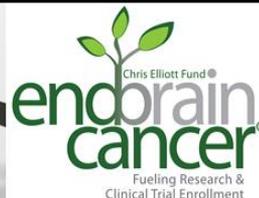


Top 10 Questions and Crucial Conversations to IMMEDIATELY ASK Your Doctor When Faced with a Brain Tumor



The EndBrainCancer Initiative is honored to provide this resource to you as you navigate your personal journey with brain cancer. You are not alone... we are here to help. Contact us for education, guidance, resources, and referrals to brain cancer specialists and “Pre-Qualification” for clinical trials.

1 BEFORE CONSENTING TO SURGERY

Q. Do I have time for a 2nd or 3rd surgical opinion?

You will be required to sign an Informed Consent for Surgery (Treatment), but it will be your responsibility to start the talk with your doctor about signing Informed Consent for Research, Advanced Treatments, and Clinical Trials. Some trials require fresh tumor tissue to be obtained at the time of your surgery for participation after your diagnosis. Ask your surgeon if any trials are available that would require you to consent for tissue collection prior to surgery.

A. Unless you are in the midst of a neuro-oncological emergency, it is reasonable to learn more about your surgical options. If you are being evaluated at a facility that is not a Brain Tumor Center of Excellence, it is important to explore the most expert options available to you. Centers of Excellence treat 300-500 brain tumor patients annually, and have access to clinical trials for your type of tumor.

Outcomes data shows that the quality and completeness of the initial tumor removal is directly correlated to the length of survival. It is critical to have your surgically removed tissue saved through cryogenic preservation for genomic testing and analysis. Ensure that your tissue is further researched either at your center or able to be shipped to other centers/neuro-oncologists for 2nd or 3rd opinions as well as pre-clinical trial information. It is vital that this Informed Consent for Research Form be signed and these options be discussed before your brain tumor resection or surgery. **This is your only opportunity to get tissue for testing.**

2 CENTER OF EXCELLENCE

Q. What kind of tumor do you suspect I have? How many resections do you do annually for my type of tumor? Will my care be managed by a neuro-oncologist, or a general oncologist?

A. Based on the appearance and physical characteristics of your tumor on the MRI/ CT scan and the expertise and experience of your neuro-surgeon, your team may have a suspicion as to what type of tumor you have. Confirmation of tumor type requires a pathology test which in some cases may not be an option if the tumor is “inoperable.” It is critical to get a 2nd or even a 3rd opinion, as a tumor deemed inoperable by one surgeon, may be assessed differently by another.

The discretion and skill of the neurosurgeon as well as the equipment and technology being used is factored into that determination. Even if your tumor is inoperable, it is possible to obtain a tissue sample by a biopsy. Find a brain tumor center that uses a multi-disciplinary approach, has brain tumor specialists (e.g. a neurosurgeon and a neuro-oncologist who see 200+ patients annually). Most community hospitals have neuro-surgeons, but are NOT Brain Tumor Centers of Excellence.

Brain Tumor Centers of Excellence

- Have neuro-surgeons who are Brain Tumor Specialists
- Have neuro-oncologists who are specifically trained in the most advanced treatments available for brain cancer.
- Have radiation oncologists who specialize in brain tumors
- Provide immediate access to clinical trials and advanced therapies for both the initial diagnosis and for possible recurrence of disease. Research the history, training, and education of your doctors.

3 SURGICAL OPTIONS

Q. What surgical approaches other than an open craniotomy or resection for tumor removal are available at this facility? What size is my tumor? Am I a candidate for gamma knife or CyberKnife radiosurgery? Will my surgeon perform awake brain mapping?

A If your tumor is smaller than a grape (< 3 cm), Gamma Knife, CyberKnife or Proton Beam radiosurgery might be an option. These are not actual surgeries, despite their names, but ways that radiation therapy can be given in a very focused way. Most patients still need to have some kind of surgery to obtain tissue for an accurate diagnosis before these focal radiation treatments can be considered.

The brain tumor center should perform awake brain-mapping operations, use intra-operative imaging, image-guided technology, have someone dedicated to monitoring neurological function during awake surgery, and an on-site neuro-pathologist to review brain tissue at the time of surgery. Another option to investigate with your care team is the Gliadel[®] wafer, a dissolvable, dime size chemo-infused wafer implanted at the tumor site at the time of surgery to deliver medications directly to the brain.

4 STANDARD OF CARE

Q. Can you describe what is “Standard of Care” for my particular brain tumor at your Center? What other treatments would you consider? Would you offer advanced surgical techniques, targeted therapies, vaccines, immunotherapy, or medical devices?

A. The current recommended standard FDA approved treatment protocol after surgery usually includes chemotherapy (Temozolamide/ TMZ) and 6 weeks of standard radiation depending on the type of tumor and whether it is malignant and operable. In addition to Standard of Care, it is critical to receive care at a Center that offers a wide range of treatment options such as: CyberKnife, Gamma Knife, and Proton Radiation. You may need to travel to have these

Completion of Standard of Care is your **“Starting Point”** to pursue additional treatments, however discussions related to Advanced Treatments and Clinical Trials should be addressed the moment you are told you have a brain tumor, and prior to surgery if possible.

Inquire about the availability of FDA approved Optune[®], which is a device which delivers Tumor Treatment Fields (TTF). This delivers a frequency specific, low intensity electrical field which interferes with cell division to fight and stop tumor growth. Discuss with your multi-disciplinary team whether you are a candidate for this.

5 TUMOR TESTING

Q. What are your plans for saving tissue from my tumor, and ensuring that it is preserved for further complete Genomic/DNA testing? Will I be able to have it sent out to another Center for future testing?

A. It is important that testing be done to better understand all the genomic and molecular characteristics of your tumor. In order to further guide Personalized Cancer Treatment, your tumor must undergo biological testing which includes at a minimum:

- IDH testing - Genetic Mutations and alterations
- MGMT testing to determine the likelihood of your tumor responding to Temodar
- Genomic and DNA Profiling such as FoundationOne[™] (Foundation Medicine) , MIPROFILE[™] (Caris), or other In-House Genomic Testing.
- Proteomic Testing - Identifies proteins associated with a tumor, which may be used as targets for new drugs.

IDH MUTATION TESTING identifies important molecular markers and may be associated with a more favorable prognosis.

MGMT promoter methylation is used to determine which treatments might be the most effective for your tumor. MGMT “methylated” GBM Brain Tumors appear to have an improved response to both Temoadar[®] and radiation. Unmethylated GBM tumors require an even more proactive and aggressive approach to treatment, as this type of tumor is less responsive to Temodar[®] therapy. Be sure to ask your doctors what the treatment plan (other than Standard of Care) might be if your tumor is unmethylated. Your MGMT status guides both treatment and clinical trial eligibility.

Genomic Testing, or genomic sequencing tests, looks at alterations in the 200+ genes that have been identified as potentially cancer-related and links any abnormalities it finds to specific targeted treatments (where they exist). It is critical to have your surgically removed tissue saved in paraffin treated slides for **GENOMIC TESTING AND ANALYSIS**. The test must be ordered by the surgeon **prior to surgery** so that sufficient tissue is available for the extra pathology slides required for this test. This is often not included in the “Standard of Care” so **your self-advocacy will be critical here**. Proteomic testing is similar to Genomic testing , but examines proteins rather than DNA.

6 CLINICAL TRIALS

Q. Can you tell me about clinical trials available at your Center? How will you handle referring me to other facilities and specialists to participate in clinical trials? Will you suggest trials to me, or is that research my responsibility?

A. Find out how many Brain Tumor clinical trials are active at the Medical Center and what phase the trial is in (1, 2 or 3). Ask about upcoming clinical trials. Be sure to ask if having surgery, chemo or radiation would exclude you from any of the clinical trials.

There are active clinical trials happening all over the US. It is important that your care team is willing to help you enroll in ANY trial (for which you are eligible) at any point in your care. Listen for responses that make you feel that your team will help investigate trials on your behalf.

7 MULTI-DISCIPLINARY CARE

Q. Besides my surgeon, neuro-oncologist, and radiation oncologist, who are the members of my care team? Does my facility offer an Integrative Support Program? What support group options are available to me and my caregivers?

A. Ideally your physicians work as part of a team with other professionals involved in your care. Integrative Care usually includes the involvement of a social worker and others who may provide patient counseling, family support and referrals to needed resources. Social workers can also address the financial impact of Brain Cancer Treatment, and can provide resources to assist with these issues as well.

Multi-disciplinary teams often include nutritionists, pharmacists, and family life specialists (both for pediatric patients and children of adult patients). Your physician may also recommend home care, occupational or vocational therapy, pain management, physical therapy and participation in support groups.

Support groups are often available in many different formats. There are online groups, as well as in-person gatherings for both patients and caregivers. Being a caregiver for any patient is challenging, and the support of others with a shared experience can be very helpful.

It is important to ask who is included on your treatment team, how they can be contacted, and the role of each person in your treatment and care. Ask who coordinates this care, how predictable is my schedule, and what efforts are made to cluster appointments together.

8 RADIATION EXPOSURE

Q. Should I be concerned about too much exposure to radiation?

A. Radiation exposure occurs both in diagnostic scans and in radiation therapy for treatment. The Standard of Care currently includes 6 weeks of standard radiation. Before beginning radiation treatment, inquire about whether Proton Therapy might be appropriate for your type of tumor. Proton Beam Therapy delivers a focused beam of radiation, which means that higher doses of radiation can be used to control and manage your cancer while significantly reducing damage to healthy tissue and vital organs. Compared to other forms of radiation therapy including Cyberknife[®] and Gamma Knife, Proton Beam Therapy has a very clear stopping point, so that tissue beyond the immediate targeted area is not affected, which is important when treating brain tumors. Your radiation oncologist can provide details about whether this therapy is an option for you.

In order to assess the response to treatment and to be immediately alerted should your tumor ever recur, you will likely receive a surveillance MRI every 8 weeks during treatment. MRI works by exposure to a strong magnetic field, rather than subjecting you to radiation. Discuss with your oncologist how frequently you will have follow-up MRIs once the initial Standard Treatment is complete. It is important to advocate for frequent MRI imaging, so changes and recurrence can be detected as early as possible.

9 FOLLOW UP

Q. Who is responsible for guiding my follow-up? Who is my contact person? What should I be doing during my initial treatment? What happens once I've completed my Standard of Care treatment?

A. The period following completion of radiation and chemotherapy feels different. During your treatment, you are overwhelmed with appointments and adjusting to the effects of your therapies. Now is the time to also be thinking about your next steps (your "Plan B"). This process involves learning, research, and partnering with a Patient Services Organization such as The EndBrainCancer Initiative (EBCI). The Direct Connect Program, which is free to the patient and caregiver, facilitates referrals and relationships with the doctors leading the clinical trials. EBCI pre-qualifies patients for appropriate clinical trials, and are typically able to connect patients to the doctor within 48 hours. Exact response times may vary depending on case load.

Once the treatments are complete, another phase begins which includes recovery, and adjustment to a "new normal". Transitioning from the active process of treatment, to the passive experience of "what now" can be challenging. Regular follow-up treatment is extremely important after treatment for a brain tumor and we encourage you to have conversations with your medical team as to planned next steps.

Besides regular physical and neurological exams and blood tests, you may need periodic scans, ideally more frequently than once every 2 months.

Several types of scans may be used to monitor your tumor, including magnetic resonance imaging (MRI), MR spectroscopy, perfusion or diffusion MRI, and/or computed tomography (CT). Positron Emission Tomography (PET) scans are another tool that can identify activity within the tumor or to detect extracranial (outside of the brain) disease.

This follow-up care will help your physician to:

- spot any sign that the tumor is returning
- monitor the health of your brain
- identify and treat the side effects of chemotherapy or radiation therapy
- detect the presence of other types of cancer at the earliest possible stage

Sometimes the MRI after treatment can be difficult to interpret due to reactions in the sensitive brain tissue to surgery and radiation. This is called **PSEUDOPROGRESSION** or ‘necrosis’ and can make it hard for your doctor to tell whether your tumor is growing or not. This is a stressful but common situation.

You should know exactly who to contact and how to reach them for any problems or questions that arise. This person is often a care coordinator / case manager at your oncologist’s office. Find out the expected response time when you contact this person with a question or problem. Before you leave the doctor’s appointment, know when your next regularly scheduled appointment will be.

Care Coordinator _____ Phone _____
 Email _____

10 PLAN B

Q. What might happen next?

A. Everyone’s brain cancer journey is different. It’s important to be thinking about **WHAT IS YOUR PLAN B?** You should have a plan in place in the event that a treatment fails, a tumor grows, or you need to shift directions quickly. Have discussions with your doctor about what the next move might be.

What we do know, is that the best chance of improved survival happens when you are engaged with trusted experts, and a team that can help you navigate a very complicated process. The EndBrainCancer Initiative is your partner for the duration of your journey and can help you prepare your “Plan B”.

<https://endbraincancer.org> [CLICK HERE FOR THE EBCI PATIENT INQUIRY FORM](#)

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