's level of neurological functioning at the time they start treatment, he says.

Smith beat the estimates. Since his diagnosis, he has had seven other brain tumors removed, with his last surgery in December 2007. His attitude is almost sunny. "I didn't know it at

the time but [having cancer] was a blessing," he says. "I was always cynical. But after having my cancer, things matter more. When I see somebody doing something intentionally wrong, it makes me mad. By the same token, my love and kindness, my sense of seeing, is just heightened."

## THE CHALLENGE OF SURVIVAL

But with survival came other challenges. After having surgery to remove a tumor growing in a part of the brain that controls movement, Smith now has trouble with balance and coordination, making even sitting in a chair a challenge. "I have to consciously make sure I get my foot all the way in front of the chair so that when I sit, I'm centered. If not, I'm only on half of the chair," he explains.

Smith also lost most of the vision on his left side after another surgery last November.

This is not uncommon, Dr. Schiff says. Brain tumors can create gaps in vision as well as weakness on one side of the body.

Most challenging, though, was the cognitive loss that resulted from the first brain surgery, which ultimately cost Smith his job. "I was at a factory, so you're trying to keep pace with a machine that is kicking paper out really fast. There's a lot of pre-thinking involved. I just couldn't get things squared away. [The

tumor] changed how my thought pattern worked."

Currently unemployed, Smith receives disability benefits from the government and lives with his parents. He isn't alone in struggling to adjust to a different life after surviving brain cancer.

"What happens when someone's treatment is over? How do they fare? This is still understudied in malignant brain tumors," says Tracy Batchelor, M.D., executive director of the Stephen and Catherine Pappas Center for Neuro-oncology at the Massa-

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achusetts General Hospital Cancer Center in Boston, MA.

"I've had this conversation about helping survivors more this past year than I've had in the past 18 years doing this," says Roberta Calhoun-Egan, LCSW, a social worker with the Preston Robert Tisch Brain Tumor Center at Duke University Medical Center in Durham, NC. "It's because there are more and more people surviving glioblastoma for longer and longer."

### COGNITIVE CHANGES

Cognitive loss can result from both cancer and cancer treatment. "Some of it may be the surgery, although in general more of it is likely to be the tumor itself or the radiation. Radiation commonly produces fatigue and deficits in concentration and short-term memory that are prominent in the first few months after treatment," he explains.

Radiation on the pituitary gland or hypothalamus, which are located in the middle of the brain, can affect a person's endocrine function, according to neuro-oncologist Susan Chang, M.D. director of the Division of Neuro-oncology at the University of California, San Francisco. The endocrine system is responsible for secreting hormones that regulate mood, tissue function, metabolism, and growth. "If you have a low thyroid you're going to be very tired, and will have a slow metabolism," Dr. Chang says, adding that a doctor can prescribe hormone replacement therapy to improve energy.

Not everyone, though, experiences cognitive changes. "One factor is the location of the tumor," says Dr. Batchelor. "Some people may be completely intact and normal, but there are many people left with residual deficits like memory or language difficulties." According to Dr. Batchelor, there are no specific data available about the prevalence of such cognitive changes, but it isn't rare.

Neurocognitive testing, performed by a neuropsychologist, can help people understand their cognitive strengths and weaknesses and develop compensatory strategies, Dr. Schiff says.

Dr. Chang notes that her patients sometimes undergo neurocognitive testing in order to prove that they qualify for disability benefits. "Physically, they look perfectly fine, and a lot of times employers don't understand that they can't go back and work at the same level as before," she says.

This exam, which can last from one hour to four hours, is administered at most major brain-tumor centers, notes Calhoun-Egan.

Surviving brain cancer also doesn't mean an end to doctor visits, Dr. Chang emphasizes. "I tell my patients that even though we schedule you for a follow-up in six months, if anything changes neurologically between now and then, call us."

### WHAT'S NEXT?

"When patients go off treatment, it's wonderful. They've finally gotten through it," Calhoun-Egan says. "But on the other hand, the staff that has been involved on a daily basis is not there as much. So patients are kind of out there on their own, and there's this huge question about what's next."

Social workers can help people navigate the transition from battling cancer to dealing with everyday life. "That's a process that takes months or years," Calhoun-Egan says, "and part of what we do is help people deal with the change. It might be helping families deal with this 'new' person who might express more anger or do things differently around the house. Sometimes it's that the patient uses all their energy up at work and there is nothing left over for family, and the family is feeling left out."

Returning to work is also a common problem, according to Calhoun-Egan: some people can; others cannot. Social workers can help people find new jobs, apply for disability benefits, or get accommodations from their employers, such as a quieter work space with few distractions or a flexible schedule with the possibility of working from home.

"I also think people with brain cancer are not referred often enough to rehabilitation," Calhoun-Egan says. Finding a program that is tailored for brain-tumor survivors is important, as they often get lumped in with groups of patients have more significant cognitive problems, she notes.

One strategy taught in rehab programs for dealing with fatigue is to learn which times of day you best handle demanding activities. If you have seizures, a common symptom after brain-tumor surgery, Calhoun-Egan suggests keeping a diary to track when they occur, so you'll learn to avoid these particular triggers.

### A NEW NORMAL

Brain-tumor survivors can also benefit from attending support groups, where they can talk with people who have gone through the same experience, Calhoun-Egan says.

"Patients often don't realize how much energy they expend trying to look normal for people who have no idea what they've been through," she says.

What does "trying to look normal" involve? "Saying things are fine when you're worried," she explains, "or spending 30 minutes with someone and forcing yourself to be animated, and then you get in your car and on the way home you're exhausted from the effort."

"In the brain-tumor world we call it a 'new normal' because you're never going to be the same person," says Jeffrey

E. Schanz of Washington, D.C., an 11-year survivor of a glioblastoma who runs a support group at the George Washington Cancer Institute in Washington, D.C.

Schanz, 56, was able to return to his high-pressure job with the U.S. Department of Justice as director of the Office of Policy and Planning within the Audit Division. And he recently accepted a new job as inspector general of Legal Services Corporation, an organization that provides legal assistance to low-income people.

Yet attending a support group still helps Schanz deal with the ups and downs of his recovery. Though his cognition is relatively the same as it was before his brain tumor, “not every day is a good day,” he says. “There have been cases where I’ve had to be more deductive to figure out what was going on instead of just snapping my fingers and going ‘oh yeah, I understand that.’”

Support-group members share nutrition and exercise tips, information about alternative therapies, and much-needed humor, Schanz says.

Gary Smith has also stayed plugged into the brain-tumor community, serving as a mentor through a program run by the Brain Tumor Society ([tbts.org](http://tbts.org)). He talks by phone to people battling brain tumors and their family members, answering their questions and relating their issues to his own experience.

Schanz understands this need for camaraderie. “It’s almost unfair to my loved ones,” he says, “but I’m more comfortable with brain-tumor survivors because we all know what we’ve gone through. It’s still hard to articulate how hard you have to fight.” NN

*Sadly, Gary Smith passed away as we were going to press. We would like to thank him and his family for helping us tell his story.*

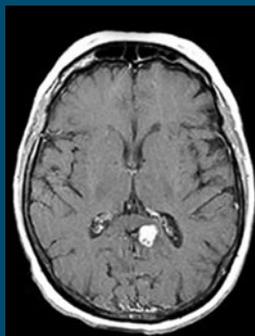


For more information on brain tumors, see **RESOURCE CENTRAL** on page 37.

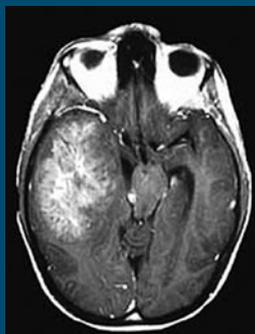
## Grading Brain Tumors

According to the National Institute of Neurological Disorders and Stroke ([ninds.nih.gov](http://ninds.nih.gov)), more than 195,000 Americans are diagnosed with a brain tumor each year. Tumors are classified as either benign or malignant. Benign tumors are slow-growing, non-cancerous cell masses that have a defined edge and do not spread to other parts of the body. The tumor cells are similar to normal cells; often, benign tumors can be removed surgically, and they usually do not recur. Malignant tumors have cells that look different from normal cells. They can quickly invade surrounding tissue and often have edges that are hard to define, which makes it difficult to remove the entire tumor surgically.

The accepted scale for grading tumors of the central nervous system, approved by the World Health Organization in 1993, is based on the tumor’s cellular makeup, location, and rate of growth. Some tumors change grades as they progress (usually to a higher grade) and can become a different type of tumor. Tumors are graded by a pathologist following a biopsy or during surgery and classified on a scale of I to IV:



Grade I tumor



Grade IV tumor

**GRADE I** tumors grow slowly and generally do not spread to other parts of the brain. It is often possible to surgically remove an entire grade I benign tumor. This type of tumor may also be monitored periodically, without further treatment.

**GRADE II** tumors also grow slowly, sometimes into surrounding tissue, and can become a higher-grade tumor. Treatment varies according to tumor location and may require chemotherapy, radiation, or surgery followed by close observation.

**GRADE III** tumors are malignant and can spread quickly into other central nervous system tissue. Tumor cells will look different than those in surrounding tissue. Aggressive treatment, often using a combination of chemotherapy, radiation, and/or surgery, is required.

**GRADE IV** tumors invade nearby tissue very quickly and are difficult to treat. The cancerous tissue will look very different from surrounding tissue. Aggressive treatment is required.