There are no clear answers for me, so I had to learn that emotionally and medically, my brain tumor care is something we'd have to manage for a long time. That's why it was so important for me, us, to interview and find the best doctors for us.

— Darren, patient
CHAPTER 3 / TREATMENT OPTIONS

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Treatment Options

Once you have a medical team in place, talk to them about your questions, fears, and concerns. You and your loved ones are the only people who know everything about your care and what you need. It’s critical to speak-up and learn about all of your treatment options before you decide what care you need.

THINGS TO REMEMBER

- Talk openly and honestly with your medical team. It may seem difficult, but it will help you get better care.
- Keep a notebook and schedule planner to track daily questions, side effects, notes, and appointment information.
- Learn about your treatment options over the short and long term.
- All questions are valuable.
  - Ask about the risks and benefits of each treatment option presented.
  - Ask about what to expect at the time of treatment, just after treatment, over the course of recovery, and in the long-term.
- Ask about clinical trials. This is the only way to access some promising new treatments.
- Ask about how to maintain a high quality of life over time.
- Ask about palliative care or other options to help manage your symptoms.
- If you feel overwhelmed: contact the Cancer Support Community’s “Open to Options” treatment decision counseling program. (See p. 27)
EMPOWERED COMMUNICATION

To talk more effectively with your health care team:

1. **Keep a notebook.** A notebook can help you keep track of questions and issues that you’d like to discuss at appointments. If you’re not feeling well enough to write everything down, ask someone to help. This notebook can include:
   a. Questions
   b. Side effects or symptom tracking
   c. Supplements
   d. Other medications
   e. Your “to do” list

2. **Know how to get your questions answered.** Will there be enough time during appointments to talk through your questions? Is email better? Do you need to schedule an extra appointment just to talk through everything? Is it better to schedule a time with the nurse? Ask these types of questions up-front so you and your doctor can maintain a productive relationship.

3. **Bring someone with you to appointments.** It is hard to manage all of the information and emotions. A family member or friend can be very helpful as an extra set of ears, to help take notes, and to discuss what you heard or remember things you might forget.

4. **Use a schedule-planner to organize help.** In addition to a regular calendar, consider an online resource (like www.rci.lotsahelpinghands.com or www.mylifeline.org) to help you stay organized and recruit help when you need it. You can plan for things like a ride to medical appointments, or help with dinner or childcare.

QUESTIONS ABOUT TREATMENT OPTIONS

1. What is the goal of treatment for me?
2. What are my treatment options?
3. Am I eligible for any clinical trial— and when? What is the goal of the trial(s)?
4. What are the possible side effects of each treatment option?
5. What can I do to prepare for treatment?
6. What will my recovery look like?
7. What is the likelihood this tumor will return after treatment?
8. What additional treatments might I need?
9. Will I need rehabilitation services, like speech therapy or physical therapy?
10. How can I reach you if I have questions after today?
11. Who would you recommend that I see for a second opinion?
Treatment for brain tumors is based on:
- Your age, overall health, and medical history
- The type, location, and size of the tumor
- How likely the tumor is to spread or recur
- Your tolerance for specific medications, procedures, or therapies
- Your opinion or preference

The first step is to address symptoms:
- **Seizures** - range from visual problems, to sensations such as numbness or tingling, to feelings of being disconnected and unable to speak, to uncontrollable body movements. (See p. 36).
- **Brain tissue swelling /edema** – causes problems like memory loss, personality change, confusion, speech problems, visual problems, muscle weakness, sensory alterations, and decreased levels of consciousness.
- **Headaches** – are very common.
- **Hydrocephalus** - causes pressure in the brain from cerebrospinal fluid. If removing all or part of the tumor cannot resolve this problem, a shunt to re-direct the path of fluid may be required.
- **Other common symptoms** – can include muscle weakness, or changes in sensation, cognitive functions, and personality.

Treatment for these symptoms may include:

**Antiseizure/Antiepileptic Drugs (AEDs)**

Antiseizure drugs treat and prevent seizures associated with pressure in the brain from a tumor, from surgery, or from an irritating treatment. In general, AEDs are recommended around the time of surgery, or for a longer period of time for people with a history of seizures. Some people experience sleepiness, unsteadiness, or confusion when taking AEDs. If a rash occurs, your doctor must be contacted immediately and AED use must stop.
**Steroids**

Steroids are used to treat and prevent swelling and pressure in the brain. They are very helpful, but they also cause side effects such as weight gain, “moon face”, mood changes, difficulty sleeping, muscle weakness, osteoporosis, or joint pain, increased risk for infections and bruising, an increase in blood sugar, and possibly gastrointestinal bleeding. It is important to take steroids to reduce swelling, but it is equally important to manage their side effects. If you experience these types of side effects, talk with your doctor or nurse so they can help you with strategies for relief, including changes to the dose and type of steroid used. This can take some time. (More in Chapter 4)

**Surgery**

The ultimate goal of surgery is to remove as much of the brain tumor as possible. Removing the tumor often relieves the symptoms caused by it. Surgery is only possible if the tumor is in a location that can be reached without damaging important brain functions. It is critical to balance the possible impacts of surgery with the benefits.

Sophisticated *neurosurgical navigation* equipment is used in nearly all brain surgery centers to map around the brain to the tumor. The best comparison is like a GPS map for the brain. Brain mapping for surgery involves a special scan that is synchronized with operating equipment before surgery so the surgeon can identify abnormal brain tissue and provide the most complete and safest surgery possible.

**SOME PLACES TO CONTACT FOR REFERRALS**

- You can ask your primary physician to recommend a neuro-oncology expert
- The National Brain Tumor Society website can provide links to information and locations of treatment facilities near you. 1-800-934-2873 or www.braintumor.org
- The National Cancer Institute can locate a Comprehensive Cancer Center near you. 1-800-422-6237 or www.cancer.gov/researchandfunding/extramural/cancercenters/find-a-cancer-center
TREATMENT FOR LOW GRADE TUMORS

Often, low grade tumors (grade I and II) are treated with watchful monitoring or surgery alone. Though all tumors are monitored with repeat scans, grade II tumors are watched more closely after surgery and over time to make sure there is no recurrence.

Try to talk openly about how you’re doing with your family, close friends, and your employer so that you can make plans with them as you strive to return to more regular routines and responsibilities.

TREATMENT PLANNING FOR HIGH GRADE TUMORS

Higher-grade tumors are more difficult to remove and require additional treatments, beyond surgery, such as radiation, chemotherapy, or a clinical trial if one is available. Microscopic tumor cells can remain after surgery and will eventually grow back. All treatments, therefore, are intended to prolong and improve life for as long as possible.

Try to ask straight-forward questions that consider your quality of life during and after treatment. There may not be clear answers, but it’s important to ask your questions anyway.

BOOK RECOMMENDATIONS FOR MORE INFORMATION

Johns Hopkins Patient’s Guide to Brain Cancer by Deanna Glass-Macenka and Alessandro Olivi

Navigating Life with a Brain Tumor by Lynne P. Taylor, Alyx B. Porter Umphrey and Diane Richard

The doctor didn’t speak plainly to us. I think it’s important to learn as much as you can about what to expect over time, so you can feel more prepared.
— Candice, caregiver
Treatment Questions

**TREATMENT QUESTIONS FOR ALL BRAIN TUMORS**

1. What are the risks and benefits of surgery for me?
2. What can I do to manage symptoms or side effects?
3. Will my symptoms go away?
4. Will I experience different symptoms or cognitive problems after surgery?
5. Where and how big will the incision be? Will you have to shave my head?
6. How long will I be hospitalized after surgery?
7. Who will be involved with care for my recovery? How long?
8. Will I need rehabilitative care such as speech, physical, or occupational therapy? How long?
9. Will I have to see a neuro-oncologist for chemotherapy or radiation oncologist for radiation therapy?
10. Who is responsible for my follow-up care?
11. Do you anticipate a recurrence of this type of tumor?
12. Can I donate my tumor tissue to research?

**TREATMENT QUESTIONS FOR HIGH GRADE TUMORS**

1. How can I tell the difference between treatment side effects and brain tumor symptoms?
2. What are the standard guidelines to treat my tumor vs. what you recommend? Why?
3. Can you recommend a clinical trial for my care?
4. What will my life be like after treatment?
5. What is the likelihood that radiation and chemotherapy will help? What are the pros and cons of my options?
6. If I decide not to undergo further treatment, what will my progression look like?
7. Can you recommend a social worker or support group to help me and my family cope with my future life?
8. What else can I do to improve my quality of life, and the quality of life of those who care for me?

The National Comprehensive Cancer Network (NCCN) guidelines set the standard for treating brain tumors. The way that different institutions and physicians approach treatment starts with these guidelines, but may differ with institutional or personal opinions. It is worth looking at the NCCN guideline for your tumor type as you consider treatment opinions. [www.nccn.org/professionals/physician_gls/f_guidelines.asp#cns](www.nccn.org/professionals/physician_gls/f_guidelines.asp#cns)
Radiation Therapy
When surgery is not enough, radiation treatment uses x-rays and other forms of radiation to destroy tumor cells, or delay tumor growth. This can also be used when tumor cells are found in hard-to-reach areas.

By planning treatment carefully with brain mapping techniques, radiation oncologists try to avoid killing healthy cells, thereby reducing side effects. You may wear a special mask that fits around your head to hold your head in place during radiation treatment.

For higher grade gliomas, radiation treatment is often given with low daily doses of chemotherapy (such as temozolomide (Temodar®) to help delay a recurrence and allow patients to live longer.

Side effects from radiation may include swelling, fatigue, headaches, nausea, possible hair loss, and changes in your sensations or movement. Damage to normal brain cells is often subtle, but it can affect mental sharpness and the ability to think clearly. Cognitive impairment can worsen to become a long-term problem for some people.

There are ways to reduce the side effects from radiation treatment, so as always, it is important to tell your medical team how you feel so they can help provide relief.

More Treatment Options for High Grade Tumors

I know now that I waited too long before I got my headaches checked out. Now I want to bring awareness to this disease. I overcame my brain tumor, and I want people to know they can overcome it, too.

— Anthony, patient
• **Stereotactic radiosurgery** is a technique that focuses high doses of radiation at the tumor from many different angles. This form of radiation, often performed with the Gamma Knife® unit or the newer CyberKnife® unit, can be used to treat both benign and malignant tumors, but is most appropriate for tumors with well-defined edges.

• **Proton beam radiation therapy** is a type of high-energy, external radiation therapy that kills tumor cells with little damage to nearby tissues. It is most appropriate for tumors located at the base of the skull or behind the eyes.

Chemotherapy

Chemotherapy is the use of drugs to kill cells that rapidly divide, such as cancer cells. It is prescribed when surgery is not enough to remove a tumor – most often for higher-grade tumors. Low doses may reduce the impact of chemotherapy-related side effects, such as hair loss, nausea, fatigue, weight loss, and gastrointestinal problems. Patients are monitored closely to manage problems that may occur.

*Chemotherapy is provided in three forms:*

• **Chemotherapy wafers** containing drug called carmustine or BCNU are inserted directly into a high grade glioma during surgery. The wafer, named Gliadel®, slowly dissolves over 2-3 weeks to kill tumor cells.

• **Intravenous chemotherapy** is when the chemotherapy is given through a vein, in a clinic setting. Examples for high grade gliomas include:
  - Nitrosurea: BCNU
  - Vinca alkaloids: vincristine
  - Platinum Analogues: carboplatin, cisplatin

• **Oral Chemotherapy** is when chemotherapy is given in a pill, by mouth. Examples include: TMZ or temozolomide (Temodar®), lomustine (CCNU), or procarbazine (Matulane®). TMZ plus radiation is the standard treatment for high grade gliomas. Some doctors treat anaplastic oligidendrogliomas with procarbazine, vincristine, and CCNU (known as PVC chemotherapy).

Oral chemotherapy is not always effective on brain tumors. This is because of the body’s naturally protective system in the brain and cerebro-spinal fluid. This protective mechanism is known as the **blood-brain barrier** and it prevents harmful substances from entering the CNS.

You can ask your doctors which chemotherapy they think would be appropriate for your treatment and why. You can also ask your insurance company what drugs are covered. The decision of whether or how much chemotherapy you’d like to use is ultimately up to you.
Clinical Trials

Clinical trials are studies designed to test the most promising new treatments. People participate in a clinical trial for a variety of reasons: to try a new and promising treatment method, to contribute to the development of future treatments, or to help find a cure. Most clinical trials require a patient to qualify with certain medical criteria. Some trials can be joined before your first surgery, others during radiation, others at the point of recurrence. You can ask your doctor if you are eligible for a trial, or get a second opinion at any time.

Though participants may be among the first people to benefit from a new treatment, there can be unexpected side effects, or the new treatment may not be better than or even as effective as the standard treatment. Patients are provided with very clear information about the treatment under investigation before they decide to participate. If they do wish to participate, they are monitored closely.

Clinical Trial Phases:

- **Phase I**: Determine maximum tolerated dose...how much, how safe, how often?
- **Phase II**: Evaluate effectiveness...does it do any good?
- **Phase III**: Compares a new treatment to the standard treatment to determine which is more effective...is the new treatment better?

QUESTIONS TO ASK ABOUT CLINICAL TRIALS

1. Do I qualify for any available clinical trial(s)?
2. What is the purpose of the study?
3. How do the possible risks and benefits of the new treatment compare with my other treatment options?
4. Does the study sponsor pay for my treatment in the clinical trial?
5. Will there be any travel, housing, or childcare costs that I need to consider while I’m in the trial?
6. If the new treatment has negative effects, what will be done for me and who will cover the cost?
7. When and where will the clinical trial’s findings be reported?
8. If I use Gliadel, will it restrict me from entering a trial?
9. Can I have a sample of my tumor tissue frozen, so I can be a candidate for a vaccine in the future, or genetic tests?

MORE ABOUT CLINICAL TRIALS

**National Brain Tumor Society’s Clinical Trials Matching Service**
1-877-769-4812  

**Cancer Support Community’s Clinical Trials Matching Service**
1-800-841-8927  
[www.cancersupportcommunity.org](http://www.cancersupportcommunity.org) search: Clinical Trials

**National Cancer Institute**
1-800-422-6237  
[www.cancer.gov/clinicaltrials](http://www.cancer.gov/clinicaltrials)
Targeted Therapy

Targeted therapies focus on specific elements of a cell, such as molecules or pathways required for cancer cell growth (i.e., cell proteins) and use them as a target. When a targeted therapy attaches itself to a designated protein in a cancer cell, it can stop certain functions in the cell. For example:

- Bevacizumab (Avastin®) is an FDA approved targeted therapy that affects a tumor’s ability to make new blood vessels. It can be helpful for recurrent glioblastomas in adults.

Other targeted and biologic therapies continue to be tested in clinical trials. Examples include tyrosine kinase inhibitor (TKI) therapy and anti-vascular endothelial growth factor (VEGF) therapy.

Electric Field Treatments

Electric field treatments are a new strategy to kill brain tumor cells, utilizing a device called NovoTTF™ (by Novicure), that is placed along the scalp. It provides a mild electric current (electrodes) that may stop the growth of tumor cells without harming normal brain cells. There is some controversy about the efficacy of this therapy.

Other promising treatments still in development are:

Vaccine Therapy

Vaccine therapy uses the patient’s immune system to recognize and then attack cancer cells. Substances made with brain tissue or made in a laboratory are used to boost, direct, or restore the body’s natural defenses against cancer – similar to the way a flu vaccine helps the body fight the flu.

Advances are being made in the area of biomarker research, where specific proteins (biomarkers) found in the RNA and DNA of brain tumor cells can be used for cancer detection and treatment. Biomarker research is a foundation for personalized medicine and provides hope for cancer cures. Research is ongoing and very promising, but more time is needed.

When a patient donates tissue samples for biomarker research, it helps bring researchers one step closer to finding a cure. To learn more about donating tissue samples: www.cancer.gov/cancertopics/factsheet/Information/donating-tissue-research, or look online for information about The Cancer Genome Atlas project.

For information about innovative new research and treatments, visit Accelerate Brain Cancer Cure’s website (www.abc2.org).
Immunostimulatory Molecules

Clinical trials are planned to begin in 2014 for the use of Ipilimumab in the treatment of glioblastoma. Ipilimumab (Yervoy™) is a monoclonal antibody (a lab-made antibody used for targeted therapy) that has been found to be beneficial in the treatment of melanoma, and is now being tested on glioblastoma. It stimulates the immune system to help destroy unwanted tumor cells.

Gene Therapy

Gene therapy uses engineered genes that can selectively kill cancer cells, stop their growth, or stimulate the immune system to fight them. This is done with the introduction of engineered genes that can enter into cells for treatment because they affect the way cancer cells behave. Gene therapy can be introduced to cancer cells by inserting them into viruses, stem cells, liposomes, or other immune cells. Gene therapy has been very promising in pre-clinical trials.
If you are diagnosed with a recurrent brain tumor, you will want to consider how additional treatment can impact your quality of life. Options available for retreatment include surgery with or without chemotherapy wafers, chemotherapy (intravenous or orally), possibly radiation, and/or clinical trials.

Supportive care is most helpful when there is a cancer recurrence – regardless of additional treatment. Supportive or palliative care refers to strategies that ease pain and other symptoms. (See p. 29)

Most patients with high grade glioma receive a life-time dose of radiation shortly after diagnosis. It is important to be aware of your risk to normal brain tissue if additional radiation treatment is offered. In rare cases, when a good period of time has passed since initial treatment, special techniques, such as stereotactic radiosurgery or brachytherapy, may allow additional radiation to be directed to the tumor safely. However, there is no proof that these radiation treatments improve survival or provide any benefit to the patient compared to supportive care alone.

It’s also helpful to ask if you are eligible for a clinical trial and to learn how it may benefit you.

You may benefit from retreatment if you have:

- Good overall health
- A smaller amount of tumor present
- A longer interval (i.e., more than one year versus less than one year) between your original treatment and the recurrence
LONG-TERM PLANNING

I had brain surgery and the aftermath left me partially paralyzed. I endured intense physical and occupational therapy. Being partially paralyzed everyone thought dancing would be over for me, but I was determined to start dancing again. Eight years later, I have regained a sense of movement which was imperative. Dance is my life.

— Zazel-Chavah (from the National Brain Tumor Society's Story Corner)

All brain tumor patients can develop a plan with their treatment team, not just for immediate treatment, but also for recovery and long-term management. This may include follow-up scans, follow-up treatment, rehabilitative care, psychiatric care, and/or estate planning. Talk with family and your medical team about what you need.

During and after treatment, all patients can receive a plan for:

• **Continuous follow-up care** to manage recovery from treatment, to detect if the tumor returns, and to manage late effects of treatment. Your medical team can tell you how often you should receive follow-up care over time.

• **Rehabilitation care** for post-surgical or other treatment to help you regain lost motor skills and muscle strength. Speech, physical, and occupational therapists may be involved in this aspect of care, based on rehabilitative needs.

• **Supportive care/Palliative care** to minimize the side effects of the tumor or treatment and provide maximum support for the caregiver. Palliative care maximizes quality (as well as quantity) of life for the patient and those who care for them—not just at the end of life but throughout the course of disease.

THE GOALS OF PALLIATIVE CARE

• To treat symptoms that impact a person’s quality of life, such as pain, nausea, insomnia, cognitive changes, and other physical symptoms caused by brain cancer or its treatment

• To treat a patient’s emotional and social needs, including symptoms such as anxiety or helping with difficult family relationships

• To address a patient’s spiritual needs or concerns

• To address a patient’s practical needs, such as transportation and financial concerns

• To provide support for the patient’s family, friends, and caregivers
MANAGING LATE EFFECTS

Treatment, and managing a brain tumor, can feel like a long haul. “Late effects” happen well after treatment is over, and they can vary for people based on age, general health, tumor type, and location.

Late effects to manage with help from your medical or palliative care team can include:

- Physical disabilities
- Learning and cognitive disabilities
- Behavioral changes and emotional issues
- Hormonal problems including diabetes and infertility
- Damage to internal organs or other body systems from treatment

Your medical team has strategies to help. Palliative care options can also relieve discomfort and provide extra assistance to families as they manage day-to-day stressors. When a caregiver needs help, sometimes family, friends, or paid professionals can also step in (See Chapter 4 and 7).

HOSPICE

High grade brain cancer typically cannot be cured and deciding when to stop aggressive treatment is difficult. Caregivers don’t have to manage this decision alone.

When a person is unlikely to live longer than six months, hospice care is often recommended. It involves the care of all aspects of a patient and family’s needs, including the physical (i.e., pain relief), psychological, social, and spiritual aspects of suffering. It does not typically involve “heroic measures” to keep a patient alive (for example, it may not provide fluids or nutrition).

Hospice is about comfort. This care may be given at home, in a nursing home or at a hospice facility. Usually multiple care providers are involved, including a physician, registered nurse, nursing aide, a chaplain or religious leader, a social worker, and volunteers.

Hospice providers work together to support the caregiver, meet the patient and family’s needs, and significantly reduce suffering for everyone. Hospice care doesn’t end when a patient dies – it remains as a service for the family members left behind, to aid in their grieving and to help them get back on their feet.

For more information about hospice, go to www.hospicenet.org.

I appreciate knowing that I can call someplace like the Cancer Support Community’s hotline to talk to someone – People around you love you so much, but they can’t fix it.

— Candice, caregiver
People with cancer who actively participate in their recovery along with their health care team will improve the quality of their lives and may enhance the possibilities for their recovery. People with cancer who actively participate in their recovery along with their health care team will improve the quality of their lives and may enhance the possibilities for their recovery.