



Advocate. Educate. Connect.

BRAINS FOR THE CURE

Powered by Head for the Cure Foundation*

PATIENT & CAREGIVER RESOURCE GUIDE



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Brains For the Cure is deeply committed to making a positive impact on the lives of individuals and families affected by brain tumors. We understand the challenges and complexities that come with a brain tumor diagnosis, and we strive to provide comprehensive support, resources, and advocacy for patients, caregivers, and healthcare professionals.

A brain tumor diagnosis changes everything. You are faced with a new and unwanted reality that forces you to process a diagnosis, grasp a new vocabulary, and make treatment decisions quickly. It can feel overwhelming and daunting, but we acknowledge the hurdles ahead and are with you every step of the way.

In this guide, you will find valuable information and resources to help you make informed decisions and cope with the various aspects of this journey. From understanding the initial stages of diagnosis to exploring treatment options and beyond, our goal is to provide you and your caregivers with a reliable source of guidance and support during this challenging time. We're here to empower you with knowledge and connect you with the resources needed to navigate this journey with resilience and confidence.



GETTING STARTED

Adjusting to a diagnosis is a gradual journey. For some recently diagnosed individuals, absorbing all the information at once can be a challenge, while others may prefer immediate understanding. It is essential to take the necessary time to grasp the situation, delve into details about your specific brain tumor, and carefully consider the presented treatment options in order to make well-informed decisions.

01

Self Education

Start by educating yourself. Identify your brain tumor type, its grade, and its effects. This booklet provides a set of questions for your healthcare team and information on more common tumor types.

02

Diagnosis Education

Treatment decisions hinge on your tumor type, grade, size, and location. While some may opt for a "wait, watch, and see" approach, others may need to decide on surgery and subsequent treatments early on. After learning about your diagnosis, explore your tumor type and assess treatment options. This involves personal research and discussions with various medical professionals, possibly seeking a second opinion.

03

Insurance Preparation

Contact your insurance provider. If you don't have one, a hospital social worker can guide you through available options. The insurance section in this booklet offers specific information to assist you.



BUILDING YOUR MEDICAL TEAM



Neuro-oncologist

A specialized oncologist, focusing specifically on brain tumor treatment. They collaborate closely with members of the healthcare team and are responsible for developing and overseeing the treatment plan.



Neurosurgeon

They are responsible for the surgical aspect of treatment and also obtaining tissue samples for further analysis by a Pathologist. Ensure that your neurosurgeon specializes in your brain tumor type.



Pathologist

A pathologist will examine tissue from the tumor under a microscope and determine what type and grade of tumor you have



Radiation Oncologist

Administers radiation therapy to target and treat cancer cells, which may involve various therapeutic modalities such as chemotherapy and radiation therapy.



Neuro-radiologist

Interprets imaging studies (MRI, CT scans, etc.) to aid in diagnosis and treatment planning.



Primary Care

Coordinates overall health care and may continue to manage other health issues alongside your specialized cancer care.



Occupational Therapist

The brain cancer journey can affect daily living skills and independence. Occupational Therapists can aid in preserving or enhancing these skills as treatment progresses.

Physical Therapist

Physical therapists can help brain tumor patients through symptoms and side effects of treatment such as lack of balance or weakness.

Speech Pathologist

Symptoms and treatments can affect patients as they speak and eat. Speech therapists can assist in regaining or relearning these skills.

BUILDING YOUR MEDICAL TEAM



Nurse Practitioner

Provides ongoing care, education, and support to patients and their families throughout the treatment process. Typically found in the clinic offices of your healthcare team.



Clinical Trial Coordinator

If you are eligible to participate in a clinical trial, this professional helps manage all trial-related aspects of care.



Patient Navigator

Assists in coordinating appointments, communicating between team members, and providing overall support. Reach out to your hospital to see what they provide.



Palliative Care Team

Focuses on providing relief from the symptoms and stress of the illness, working alongside the primary treatment team.



Social Worker

Assists in addressing practical and emotional needs, connecting patients with resources, and providing support to navigate the healthcare system.



Psychiatrist/ Psychologist

Mental health professionals who can provide counseling, therapy, and support to help the patient cope with emotional challenges.



Counselor/Therapist

Professionals trained in various therapeutic approaches to support individuals and families dealing with the emotional impact of a brain tumor diagnosis.



Support Groups

Fellow patients, survivors, and caregivers who offer understanding, empathy, and shared experiences. [brainsforthe cure.org/information-support-resources/support-groups/]



Family/Friends

Loved ones who provide emotional support, companionship, and a network to lean on during challenging times.

KEEPING IT ALL STRAIGHT

Add phone numbers, addresses, emails, notes, etc. for a quick reference guide

Neuro-oncologist

Neurosurgeon

Pathologist

Radiation Oncologist

Neuro-radiologist

Primary Care

Occupational Therapist

Physical Therapist

Speech Pathologist

KEEPING IT ALL STRAIGHT

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Nurse Practitioner

Clinical Trial Coordinator

Patient Navigator

Palliative Care Team

Social Worker

Psychiatrist/ Psychologist

Counselor/Therapist

Support Groups

Family/Friends





QUESTIONS TO ASK

When faced with a brain tumor diagnosis, it's essential to ask key questions to gain clarity in your next steps. We encourage you to take these questions to your healthcare team as they can provide personalized and unique answers to address your specific diagnosis.



Fostering an open and communicative relationship between you and your care team is crucial for achieving the best possible outcome.



Advocating for yourself may be necessary to obtain the answers you desire.



Deciding ahead of time how you want to navigate knowing your prognosis vs. not knowing your prognosis is critical in framing the conversations you have with your healthcare team.

TUMOR SPECIFIC QUESTIONS

- What is my official diagnosis?
- What information can you provide about my brain tumor?
- How do you anticipate my brain tumor will progress?
- Is my tumor operable?
- What is the likelihood of recurrence?
- How does the grade and stage of my tumor affect my prognosis?
- Is my tumor considered slow or fast-growing?
- What is my prognosis?

TREATMENT SPECIFIC QUESTIONS

- What treatment options are available?
- Is there a timeline for starting treatment? Do I have the option to wait?
- How much time do I have to decide on my treatment plan?
- What is the standard treatment for my tumor vs. clinical trials?
- Will insurance cover this treatment?
- How will this treatment be administered [oral or IV]?
- Are there alternative treatment options? Nontraditional treatment?
- How do you assess the effectiveness of the chosen treatment?
- What are the common short-term and long-term side effects of my recommended treatment? How can I manage these?
- How often do you recommend getting MRI's?
- Can I maintain work and other activities, including driving, during treatment?

QUESTIONS FOR YOUR NEUROSURGEON

- Where is the tumor located and what is the size?
- What are the potential risks with tumor removal?
- How might surgery affect my memory, cognitive abilities, physical movement or speech?
- What are the benefits to surgery?
- How long will surgery last?
- Why is surgery your recommendation?
- How many brain tumor patients with my tumor type do you treat each year?
- Are there other treatment options available based on my current condition?
- What happens if I do not have the operation?
- What is your experience in completing this operation?

GENERAL QUESTIONS FOR HEALTHCARE TEAM

- How many patients with my type of brain tumor do you treat annually?
- Which specialists constitute my healthcare team? (neuro-oncologist, neurosurgeon, radiation oncologist, nurse, social worker, nutritionist, physical therapist)
- What are the roles of each specialist?
- How will communication occur among these specialists regarding my treatment?
- In the event of hospitalization, will you be my doctor?
- What can I expect during recovery?
- Where do you recommend I get more information about my diagnosis?

QUESTIONS ABOUT CLINICAL TRIALS

- What clinical trials are currently available and when would I meet the eligibility criteria?
- Where can I access information about ongoing clinical trials?
- What potential risks and benefits should I be aware of when considering to participate in a clinical trial?
- How will the doctors overseeing the clinical trial collaborate with you during my involvement?
- Why would clinical trials be better than treatment being used now?
- Will insurance cover the clinical trial?

QUESTIONS ABOUT CLINICAL TRIALS TO ASK WHEN CONSIDERING PARTICIPATION

- What is the purpose of the trial?
- What phase is the clinical trial in?
- Why would this treatment be better than what is being used now?
- How long do I have to decide whether I want to participate?
- How does this treatment work to treat my brain tumor?
- What criteria is used to determine if I am eligible?
- How is the treatment evaluated?
- How often will I need imaging?
- How long is treatment given?
- How will I be informed of the results?
- How is treatment given? [pills, IV, surgery or procedure required]
- How often will I have to be seen in clinic or hospital?
- What are the known side effects and how are they managed?
- Are there other risks associated with participating in the trial?
- How will this trial affect my daily life?
- What are the costs to me for participating in this trial?
- Will travel be required with participation?
- How will the doctors overseeing the clinical trial collaborate with my healthcare team during my involvement?

QUESTIONS ABOUT SUPPORT

- What support services are available to me and my family/caregiver?
- Do you recommend I return to work and other normal activities at this time?
- Do you anticipate I will be able to return to work in the future?
- How do I talk to my family and friends about my diagnosis?
- What are my needs for equipment or supervision at home?
- How do I talk to my employer about my diagnosis?
- Where can I find resources for my mental health?
- Where can I find recommendations for a therapist for myself and my family?

QUESTIONS ABOUT DIAGNOSTIC TESTING

- Does the center or hospital provide genotyping services?
- When is the ideal timing for genotyping?
- If genotyping is not available at your center, where do you typically refer patients seeking this testing?

SELF REFLECTION QUESTIONS

- Is the healthcare team receptive to my inquiries?
- Do they allocate sufficient time to address my concerns during appointments?
- Am I comfortable with the doctor's recommendations?
- Is the doctor open to me seeking a second opinion?



SECOND OPINIONS

Before you decide on a treatment plan, it's a good idea to get a second opinion, which is a common and often appreciated practice. Consulting with a second brain tumor specialist can give you a different viewpoint on your diagnosis and proposed treatment. Check your insurance coverage, as some plans may require or only cover it upon request. Before pursuing a second opinion, consider the following tips:

Getting Organized

Talk to Your Doctor

Ask your doctor or a trusted source for a referral to a brain tumor specialist. When surgery or long-term treatment is on the horizon, most doctors appreciate a colleague's opinion and can assist by providing a recommendation.

Check with Insurance

Check with your insurance company for details. If you're seeking an opinion from a doctor outside your network, inquire about potential costs. Advocate for the treatment and care that aligns best with your needs.

Research

Research about other doctors and surgeons who specialize in your type of tumor.

Collect Your Medical Records

Collect ALL of your medical records from the time of diagnosis. A new doctor will need to review these records, including imaging tests, pathology, blood work, operative and consultation reports, office visit records, and any other relevant tests.

Request your records from your doctor's office or the hospital's medical records department. Know that there may be a charge for obtaining a copy.

Ensure that the specialists you choose to consult has access to your medical records before the appointment.

INSURANCE TIPS & QUESTIONS

01 NOTIFY YOUR INSURANCE

Notifying your insurance company allows them to guide you through the necessary steps, provide information about coverage, and ensure a smoother process for handling medical expenses related to your diagnosis and treatment.

02 REVIEW YOUR POLICY

It is important to review your policy, noting key points such as any deductibles, pre-authorizations needed, formulary list of medications covered and any limitations to your coverage.

03 IF YOU DON'T HAVE INSURANCE

If you don't have insurance, contact the social worker at the hospital. The social worker can outline insurance options, federal assistance programs, local and national funding organizations and other ways to help you find alternative forms of healthcare coverage.

QUESTIONS TO ASK

- Can you designate a single point of contact for my case? [Some companies offer this service]
- Is pre-authorization required for hospitalization or treatment? If so, whom should I contact?
- Is a second opinion necessary before non-emergency surgery? If so, are there any restrictions on who can provide the second opinion?
- Do I need to adhere to a specific network of hospitals or doctors to receive insurance benefits? Where can I access a list of these providers? What are the implications if I receive treatment "outside of network"?
- Does my policy include a deductible? If so, how much have I already paid this year?
- Will my insurance cover my participation in a clinical trial if I choose to enroll?

NOTES

Appointment Type:

Date :

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QUESTIONS?

Vertical list of checkboxes for questions.



UPDATES :

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NOTES

Appointment Type:

Date :

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QUESTIONS?

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JOIN
YOUR
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*Personalized
Guidance and
Resources for Every
Step of Your Brain
Tumor Journey*

