

Questions to Ask Your Medical Team When Your Child is Diagnosed With a Brain Tumor



**Pediatric Brain Tumor
Foundation®**

Part of the Family Support Learning Series™ developed by the
Pediatric Brain Tumor Foundation®

Introduction

When your child is diagnosed with a brain tumor, you'll probably hear a lot of unfamiliar medical terminology. There's much to learn about the situation, including treatment options and the effects of those treatments.

Talking with your doctors and nurses will help them handle your concerns about your child's health. One of the best ways to communicate with your medical care team is to ask questions. Because time is often rushed during medical appointments, it's helpful to prepare in advance questions you might want to ask about the diagnosis, treatment plan, hospital and more.

Doctors often answer only the questions you ask. Our list will help you prepare for your child's appointments and get the information you need.

Your child's doctor may recommend surgery, radiation and/or chemotherapy. Your child may undergo some or all of these treatments, depending on the tumor type and grade. It is important that you understand the effects of each type of treatment.

Before your child is discharged from the hospital, be sure you have a phone number for the on-call doctor. Don't hesitate to contact the doctor at any time of the day or night if you're concerned about your child's health.

The questions in this booklet cover eight important topics you might want to discuss with your medical care team to make the best decisions for your child. We hope this information will help you navigate your child's treatment journey.

Disclaimer: The information provided here is not intended to be used as a substitute for medical care and should not be used for the diagnosis or 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 a licensed healthcare provider.

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Questions About Your Child's Diagnosis

Your child's doctor will provide some information about the tumor after reviewing the magnetic resonance imaging (MRI) or computerized tomography (CT) scan. The scan will tell your doctor where the tumor is located and what physical and/or mental impact it may be having on your child. The tumor type and its grade are usually identified during surgery when a pathologist examines brain tissue under a microscope. Tumors are graded from I to IV, with IV being the most aggressive.

You may want to ask:

- How long will it take to find out my child's tumor type and grade?
 - What treatment do you recommend?
 - How quickly do we need to make a decision about treatment?
 - What would be the outcome without treatment?
 - What is my child's prognosis (chance of recovery and survival)?
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Questions About the Hospital

Depending on where they live, some families travel to a teaching hospital with a nationally acclaimed pediatric brain tumor center, for all or part of their treatment. Doctors recognize the importance of your child receiving top-notch care and may indicate that a different medical center is better suited to manage his or her condition. This is because most brain tumors require a multidisciplinary approach (neurosurgeons, oncologists, radiation oncologists, endocrinologists and many others).

Ask how many pediatric brain tumor patients your hospital and doctor treat each year. Find out how this figure stacks up against other facilities and doctors. Generally speaking, the hospitals and doctors that have the greater number of childhood brain tumor patients also have greater knowledge of the disease, treatment options and clinical trials.

Some children may do just as well at smaller hospitals. You can request a second opinion from a larger hospital by having your hospital send your child's charts and scans for review. A second opinion can confirm your child's diagnosis and optimal treatment plan and can help you make a more informed decision about treatment and care.

Don't hesitate to request second opinions; most doctors understand and respect parents' desire to have them. Be sure that the second medical center has all the required information, such as the doctor's summary, charts and imaging. In addition to a review of your child's records, it's especially helpful to have your child evaluated in person by the consulting doctor, but that is often not feasible. If a second opinion differs from the first doctor, you may wish to seek a third opinion.

You may want to ask:

- Is this the best hospital to treat my child? Can we enroll my child in any clinical research studies?
 - If we would like a second or a third opinion, whom do you recommend?
 - Will our insurance policy cover treatment at an out-of-state hospital?
 - Will our family be allowed to stay with our child in the hospital during treatment?
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Questions About Surgery

Most brain tumors are first treated by a neurosurgeon who will operate to remove as much of the tumor as possible. In many cases, other treatments may also be necessary. Surgery alone may cure some types of low-grade tumors. In high-grade brainstem tumors, or cases where disease has spread extensively, other treatments may be more appropriate.

During the surgery, the neurosurgeon shaves a small area of the child's hair, then makes an incision to the skull in a procedure called a craniotomy. The opening must be large enough for the neurosurgeon to insert instruments and remove as much tumor and surrounding tissue as safely as possible. To get to the tumor, the neurosurgeon uses a special drill to extract a piece of bone from the skull. After the procedure, the bone is put back in place and the incision is closed.

If the tumor has caused hydrocephalus, a condition in which the flow of cerebrospinal fluid (CSF) — the liquid that bathes the brain and spinal cord — has become blocked, the neurosurgeon may insert a silicone tube called a shunt. One end of the shunt is placed in a ventricle of the brain and the other is usually placed in the abdomen. The flow of CSF is controlled by a valve placed along the tubing. Shunts may be temporary or permanent.

You may want to ask:

- How much of the tumor do you expect to be able to remove?
 - What complications could arise during surgery?
 - What permanent and temporary effects could this surgery have on my child's basic abilities to function (such as swallowing, vision, hearing, walking)?
 - Could surgery damage the endocrine system? (This includes the production of hormones that control physical development, including height, puberty, stress response and metabolism.)
 - Could surgery cause diabetes insipidus? (A condition affecting the body's water balance that requires hormone replacement therapy.)
 - What kind of rehabilitation services, such as speech, physical and occupational therapies, might my child require after surgery? Where would this take place?
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Questions About Radiation

Radiation uses high-energy X-rays to kill cancer cells and is sometimes given after surgery. For some tumor types, radiation alone can provide a cure. Radiation is also given to shrink the tumor or at least slow its growth.

Brain tumors are treated with external beam radiation therapy, which is administered from a source outside the body. This is different from brachytherapy, when radioactive material is inserted into or near the tumor.

In most cases radiation is an outpatient procedure that lasts about 20 minutes per session. The total dose is typically divided into daily fractions given over several weeks.

Radiation is painless, but may cause weakness, fatigue and nausea, depending on the location and size of the treated area. Hair loss is usually temporary and is limited to the part of the head where the brain is irradiated. Other side effects may include temporary hearing loss or permanent hearing deficit if the treatment is directed near the ear. Radiation may also cause dry mouth and trigger memory loss or confusion.

Many radiation oncologists are reluctant to use radiation in children under 3 years of age, due to concerns about its potential long-term effects on brain development.

Your child's radiation oncologist may recommend proton beam radiation, which can potentially deliver radiation to the tumor more safely by doing less damage to surrounding tissue. However, the advantage of this approach remains to be firmly established and may be limited to certain types of tumors with very discernible edges. In addition, only a handful of centers in the United States offer proton beam radiation.

Stereotactic radiosurgery is sometimes recommended for small tumors in the brain or spinal cord that cannot be removed surgically. This treatment delivers a large, precise dose of radiation in a single session or in a few sessions using machines such as the Gamma Knife and CyberKnife. Note that despite the name radiosurgery, no incision is made.

While radiation is usually delivered to the specific tumor site, whole brain and spinal cord radiation (craniospinal radiation), is given to children with certain tumor types, as well as to those whose tumor has spread throughout the brain and spine. Its side effects and late effects (effects sometimes seen years after treatment) are more pronounced, especially in very young children. Total hair loss follows craniospinal radiation, but hair usually regrows weeks or months after treatment.



You may want to ask:

- Will radiation affect my child's memory and learning ability?
 - Could radiation damage the endocrine system? (This includes the production of the hormones that control physical development, including height, puberty, stress response and metabolism.)
 - Could radiation affect my child's fertility?
 - Will my child be able to attend school during treatment?
 - Will my child need to be anesthetized before each radiation session?
 - What can I do to help my child cope with the side effects of radiation?
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Questions About Chemotherapy

Chemotherapy drugs may be delivered intravenously or directly into the cerebrospinal fluid on an inpatient or outpatient basis; via injection, usually in a hospital clinic; or taken at home by mouth.

Chemotherapy is usually given in cycles, with each cycle lasting a few weeks, followed by a rest period. The number of cycles given depends on whether the chemotherapy is used to treat an existing tumor, or to prevent recurrence, as well as how the patient responds to it. Children under 3 may receive it to defer radiation.

The side effects of chemotherapy are usually short-lived but may be very debilitating. Some chemotherapy drugs can cause kidney damage and hearing loss. Tests to check for hearing and kidney functioning should be carried out regularly. One of the most serious risks is a drop in red blood cells (anemia), platelets (thrombocytopenia) and a type of white blood cell called neutrophils (neutropenia). If neutropenia is severe, your child will be at risk for serious infections. Blood transfusions and medications to stimulate the bone marrow to produce more neutrophils may be used. Blood cell counts usually return to normal after treatment.

Nausea, vomiting, diarrhea, fatigue and mouth sores are common side effects that can be eased with medication. Loss of body hair is common because these drugs work by attacking the fast-growing cells throughout the body, including those in hair roots. Hair usually grows back as soon as chemotherapy stops.

Some types of brain tumors respond very well to chemotherapy. Alternatively, your child may be prescribed a targeted therapy or an immunotherapy. These treatments differ from standard chemotherapy and are usually easier to tolerate. However, they are still being tested in clinical trials and their effectiveness against brain tumors has yet to be definitively established.

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You may want to ask:

- Do you recommend a port (a surgically implanted catheter, usually in the upper chest) or PICC line (a catheter inserted into a vein in the upper arm) for drug infusions?
 - Could chemotherapy affect my child's fertility?
 - What can be done if my child stops eating and/or loses a lot of weight during chemotherapy?
 - How frequently will my child need blood tests to check blood cell counts?
 - Should I minimize contact with my child's siblings and friends to reduce the likelihood of infection?
 - What can I do to help my child cope with the side effects caused by chemotherapy?
 - Will my child be well enough to attend school during the chemotherapy cycle?
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Questions About Inoperable Tumors

Not all brain tumor patients are candidates for surgery. Children with some inoperable low-grade tumors may be successfully treated with other therapies. But for children with a diffuse tumor in the brainstem — the part of the brain responsible for vital functions such as breathing, heartbeat and blood pressure — resection (surgical removal) is not an option. If your child's tumor has spread throughout the brain and/or spine, surgery may be viewed as more harmful than helpful. Remember that asking for a second opinion is always a good idea and that ruling out surgery does not necessarily prevent your child from being helped by other treatments.

You may want to ask:

- What is my child's prognosis (chance of recovery and survival)?
 - What treatments might be helpful and what are their goals?
 - What effect could treatment have on my child's quality of life?
 - Would a biopsy of the tumor help identify the best treatment for my child?
 - Is my child a candidate for a clinical trial?
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Questions About Clinical Trials

Clinical trials are done so doctors can determine whether a new treatment is safe and effective. Your child will need to meet very specific criteria in order to participate in a trial. Older children usually must agree to take part before a parent's consent is accepted.

Your child's health will be very closely monitored during a clinical trial, but it's important to recognize that the treatment might not be helpful and could cause unpleasant side effects. A phase I study looks at safety of a new treatment; phase II looks at its effectiveness; phase III compares its effectiveness to what is available already.

Insurance companies and the study's sponsor (the federal government, a medical center or a pharmaceutical company) usually cover treatment expenses and doctor's visits, but you should check first. Because trials are voluntary, participants may opt out at any time.

You may want to ask:

- Is the trial more likely to benefit future patients than my child?
- If the drug appears to be effective in phase I of the trial, can my child proceed to phase II?
- Could participation in the trial delay the onset of other treatments or trials, if we decide to drop out?
- What are the potential side effects?
- Would there be any costs for our family on this trial?
- Are there any resources available to cover our family's nonmedical expenses?



Questions to Ask Your Social Worker

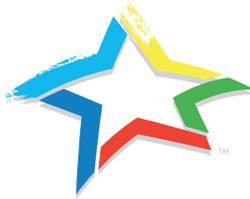
Social workers help families adjust to their child's diagnosis and treatment. They also offer practical help with issues related to financial hardship, your child's schooling and obstacles that can affect the treatment plan.

You may want to ask:

- What is the best way I can support my children (including siblings) as they cope with diagnosis and treatment?
 - Are there any support groups or camps for pediatric brain tumor patients, their parents and siblings?
 - How can I apply for financial aid, such as rent and vehicle repair assistance?
 - Does my child's condition entitle us to a disabled person parking placard?
 - How can I get an Individualized Education Plan (IEP) or a 504 Plan to help my child in school? (These programs provide specialized instruction or accommodations to help children with special needs, including cancer patients, fulfill their academic potential.)
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Notes



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