

# QUESTIONS FOR YOUR MEDICAL CARE TEAM WHEN YOUR CHILD HAS A BRAIN TUMOR



**Pediatric Brain Tumor Foundation**  
**A Resource for Families**

## **DISCLAIMER**

The Pediatric Brain Tumor Foundation does not engage in rendering medical advice or professional medical services. Information contained in this publication is NOT intended to be a substitute for medical care and should not be used for the diagnosing or the treatment of a brain tumor or any other health problem. If you have or even suspect you have a problem concerning your health or that of someone else, you should consult with your healthcare provider.

The materials provided by the Pediatric Brain Tumor Foundation are compiled based on current information at the time that they were written. Medical research concerning disease and treatments is an ongoing process. We endeavor to keep our materials current. However, you should review with your doctors and medical institutions to attempt to seek the most current information available.

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# Mission Statement

Find the cause and cure of childhood brain tumors through the support of medical research;

Increase public awareness about the severity and prevalence of childhood brain tumors;

Aid in early detection and treatment of childhood brain tumors;

Support a national database on all primary brain tumors; and

Provide hope and emotional support for the thousands of children and families affected by this life-threatening disease.



## INTRODUCTION

The Pediatric Brain Tumor Foundation is dedicated to helping parents and families of children with brain and spinal cord tumors. We are committed to your emotional health and well being. These resources are provided to assist with your journey for answers about their disease and treatment plan. Questions for the medical care team about the specifics of your child's disease and health care options are crucial for you to ask. This resource booklet provides a list of potential questions for a parent or family member to ask of the appropriate medical staff. We hope these questions will assist you to focus your attention on important issues surrounding the health of your child or family member.

All brain tumors are not alike. The type of brain tumor your child has may determine the treatment approach that is recommended. Pediatric brain tumors are unique for children and the health care provided is best when done by a specialized pediatric team. Treatment centers designated as Pediatric Brain Tumor Centers will have a specialized treatment team for pediatric brain tumor patients. Seek the treatment advice of such a team if this is possible for you.

As we are unique individuals, questions that are critical for your situation will come from your experience. The medical care team is busy, and having your questions written down will help you to remember all that you desire to ask at this visit. In addition, the health care providers will address written questions taken to a visit. At times it is beneficial to schedule an appointment, just to deal with your questions. It is appropriate, even common, to ask for an information-gathering appointment. Understanding your child's disease and treatment options will allow you to be a more effective advocate for your child's needs. The medical care team recommends treatment approaches for your case, and your responsibility is to evaluate these recommendations and decide what seems best for your child.

It may be helpful to ask some questions about the outcomes they have experienced with this type of tumor. With whatever outcome you may hear, remember to keep in mind that all things are possible.

Contact us at 1-800-253-6530 or email [familysupport@pbtfus.org](mailto:familysupport@pbtfus.org).

The following questions may help you gather information to consider treatment options for your child. The medical staff and social workers available to you will be able to give you the needed information or sources to find it.

## Questions Regarding Diagnosis

1. What is the name of my child's tumor?
2. Where is the tumor located?
3. What functions are found in the area of the brain where this tumor is located?
4. What does the MRI or CT scan show about this tumor?
5. Can this tumor or its treatment affect my child's emotions or personality?
6. What kind of treatment do you recommend for my child and why?
7. What are the potential benefits of this treatment?
8. What are the potential side effects and risks of this treatment?
9. What are the potential long-term effects of this treatment?
10. What would be the outcome without treatment?
11. What is my child's prognosis?
12. What surgeon do you feel is the best qualified to do this type surgery?
13. Is there a medical center that specializes in this type of tumor and its treatment?
14. How do I contact this doctor and get my child's medical records to him/her?
15. Will the social worker or nurse help us coordinate these appointments and treatments?
16. Where would I need to take my child for radiation or chemotherapy treatments?
17. How quickly do we need to make a decision about treatment?
18. If we would like a second opinion, whom would you recommend?
19. Will you help us explain this to our child and answer his/her questions?
20. How should we explain this to our other children?

21. Is there a support group we can contact regarding pediatric brain and spinal cord tumors?

## **Questions Regarding Hospitals or Medical Institutions**

1. Does this institution have a designated pediatric brain tumor center?
2. How many pediatric brain tumor patients are treated each year at the institution?
3. Who is the pediatric neurologist at the facility?
4. Who is the pediatric neurosurgeon at the facility?
5. Who is the pediatric oncologist?
6. Who is the pediatric social worker?
7. Who is the pediatric oncology nurse?

## **Questions Regarding Radiation and Chemotherapy**

1. What is this treatment and what does it entail?
2. What is my child's prognosis with this/these treatment(s)?
3. Will the treatment cause my child pain and if so, what can be done about it?
4. How will this treatment be given to my child?
5. What are the potential risks to my child?
6. What late effects may my child experience from these treatments?
7. What are the potential complications of this treatment for my child?
8. What are the potential side effects my child may experience?
9. What can be done about these side effects to make my child more comfortable?
10. Where will these treatments take place?
11. Will I be able to be with my child during chemotherapy?
12. If chemotherapy, what schedule can we anticipate following?
13. If chemotherapy, can some of these treatments be done at home by home health nurses?

14. How long will each treatment take?
15. How long will my child be receiving these treatments?
16. What side effects might we be looking for during this treatment?
17. Will my child lose his/her hair as a result of this treatment?
18. At this time, how should my child's education be handled?
19. Will you help us explain this to our child and answer his/her questions?
20. How should we explain this to our other children?
21. What kind of lab tests will my child need to monitor the effects of these treatments?
22. Can a home health nurse draw these lab tests at home or will I need to bring my child in?

## **Questions Regarding Surgery**

1. What are the benefits to my child in having this surgery?
2. How will this surgery be performed-what will you do?
3. What is my child's prognosis with this surgery?
4. What are the risks to my child regarding this surgery?
5. Explain any potential complications following surgery.
6. Can you predict how much of the tumor you will be able to remove?
7. Approximately how long should this surgery take?
8. What kind of anesthesia will my child have?
9. How soon after surgery can I see my child?
10. How long is the usual recovery time?
11. Approximately when can I take my child home?
12. Is there a time during the recovery period that my child should have a home/hospital teacher?
13. What kind of follow-up should we anticipate?
14. Should my child receive some follow-up care by a home health nurse?

15. Will you help us explain this to our child and answer his/her questions?
16. How do you recommend we tell our other children about this?

## **Questions Regarding Medications**

1. What medications will my child need to take during treatment?
2. What is the purpose of these medications?
3. List the potential side effects of the medications.
4. Will these medications be taken at home?
5. Are these medications taken with or without food?
6. Is the medication available in a pill or liquid form?
7. Could these medications interact with other medications that my child is currently taking?

## **Questions Regarding the Inoperable Tumor**

1. What makes this tumor inoperable?
2. Is there a pediatric neurosurgeon anywhere who has had any kind of success operating on this type tumor?
3. If surgery were attempted what would be my child's outlook for recovery?
4. Since surgery is not an option, what other treatment can be started?
5. What is my child's prognosis without surgery?
6. What is my child's prognosis without surgery but with other treatments?
7. Will you help us explain this to our child and answer his/her questions?
8. How do you recommend we tell our other children?

## **Questions Regarding Clinical Trials**

1. What is a clinical trial?
2. Who is conducting the study?
3. Where is the clinical trial being conducted?

4. Who is the sponsor of this trial?
5. Are there any costs that the patient or patient's insurance is responsible for?  
(Check to see if your insurance will pay these costs.)
6. Describe the phases of this study and what phase it is in currently.
7. What are the potential benefits from participating in this trial?
8. What are the potential risks associated with this trial?
9. How will my child be medically monitored while participating in this trial?
10. How will my child be medically treated if temporarily or permanently harmed by this trial?
11. Can I withdraw my child from the clinical trial at any time?
12. What are the consequences of leaving the trial?
13. What could cause my child to be withdrawn from a clinical trial?
14. What are my child's rights during the trial?
15. Will this trial have a blind study component?
16. At this time are there any approved treatment alternatives comparable to this trial for my child?
17. If my child has medically benefited from this clinical trial can he/she continue with this treatment when the trial is concluded?
18. Will you help us explain this to our child and answer his/her questions?
19. How should we explain this to our other children?

## The Pediatric Brain Tumor Foundation Programs

- **National Research Grants Program** – The Foundation supports a national grant program funding basic, clinical, and translational research projects as well as clinical fellowships to develop new and improved therapies for children with brain tumors.
- **National Family Support Program** - The Foundation administers a national Family Support Program providing patient education and resource materials, access to an 800 help-line staffed by a family support program coordinator, and hope to pediatric patients and their families in a safe, accepting and compassionate environment.
- **Patient Education and Resource Materials** – Patient education and resource materials, published by the Foundation, are made available at no cost to patient families, the medical community, and social service specialists. (See back cover for listing of booklets on various types of tumors)
- **Ride for Kids®** - The Foundation created and conducts a national grassroots program appealing to the general public to support the Foundation's goals through efforts of the motorcycling community. The Ride for Kids® serves as a patient support program bringing together thousands of motorcyclists, patient families, the medical community and the general public.
- **National Brain Tumor Database** –The Foundation funds the work of the Central Brain Tumor Registry of the U.S., the nation's database on pediatric and adult brain tumors, so that they may provide statistical data on brain tumors to the neuroscience community and patient population.
- **National Newsletters** – *The Helping Hand* and *The Caring Hand*, quarterly newsletters, report to patients, families, the medical community and the general public on the progress of the Foundation's work, research advances, and services available to patients and their families. *The Helping Hand* and *The Caring Hand* also convey stories of hope and healing to provide encouragement and support to patients and their families.
- **National and International Brain Tumor Conferences** – The Foundation offers educational grants to national and international brain tumor conferences in an effort to promote the development of neuro-oncology.

- **Informed Parent Internet Series** – These conferences are designed as an outreach to pediatric brain tumor patient families around the world, to help them be better informed about medical, quality of life issues as well as patient family concerns. (See back cover for listing of audio CDs available to families)

- **Scholarships** – The PBTF scholarship program is designed for individuals who have been diagnosed with a primary malignant or non-malignant childhood brain and/or spinal cord tumor.

## *Pediatric Brain Tumor Foundation Reference Library*

The following resource literature and archived Internet Conference audio compact discs are available to patient families, medical professionals and social services specialists at no charge by calling (800) 253-6530 or by e-mailing [familysupport@pbtfus.org](mailto:familysupport@pbtfus.org).

1. Questions For Your Medical Care Team When Your Child Has a Brain Tumor
2. Basic Facts About Pediatric Brain and Spinal Cord Tumors
3. Basic Facts About Medulloblastoma/PNET
4. Basic Facts About Juvenile Pilocytic Astrocytoma
5. Basic Facts About Astrocytoma
6. Basic Facts About Glioma
7. Basic Facts About Ependymoma
8. Helping Hand National Newsletter
9. Caring Hand National Newsletter
10. **Informed Parent Internet Series** - The Importance of a Multi-Disciplinary Approach to Treating Children with Brain Tumors
11. **Informed Parent Internet Series** - The Clinical Trials Process
12. **Informed Parent Internet Series** - School Re-entry Following the Diagnoses and Treatment of Your Child's Brain Tumor
13. **Informed Parent Internet Series** - Healing the Family
14. **Informed Parent Internet Series** - Growth and Development: Endocrine Issues Facing Pediatric Brain Tumor Survivors
15. **Informed Parent Internet Series** - Post Traumatic Stress: Helping Families Survive Childhood Cancer
16. **Informed Parent Internet Series** - Siblings Issues: The Impact of Cancer on Healthy Siblings
17. **Informed Parent Internet Series** - Brothers & Sisters & Brain Tumors: A Child's Point of View of Coping with Cancer in the Family
18. **Informed Parent Internet Series** - Combining Curative and Palliative Care for Children with Brain Tumors



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