



American Brain Tumor Association

NEWLY DIAGNOSED HIGH-GRADE MALIGNANT GLIOMAS: WHAT PATIENTS AND THEIR FAMILIES NEED TO KNOW

Gliomas arise from the glial, or supportive, cells in the brain. There are different types of gliomas. Astrocytomas are gliomas arising from “star-shaped” cells called astrocytes. Oligodendrogliomas arise from “fried-egg shaped” cells called oligodendrocytes. Ependymomas arise from “corn-kernel shaped” cells called ependymal cells. When the specific tumor diagnosis is made by the pathologist, the tumor is also “graded.” This number grade is based on how normal – or abnormal – the tumor cells appear when examined under a microscope. Grade I tumor cells look slightly unusual when compared to normal brain tissue cells. On the other end of the scale, grade IV tumor cells appear to be very abnormal. In this four tier system, grade I tumors are called “benign,” grade II tumors are called “low-grade,” grade III (or anaplastic) and grade IV (or glioblastoma) tumors are called “high grade” tumors.

In this article, Henry Brem, MD, Director of Neurosurgery at The Johns Hopkins Hospital in Baltimore, Maryland offers an overview of treatments for people newly diagnosed with “high grade – grade III or grade IV – glioma.”

As a neurosurgeon, most people envision that my job involves mostly surgery, medical science and academic research. But the truth is, my job involves a great deal of emotion – as I am personally impacted by every patient I see and every diagnosis I make. To me, the best feeling in the world comes from helping patients live longer and healthier lives with their loved ones. With today’s state-of-the-art technology, I feel that there is a tremendous amount of hope and excitement for treating brain tumors. The chance for survival is greater than ever before, and as research continues to develop new therapies and combination treatments, the odds of beating this formidable disease get better and better.

When I give a high-grade glioma diagnosis to a patient and their family, I sit with them to talk about the tumor, its shape, size, and position. Then we talk about how *together* we will do everything we can to remove the tumor and its surrounding cells, and minimize the risk of the tumor spreading or growing back.

Given the nature of high-grade gliomas, most patients require early and aggressive treatment. To receive the best medical care - and to know what they can expect from treatment and follow-up care - patients and their loved ones should be fully informed, ask questions, and do their own research before proceeding with a treatment plan.

TREATMENTS

While treatment may vary according to each patient's circumstances and wishes, the recommended program for treating high-grade gliomas generally combines surgery, radiation, and chemotherapy.

Surgery to remove the tumor, known as craniotomy, is the standard treatment for high-grade gliomas. It is the first step in an overall treatment plan, and is usually scheduled soon after the initial diagnosis. It is important to realize that surgery alone is not considered sufficient treatment. Because these gliomas have tentacles that can spread into surrounding brain tissue, complete surgical removal of all tumor cells is almost impossible.

After removing the tumor, cells too tiny to be seen with the high-powered microscopes used in surgery may remain. Some of these cells, if left untreated, have the ability to rapidly double in number. Because of this potential for growth, the treatment plan includes additional therapies. Some may be considered at the time of surgery. Gliadel wafers, containing chemotherapy drugs, might be inserted directly into the cavity of the removed tumor. The wafers release chemotherapy directly into the brain for several days before eventually dissolving. GliaSite is another option at the time of surgery. This treatment option provides internal radiation therapy via a balloon catheter that is placed in the tumor cavity after the tumor is removed. There are also several clinical trials, or research studies, which place biologic therapies into the tumor site at the time of surgery. These pre-emptive strikes work to help prolong survival and minimize the risk of recurrence.

Radiation, the use of energy beams to stop or slow tumor growth, is typically started two to four weeks after surgery. The most common type of radiation used for brain tumor treatment is "conventional radiation" which is given daily and usually takes about six weeks. Sometimes focused radiation is used as a "boost" toward the end of the course of radiation. The goal of radiation therapy is to shrink tumor cells and make them unable to reproduce themselves.

Chemotherapy, the use of toxic drugs to kill tumor cells, has made significant advances in recent years. Instead of injecting these drugs into the blood stream, sometimes with serious side effects, oral chemotherapy with a drug called temozolomide, has emerged as an important therapy after surgery. This drug is given during radiation therapy, and continues for awhile afterward as a maintenance treatment.

Clinical Trials. Clinical trials are research treatments. These studies of new therapies give patients the option of participating in research while accessing the latest available treatments. Patients interested in learning about clinical trials can begin by asking their doctor. For a listing of clinical trials being offered for your type of tumor, call the National Cancer Institute's Cancer Information Service at 800-422-6237.

QUESTIONS TO ASK YOUR DOCTOR

After I've discussed the diagnosis with my patients and their families, they sometimes feel overwhelmed by anxiety, fear, confusion, denial, anger, or a sense of helplessness. During this difficult time, it is in their best interest to become as well-informed as possible about the specifics of your treatment options.

When time allows, find out as much as you can before making decisions about a treatment program. Write a list of questions to ask your healthcare team, and keep a written record of the responses. Ask your doctor to print the diagnosis for you, or ask for a copy of the pathology report. Also ask for a copy of the treatment plan once it has been decided.

Here are questions I would suggest patients and their families ask their physicians about treatment and post-treatment care:

- 1) **Know the Choices:** What are my treatment options? Tell me what is known about the latest therapies for this tumor, as well as traditional therapies.
- 2) **Advocate for Yourself:** What are the most aggressive treatments available? What is the time frame for me to make a treatment decision? Is there time for a second opinion? How early can treatment start?
- 3) **Specialized Care:** Is the center known for its treatment of brain tumors? Will my medical team include neuro-oncology (brain tumor) specialists? Do I have access to neurosurgeons, neurologists, neuro-ICU staff, neuroradiologists, and neuropathologists with experience in brain tumors?
- 4) **Physician's Background:** How often does the neurosurgeon perform brain tumor operations – how many times per week or per year? (There isn't a magic number to look for, but rather the fact the neurosurgeon routinely does brain tumor surgeries.)
- 5) **Available Technology:** What specialized equipment is available in the operating room? Is there a computer navigation guidance system, an operating microscope, an intraoperative ultrasound, an intraoperative MRI? If I am interested in additional therapy at the time of surgery, is that available to me?
- 6) **Social Needs:** When will I be able to return to work or my normal activities? Will I need help at home or someone to stay with me? Will I need to go to an inpatient rehabilitation center or outpatient physical therapy? If so, what are my options?
- 7) **Risks:** Based on the post-surgery treatment I have chosen, what side effects might I expect from treatment? Are there any special precautions I will need to take, or medications I will need to reduce side effects?
- 8) **Recurrence Expertise:** If my tumor recurs, will I be treated at the same facility or transferred to another center?
- 9) **Follow-up Needs:** What resources will be available to me after treatment? For instance, is there an emergency number for this practice after hours? If I need post-treatment rehabilitation, what arrangements can be made?
- 10) **Personal Support:** Can I meet other patients who are going through something similar? What support groups are available?
- 11) **Expectations:** What will my life be like during and after treatment? What kind of quality of life can I expect?

Even if you already know some of the answers, the questions are still worth asking – as a way to obtain more complete information and to spark a dialogue with your doctor. Open, honest and thorough discussions between you, your family, and your healthcare team will facilitate decision-making and help make it easier to address challenges that may occur.

The American Brain Tumor Association expresses appreciation to Dr. Henry Brem and to MGI Pharma, the manufacturers of Gliadel wafers, for providing this informative article for us. Years ago, ABTA funded early research studies which led to this therapy. ABTA continues this tradition of funding innovative research into both the causes -- and cures -- for brain tumors.