# Can Brain and Spinal Cord Tumors in Children Be Found Early?

Children with certain inherited syndromes

Screening is testing for a disease (such as brain or spinal cord tumors) in people without any symptoms. At this time there are no widely recommended screening tests for most children to look for brain or spinal cord tumors before they start to cause symptoms. These tumors usually are found as a result of signs or symptoms the child is having.

Most often, the outlook for children with brain or spinal cord tumors depends more on the type of tumor and its location than on how early it is detected. But as with any disease, earlier detection and treatment is likely to be helpful.

#### Children with certain inherited syndromes

For children with certain <u>inherited syndromes</u><sup>1</sup> that put them at higher risk for brain tumors, such as neurofibromatosis or tuberous sclerosis, doctors often recommend frequent physical exams and other tests. These tests might find tumors when they are still small. Not all tumors related to these syndromes may need to be treated right away, but finding them early might help doctors monitor them so that they can be treated

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# Signs and Symptoms of Brain and Spinal Cord Tumors in Children

- General symptoms
- Symptoms of tumors in different parts of the brain or spinal cord

Signs and symptoms from brain and spinal cord tumors might occur gradually and become worse over time, or they can happen suddenly, such as with a seizure.

#### **General symptoms**

Tumors in any part of the brain might raise the pressure inside the skull (known as *intracranial pressure*). This can be caused by growth of the tumor, swelling in the brain, or blocked flow of cerebrospinal fluid. Increased pressure can lead to general symptoms such as:

- Headache
- Nausea
- Vomiting
- Crossed eyes or blurred vision
- Balance problems
- · Behavior changes
- Seizures
- Drowsiness or even coma

**Headaches** that get worse over time are a common symptom of brain tumors. But not all brain tumors cause headaches, and most headaches are not caused by tumors.

In some children, **seizures** are the first symptom of a brain tumor. Most seizures in children are not caused by brain tumors, but if your child has a seizure, your child's doctor may refer you to a neurologist (a doctor who specializes in brain and nervous

system problems) to make sure it wasn't caused by a brain tumor or other serious disease.

In the first few years of life, other symptoms of tumors can include:

- Irritability
- · Loss of appetite
- Developmental delays
- Drop in intellectual and/or physical abilities
- Increased head size, sometimes along with bulging of the soft spots of the skull (fontanelles)

In the school-aged child, other general symptoms of tumors can include **poor school performance**, **fatigue**, **and personality changes**.

If the child can cooperate, the doctor can sometimes tell if pressure inside the skull is increased by looking inside the child's eyes for swelling of the optic nerve (known as papilledema).

#### Symptoms of tumors in different parts of the brain or spinal cord

Tumors in different parts of the brain or spinal cord can cause different symptoms. But these symptoms can be caused by any abnormality in that particular location – they don't always mean a child has a brain or spinal cord tumor.

- Tumors in the parts of the cerebrum (the large, outer part of the brain) that control movement or sensation can cause **weakness or numbness in a part of the body**, often on just one side.
- Tumors in or near the parts of the cerebrum responsible for language can cause problems with speech or even understanding words.
- Tumors in the front part of the cerebrum can sometimes affect thinking, personality, and language skills.
- Tumors in the cerebellum (the lower, back part of the brain that controls coordination) can cause **trouble walking**, **trouble with precise movements of hands**, **arms**, **feet**, **and legs**, **problems swallowing or synchronizing eye movements**, and changes in speech rhythm.
- Tumors in the back part of the cerebrum, or around the pituitary gland, the optic nerves, or certain other cranial nerves can cause **vision problems**.
- Tumors in or near other cranial nerves might lead to **hearing loss (in one or both**

ears), balance problems, weakness of some facial muscles, facial numbness or pain, or trouble swallowing.

 Spinal cord tumors may cause numbness, weakness, or lack of coordination in the arms and/or legs (usually on both sides of the body), as well as bladder or bowel problems.

Having one or more of the symptoms above does not necessarily mean that your child has a brain or spinal cord tumor. All of these symptoms can have other causes. Still, if your child has any of these symptoms, especially if they don't go away or get worse over time, see your child's doctor so that the cause can be found and treated, if needed.

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### Tests for Brain and Spinal Cord Tumors in Children

Brain and spinal cord tumors are usually found because of signs or symptoms a child is having. If a tumor is suspected, tests will be needed to confirm the diagnosis.

- Medical history and physical exam
- Imaging tests
- Brain or spinal cord tumor biopsy
- Lumbar puncture (spinal tap)

injected into a vein before the scan to help see details better.

MRI scans can take a long time, and they require a person to stay still for several minutes at a time. Some children might need medicine to help them relax or even go to sleep during the test.

Special types of MRI can be useful in some situations:

Magnetic resonance angiography (MRA) and magnetic resonance venography (MRV): These special forms of MRI may be done to look at the blood vessels in the brain, especially in and around a tumor. This can be very useful before surgery to help the surgeon plan an operation.

Magnetic resonance spectroscopy (MRS): This test can be done as part of an MRI. It measures biochemical changes in an area of the brain (which are displayed in graph-like results called *spectra*). By comparing the results from a tumor to that of normal brain tissue, it can sometimes help determine the type of tumor (or how quickly it is likely to grow), although a biopsy of the tumor is often still needed to get an accurate diagnosis. MRS can also be used after treatment if another test shows an area still looks abnormal. The MRS can help determine if the area is remaining tumor or if it is more likely to be scar tissue.

**Magnetic resonance perfusion (perfusion MRI):** For this test, a contrast dye is injected quickly into a vein. Then this type of MRI can show the amount of blood going through different parts of the brain and tumor. Tumors often have a bigger blood supply than normal areas of the brain. A faster growing tumor may need more blood.

Perfusion MRI can give doctors an idea of the best place to take a biopsy. It can also be used after treatment to help determine if an area that still looks abnormal is remaining tumor or if it is more likely to be scar tissue.

**Functional MRI (fMRI):** This test looks for tiny blood flow changes in an active part of the brain. It can be used to determine what part of the brain handles a function such as speech, thought, sensation, or movement. Doctors can use this to help determine which parts of the brain to avoid when planning surgery or radiation therapy.

This test is like a regular MRI, except that your child will be asked to do certain tasks (like answering simple questions or moving their fingers) to activate different areas of the brain while the scans are being done.

**Diffusion tensor imaging (DTI), also known as tractography:** This is a type of MRI test that can show the major pathways (tracts) of white matter in the brain. This

information can be used by surgeons to help avoid these important parts of the brain when removing tumors.

#### Computed tomography (CT) scan

The <u>CT scan</u><sup>2</sup> uses x-rays to make detailed cross-sectional images of your child's brain and spinal cord. Unlike a regular x-ray, a CT scan creates detailed images of the soft tissues in the body.

For brain and spinal cord tumors, CTscans are not used as often as MRI scans, which give slightly more detailed images and do not use radiation. Still, there are instances where CT scans may have advantages over MRI scans:

- CT scans take much less time than MRIs, which can be particularly helpful for children who have trouble staying still.
- CT scans provide greater detail of the bone structures near the tumor than MRIs do.
- CT angiography (CTA), described below, can provide better details of the blood vessels in and around a tumor than MRA in some cases.

Before the scan, your child may get an injection of a contrast dye through an IV (intravenous) line. This helps better outline any tumors that are present.

**CT angiography (CTA):** For this test, your child gets an injection of contrast material through an IV line while they are in the CT scanner. The scan creates detailed images of the blood vessels in the brain, which can help doctors plan surgery.

#### Positron emission tomography (PET) scan

For a <u>PET scan</u><sup>3</sup>, a radioactive substance (usually a type of sugar known as *FDG*) is injected into the blood. The amount of radioactivity used is very low and passes out of the body within a day or so. Because tumor cells in the body are growing quickly, they absorb larger amounts of the sugar than most other cells. A special camera is then used to create a picture of areas of radioactivity soft

This test is also useful after treatment to help determine if an area that still looks abnormal on an MRI scan is remaining tumor or if it is more likely to be scar tissue. Remaining tumor might show up on the PET scan, while scar tissue will not.

#### Brain or spinal cord tumor biopsy

Imaging tests such as MRI and CT scans may show that a child has a brain or spinal cord tumor. But often the type of tumor can only be determined by removing a sample of it, which is called a biopsy<sup>4</sup>. A biopsy may be done as a procedure on its own for diagnosis, or it may be part of surgery to treat the tumor.

In some cases (such as for many astrocytomas or brain stem gliomas), it may not be necessary or possible to biopsy the tumor safely, so the diagnosis is made based only on how the tumor looks on imaging tests.

Biopsies can be done in different ways.

#### Stereotactic needle biopsy

This type of biopsy may be used if imaging tests show surgery to remove the tumor might be too risky (such as with some tumors in vital areas or deep within the brain), but a sample is still needed to make a diagnosis.

Depending on the situation, the biopsy may be done with the child awake or under general anesthesia (asleep). If the child is awake, the neurosurgeon injects a local anesthetic into areas of skin over the skull to numb them. (The skull and brain itself do not feel pain.)

The biopsy itself can be done in 2 main ways:

- The most common approach is to get an MRI or CT scan, and then use either markers (each about the size of a nickel) placed on different parts of the scalp, or facial and scalp contours, to create a map of the inside of the head. An incision (cut) is then made in the scalp, and a small hole is drilled in the skull. An imageguidance system is then used to direct a hollow needle into the tumor to remove small pieces of tissue.
- In an approach that's used less often, a rigid frame is attached to the head. An MRI or CT scan is used along with the frame to help the neurosurgeon guide a hollow needle into the tumor to remove small pieces of tissue. This also requires an incision in the scalp and a small hole in the skull.

The biopsy samples are then sent to a pathologist (a doctor specializing in diagnosis of diseases by lab tests). The pathologist looks at it under a microscope (and might do other lab tests) to determine if the tumor is benign or malignant (cancerous) and exactly what type of tumor it is. This helps determine the best course of treatment and the prognosis (outlook).

#### Craniotomy (surgical or open biopsy)

If imaging tests show the tumor can likely be treated with surgery, the neurosurgeon may not do a needle biopsy. Instead, an operation called a **craniotomy** (described in <u>Surgery for Brain and Spinal Cord Tumors in Children</u><sup>5</sup>) might be done to remove all or most of the tumor. (Removing most of the tumor is known as *debulking*.)

Small samples of the tumor are looked at right away by the pathologist while the child is still in the operating room, to get a preliminary diagnosis. This can help guide treatment, including whether further surgery should be done at that time. A final diagnosis is made a within a few days in most cases.

#### Lab tests of biopsy specimens

Finding out which type of tumor a child has is very important in helping to determine their outlook (prognosis) and treatment options. But in recent years, doctors have found that changes in certain genes, chromosomes, or proteins within the tumor cells can also be important. Some tumors are now tested for these types of changes. For example:

- Gliomas that are found to have *IDH1* or *IDH2* gene mutations tend to have a better outlook than gliomas without these gene mutations.
- Oligodendrogliomas whose cells are missing parts of certain chromosomes (known as a 1p19q co-deletion) are much more likely to be helped by chemotherapy than patients whose tumors do not.
- In high-grade gliomas, MGMT promoter methylation is linked with better outcomes and a higher chance of responding to chemotherapy, so it can sometimes be used to help guide treatment.
- For low-grade gliomas, the tumor cells might be tested for certain gene changes, such as in the *BRAF*, *IDH1*, *and IDH2 genes*, to see if treatment with certain targeted therapy drugs<sup>6</sup> might be an option.
- For medulloblastomas, changes in certain genes can be used to divide these tumors into groups, some of which have a better prognosis (outlook) than others.

You can read more about the kinds of tests that are done on biopsy or tissue samples in Testing Biopsy and Cytology Specimens for Cancer<sup>7</sup>.

#### **Lumbar puncture (spinal tap)**

This test is used mainly to look for signs of cancer in the cerebrospinal fluid (CSF), which is the liquid that bathes the brain and spinal cord. For this test, the doctor first numbs an area in the lower part of the back over the spine. The doctor may also recommend that the child be given something to make them sleep so the lumbar puncture can be done more easily and safely. A small, hollow needle is then placed between the bones of the spine to withdraw some of the fluid.

The fluid is looked at under a microscope for cancer cells. The CSF can also be tested for certain substances released by some germ cell tumors.

Lumbar punctures are often used if a tumor has already been diagnosed as a type that can commonly spread through the CSF (such as a medulloblastoma). Information from

#### **Blood and urine tests**

These <u>lab tests</u><sup>8</sup> are rarely used to diagnose brain and spinal cord tumors, but if your child has been sick for some time they may be done to check how well the liver, kidneys, and some other organs are working. This is especially important before any planned surgery.

If your child is getting <u>chemotherapy</u><sup>9</sup>, blood tests will be done routinely to check blood counts and to see if the treatment is affecting other parts of the body.

#### **Hyperlinks**

- 1. www.cancer.org/cancer/diagnosis-staging/tests/imaging-tests/mri-for-cancer.html
- 2. <a href="www.cancer.org/cancer/diagnosis-staging/tests/imaging-tests/ct-scan-for-cancer.html">www.cancer.org/cancer/diagnosis-staging/tests/imaging-tests/ct-scan-for-cancer.html</a>
- 3. <u>www.cancer.org/cancer/diagnosis-staging/tests/imaging-tests/nuclear-medicine-scans-for-cancer.html</u>
- 4. www.cancer.org/cancer/diagnosis-staging/tests/biopsy-and-cytology-tests.html
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- 8. <u>www.cancer.org/cancer/diagnosis-staging/tests/understanding-your-lab-test-results.html</u>
- 9. <u>www.cancer.org/cancer/types/brain-spinal-cord-tumors-children/treating/chemotherapy.html</u>

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## Prognostic Factors for Brain and Spinal Cord Tumors in Children

- Why aren't brain and spinal cord tumors staged like other cancers?
- What factors can affect prognosis?
- Risk groups for medulloblastoma

#### Why aren't brain and spinal cord tumors staged like other cancers?

For most types of cancer, the **stage** – a measure of how far the cancer has spread – is one of the most important factors in selecting treatment options and in determining a person's outlook (prognosis).

But tumors of the brain and spinal cord differ in some important ways from cancers in other parts of the body. One of the main reasons other types of cancer are dangerous is that they can spread throughout the body. Tumors starting in the brain or spinal cord

can spread to other parts of the central nervous system, but they almost never spread to other organs. These tumors are dangerous because as they grow, they can interfere with essential functions of the brain.

Because most tumors in the brain or spinal cord do not usually spread, they do not have

Doctors are still refining this system to make it as accurate as possible.

Along with these risk groups, medulloblastomas can also be grouped based on:

- How the tumor cells look under a microscope
- Whether the cells have certain gene changes

For example, based on gene changes, medulloblastomas can be divided into 4 types. Some of these tend to have a better outlook, so doctors may be able to use this to

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# **Survival Rates for Selected Childhood Brain and Spinal Cord Tumors**

- What is a 5-year survival rate?
- Survival rates don't tell the whole story
- Survival rates for more common brain and spinal cord tumors in children

Survival rates are a way to get a general idea of the outlook (prognosis) for people with a certain type of tumor. They tell you what portion of people with the same type of tumor are still alive a certain amount of time (usually 5 years) after they were diagnosed. They can't tell you what will happen, but they may help give you a better understanding about how likely it is that treatment will be successful. Some people will want to know about survival rates, and some people won't. If you don't want to know, you don't have to.

#### What is a 5-year survival rate?

The 5-year survival rate is the percentage of children who live *at least* 5 years after their cancer is diagnosed. For example, a 5-year survival rate of 80% means that an estimated 80 out of 100 children who have that type of tumor are still alive 5 years after being diagnosed. Of course, many children live much longer than 5 years (and many are cured).

#### Survival rates don't tell the whole story

Survival rates are often based on previous outcomes of large numbers of people who had the disease, but they can't predict what will happen in any child's case. There are some limitations to keep in mind:

- The numbers below are among the most current available. But to get 5-year survival rates, doctors have to look at children who were treated at least 5 years ago. As treatments improve over time, children who are now being diagnosed with brain or spinal cord tumors may have a better outlook than these statistics show.
- The outlook for children with brain or spinal cord tumors varies by the type of tumor. But many other factors can also affect a child's outlook, such as their age, the location and size of the tumor, and how well the tumor responds to treatment. The outlook for each child is specific to their circumstances.

Your child's doctor can tell you how the survival rates below might apply to your child's situation.

### Survival rates for more common brain and spinal cord tumors in children

The numbers below come from the Central Brain Tumor Registry of the United States (CBTRUS) and are based on children aged 14 or younger who were treated between 2000 and 2014. There are some important points to note about these numbers:

- These numbers are for some of the more common types of tumors. Numbers are not readily available for all types of tumors that occur in children, often because they are rare or are hard to classify.
- In some cases, the numbers include a wide range of different types of tumors that
  can have different outlooks. For example, the survival rate for embryonal tumors
  below includes medulloblastomas, as well as other types of tumors.
   Medulloblastomas tend to have a better outlook than the other embryonal tumors.
   Therefore the actual survival rate for medulloblastomas would be expected to be
  higher than the number below, while the number for other embryonal tumors would
  likely be lower.

**Type of Tumor** 

5-Year Survival Rate

Pilocytic astrocytoma

About 95%

#### When you're told your child has a brain or spinal cord tumor

- What kind of tumor<sup>1</sup> does my child have? What does this mean?
- Where is the tumor located? Has it grown into nearby areas?
- Will my child need other tests before we can decide on treatment?
- Will we need to see any other types of doctors?

#### When deciding on a treatment plan

- How much experience do you have treating this type of tumor?
- What are our treatment options<sup>2</sup>? What do you recommend? Why?
- Should we get a <u>second opinion</u><sup>3</sup>? Can you recommend a doctor or cancer center?
- How soon do we need to start treatment?
- What should we do to be ready for treatment?
- How long will treatment last? What will it be like? Where will it be done?
- How might treatment affect our daily activities?
- What are the possible risks and side effects of treatment?
- How might treatment affect my child's ability to learn, grow, and develop?
- How likely is it that treatment could affect my child's future ability to have children?
- Based on what you've learned about my child's tumor, what is the expected prognosis (outlook)?

#### **During treatment**

Once treatment begins, you'll need to know what to expect and what to look for. Not all of these questions may apply, but getting answers to the ones that do may be helpful.

- How will we know if the treatment is working?
- Is there anything we can do to help manage side effects?
- What symptoms or side effects should we tell you about right away?
- How can we reach someone from your office on nights, holidays, or weekends?
- Are there any limits on what my child can do?

#### After treatment

- What type of follow-up4 will we need after treatment?
- How often will my child need to have follow-up exams and tests?
- Are there any limits on what my child can do?
- How will we know if the tumor has come back? What should we watch for?
- Are there nearby <u>support groups</u><sup>5</sup> or other families who have been through this that we could talk to?

Along with these sample questions, be sure to write down any others you might want to ask. For instance, you might want information about recovery times so you can plan your work and your child's school and activity schedule. Or you may want to ask about <u>clinical trials</u><sup>6</sup> for which your child may qualify.

Also keep in mind that doctors aren't the only ones who can give you information. Other members of the treatment team, such as nurses and social workers, can answer some of your questions. You can find out more about speaking with your child's health care team in The Doctor-Patient Relationship<sup>7</sup>.

#### **Hyperlinks**

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