Answers to Questions You May Have 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

No parent is prepared to hear that their child has a brain or spinal cord tumor. The specter of a brain tumor diagnosis can be overwhelming. All at once the triumphs and trials of everyday existence hold little importance.

Learning more about your child’s diagnosis can empower you to move forward and take an active part in selecting which approaches will result in the best care for your child.

Your child’s medical team is always the best source of information, but sometimes your questions may not be answered as quickly as you would like. The PBTF does not provide medical advice. However, we can provide answers to many questions by providing basic information about fairly complex topics.

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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Diagnostic Tools and Imaging

Can a brain tumor be diagnosed by its symptoms alone?
No, the symptoms of a brain tumor frequently mimic disorders that are much more common. Confirmation of a tumor is made after a scan, such as computerized tomography (CT), which is usually followed by magnetic resonance imaging (MRI).

Will my child need to be under anesthesia for the MRI?
Patients need to remain completely still during an MRI, and the procedure may last up to an hour. Therefore, anesthesia may be required for children younger than 8 and older ones who are anxious. This means that your child will not be allowed to eat for several hours before the MRI and may be drowsy afterwards.

Video goggles and headphones, as well as your presence (if the hospital allows it), may help calm children who are old enough to have the MRI without anesthesia.

What happens during the MRI?
Before the test, a compound to enhance contrast may be injected into your child’s vein. This will help doctors identify fine detail of a tumor and any abnormalities of the brain. Your child will lie on a mechanical table, which is moved into a large structure with a doughnut-shaped opening. An “open MRI” means the top and sides are open, while a “closed MRI” will feel like going into a tunnel.

MRIs do not use ionizing radiation, which is a carcinogen. Because of this they are safe. They provide very intricate images of the brain and soft tissue, and are the most sensitive tool for detecting brain abnormalities.

In general, MRI is used instead of CT to follow the progress of brain tumors over time and after treatment.

Can a CT scan cause cancer?
Unlike MRIs, a CT scan does use ionizing radiation, which with repeated exposure can increase the chance of developing cancer many years later. For this reason doctors are conservative in recommending CTs for children.

When used appropriately, CT scans can be very useful. CT is a much quicker procedure than an MRI, making it lifesaving in its ability to identify neurological emergencies. Consequently, it is often the first type of scan done when your child is being diagnosed. CTs can more accurately detect calcium deposits, a feature of some tumors, and can provide more detailed pictures of the outer layer of the skull than other imaging techniques.
Will my child need a PET scan?

A positron emission tomography (PET) scan is not often used in diagnosing central nervous system (CNS) tumors. However, it can provide information about the aggressiveness of the disease and help to distinguish between scar tissue and a recurring tumor.

A PET scan provides a picture of the brain’s metabolic activity, rather than its structure, by measuring the rate at which a tumor absorbs glucose (sugar). Your child will need to skip eating for four to six hours before a radioactive glucose tracer is injected through a vein. This tracer is needed so the radiologist can track how it is absorbed by the body.

After the injection, you child must wait for about 30 minutes while the tracer circulates throughout the body. Next your child will lie on a table that slides into a large tunnel-shaped scanner, then remain still for up to 30 minutes.

The PET detects signals from the tracer and changes them into 3-D pictures for the doctor to read. The amount of radiation used in a PET scan is about the same as for a CT scan. As is the case for MRI scans, younger children and those who are anxious may need to be under anesthesia.

What’s the difference between a resection and a biopsy?

A tumor resection is a surgical procedure performed to remove a tumor. A tumor biopsy is the removal of a small amount of tumor tissue to be sent to the pathologist for evaluation under a microscope to confirm a diagnosis. A biopsy can be performed as part of the tumor resection or separately.

Biopsies can be either “open” or “closed” depending on the surgical technique used. In a closed biopsy, also known as a needle biopsy, a small hole is drilled into the skull and a tumor tissue sample is removed via a narrow hollow needle. The same procedure performed with a computer-assistance guidance system is called a stereotactic biopsy. A biopsy done during surgery is called an open biopsy. The pathologist’s report will help your child’s medical team devise the best treatment plan.

How long will my child require scans after treatment?

It depends on the tumor type and clinical scenario. Often, routine follow-up MRI scans are performed every three or four months for the first year after treatment is completed. They are usually done less frequently over the next several years unless there is clinical concern about recurrence.
How common are brain tumors in children?

They are very rare. About 4,600 cases of tumors in the central nervous system (CNS), which is the brain and spinal cord, are diagnosed in children and adolescents up to 19 years of age every year in the United States. Most of these cases are in children under 15 years of age. There are over 100 different types of brain tumors. CNS tumors are much more common in older adults. In fact, CNS tumors in childhood represent less than 10 percent of all CNS tumors diagnosed each year.

What could have caused my child's brain tumor?

Nobody knows the cause of most brain tumors, although genetic disorders explain a minority of cases. Exposure to environmental toxins has been suspected, but has not been confirmed by research data. It is important to recognize that nothing you did as a parent led to your child’s diagnosis.

Note the distinction between primary CNS tumors, which start in the brain and/or spine, and secondary CNS tumors that spread from other parts of the body. The information in this booklet focuses on primary CNS tumors.

What’s the difference between a benign and a malignant tumor?

CNS tumors are classified by pathologists as benign (nonmalignant) or malignant based on the appearance of the cells under a microscope. Benign tumors are usually slow growing and do not spread from their original site. In some cases they have well-defined borders that make them easier to remove.

A malignant or cancerous brain tumor is always life threatening and is more challenging to treat. It typically grows rapidly, invading normal tissue. In some cases, cells from a malignant tumor break free from the mass and metastasize, or spread, to other parts of the CNS. (In rare cases, they spread to other parts of the body.)

So a benign brain tumor is not dangerous?

Judging from its name, you would think so. But all CNS tumors (either benign or malignant) can be dangerous. For example, if a benign CNS tumor is located in a vital area of the brain or spinal cord, it can be life threatening because the CNS controls breathing and swallowing, as well as movement, coordination, senses and behavior. Consequently some doctors refer to these tumors as nonmalignant rather than benign. These nonmalignant tumors can grow and become malignant. The specific type of your child’s tumor (for example, medulloblastoma) is much more informative than describing it as benign or malignant.

How do doctors determine the type of tumor and its level of aggressiveness?

Most medical institutions identify tumor type and their grade, or level of aggressiveness, according to the classification system of the World Health Organization. A pathologist will determine type and grade after examining brain tissue under a microscope. Getting a second opinion can be useful, especially if the diagnosis is uncertain, because one pathologist’s assessment may not match another’s. Over time, both the type and grade of the tumor may change. Grades range from I (noncancerous) to IV, the most aggressive.
Does the grade of tumor determine the outcome for my child?

Not entirely. The grade provides information about the aggressiveness of that tumor type but does not indicate whether there are effective treatments. For example, most children with medulloblastoma, a grade IV tumor, survive. Additionally, a child with a grade III tumor who undergoes a gross total resection (GTR), or entire removal of the tumor, may fare better than one with a grade II tumor with a subtotal resection (STR). Age of diagnosis is another prognostic factor for some tumor types.

What is medulloblastoma?

Medulloblastoma is the most common malignant brain tumor in children. Medulloblastomas typically originate in the cerebellum, the lower back part of the brain. They are grade IV tumors that grow quickly and may spread to other parts of the CNS.

Research has identified four subtypes of medulloblastoma. Over time it is hoped that treatment will be tailored for each group to optimize effectiveness. Both radiation therapy and chemotherapy can be helpful to treat medulloblastoma.

What are gliomas?

Gliomas are any type of tumor that comes from cells, called glial cells, that surround and support neurons in the brain.

What are astrocytomas?

Astrocytomas are a type of glioma that arises from star-shaped brain cells called astrocytes and are the most common type of childhood brain tumor, representing about one-third of diagnoses. They include grade I juvenile pilocytic astrocytoma (JPA), grade II fibrillary astrocytoma and grade III anaplastic astrocytoma, as well as glioblastoma, a grade IV tumor that is significantly more common in adults but that also affects some children.

Several other names are used for specific types of grade I to IV astrocytomas. These include optic gliomas, which are generally slow-growing tumors and often found in children with neurofibromatosis type I, an inherited disorder that can cause additional medical complications. Brainstem gliomas can also be malignant or nonmalignant. Low-grade brainstem gliomas can be resected in some cases, but surgery is generally not used to treat diffuse intrinsic pontine gliomas (DIPG), an aggressive grade IV tumor that spreads widely throughout the brainstem.

What is ependymoma?

An ependymoma is a type of glioma and the third most common type of childhood brain tumor. It usually develops from the cells lining the hollow cavities of the brain (more common in pediatric cases), or the canal that contains the spinal cord (more common in adults).

Most children have grade II or grade III variants occurring in the brain. Grade III ependymoma, also known as anaplastic ependymoma, grows more rapidly and is more likely to spread to other parts of the brain and spine.
What are some other types of brain and spinal cord tumors?
Tumors can develop when cells in the embryo that migrate to the developing gonads mistakenly travel to the brain. These tumors are called CNS germ cell tumors and include choriocarcinoma, embryonal carcinoma, germinoma, mixed germ cell tumors, teratoma and yolk sac tumors. They can be nonmalignant or malignant.

Other types of tumors include choroid plexus papilloma, craniopharyngioma, vestibular schwannoma, mixed neuronal-glial tumors (including gangliogliomas), meningioma and pituitary adenoma. These tumors are generally nonmalignant. However, some can be malignant or may become malignant over time.

What’s the difference between a brain tumor recurrence and secondary cancer?
Recurrence means that your child’s original tumor has returned. This can occur weeks, months or up to five years following the original diagnosis. In rare cases it can happen much later.

Secondary cancers are new cancers caused by treatment and usually develop at least five years after treatment of the original tumor. This is much less common than recurrence of the original tumor. For example, chemotherapy can cause the blood cancer acute myelogenous leukemia (AML) around five to nine years after treatment.

In addition, children who have undergone radiation are at risk for secondary brain tumors, which can be malignant or nonmalignant. These tumors usually occur at least 10 years after radiation. It’s important to recognize that the danger of developing a secondary cancer, while not insignificant, is small compared to the danger of not undergoing treatment.

Treatment Overview

Can a child with a brain tumor be cured?
Yes, there are absolutely children who have been “cured,” meaning they have remained tumor-free for many years, but the probability of this depends on the type and grade of brain tumor. However, even children with some types of aggressive brain tumors have been cured. Depending on the area of the brain that has been affected and the type of treatment they’ve needed, some children go on to function very well both at school and in their social lives. Also encouraging are recent developments in our understanding of the biology of brain tumors. Doctors hope these will lead to more effective treatments.

What’s the first thing I should do to help my child?
You need to find out if the medical center where your child is diagnosed is an appropriate place for his or her treatment. The care of children with brain tumors is complex and requires input from multiple types of specialists (including neurosurgeons, oncologists, radiation oncologists, endocrinologists and many others). It’s important to confirm that
your medical center and doctor have this expertise and are comfortable treating children with brain tumors. Do not hesitate to ask how many pediatric brain tumor patients they treat each year. Find out how this figure stacks up against other facilities and doctors. Generally speaking, those that have the highest volume of childhood brain tumor patients also have greater knowledge of the disease, treatment options and clinical trials.

Some families travel to different cities or even out of state for surgery, radiation and follow-up care. Other children are treated at centers close to home. Parents can obtain second opinions by having their child's charts and imaging couriered to hospitals recognized as having nationally acclaimed pediatric brain tumor centers.

What are the treatments used for pediatric brain tumors?

The treatments used for pediatric brain tumors include surgery, chemotherapy and radiation therapy (traditional and proton beam). Different tumor types respond differently to these treatments, so the specific plan for your child's tumor depends on the specific diagnosis. Although some types of tumors, such as CNS germ cell tumors, can be cured without surgery, the priority is usually to surgically remove as much of the tumor as safely possible.

If the tumor is located in a position where surgery is not feasible, other treatments will be explored. Surgery may be ruled out in favor of other systemic therapies (chemotherapy or radiation therapy) if the tumor has metastasized (spread) throughout the brain and spine. In cases like these, getting a second opinion may be particularly helpful.

Our doctor said she has sought additional opinions. Should I get a second opinion anyway?

Doctors routinely consult with their colleagues at their own hospital as well as other medical centers when it comes to challenging cases, so many second and third opinions are provided without the patient’s family being aware of them. However, families might not be included in these exchanges, and many parents prefer for that information to be given to them directly.

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

Do I need to tell the doctor about dietary supplements that I want to give my child to try to help treat the tumor?

It’s very important that you tell the doctor about alternative medicines you would like your child to take. While doctors are generally quite sensitive to parents’ desires to help their child get better, some alternative medicines may pose serious side effects that can delay standard treatments, giving the tumor more time to grow. Keep in mind that supplements marketed as a cure have not been proven safe and effective in clinical trials.

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Are vitamins off limits?
While most doctors are fine with a daily multivitamin, there is concern about taking vitamins A, E and C, as well as other antioxidants (nutrients that protect and repair cells from damage) like selenium and co-enzyme Q10.

Although there’s evidence that having sufficient antioxidants might reduce the risk of getting some cancers, this may also make cancer treatment less effective. That’s because antioxidants prevent the formation of ions, electrically charged particles that damage the DNA in cells. When those cells are cancerous, damage to the DNA is the goal of radiation and chemotherapy, so taking antioxidants may weaken the effects of treatment. Ask your doctor when it might be safe to start vitamins or other supplements.

Are doctors open to the use of complementary medicine for treating my child’s pain and stress?
Most doctors recognize that complementary medicine such as massage, guided imagery and biofeedback can be useful during your child’s treatment and recovery. In fact, many leading cancer hospitals have centers for integrative medicine with practitioners in specialties like yoga, nutrition and acupuncture. When working with any complementary or alternative health practitioner, make sure there is open communication with your child’s doctors.

How can I help my child deal with the stress and depression associated with treatment?
Your hospital’s social worker and child life specialist (not all hospitals have them) can assess your child’s well-being in a casual, friendly manner and offer age-appropriate support throughout treatment. They can also advise you on how to talk to your child and any siblings about the cancer diagnosis, its treatment and other health-related concerns.

What happens if my child’s brain tumor recurs or the existing tumor grows larger?
For recurrent tumors, your child’s medical team will decide if surgical removal is feasible and whether it offers benefit to the child. Stereotactic radiosurgery, in which a large, precise dose of radiation is delivered in a single session or a few sessions, might be an alternative if the recurrent tumor is small. Note that despite the name, this is not surgery as we understand it, because no incision is made.

High-dose chemotherapy with autologous stem cell rescue can be used for some patients with recurrent brain tumors. This involves collecting a patient’s own healthy stem cells before chemotherapy and infusing them back into the patient after treatment to stimulate bone marrow growth; this allows for higher doses of chemotherapy to be given. It is also used for some children with high-risk tumors at the time of diagnosis.

For recurrent or refractory tumors, ones that do not respond to treatment, additional radiation therapy may be a possibility, depending on the details of the previous treatment, including how much time has elapsed since it was given.

Your oncologist may also consider targeted therapies or immunotherapy (treatments that stimulate the body’s immune response). These treatments differ from standard chemotherapy and are usually easier to tolerate. Both therapies are being tested for safety and effectiveness in clinical trials.
Surgery

**Is surgery always performed for children with brain tumors?**

Not always. Brain tumors can be located in areas that make them dangerous or even impossible to remove safely (if they involve critical brain structures). When a tumor cannot be safely resected and can be clearly diagnosed by imaging alone, a biopsy may offer no advantage in your child's treatment plan, depending on the type of tumor.

Some medical centers are starting to biopsy unresectable tumors more frequently to get a better understanding of their biologic makeup and obtain hints about potential treatments. In some cases, these types of biopsies may be required to allow your child to participate in a clinical trial in which the safety and effectiveness of a new drug is studied. Tumor tissue is not always required for enrollment in clinical trials, however.

**What's the difference between a GTR, NTR and STR in surgery?**

A gross total resection (GTR) means that there are no visible residual tumor cells under the operating microscope or on the postoperative MRI. A near total resection (NTR) means there is less than 10 percent of residual tumor; subtotal resection (STR) means between 10 to 50 percent remains.

A partial resection means that half or less of the tumor was removed. Keep in mind that even partial resections can have significant effects on relieving pain and other symptoms. For some tumor types, they can be associated with improved survival.

**What are the risks of surgery?**

These vary greatly according to the location and size of the tumor. Your neurosurgeon can best advise you on the specific potential risks based on the characteristics of your child’s tumor.

One of the biggest concerns is loss of specific brain functions related to the site being operated on, which is why neurosurgeons are extremely careful about how much tissue to remove. Some children may require speech, occupational and physical therapies after surgery. About one-third of children who have surgery in the posterior fossa — an area at the back and bottom of the brain — experience symptoms of posterior fossa syndrome, which includes a temporary loss of the ability to speak, poor coordination and difficulty swallowing.

Your child may need a surgically implanted shunt to treat hydrocephalus, a buildup of cerebrospinal fluid (CSF) in the brain, and medication to help prevent seizures. Both of these complications may arise from the tumor or surgery. Postsurgical brain swelling is a risk that can be reduced with corticosteroids, a different type of steroid than those that are used to build up muscle. Leakage of CSF is another complication that might indicate infection caused by a tear in the dura, the tissue surrounding the brain and spinal cord.

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What’s the risk of recurrence when the entire tumor has been removed?
This depends on the grade and type of tumor. It’s important to remember that tumors can recur without any symptoms. If a recurrent tumor is identified early, better treatment options may be open to your child.

Will my child’s tumor tissue be ‘banked’ after surgery?
Before your child’s surgery you will likely be asked to sign a consent form offering permission for the tumor tissue to be used for research and/or stored in a tissue bank. Clinical characteristics of the tissue will be logged into a database, but your child’s identity will be protected. This information will help researchers understand more about brain tumors in order to develop better treatments. This process does not interfere with the pathologist’s work in determining the tumor type and grade. With your consent, the tumor tissue is only used for research after all necessary clinical testing has been done.

Radiation

How effective is radiation if the tumor cannot be removed by surgery?
Radiation therapy (RT) uses high-energy X-rays directed at the tumor and the area surrounding it. It works by damaging the DNA of cancer cells (but will damage healthy cells in that area, too). Radiation alone can be effective in curing some cases of cancers, including germinomas (a type of CNS germ cell tumor). It can also be used to destroy the part of the tumor that the neurosurgeon could not remove and prevent recurrences. It can also successfully shrink those tumors that are not resectable.

Our neurosurgeon said that he removed the entire tumor. Why would radiation be recommended?
Depending on the tumor type and grade, radiation may be recommended even if total tumor removal has been achieved. That’s because not every cancer cell can be seen on an MRI scan and therefore some may be left behind. Treating with radiation or chemotherapy in this situation can improve outcomes for children with some tumor types.

Questions and concerns about the use of radiation therapy for your child can be directed to your child’s radiation oncologist and medical oncologist. If you’re hesitant about radiation for your child, which can be a difficult decision, seek a second opinion.

Is proton radiation better than photon radiation?
Techniques such as intensity-modulated radiation therapy (IMRT) and three-dimensional conformal radiotherapy (3DCRT) are commonly used at hospitals with renowned brain tumor centers. The goal of both of these types of photon radiation is to deliver high-energy X-rays to the tumor or resected tumor area, and to minimize damage to the surrounding healthy tissues.

Proton beam therapy is also a form of external beam radiotherapy. However, a proton beam delivers most of its energy at exact depths directly in the tumor, whereas standard X-ray radiation releases radiation from the moment it penetrates the body on its way to the tumor.
and as it exits. It is thought that proton radiation results in less damage to healthy brain tissue. It is being studied to determine if, in practice, it improves outcomes or reduces treatment side effects. There are only a few proton beam centers in the United States at this time.

**What happens during radiation?**

In children, radiation is usually delivered to the tumor from outside of the body (as opposed to brachytherapy, when radioactive material is implanted into or near the tumor). Before treatment, your child will undergo simulation in which the targeted treatment field is defined and the angles for aiming the beams are determined. A mask will be made that will enable your child to stay still during treatments.

Usually the total dose of radiation is divided into daily fractions given over a course of several weeks, with larger amounts directed at the tumor than at the surrounding areas. Radiation is typically an outpatient procedure, with each session lasting about 20 minutes. Although RT is much quicker than an MRI, very young children may require anesthesia to remain sufficiently still for their treatments.

**Is radiation painful?**

Treatment is not painful, but it can cause skin irritation. Nausea and vomiting are uncommon but are more likely in children undergoing spinal radiation. Fatigue and appetite loss may occur but are usually mild. In children undergoing craniospinal radiation (full brain and spine), symptoms can be more severe.

Some children become drowsy a few weeks after radiation is completed. This is called radiation somnolence syndrome and usually resolves after a few weeks.

**Will radiation make my child's hair fall out?**

Your child will only lose hair in the area of the head that has been treated. Children undergoing craniospinal radiation receive treatment to their full brain and spine, so they will lose all of their hair. Hair usually starts to regrow a few weeks after treatment completion, but may be sparse or not grow back at all in some spots.

**Chemotherapy**

**Is chemotherapy harsher than radiation?**

Generally, more side effects are seen with chemotherapy than radiation therapy during the period of cancer treatment. Researchers are developing a new class of chemotherapy called targeted therapies. This type of treatment acts more precisely on cancer cells by focusing on the molecular and cellular changes related to malignancy, and is significantly easier to tolerate than standard chemotherapy. However, its effectiveness for pediatric brain tumors has not yet been determined.

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Most types of chemotherapy work by attacking the fast-growing cancer cells in the body. This includes those in the hair roots — leading to hair loss or thinning — and healthy blood cells. A drop in red blood cells (anemia), platelets (thrombocytopenia) and a type of white cells called neutrophils (neutropenia) can occur and may need to be treated with blood transfusions and medications that stimulate the bone marrow.

Neutropenia is a serious side effect because it puts your child at risk for infections that will require urgent treatment. The good news is that blood cell counts frequently return to normal soon after treatment, which may last for a few months or more than a year, typically in cycles with rest periods in between.

Nausea, mouth sores, diarrhea and appetite loss are common side effects that can be prevented or eased with drugs. Hearing loss and kidney damage are more serious issues that need to be diagnosed promptly with regular screening.

**Does my child need to be hospitalized for chemotherapy?**

It depends on the type of treatment. For standard chemotherapy involving multiple potent medications, your child will be hospitalized for a few days at the start of each cycle, so any side effects or complications can be carefully monitored. Other types of chemotherapy can be taken in a hospital clinic or even at home. Chemotherapy can be delivered intravenously, via a subcutaneous or intramuscular injection, or by mouth in pill or liquid form.

**My child is terrified of needles. How are we going to get through chemotherapy?**

Numbing cream (Lidocaine) can be applied before blood draws and injections. Chemotherapy drugs are usually delivered by a catheter, equivalent to a long term intravenous (IV) infusion. Those commonly used include a PICC line (peripherally inserted central catheter), which is a long plastic catheter placed into one of the veins of the arms.

Central venous catheters such as port-a-cath and tunneled catheter (known by their brand names: Broviac, Groshong and Hickman) are placed under the skin on the chest.

All types of catheters have advantages and disadvantages in terms of maintenance, insertion and removal. These catheters are removed after they are no longer needed for chemotherapy or other IV medications.

**Why is my doctor concerned about the weight my child has lost since starting chemotherapy?**

It’s not unusual for children on treatment to lose weight, especially during chemotherapy when nausea can be persistent and food may taste different. But during chemotherapy your child needs calories not only for healing and to increase stamina, but to create the new cells needed to help the immune system fight infection.

Your hospital’s registered dietician can advise you on ways to supplement your child’s nutrition and prevent weight loss. Adding ice cream or calorie-rich smoothies might do the trick, but some children may be disgusted by foods they once craved.

Prescription drugs can sometimes be effective in stimulating appetite, but may come with undesirable side effects. In some cases a nasogastric tube, which carries food and medicine to the stomach through the nose, can be the best way to deliver the nutrients children need to see them through treatment.
Conversely, corticosteroids, like prednisone and dexamethasone (Decadron), which are prescribed to treat brain swelling, can cause rapid appetite increase and weight gain.

**Why isn’t my child allowed to take ibuprofen (Advil, Motrin) or acetaminophen (Tylenol) while on chemotherapy?**

When your child’s white blood count is low during chemotherapy (neutropenia), he or she will be susceptible to severe infections. When an immune system is compromised, these infections usually require intravenous antibiotics that need to be started urgently. Fever may be the first indication that your child is developing an infection, so it’s critical that it isn’t masked by pain medications that also reduce fevers.

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**Late Effects of Treatment**

**Will treatment lower my child’s IQ?**

It’s virtually impossible to treat a brain tumor without affecting healthy parts of the brain. While surgery and chemotherapy can affect a child’s cognitive ability, radiation is the treatment that causes the most concern. The amount and location of radiation and the child’s age at the time of treatment (children under 3 being most vulnerable) influence the impact of radiation on your child’s thought processing, attention span, short-term memory and impulsivity.

While effects from surgery can improve over time, those related to radiation may not become fully apparent until years later. But not every child will experience learning problems, and most children don’t lose skills that were mastered before treatment. Neuropsychological testing can identify areas where children may need specialized help to reach their potential.

**Will radiation change my child’s personality?**

Some families have reported behavioral changes following radiation treatment. These may include compulsive tendencies, lowered inhibitions, social withdrawal and poor control of anger and frustration. This is not universal. Other reports indicate that brain tumor survivors have better coping mechanisms and a greater appreciation of life than their peers.

**Can treatment affect my child’s height and reproductive system?**

Radiation to the brain and spine can slow or stunt growth, but human growth hormone may be given if your child is no longer on treatment and MRIs show tumor stability. Chemotherapy and radiation may cause hormone problems, including preventing your child from going through puberty, but this can be treated with hormone replacement. Treatment can also cause precocious puberty (early puberty), which can be postponed with hormones.

Chemotherapy and radiation can have a profound effect on fertility in both girls and boys. Sperm and egg freezing are options for some patients.