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EASY READING

If Your Child Has a Brain or Spinal Cord Tumor

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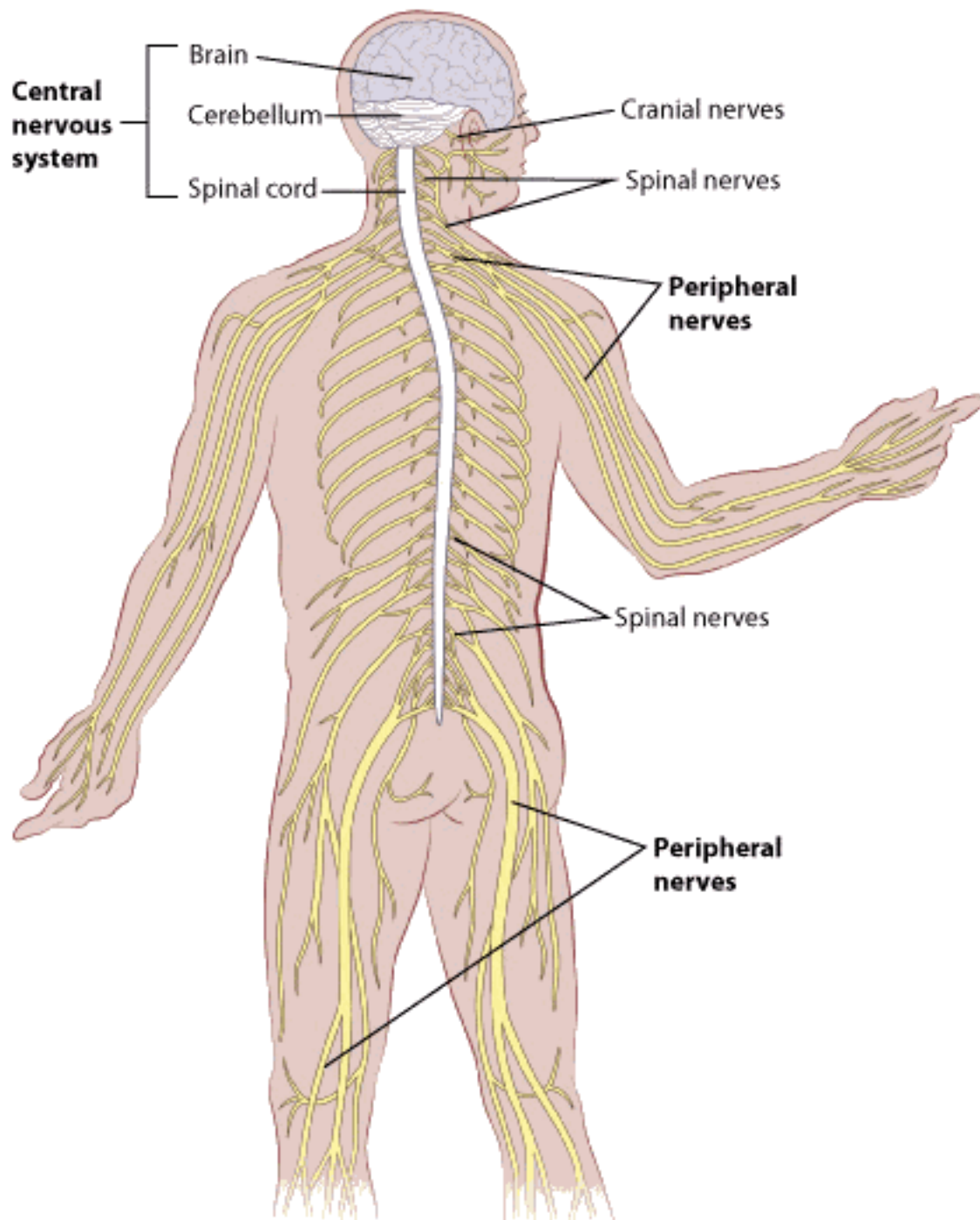
What are brain and spinal cord tumors?

Brain and spinal cord tumors are masses of changed cells in the brain or spinal cord that have grown out of control. They may or may not be [cancer](#)¹. If the tumor is not cancer it may be called benign. But even benign tumors in the brain or spinal cord can be harmful.

If not treated, tumors in the brain or spinal cord can press on or spread into normal tissue as they grow. This can make it hard for the brain and spinal cord to work the way they should to control the rest of the body.

The main concerns with brain and spinal cord tumors are:

- How fast they will grow
- How quickly they spread to nearby parts of the brain or spinal cord
- Whether they can be taken out and not come back



The brain and spinal cord

The brain and spinal cord together are called the *central nervous system* or *CNS*. They

serve as the main “processing center” for all of the nervous system.

The brain and spinal cord are surrounded and protected by a special liquid, called *CSF* or *cerebrospinal fluid*. The brain is also protected by the skull. The spinal cord is protected by the stack of spinal bones called *vertebrae*.

Different parts of the brain control different things, like the way we see, move, or think. The spinal cord connects to nerves all over the body to carry messages back and forth between the brain and the body.

Are there different kinds of brain and spinal cord tumors in children?

There are many [kinds of brain and spinal cord tumors](#)². Some types are more common in children than in adults. Some types of tumors tend to start in certain parts of the brain or spinal cord. Some are more likely to grow and spread than others.

Your doctor can tell you more about the kind your child has. Here are some of the more common types and how to say them:

- Astrocytoma (AS-troh-sy-**TOE**-muh)
- Glioblastoma (GLEE-o-blast-**O**-muh)
- Brain stem glioma (glee-**O**-muh)
- Ependymoma (ih-PEN-dih-**MO**-muh)
- Oligodendroglioma (AHL-ih-go-DEN-dro-glee-**O**-muh)
- Medulloblastoma (**MED**-yew-lo-blas-**TOE**-muh)
- Meningioma (muh-NIN-jee-**O**-muh)
- Craniopharyngioma (CRAY-nee-0-fuh-RIN-jee-**O**-muh)
- Ganglioglioma (GANG-lee-o-glee-**O**-muh)
- Schwannoma (shwah-**NO**-muh), also called neurilemmoma (NOR-uh-leh-**MO**-muh)

Questions to ask the doctor

- How sure are you that my child has a brain or spinal cord tumor?
- Is there a chance he/she doesn't have one?
- Would you please write down the kind of tumor you think my child has?
- What will happen next?

How does the doctor know my child has a brain or spinal cord tumor?

Some [symptoms of brain and spinal cord tumors](#)³ may start slowly and get worse over time. Sometimes they happen very fast. Symptoms might include:

- Headaches
- Seizures
- Vision problems
- Feeling sick to your stomach
- Changes in the way your child feels or acts.

Other symptoms can happen, too, based on where the tumor is. The doctor will ask questions about your child's health and do a physical exam.

The doctor may send your child to a pediatric neurologist or a pediatric neurosurgeon. These are doctors who treat problems in a child's nervous system.

Tests that may be done

If signs are pointing to a brain or spinal cord tumor, [tests](#)⁴ will be done. Here are some of the tests your child may need:

MRI scan: This test uses radio waves and strong magnets to make detailed pictures of the inside of the body. MRI is the best way to look for tumors in the brain and spinal cord. Different kinds of MRIs may be used to look at blood vessels, blood flow, and activity in the brain.

CT or CAT scan: This test uses x-rays to make detailed pictures of the inside of the body. It can be helpful for looking at the bones around the tumor.

MR or CT angiography: These are special types of MRI or CT scans that look at the blood vessels inside the brain and around a tumor, which can help plan surgery.

PET scan: For a PET scan, a kind of sugar is put in your child's blood. The sugar can be seen inside your child's body with a special camera. If there is a tumor, this sugar shows up as a "hot spot" where the tumor is found.

Biopsy: In a biopsy, the doctor takes out a small piece of an abnormal area to see if it's a tumor. A biopsy is often the only way to tell exactly what kind of tumor it is.

Questions to ask the doctor

- What tests will my child need?
- Who will do these tests?
- Where will they be done?
- Who can explain them to us?
- How and when will we get the results?
- Who will explain the results to us?
- What do we need to do next?

How serious is my child's tumor?

For many types of cancer, the stage (extent) of the cancer is used to decide what type of treatment is best and how likely it is that a person will get better. But brain and spinal cord tumors are not staged like most cancers.

Some of the things that doctors use to decide on treatment and a child's chances of getting better are:

- The type of tumor
- The grade of the tumor (how quickly it's likely to grow, based on how the tumor cells look)
- The size of the tumor
- Where the tumor is
- How much of the tumor can be taken out with surgery (if it can be done)
- The child's age
- Whether the tumor is affecting normal brain functions

Questions to ask the doctor

- Where is the tumor?
- What type of tumor is it?
- How fast is the tumor likely to grow?
- How big is the tumor?
- Can the tumor be removed or destroyed?
- Has the tumor spread to other parts of the brain and spinal cord?
- What are the chances of curing the tumor?

- What will happen next?

What kind of treatment will my child need?

Treatment for brain and spinal cord tumors depends on things like the type of tumor and where it is.

Surgery

[Surgery](#)⁵ is the first treatment for most kids. Surgery may be used to:

- Get a biopsy sample
- Take out or destroy the tumor
- Make the tumor smaller so it can be better treated with radiation or chemo
- Help prevent or treat problems from the tumor (like putting in a tube to drain fluid from around the brain)

There are many kinds of surgery. The type used depends on where the tumor is and how big it is.

Ask your doctor what type of surgery your child will need and what to expect.

Side effects of surgery

Any type of surgery can have risks and side effects. Ask the doctor what you can expect. If your child has problems, let the doctors know. Doctors who treat children with brain and spinal cord tumors should be able to help with any problems that come up.

Radiation treatments

[Radiation](#)⁶ uses high-energy rays (like x-rays) to kill cancer cells. It may be used:

- After surgery to kill any tumor cells left behind
- As the main treatment if surgery can't be done
- To help ease or prevent problems from the tumor

Radiation is not often used in children younger than 3 years because it might cause long-term problems with the way the brain grows.

There are different ways to give radiation treatments.

- Radiation can be aimed at the tumor from a machine outside the body. This is called **external beam radiation**. The radiation may be given all at once or in smaller doses given over a few days or weeks. Each treatment is a lot like getting an x-ray. The radiation is stronger, but your child will not feel it.
- Less often, radiation can be given by putting tiny seeds of radiation into or near the tumor. This is called **brachytherapy**.

Side effects of radiation treatments

Radiation might cause some children to feel tired, or feel sick and throw up. If it is given to large parts of the brain, it might also affect thinking and learning. This can be a bigger problem in very young children.

Most side effects get better after treatment ends. Some might last longer. Talk to your child's cancer care team about what to expect during and after treatment. There may be ways to ease side effects.

Chemo

[Chemotherapy](#)⁷, or just chemo, is the use of drugs to fight cancer. The drugs are often given through a needle into a vein or taken as a pill. These drugs go into the blood and spread through the body.

Chemo can also be put right into the CSF during surgery. Ask the treatment team how your child will get chemo.

Chemo is most helpful for fast growing tumors.

Chemo is often given in cycles or rounds. Each round of treatment is followed by a break. Sometimes more than one chemo drug might be given. Treatment often lasts for many months.

Side effects of chemo

Chemo can make your child feel very tired, sick to their stomach, or cause their hair to fall out. It might also cause other problems. But these tend to go away after treatment ends.

There are ways to treat most chemo side effects. If your child has side effects, talk to the cancer care team so they can help.

Targeted drugs

[Targeted drugs](#)⁸ are made to work mostly on the changes in cells that make them cancer. These drugs affect mainly tumor cells and not normal cells in the body. They may be used to treat certain types of brain and spinal cord tumors.

Side effects of targeted drugs

Side effects depend on which drug is used, but they tend to go away after treatment ends.

There are ways to treat most of the side effects caused by targeted drugs. If your child has side effects, talk to the cancer care team so they can help.

Drugs to help with symptoms

Some drugs don't treat the tumor itself, but they can [help with symptoms](#)⁹ from the tumor. For example:

- **Steroid drugs** can be given for short periods of time to help reduce swelling around brain tumors.
- **Anti-seizure drugs** can be given to help lower the risk of seizures.
- **Hormone drugs** might be needed if the pituitary is damaged by the tumor or its treatment.

Each of these types of drugs might have different types of side effects. Talk to your child's care team about what to expect.

Clinical trials

Clinical trials are research studies that test new drugs or other treatments in people. They compare standard treatments with others that may be better. Clinical trials are one way to get the newest treatments. They are the best way for doctors to find better ways to treat tumors. But they might not be right for everyone. If your child's doctor can find one that's studying the kind of tumor your child has, it's up to you whether to take part.

If you would like to learn more about clinical trials that might be right for your child, start

by asking the doctor if your child's clinic or hospital conducts clinical trials. See [Clinical Trials](#)¹⁰ to learn more.

What about other treatments that I hear about?

When your child has a tumor, you might hear about [other ways](#)¹¹ to treat it or treat symptoms from it. These may not always be standard medical treatments. These treatments may be vitamins, herbs, diets, and other things. You may wonder about these treatments.

Some of these are known to help, but many have not been tested. Some have been shown not to help. A few have even been found to be harmful. Talk to your child's doctor about anything you're thinking about using, whether it's a vitamin, a diet, or anything else.

Questions to ask the doctor

- What treatment do you think is best for my child?
- What's the goal of this treatment? Do you think it could cure the tumor?
- Will treatment include surgery? If so, who will do the surgery?
- What will the surgery be like?
- Will my child need other types of treatment, too?
- What will these treatments be like?
- What's the goal of these treatments?
- What side effects could my child have from these treatments?
- What can we do about side effects that my child might have?
- Is there a clinical trial that might be right for my child?
- What about vitamins or diets that friends tell me about? How will we know if they are safe?
- How soon does my child need to start treatment?
- What should we do to be ready for treatment?
- Is there anything we can do to help the treatment work better?
- What's the next step?

What will happen after treatment?

You'll be glad [when treatment is over](#)¹². But it's hard not to worry about the tumor coming back. Even if it never comes back, you might still worry about it. For years after

treatment ends, your child will still need to see their doctor. At first, visits may be every few weeks or months. Then, the longer your child is tumor-free, the less often the visits are needed.

Be sure to take your child to all of these follow-up visits. The doctors will ask about symptoms, do physical exams, and may do tests to see if the tumor has come back. They may also test your child to see if the tumor or its treatment has caused any long-term problems. If needed, they will help you and your child learn to deal with the changes.

Hyperlinks

1. www.cancer.org/cancer/cancer-basics/what-is-cancer.html
2. www.cancer.org/cancer/brain-spinal-cord-tumors-children/about/types-of-brain-and-spinal-tumors.html
3. www.cancer.org/cancer/brain-spinal-cord-tumors-children/detection-diagnosis-staging/signs-and-symptoms.html
4. www.cancer.org/cancer/brain-spinal-cord-tumors-children/detection-diagnosis-staging/how-diagnosed.html
5. www.cancer.org/cancer/brain-spinal-cord-tumors-children/treating/surgery.html
6. www.cancer.org/cancer/brain-spinal-cord-tumors-children/treating/radiation-therapy.html
7. www.cancer.org/cancer/brain-spinal-cord-tumors-children/treating/chemotherapy.html
8. www.cancer.org/cancer/brain-spinal-cord-tumors-children/treating/targeted-therapy.html
9. www.cancer.org/cancer/brain-spinal-cord-tumors-children/treating/other-drug-treatments.html
10. www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html
11. www.cancer.org/treatment/treatments-and-side-effects/complementary-and-alternative-medicine.html
12. www.cancer.org/cancer/brain-spinal-cord-tumors-children/after-treatment/follow-up.html
13. <http://www.cancer.org>

Words to know

Biopsy (BY-op-see): Taking out a small piece of tissue to see if there are cancer cells

in it.

Central nervous system: The brain and the spinal cord, which serve as the main “processing center” for all of the nervous system. Often called the CNS.

Cerebrospinal fluid (suh-**REE**-bro-SPY-nuhl FLEW-id): The clear liquid that surrounds and cushions the brain and spinal cord. Often called CSF.

Neurologist (nur-AHL-uh-jist): A doctor who specializes in treating nervous system problems or diseases.

Neurosurgeon(**NUR**-o-SUR-jun): A doctor who specializes in using surgery to treat nervous system problems or diseases.

Neuroradiologist (NUR-o-ray-dee-**AHL**-uh-jist: A doctor who specializes in using imaging tests to look at the nervous system.

Ommaya reservoir (o-MY-uh REZ-er-vwahr): A plastic, dome-shaped drum that’s put just under the scalp during surgery. A tube attached to it goes into the brain where it reaches the CSF. Doctors and nurses can use a thin needle to give chemo through the drum or to take out CSF for testing.

VP shunt: Also called a ventriculoperitoneal (ven-TRIK-yew-lo-pair-ih-tuh-**NEE**-ahl) shunt. A thin tube used to drain extra CSF to ease pressure in the brain. Surgery is done to put one end of the shunt in the brain and the other end in the abdomen (belly). The tube runs under the skin of the neck and chest. The flow of CSF is controlled by a valve in the tubing. Shunts may be short-term or permanent.

How can I learn more?

We have a lot more information for you. You can find it online at www.cancer.org (<http://www.cancer.org>)¹³. Or, you can call our toll-free number at 1-800-227-2345 to talk to one of our cancer information specialists.

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