If You're an Adult with a Brain or Spinal Cord Tumor

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What are adult brain and spinal cord tumors?

Brain and spinal cord tumors are masses of cells in the brain or spinal cord that have changed and grown out of control.

Tumors in the brain or spinal cord can press on or spread into nearby normal tissue as they grow. This can make it hard for the brain and spinal cord to work the way they should to control functions in the rest of the body.

The main concerns with brain and spinal cord tumors are how fast they will grow and whether they can be taken out (or destroyed) and not come back.

Some types of brain and spinal cord tumors grow faster and are more likely to spread into nearby parts of the brain or spinal cord than are others. Slow-growing tumors are sometimes called benign. But even benign brain or spinal cord tumors can sometimes cause serious problems.
Many other types of cancer, such as lung cancer or breast cancer, can spread (metastasize) to the brain from another part of the body. These are not the kind of tumors we talk about here. We are talking about tumors that start in cells in the brain or spinal cord. These tumors rarely spread to other parts of the body.
The brain and spinal cord

The brain and spinal cord are called the central nervous system (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 cerebrospinal fluid (CSF). 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, feel, or think. The spinal cord connects the brain to nerves all over the body to carry messages back and forth.

**Are there different kinds of brain and spinal cord tumors?**

There are many kinds of brain and spinal cord tumors. Your doctor can tell you more about the kind you have. Here are some of the more common types and how to say them:

- Glioblastoma (GLEE-o-blast-O-muh)
- Astrocytoma (AS-troh-sy-TOE-muh)
- Oligodendroglioma (AHL-ih-go-DEN-dro-glee-O-muh)
- Ependymoma (eh-PEN-dih-MO-muh)
- Meningioma (meh-NIN-jee-O-muh)
- Medulloblastoma (MED-yew-lo-blas-TOE-muh)
- Schwannoma (shwah-NO-muh)
- Craniopharyngioma (KRAY-nee-o-fuh-RIN-jee-O-muh)

**Questions to ask the doctor**

- Why do you think I have a brain or spinal cord tumor?
- Is there a chance I don’t have one?
- Would you please write down the kind of tumor you think I might have?
- What will happen next?

**How does the doctor know I have a brain or spinal cord tumor?**

The symptoms of brain and spinal cord tumors depend mainly on where the tumor is. Some symptoms may start slowly and get worse over time. Sometimes they happen very fast. Common symptoms are headaches and seizures. Others are blurry vision, feeling sick to your stomach, and changes in the way you feel or act. Of course, these symptoms can have other causes as well.
The doctor will ask you questions about your health and do a physical exam.

If your doctor thinks you might have a tumor, they may send you to a **neurologist** or a **neurosurgeon**. These are doctors who treat problems in the nervous system.

**Tests that you might have**

If signs are pointing to a brain or spinal cord tumor, tests will be done to find out. Here are some of the tests you 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 (CAT) scan**: This test uses x-rays to make detailed pictures of the inside of your body. It can be helpful for looking at the bones around the tumor.

- **MR or CT angiography**: These tests use special types of MRI or CT scans to look at the blood vessels inside the brain and around a tumor.

- **PET scan**: For a PET scan, a kind of dye that has sugar is put into your blood. The sugar can be seen inside your 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 small pieces of brain or spinal cord tissue to check for tumor cells. This can be done during surgery or with a special hollow needle. A biopsy is often the only way to tell exactly what kind of tumor it is. If tumor cells are found, special lab tests might be done on them to learn more about them.

**Questions to ask the doctor**

- What tests will I need?
- Who will do these tests?
- Where will they be done?
- How and when will I get the results?
- Who will explain the results to me?
- What do I need to do next?
How serious is my 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 a person is to 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 person’s chances of getting better are:

- The person’s age
- Whether the tumor is affecting normal brain functions
- The type of tumor
- The grade of the tumor (how quickly it’s likely to grow, based on how the cells look)
- If the tumor cells have certain gene (DNA) changes
- 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)
- Whether the tumor has spread to other parts of the brain or spinal cord

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 all of the tumor be removed?
- Has the tumor spread to other parts of my brain and spinal cord?
- What will happen next?

What kind of treatment will I need?

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

Surgery

Surgery is the first treatment for most people. Surgery may be used to:
- Get a biopsy sample
- Take out 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. Radiation may be used with surgery to try to cure the tumor or help keep it from growing.

Ask your doctor what type of surgery you will need. Every type has pros and cons.

**Side effects of surgery**

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

**Radiation treatments**

Radiation 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

There are different ways to give radiation treatments.

Radiation is usually 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.

Radiation can also be given by putting tiny seeds of radiation into or near the tumor. This is called brachytherapy. This kind of radiation is most often given along with external beam radiation.

**Side effects of radiation treatments**

If your doctor suggests radiation treatment, talk about what side effects might happen.
Radiation might cause some people to feel tired, or feel sick and throw up. If large parts of the brain are treated, radiation can change how the brain works.

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

**Chemo**

*Chemo*⁶ is the short word for chemotherapy, 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 or right into the brain during surgery. Ask your doctor how you will get chemo.

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 might make you feel very tired, sick to your stomach, and cause your hair to fall out. But these problems go away after treatment ends.

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

**Targeted drugs**

*Targeted drugs*⁷ 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 work even if other treatment doesn't. They may be given alone or along with chemo to treat certain types of brain and spinal cord tumors.

**Side effects of targeted drugs**

Side effects depend on which drug is used. These effects usually go away after treatment ends.

There are ways to treat most of the side effects caused by targeted drugs. If you have
side effects\textsuperscript{8}, talk to your cancer care team so they can help.

Other drugs

Some other drugs\textsuperscript{9} don't treat tumors directly, but they can still be helpful. For example:

- **Steroid drugs** can help reduce swelling in the brain.
- **Anti-seizure drugs** can help lower the risk of seizures.
- **Hormones** might be needed if the tumor or its treatment damages the pituitary gland, which sits just under the brain.

Electric field therapy

For some types of brain tumors, sets of electrodes\textsuperscript{10} can be placed on the scalp for most of the day. They make mild electric currents that seem to slow the growth of some tumor cells. They can be used along with or instead of chemo. Side effects tend to be mild.

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.

If you would like to learn more about clinical trials that might be right for you, start by asking your doctor if your clinic or hospital conducts clinical trials. See Clinical Trials\textsuperscript{11} to learn more.

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 doctor can find a clinical trial that's studying the kind of tumor you have, it's up to you whether to take part. And if you do sign up for a clinical trial, you can always stop at any time.

What about other treatments that I hear about?

When you have a tumor you might hear about other ways\textsuperscript{12} to treat it or treat your symptoms. 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 doctor about anything you’re thinking about using, whether it’s a vitamin, an herb, a diet, or anything else.

Questions to ask the doctor

- What treatment do you think is best for me?
- 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 I need other types of treatment, too?
- What will these treatments be like?
- What’s the goal of these treatments?
- What side effects could I have from these treatments?
- What can I do about side effects that I might have?
- Is there a clinical trial that might be right for me?
- What about vitamins or diets that friends tell me about? How will I know if they are safe?
- How soon do I need to start treatment?
- What should I do to be ready for treatment?
- Is there anything I can do to help the treatment work better?
- What’s the next step?

What will happen after treatment?

Some tumors can be removed (or destroyed) completely, but others might not be. Even if it’s gone, it can be hard not to worry about it coming back. Whether the tumor is gone or you are still getting treatment, you will still need to see your doctor.

Be sure to go to all of these follow-up visits. Your doctors will ask about symptoms, do physical exams, and may do tests to see if the tumor has grown or come back. They will also test you to see if treatment has damaged your brain. If needed, they will help you learn to deal with the changes.

Having a brain tumor and dealing with treatment can be hard, but it can also be a time to look at your life in new ways. You might be thinking about how to improve your health. Call us at 1-800-227-2345 or talk to your doctor to find out what you can do to
feel better.

You can’t change the fact that you have had a tumor. What you can change is how you live the rest of your life – making healthy choices and feeling as good as you can.

**For connecting and sharing during a cancer journey**

Anyone with cancer, their caregivers, families, and friends, can benefit from help and support. The American Cancer Society offers the Cancer Survivors Network (CSN), a safe place to connect with others who share similar interests and experiences. We also partner with CaringBridge, a free online tool that helps people dealing with illnesses like cancer stay in touch with their friends, family members, and support network by creating their own personal page where they share their journey and health updates.

**Hyperlinks**

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.

**Debulking**: Removing as much of the tumor as is safely possible. For tumors that can’t be removed completely, this might be done to help with symptoms or to help other treatments like radiation or chemo work better.

**Grade**: A number given to a tumor based on how quickly a tumor is likely to grow and spread into nearby normal tissue, and on how the tumor cells look. Brain and spinal cord tumors are given a grade from I (1) to IV (4), with grade IV tumors tending to grow and spread the fastest.

**Malignant** (mah-LIG-nent): A tumor that grows quickly and often grows into nearby normal tissues.

**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-vahr): 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 (www.cancer.org)\(^5\). 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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