Brain and Spinal Cord Tumors in Children

What are brain and spinal cord tumors in children?

Brain and spinal cord tumors are masses of abnormal cells in the brain or spinal cord that have grown out of control. Cells in nearly any part of the body can become cancer, and can spread to other areas of the body. To learn more about how cancers start and spread, see What Is Cancer?

In most other parts of the body, it is very important to distinguish between benign (non-cancerous) and malignant (cancerous) tumors. Benign tumors do not invade nearby tissues or spread to distant areas, so in other parts of the body they are almost never life threatening. One of the main reasons malignant tumors (cancers) are so dangerous is because they can spread throughout the body.

Although brain tumors rarely spread to other parts of the body, most of them can spread through the brain and spinal cord tissue. Even so-called benign tumors can, as they grow, press on and destroy normal brain tissue, causing damage that is often disabling and can sometimes cause death. This is why doctors usually speak of “brain tumors” rather than “brain cancers.” The main concerns with brain and spinal cord tumors are how fast they grow, how readily they spread through the rest of the brain or spinal cord, and if they can be removed or treated and not come back. But both benign and malignant tumors can be life threatening.

Brain and spinal cord tumors in children tend to be different from those in adults. They often form in different places, develop from different cell types, and may have a different treatment and prognosis (outlook). For information about the differences between childhood cancers and adult cancers, see Cancer in Children. This document refers only to brain and spinal cord tumors in children. Tumors in adults are discussed in our document Brain and Spinal Cord Tumors in Adults.
The central nervous system

To understand brain and spinal cord tumors, it helps to know about the normal structure and function of the central nervous system (CNS), which is the medical name for the brain and spinal cord.

The brain is the center of thought, feeling, memory, speech, vision, hearing, movement, and much more. The spinal cord and special nerves in the head called cranial nerves carry messages between the brain and the rest of the body. These messages tell our muscles how to move, transmit information gathered by our senses, and help coordinate the functions of our internal organs.

The brain is protected by the skull. Likewise, the spinal cord is protected by the bones (vertebrae) of the spinal column.

The brain and spinal cord are surrounded and cushioned by a liquid called cerebrospinal fluid (CSF). Cerebrospinal fluid is made by the choroid plexus, which is located in spaces in the brain called ventricles. The ventricles and the spaces around the brain and spinal cord are filled with CSF.

Parts of the brain and spinal cord

The main areas of the brain include the cerebrum, cerebellum, and brain stem. Each area has a special function.
**Cerebrum:** The cerebrum is the large, outer part of the brain. It is made up of 2 hemispheres (halves) and controls reasoning, thought, emotion, and language. It is also responsible for planned (voluntary) muscle movements (throwing a ball, walking, chewing, etc.) and for taking in and interpreting sensory information such as vision, hearing, smell, touch, and pain.

The symptoms caused by a tumor in a cerebral hemisphere depend on where the tumor is. Common symptoms include:

- Seizures
- Trouble speaking
- A change of mood such as depression
- A change in personality
- Weakness or paralysis in part of the body
- Changes in vision, hearing, or other senses

**Cerebellum:** The cerebellum lies under the cerebrum at the back part of the brain. It helps coordinate movement.

Tumors of the cerebellum can cause problems with coordination in walking; trouble with precise movements of hands, arms, feet, and legs; problems with swallowing or synchronized eye movements; and changes in speech rhythm.

**Brain stem:** The brain stem is the lower part of the brain that connects to the spinal cord. It has bundles of very long nerve fibers that carry signals controlling muscles and sensation or feeling between the cerebrum and the rest of the body. Special centers in the brain stem also help control breathing and the heart beating. In addition, most cranial nerves (described below) start in the brain stem.

The brain stem is divided into 3 main parts: the midbrain, pons, and medulla oblongata.

Tumors in this critical area of the brain can cause weakness, stiff muscles, or problems with sensation, facial or eye movement, hearing, or swallowing. Double vision is a common early symptom of brain stem tumors, as are problems with coordination in walking. Because the brain stem is a small area that is so essential for life, it might not be possible to surgically remove tumors in this area.

**Spinal cord:** The spinal cord has bundles of very long nerve fibers that carry signals that control muscles, sensation or feeling, and bladder and bowel control.

Spinal cord tumors can cause weakness, paralysis, or numbness. The spinal cord is a narrow structure, so tumors that develop there usually cause symptoms on both sides of the body (for example, weakness or numbness of both legs). This is different from symptoms of most brain tumors, which often affect only one side of the body.
The nerves that reach the arms leave the spinal cord at the level of the neck (cervical spine). Nerves to the legs, bowel, and bladder branch off the spinal cord in the back (thoracic and lumbar spine). Spinal cord tumors in the neck (cervical spine) can cause symptoms in both the arms and legs, as well as affect bowel and bladder function. Spinal cord tumors below the neck only affect the legs and bowel and bladder function.

**Cranial nerves:** The cranial nerves extend directly out of the base of the brain (as opposed to coming out of the spinal cord). These nerves carry signals directly between the brain and the face, eyes, tongue, mouth, and some other areas.

The most common cranial nerve tumors in children are called *optic gliomas*, which are tumors of the optic nerve (the large nerve that runs between the brain and each eye). These tumors cause vision problems. Tumors starting in other cranial nerves can cause double vision; trouble swallowing; hearing loss in one or both ears; or facial paralysis, numbness, or pain.
Types of cells and body tissues in the brain and spinal cord

The brain and spinal cord have many kinds of tissues and cells, which can develop into different types of tumors.

**Neurons (nerve cells):** These are the most important cells in the brain. They transmit chemical and electric signals that determine thought, memory, emotion, speech, muscle movement, sensation, and just about everything else that the brain and spinal cord do. Neurons send these signals through their nerve fibers (axons). Axons in the brain tend to be short, while those in the spinal cord can be as long as several feet.

Unlike many other types of cells that can grow and divide to repair damage from injury or disease, neurons in the brain and spinal cord largely stop dividing about a year after birth (with a few exceptions). Neurons do not usually form tumors, but they can be damaged by tumors that start nearby.

**Glial cells:** Glial cells are the supporting cells of the brain. Most brain and spinal cord tumors develop from glial cells. These tumors are sometimes referred to as a group called gliomas.

There are 3 types of glial cells – astrocytes, oligodendrocytes, and ependymal cells. A fourth cell type called microglia is part of the immune system and is not truly a glial cell.

- **Astrocytes** help support and nourish neurons. When the brain is injured, astrocytes form scar tissue that helps repair the damage. The main tumors starting in these cells are called astrocytomas or glioblastomas.

- **Oligodendrocytes** make myelin, a fatty substance that surrounds and insulates the nerve cell axons of the brain and spinal cord. This helps neurons send electric signals through the axons. Tumors starting in these cells are called oligodendrogliomas.

- **Ependymal cells** line the ventricles (fluid-filled areas) within the central part of the brain and form part of the pathway through which cerebrospinal fluid (CSF) flows. Tumors starting in these cells are called ependymomas.

- **Microglia** are the immune (infection fighting) cells of the central nervous system.

**Neuroectodermal cells:** These are very early forms of nervous system cells that are probably involved in brain cell development. They are found throughout the brain. The most common tumors that come from these cells are called medulloblastomas, which start in the cerebellum.

**Meninges:** These are layers of tissue that line and protect the brain and spinal cord. The meninges help form the spaces through which CSF travels. The most common tumors that start in these tissues are called meningiomas.
**Choroid plexus:** The choroid plexus is the area of the brain within the ventricles that makes CSF, which nourishes and protects the brain. Tumors that start here include choroid plexus papillomas and choroid plexus carcinomas.

**Pituitary gland and hypothalamus:** The pituitary is a small gland at the base of the brain. It is connected to a part of the brain called the hypothalamus. Both make hormones that help regulate the activity of several other glands in the body. For example, they control the amount of thyroid hormone made by the thyroid gland, the production and release of milk by the breasts, and the amount of male or female hormones made by the testicles or ovaries. They also make growth hormone, which stimulates body growth, and vasopressin, which regulates water balance by the kidneys.

The growth of tumors in or near the pituitary or hypothalamus, as well as surgery and/or radiation therapy in this area, can affect these functions. For example, tumors starting in the pituitary gland sometimes make too much of a certain hormone, which can cause problems. On the other hand, a child may have low levels of one or more hormones after treatment and may need to take hormones to make up for this.

**Pineal gland:** The pineal gland is not really part of the brain. It is a small endocrine gland that sits between the cerebral hemispheres. It makes melatonin, a hormone that regulates sleep, in response to changes in light. The most common tumors of the pineal gland are called pineoblastomas.

**Blood-brain barrier:** The inner lining of the small blood vessels (capillaries) in the brain and spinal cord creates a very selective barrier between the blood and the tissues of the central nervous system. This barrier normally helps maintain the brain’s metabolic balance and keeps harmful toxins from getting into the brain. Unfortunately, it also keeps out most chemotherapy drugs that are used to kill cancer cells, which in some cases limits their usefulness.

**Types of brain and spinal cord tumors in children**

Tumors can form in almost any type of tissue or cell in the brain or spinal cord. Some tumors have a mixture of cell types. Tumors in different areas of the central nervous system may be treated differently and have a different prognosis (outlook).

Brain tumors in children are more likely to start in the lower parts of the brain, such as the cerebellum and brain stem, than they are in adults. But they can start in the upper parts of the brain as well.
Gliomas

Gliomas are not a specific type of tumor. Glioma is a general term for a group of tumors that start in glial cells. A number of tumors can be considered gliomas, including glioblastoma (also known as glioblastoma multiforme), anaplastic astrocytoma, astrocytoma, oligodendroglioma, ependymoma, brain stem glioma, and optic glioma. About half of all brain and spinal cord tumors in children are gliomas.

Astrocytomas

Astrocytomas are tumors that start in cells called astrocytes, a kind of glial cell.

Most astrocytomas can spread widely throughout the brain and blend with the normal brain tissue, which can make them very hard to remove by surgery. Sometimes they spread along the cerebrospinal fluid (CSF) pathways. It is very rare for them to spread outside of the brain or spinal cord.

Astrocytomas are often grouped as high grade, intermediate grade, or low grade, based largely on how the cells look under the microscope.

Intermediate- and high-grade astrocytomas: These tumors tend to grow quickly and spread into the surrounding normal brain tissue. The highest-grade astrocytoma, known as glioblastoma, is the fastest growing. Anaplastic astrocytomas are also in this group.

Low-grade astrocytomas: These tumors tend to grow slowly and are the most common type in children. Some special types, known as non-infiltrating astrocytomas, tend to grow very slowly and do not grow into (infiltrate) nearby tissues, so they often have a good prognosis.

- **Pilocytic astrocytomas** are slow growing and rarely infiltrate nearby tissues. They most commonly occur in the cerebellum but can also begin in the optic nerve, hypothalamus, brain stem, or other areas. They account for nearly 1 out of 5 brain tumors in children.

- **Subependymal giant cell astrocytomas** (SEGAs) occur in the ventricles. They are also slow growing and rarely infiltrate nearby tissues. These tumors are almost always linked with an inherited condition called tuberous sclerosis.

- **Fibrillary (diffuse) astrocytomas** are also slow-growing tumors, but with the important characteristic of growing into nearby tissues, which makes them hard to remove with surgery. Though these tumors are thought of as low grade, they tend to become more aggressive and fast growing over time.

- **Optic gliomas** are low-grade astrocytomas that start in the optic nerves (the nerves leading from the eyes to the brain). They are often linked with an inherited condition called neurofibromatosis type 1. These tumors are rarely fatal, but they may cause vision loss and injury to nearby brain tissue.
Oligodendrogliomas

These tumors start in brain glial cells called oligodendrocytes. These tumors tend to grow slowly, but like astrocytomas, most of them can grow into nearby brain tissue and can’t be removed completely by surgery. Oligodendrogliomas rarely spread along the CSF pathways and even less frequently spread outside the brain or spinal cord. Only about 1% of brain tumors in children are oligodendrogliomas. As with astrocytomas, they can become more aggressive over time.

Ependymomas

About 5% of brain tumors in children are ependymomas. These tumors start in the ependymal cells that line the ventricles or central canal of the spinal cord. They can range from fairly low-grade (slow growing) tumors to higher grade ones, which are called anaplastic ependymomas.

Ependymomas may spread along the CSF pathways but do not spread outside the brain or spinal cord. These tumors can block the flow of CSF out of the ventricles, causing the ventricles to become very large – a condition called hydrocephalus.

Unlike astrocytomas and oligodendrogliomas, ependymomas usually do not grow into normal brain tissue. As a result, some (but not all) ependymomas can be removed and cured by surgery. But because they can spread along ependymal surfaces and CSF pathways, treating them can sometimes be difficult.

Mixed gliomas

These tumors contain more than one cell type. For example, oligoastrocytomas have some of the same types of cells as both oligodendrogliomas and astrocytomas. Treatment is typically based on the fastest-growing component of the tumor.

Brain stem gliomas

This term refers to the location of the tumor, rather than the type of cell it starts in. A small number of brain stem gliomas occur as a tumor with very distinct edges (called a focal brain stem glioma). More often, brain stem gliomas grow diffusely throughout the brain stem, rather than growing as a focal tumor. These tumors often start in the pons, where they are called diffuse intrinsic pontine gliomas (DIPGs).

About 10% to 20% of brain tumors in children are brain stem gliomas. Nearly all of these tumors are some type of astrocytoma.
Primitive neuroectodermal tumors (PNETs)

These tumors start in primitive (immature) cells of the central nervous system called neuroectodermal cells. About 1 out of 5 brain tumors in children are PNETs. They are more common in younger children than older ones, and are rare in adults. PNETs tend to grow quickly and often spread throughout the CSF pathways. These tumors can have different names depending on where they occur.

**Medulloblastomas:** PNETs that start in the cerebellum are called medulloblastomas. Most PNETs in children are medulloblastomas. These tumors can often be treated effectively and tend to have a better outlook than PNETs in other parts of the brain.

**Pineoblastomas:** PNETs that occur in the pineal gland are called pineoblastomas. These tumors are usually harder to treat than medulloblastomas.

**Other PNETs:** Other, less common types of central nervous system PNETs include medulloepitheliomas, ependymoblastomas, and neuroblastomas that start in the brain or spinal cord.

Craniopharyngiomas

These slow-growing tumors start above the pituitary gland but below the brain itself. They account for about 4% of brain tumors in children. These tumors may press on the pituitary gland and the hypothalamus, causing hormone problems. Because craniopharyngiomas start very close to the optic nerves, they can also cause vision problems. This makes them hard to remove completely without damaging the child’s vision or hormone balance.

Mixed glial and neuronal tumors

Certain tumors that develop in children and young adults (and rarely in older adults) have both glial and neuronal cell components. They tend to have a fairly good prognosis.

- **Pleomorphic xanthoastrocytoma** (PXA) and **dysembryoplastic neuroepithelial tumors** (DNETs) look as if they could grow quickly when seen under the microscope, but these tumors tend to be fairly benign, and most are cured by surgery alone.

- **Ganglioglioma** is a type of tumor that has both mature neurons and glial cells. Most can be cured by surgery alone or surgery combined with radiation therapy.

Choroid plexus tumors

These rare tumors start in the choroid plexus within the ventricles of the brain. Most are benign (choroid plexus papillomas) and are cured by surgery. However, some are malignant (choroid plexus carcinomas).
Schwannomas (neurilemmomas)

This type of tumor starts in Schwann cells that surround and insulate cranial nerves and other nerves. Schwannomas are usually benign tumors. They often form near the cerebellum on the cranial nerve responsible for hearing and balance, in which case they are called *vestibular schwannomas* or *acoustic neuromas*. They may also develop on spinal nerves past the point where the nerves have left the spinal cord. When this is the case, the tumor can press on the spinal cord, causing weakness, sensory loss, and bowel and bladder problems.

These tumors are rare in children. When schwannomas are found in a child, particularly if there are tumors on both sides of the head, it often means the child has an inherited tumor syndrome such as neurofibromatosis type 2 (see “What are the risk factors for brain and spinal cord tumors in children?”).

Other tumors that start in or near the brain

Meningiomas

These tumors begin in the meninges, the layers of tissue that surround the outer part of the brain and spinal cord. Meningiomas cause symptoms by pressing on the brain or spinal cord. They are much less common in children than in adults.

Meningiomas are almost always benign and are usually cured by surgery. Some, however, are located very close to vital structures in the brain and can’t be cured by surgery alone.

Meningiomas are often assigned a grade based on how the tumor cells look.

- Grade I tumors, which look most like normal cells, make up about 80% to 90% of meningiomas.
- Grade II (atypical) meningiomas look slightly more abnormal.
- Grade III (anaplastic) meningiomas, which look the most abnormal, make up only about 1% to 3% of meningiomas.

Higher-grade meningiomas are more likely to come back after treatment, and some grade III meningiomas can spread to other parts of the body.

Chordomas

These tumors start in the bone at the base of the skull or at the lower end of the spine. These tumors don’t start in the central nervous system, but they can injure nearby parts of the brain or spinal cord by pressing on them. Chordomas tend to come back after treatment, if they are not removed completely, causing more damage. They usually do not spread to other organs.
Chordomas are much more common in adults than in children. For more on these tumors, see our document *Bone Cancer*.

**Germ cell tumors**

These rare tumors develop from germ cells, which normally form eggs in women and sperm in men. During normal development before birth, germ cells travel to the ovaries or testicles and develop into eggs or sperm cells. But sometimes some germ cells don’t move where they should and end up in abnormal locations such as the brain. They may then develop into germ cell tumors, similar to those that can form in the ovaries or testicles.

Germ cell tumors of the nervous system usually occur in children, most often in the pineal gland or above the pituitary gland. These tumors can sometimes be diagnosed without a biopsy by measuring certain chemicals in the cerebrospinal fluid (CSF) or blood.

The most common germ cell tumor of the nervous system is the germinoma. Other tumors that start in germ cells include choriocarcinomas, embryonal carcinomas, teratomas, and yolk sac tumors (endodermal sinus tumors).

**Neuroblastomas**

These nerve cell tumors are the third most common cancer in children. Neuroblastomas rarely develop in the brain or spinal cord; most develop from nerve cells inside the abdomen or chest. This type of cancer is most common during early infancy. For more information, see our document *Neuroblastoma*.

**Lymphomas**

Lymphomas are cancers that start in cells called *lymphocytes* (one of the main cell types of the immune system). Most lymphomas start in other parts of the body, but a small portion start in the central nervous system (CNS). CNS lymphomas are rare in children. For more on childhood lymphomas, see our document *Non-Hodgkin Lymphoma in Children*.

**Pituitary tumors**

Tumors that start in the pituitary gland are almost always benign (non-cancerous). But they can still cause problems if they grow large enough to press on nearby structures or if they make too much of any kind of hormone. These tumors are more common in teens than in younger children. For more information, see our document *Pituitary Tumors*.

**Cancers that spread to the brain from other sites**

Sometimes brain tumors are found not to have started in the brain but rather to have metastasized (spread) there from some other part of the body. Tumors that start in other
organs and then spread to the brain are called metastatic or secondary brain tumors (as opposed to primary brain tumors, which start in the brain). This is important because metastatic and primary brain tumors are often treated differently.

In children, metastatic brain tumors are much less common than primary brain tumors. Childhood leukemias can sometimes spread to the CSF around the brain and spinal cord. When this happens, the cancer is still considered a leukemia (the cancer cells in the CSF are leukemia cells), so doctors use treatments directed at the leukemia. For more information, see our document *Childhood Leukemia*.

This document covers only primary childhood brain tumors.

**What are the key statistics about brain and spinal cord tumors in children?**

Brain and spinal cord tumors are the second most common cancers in children (after leukemia). They account for about 1 out of 4 childhood cancers. More than 4,000 central nervous system tumors are diagnosed each year in children and teens. The incidence rate (number of tumors per 100,000 children) has not changed much in recent years.

Boys develop these tumors slightly more often than girls.

About 3 out of 4 children with brain tumors (all types combined) survive at least 5 years after being diagnosed. The outlook can vary a great deal based on the type of tumor, where it is, and other factors. For survival information on some particular tumor types, see “Survival rates for selected brain and spinal cord tumors.”

Visit the American Cancer Society’s Cancer Statistics Center for more key statistics.

**What are the risk factors for brain and spinal cord tumors in children?**

A risk factor is anything that affects a person’s chance of getting a disease such as a brain or spinal cord tumor. Different types of cancer have different risk factors.

Lifestyle-related risk factors such as diet, body weight, physical activity, and tobacco use play a major role in many adult cancers. But these factors usually take many years to influence cancer risk, and they are not thought to play much of a role in childhood cancers, including brain tumors.

Very few risk factors have been found for brain and spinal cord tumors. There is no clear cause for most of these tumors.
Radiation exposure

The only well-established environmental risk factor for brain tumors is radiation exposure to the head, which most often comes from the treatment of other conditions.

For example, before the risks of radiation were well known (more than 50 years ago), children with ringworm of the scalp (a fungal infection) often received low-dose radiation therapy. This was later found to increase their risk of brain tumors as they got older.

Today, most radiation-induced brain tumors are caused by radiation given to the head to treat other cancers, such as leukemia. These brain tumors usually develop around 10 to 15 years after the radiation.

Radiation-induced tumors are still fairly rare, but because of the increased risk (as well as the other side effects), radiation therapy is only given to the head after carefully weighing the possible benefits and risks. For most patients with cancer in or near the brain, the benefits of getting radiation therapy as part of their treatment far outweigh the small risk of developing a brain tumor years later.

The possible risk from fetal or childhood exposure to imaging tests that use radiation, such as x-rays or CT scans, is not known for sure. These tests use much lower levels of radiation than those used in radiation treatments, so if there is any increase in risk, it is likely to be very small. But to be safe, most doctors recommend that pregnant women and children not get these tests unless they are absolutely needed.

Inherited and genetic conditions

In rare cases (less than 5% of brain tumors), children have inherited abnormal genes from a parent that put them at increased risk for certain types of brain tumors. In other cases, these abnormal genes are not inherited but occur as a result of changes (mutations) in the gene before birth.

People with inherited tumor syndromes often have many tumors that start when they are young. Some of the more well-known syndromes include:

**Neurofibromatosis type 1 (von Recklinghausen disease)**

This is the most common syndrome linked to brain or spinal cord tumors. It is often inherited from a parent, but it can also start in some children whose parents don’t have it. Children with this syndrome may have optic gliomas or other gliomas of the brain or spinal cord, or neurofibromas (benign tumors of peripheral nerves). Changes in the *NF1* gene cause this disorder.

**Neurofibromatosis type 2**

Less common than von Recklinghausen disease, this condition can also either be inherited or may start in children without a family history. It is associated with cranial or spinal nerve
schwannomas, especially vestibular schwannomas (acoustic neuromas), which almost always occur on both sides of the head. It is also linked to an increased risk of meningiomas, as well as spinal cord gliomas or ependymomas. Changes in the \( NF2 \) gene are responsible for neurofibromatosis type 2.

**Tuberous sclerosis**

Children with this condition may develop subependymal giant cell astrocytomas (SEGAs), as well as other benign tumors of the brain, skin, heart, kidneys, or other organs. This condition is caused by changes in either the \( TSC1 \) or the \( TSC2 \) gene.

**Von Hippel-Lindau disease**

Children with this disease tend to develop blood vessel tumors (hemangioblastomas) of the cerebellum, spinal cord, or retina, as well as tumors in the kidney, pancreas, and some other parts of the body. It is caused by changes in the \( VHL \) gene.

**Li-Fraumeni syndrome**

People with this syndrome have an increased risk of gliomas, as well as breast cancer, soft tissue sarcomas, leukemia, adrenal gland cancer, and some other types of cancer. It is caused by changes in the \( TP53 \) gene.

**Other syndromes**

Other inherited conditions linked with increased risks of certain types of brain and spinal cord tumors include:

- Gorlin syndrome (basal cell nevus syndrome)
- Turcot syndrome
- Cowden syndrome
- Hereditary retinoblastoma
- Rubinstein-Taybi syndrome

Some families may have genetic disorders that are not well recognized or that could even be unique to a particular family.
Factors with uncertain, controversial, or unproven effects on brain tumor risk

Cell phone use

Cell phones give off radiofrequency (RF) rays, a form of electromagnetic energy on the spectrum between FM radio waves and those used in microwave ovens, radar, and satellite stations. Cell phones do not give off ionizing radiation, the type that can cause cancer by damaging the DNA inside cells. Still, there have been concerns that the phones, whose antennae are built-in and therefore are placed close to the head when being used, might somehow raise the risk of brain tumors.

Some studies have suggested a possible increased risk of brain tumors or of vestibular schwannomas in adults with cell phone use, but most of the larger studies done so far have not found an increased risk, either overall or among specific types of tumors. Still, there are very few studies of long-term use (10 years or more), and cell phones haven’t been around long enough to determine the possible risks of lifetime use. The same is true of any possible higher risks in children, who are increasingly using cell phones. Cell phone technology also continues to change, and it’s not clear how this might affect any risk.

These risks are being studied, but it will likely be many years before firm conclusions can be made. In the meantime, for people concerned about the possible risks, there are ways to lower their (and their children’s) exposure, such as using the speaker function or an earpiece to move the phone itself away from the head when used. For more information, see our document Cellular Phones.

Other factors

Exposure to aspartame (a sugar substitute), exposure to electromagnetic fields from power lines and transformers, and infection with certain viruses have been suggested as possible risk factors, but most researchers agree that there is no convincing evidence to link these factors to brain tumors. Research on these and other potential risk factors continues.

Do we know what causes brain and spinal cord tumors in children?

The cause of most brain and spinal cord tumors is not fully understood. But researchers have found some of the changes that occur in normal brain cells that may lead them to form tumors.

Normal human cells grow and function based mainly on the information contained in each cell’s chromosomes. Chromosomes are long strands of DNA in each cell. Brain and spinal cord tumors, like other tumors, are usually caused by changes (mutations) in the DNA inside
DNA is the chemical that makes up our genes – the instructions for how our cells function. We usually look like our parents because they are the source of our DNA. But DNA affects more than how we look.

Some genes control when our cells grow, divide into new cells, and die. Certain genes that help cells grow, divide, and stay alive are called *oncogenes*. Others that slow down cell division, or cause cells to die at the right time, are called *tumor suppressor genes*. Cancers can be caused by DNA changes that turn on oncogenes or turn off tumor suppressor genes. These gene changes can be inherited from a parent (as is sometimes the case with childhood cancers), but more often they happen spontaneously during a person’s lifetime.

In recent years, researchers have found the gene changes that cause some rare inherited syndromes (like neurofibromatosis, tuberous sclerosis, Li-Fraumeni syndrome, and von Hippel-Lindau syndrome) and increase the risk of developing some brain and spinal cord tumors. For example, the Li-Fraumeni syndrome is caused by changes in the *TP53* tumor suppressor gene. Normally, this gene prevents cells with damaged DNA from growing. Changes in this gene increase the risk of developing brain tumors (particularly gliomas), as well as some other cancers.

In most cases, it is not known why people without inherited syndromes develop brain or spinal cord tumors. Most risk factors for cancer somehow damage genes. For example, tobacco smoke is a risk factor for lung cancer and several other cancers because it contains chemicals that can damage genes. The brain is relatively protected from tobacco smoke and other cancer-causing chemicals that we might breathe in or eat, so these factors are not likely to play a major role in these cancers.

Several different gene changes must usually occur in normal cells before they become cancerous. There are many kinds of brain tumors, each of which may have different sets of gene changes. A number of gene or chromosome changes have been found in different brain tumor types, but there are probably many others that have not yet been found.

Researchers now understand some of the gene changes that occur in different types of brain tumors, but it’s still not clear what causes these changes. Some gene changes might be inherited, but most brain and spinal cord tumors in children are not the result of known inherited syndromes. Most gene changes are probably just random events that sometimes happen inside a cell, without having an outside cause.

Other than radiation, there are no known lifestyle-related or environmental causes of childhood brain tumors, so it is important to remember that there is nothing these children or their parents could have done to prevent these cancers.
Can brain and spinal cord tumors in children be prevented?

Adults can lower their risk of certain cancers with lifestyle changes (such as staying at a healthy weight or quitting smoking), but at this time there are no known ways to prevent most cancers in children.

Other than exposure to radiation, there are no known lifestyle-related or environmental causes of brain and spinal cord tumors in children, so at this time there is no way to protect against most of these cancers.

For most children with other types of cancer in or near the head, radiation therapy may be given if the doctors feel the benefits outweigh the small risk of developing a brain tumor years later. Still, when it is needed, doctors try to limit the dose of radiation as much as possible.

X-rays or CT scans done before birth or during childhood use much lower levels of radiation than those used for treatment. If there is any increase in risk from these tests, it is likely to be very small, but to be safe, most doctors recommend that pregnant women and children not get these tests unless they are absolutely needed.

Can brain and spinal cord tumors in children be found early?

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 people with brain or spinal cord tumors depends on the type of tumor and its location, not how early it is detected. But as with any disease, earlier detection and treatment is likely to be helpful.

For children with certain inherited syndromes 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 quickly if they begin to grow or cause problems.
Signs and symptoms of brain and spinal cord tumors in children

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 delay, and a drop in intellectual and physical abilities. In very young children who can’t complain of symptoms, a parent may notice an increase in head size, sometimes along with bulging of the soft spots of the skull (fontanelles). This happens because the bones of the skull haven’t grown together yet, and increased pressure from a tumor can push them apart.

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 central nervous system**

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

Brain and spinal cord tumors often cause problems with the specific functions of the region they develop in. For example:

- 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 an area of the brain called the *basal ganglia* typically cause abnormal movements and body positions.

- Tumors in the cerebellum, which controls coordination, can cause trouble walking or with other normal functions, even eating.

- 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 loss of hearing, balance problems, weakness of some facial muscles, 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 mean that your child definitely 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.
How are brain and spinal cord tumors diagnosed 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

If your child has symptoms that suggest a brain or spinal cord tumor, the doctor will get a complete medical history, focusing on the symptoms and when they began. The doctor will also do a neurologic exam to check your child’s brain and spinal cord function, if possible. Depending on the child’s age, the exam may test reflexes, sensation, muscle strength, vision, eye and mouth movement, coordination, balance, alertness, and other functions.

If the results are abnormal, your child’s doctor may refer you to a neurologist (a doctor specializing in medical treatment of nervous system diseases) or a neurosurgeon (a surgeon specializing in nervous system diseases), who will do a more detailed exam and might order other tests.

Imaging tests

Your child’s doctors may order one or more imaging tests. These tests use x-rays, strong magnets, or radioactive substances to create pictures of internal organs such as the brain and spinal cord. The pictures may be looked at by doctors specializing in this field (neurosurgeons, neurologists, and neuroradiologists) as well as by your child’s primary care doctor.

Magnetic resonance imaging (MRI) and computed tomography (CT) scans are used most often for brain diseases. These scans will show a brain or spinal cord tumor, if one is present, in almost all cases. Doctors can often also get an idea about what type of tumor it might be, based on how it looks on the scan and where it is in the brain (or spinal cord).

Magnetic resonance imaging (MRI) scan

MRI scans are very good for looking at the brain and spinal cord and are considered the best way to look for tumors in these areas. MRI images are usually more detailed than those from CT scans (described below). But they do not image the bones of the skull as well as CT scans and therefore might not show the effects of tumors on the skull.

MRI scans create detailed images using radio waves and strong magnets instead of x-rays, so they do not expose the child to radiation. A contrast material called gadolinium may be injected into a vein before the scan to help see details better.
MRI scans can take a long time – often up to an hour. Your child may have to lie on a table that slides inside a narrow tube, which is confining and can be distressing. The test also requires a person to stay still for several minutes at a time. Some children might need medicine to help them relax or even be asleep during the test. Open MRI machines may be another option, though they might result in less detailed images. The MRI machine makes loud buzzing and clicking noises that your child may find disturbing. Some places provide headphones or earplugs to help block this noise out.

**Magnetic resonance angiography (MRA):** This special form of MRI may be done to look at the blood vessels in the brain. This can be very useful before surgery to help the surgeon plan an operation.

**Magnetic resonance spectroscopy (MRS):** This test is like an MRI, except it measures the radio wave interactions with different chemicals in the brain. MRS highlights some features of brain tumors that may not be seen clearly with MRI. It creates graph-like results called *spectra* (but crude images can also be created). This might give clues to the type of tumor, but in most cases a biopsy of the tumor is still needed to get an accurate diagnosis. MRS can also be used after treatment to help determine if an area that still looks abnormal on another test is remaining tumor or if it is more likely to be scar tissue.

**Magnetic resonance perfusion:** For this test, also known as *perfusion MRI*, a contrast dye is injected quickly into a vein. A special type of MR image is then obtained to look at 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 newer type of MRI 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 determine which parts of the brain to avoid when planning surgery or radiation therapy.

This test is similar to a standard MRI, except that your child will be asked to perform specific tasks (such as answering simple questions or moving their fingers) while the scans are being done.

**Computed tomography (CT) scan**

The CT scan uses x-rays to produce detailed cross-sectional images of your child’s brain and spinal cord. Instead of taking one picture, like a regular x-ray, a CT scanner takes many pictures as it rotates around your child while he or she lies on a table. A computer then combines these pictures into images of slices of the body. Unlike a regular x-ray, a CT scan creates detailed images of the soft tissues in the body.
For brain and spinal cord tumors, CT scans 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), which is 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. The contrast contains iodine and may cause some flushing (a feeling of warmth, especially in the face). Some people are allergic to the dye and get hives. Rarely, more serious reactions like trouble breathing or low blood pressure can occur. Be sure to tell the doctor if your child has any allergies or has ever had a reaction to any contrast material used for an imaging test.

CT scans take longer than regular x-rays but not as long as MRI scans. Your child will need to lie still on a table while they are being done. A CT scanner has been described as a large donut, with a narrow table that slides in and out of the middle opening. Some people feel a bit confined by the ring they lie in while the pictures are being taken, although it is not as narrow as an MRI tube. Some children may need to be sedated before the test to keep them as still as possible and help make sure the pictures come out well.

**CT angiography (CTA):** For this test, your child gets an injection of contrast material through an IV line while he or she is in the CT scanner. The scan creates detailed images of the blood vessels in the brain, which can help doctors plan surgery. CT angiography can provide better details of the blood vessels in and around a tumor than MR angiography in some cases.

**Positron emission tomography (PET) scan**

For this test, 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. After about an hour, your child is moved onto a table in the PET scanner. He or she will lie on the table for about 30 minutes while a special camera creates a picture of areas of radioactivity in the body. If your child is not able to stay still for the test, this might require sedation.

The PET scan image is not as detailed as a CT or MRI scan, but it can provide helpful information about whether abnormal areas seen on other tests (such as MRIs) are likely to be tumors or not.
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. Any remaining tumor will show up on the PET scan, while scar tissue will not.

**Angiogram**

For this test, a special dye is injected into blood vessels near the tumor, and then the area is viewed with x-rays. This helps doctors look at a tumor’s blood supply. This test is not done much for brain or spinal cord tumors anymore, as it has largely been replaced by magnetic resonance angiography (MRA) or computerized tomographic angiography (CTA).

**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 usually the type of tumor can be determined only by removing a sample of it, which is called a biopsy. A biopsy may be done as a procedure on its own for diagnosis, or it may be part of surgery to treat the tumor.

The biopsy samples are looked at under a microscope by a pathologist (a doctor specializing in diagnosis of diseases by lab tests). Sometimes it might need to be looked at by a neuropathologist, a pathologist who specializes in nervous system diseases. The pathologist determines if the tumor is benign or malignant (cancerous) and exactly what type of tumor it is.

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.)

A rigid frame may then be attached onto the child’s head. This helps make sure the surgeon will target the tumor precisely. A small cut is made in the scalp, and a small hole is drilled in the skull. 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.
Another approach is to get an MRI or CT scan, use scalp markers or facial and scalp contours to create a map of the inside of the head, and then use an image-guidance system to direct the needle into the tumor. This still requires making an incision and drilling a small hole into the skull.

The biopsy samples are then looked at under a microscope by a pathologist. The doctor can usually tell exactly what type of tumor it is. This helps determine the best course of treatment and the prognosis (outlook).

**Craniotomy**

If imaging tests show the tumor can be treated with surgery, the neurosurgeon may not do a needle biopsy. Instead, he or she may do an operation called a *craniotomy* (described in the “Surgery” section) 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 within a few days in most cases.

You can read more about the kinds of tests that are done on biopsy or tissue samples in our document *Testing Biopsy and Cytology Specimens for Cancer.*

**Lumbar puncture (spinal tap)**

This test is used to look for cancer cells or chemicals released by tumors 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 (such as a medulloblastoma) that can commonly spread through the CSF. Information from the spinal tap can influence treatment.

**Bone marrow aspiration and biopsy**

Because some tumors (especially medulloblastomas) can spread beyond the nervous system, in some instances the doctor may recommend looking at cells in your child’s bone marrow (the soft, inner part of certain bones) to see if tumor cells have spread there.
The bone marrow aspiration and biopsy are often done at the same time. The samples are usually taken from the back of the pelvic (hip) bone, but in some cases they may be taken from other bones.

In bone marrow aspiration, the skin over the hip and the surface of the bone is cleaned and then numbed with local anesthetiic. In most cases, the child is also given other medicines to make them drowsy or even asleep during the procedure. A thin, hollow needle is then inserted into the bone, and a syringe is used to suck out (aspirate) a small amount of liquid bone marrow.

A bone marrow biopsy is usually done just after the aspiration. A small piece of bone and marrow is removed with a slightly larger needle that is pushed down into the bone. Once the biopsy is done, pressure is applied to the site to help stop any bleeding.

The specimens are then looked at under a microscope for tumor cells.

**Blood and urine tests**

These lab tests 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 chemotherapy, blood tests will be done routinely to check blood counts and to see if the treatment is affecting other parts of the body.

**How are brain and spinal cord tumors in children staged?**

The stage of a cancer is a measure of how far it has spread. The extent of spread is based on the results of imaging tests (see “How are brain and spinal cord tumors in children diagnosed?”) and any other tests that have been done.

For most types of cancer, the stage is one of the most important factors in selecting treatment options and in determining the 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 cancers 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 when they grow, it can interfere with essential functions of the brain.

Because most tumors in the brain or spinal cord do not usually spread, they are not formally staged. Some of the most important factors that determine your child’s prognosis include:

- The type of tumor (such as astrocytoma, ependymoma, etc.)
• The grade of the tumor (how quickly the tumor is likely to grow, based on how the cells look under a microscope)

• The location and size of the tumor

• How much of the tumor can be removed by surgery (if it can be done)

• Your child’s age

• Your child’s functional level (whether the tumor is affecting normal brain functions and everyday activities)

• Whether or not the tumor has spread through the cerebrospinal fluid (CSF) to other parts of the brain or spinal cord

• Whether or not tumor cells have spread beyond the central nervous system

**Medulloblastoma risk groups**

A *staging system* is a standard way for the cancer care team to describe the extent of tumor spread. Formal staging systems have been proposed for some childhood brain tumors.

For example, many clinical trials for treating medulloblastoma use a system that places children into either standard-risk or high-risk groups. Children are placed in the high-risk group if any of these apply:

• The child is younger than 3

• A lot of the tumor can’t be removed during surgery

• Tumor cells are in the CSF or have spread to other parts of the brain or elsewhere

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

Recent research has shown that medulloblastomas can be divided into 4 types, based on the major gene changes found in the cancer cells. Each type of medulloblastoma has a different outlook, so doctors may be able to use this to better tailor the treatment each child gets (see “What’s new in research and treatment for brain tumors in children?”).

**Survival rates for selected childhood brain and spinal cord tumors**

Survival rates are often used by doctors as a standard way of discussing a person’s prognosis (outlook). Some parents may want to know the survival statistics for children in similar situations, while others may not find the numbers helpful, or may even not want to know them. If you do not want to read about the survival statistics for brain and spinal cord tumors given in the next few paragraphs, skip to the next section.
The 5-year survival rate refers to the percentage of children who live at least 5 years after their cancer is diagnosed. Of course, many children live much longer than 5 years (and many are cured).

To get 5-year survival rates, doctors have to look at children who were treated at least 5 years ago. Improvements in treatment since then might result in a better outlook for children now being diagnosed with brain tumors.

The numbers below come from the Central Brain Tumor Registry of the United States (CBTRUS) and are based on children aged 19 or younger who were treated between 1995 and 2010. 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 PNETs below includes medulloblastomas, pineoblastomas, and PNETs in other parts of the brain. Medulloblastomas tend to have a better outlook than the other PNETs. Therefore the actual survival rate for medulloblastomas would be expected to be higher than the number below, while the number for other PNETs would likely be lower.

<table>
<thead>
<tr>
<th>Type of Tumor</th>
<th>5-Year Survival Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pilocytic astrocytoma</td>
<td>About 95%</td>
</tr>
<tr>
<td>Fibrillary (diffuse) astrocytoma</td>
<td>About 80% to 85%</td>
</tr>
<tr>
<td>Anaplastic astrocytoma</td>
<td>About 30%</td>
</tr>
<tr>
<td>Glioblastoma</td>
<td>About 20%</td>
</tr>
<tr>
<td>Oligodendroglioma</td>
<td>About 90% to 95%</td>
</tr>
<tr>
<td>Ependymoma/anaplastic ependymoma</td>
<td>About 75%</td>
</tr>
<tr>
<td>PNETs (includes medulloblastoma and pineoblastoma)</td>
<td>About 60% to 65%</td>
</tr>
</tbody>
</table>

Survival rates are often based on previous outcomes of large numbers of children who had the disease, but they can’t predict what will happen in any particular child’s case. Knowing the type of a child’s brain tumor is important in estimating their outlook. But many other factors can also affect a child’s outlook, such as the location and extent of the tumor and how well it responds to treatment. Even taking these other factors into account, survival rates are at best rough estimates. Your child’s doctor knows your child’s situation and is your best source of information on this topic.
How are brain and spinal cord tumors in children treated?

General comments about treatment

Children and teens with brain and spinal cord tumors and their families have special needs that can be met best by cancer centers for children and teens, working closely with the child’s primary care doctor. These centers offer the advantage of being treated by teams of specialists who know the differences between cancers in adults and those in children and teens, as well as the unique needs of younger people with cancer.

For childhood brain and spinal cord tumors, this team is often led by a pediatric neurosurgeon, a doctor who uses surgery to treat brain and nervous system tumors in children. Other doctors on the team may include:

- Pediatric neurologist: a doctor who treats brain and nervous system diseases in children
- Radiation oncologist: a doctor who uses radiation to treat cancer
- Pediatric oncologist: a doctor who uses chemotherapy and other medicines to treat children’s cancers
- Endocrinologist: a doctor who treats diseases in glands that secrete hormones

Many other specialists may be involved in your child’s care as well, including physician assistants (PAs), nurse practitioners (NPs), nurses, psychologists, social workers, rehabilitation specialists, and other health professionals.

Going through cancer treatment with a child often means meeting lots of specialists and learning about parts of the medical system you probably haven’t had contact with before. You can find out more about this in our document *Children Diagnosed With Cancer: Understanding the Health Care System*.

Before treatment, the doctors and other members of the team will help you, as a parent, understand the tests that will need to be done. The team’s social worker will also counsel you about the problems you and your child might have during and after treatments such as surgery, and might be able to help you find housing and financial aid if needed.

Other team members, such as a psychologist and specialists in rehabilitation, may also see your child before treatment begins. For example, if the tumor is slow growing and your child’s condition is stable, he or she may be seen by a psychologist before treatment to assess any damage the tumor may have caused. Most of the work of these specialists takes place after treatment.

The main treatments for children with brain and spinal cord tumors are:
• Surgery
• Radiation therapy
• Chemotherapy
• Targeted therapy
• Other drug treatments

In many cases children will get some combination of these treatments. Treatment is based on the type of tumor and other factors. Doctors plan each child’s treatment individually to give them the best chance of a cure while limiting side effects as much as possible.

It’s important to discuss your child’s treatment options as well as their possible side effects with the treatment team to help make the decision that’s the best fit for your child. If there is anything you don’t understand, ask to have it explained. (See the section “What should you ask your doctor about your child’s brain or spinal cord tumor?” for some questions to ask.)

If time allows, getting a second opinion from another doctor experienced with your child’s type of tumor is often a good idea. It can give you more information and help you feel more confident about the treatment plan you choose.

**Thinking about taking part in a clinical trial**

Clinical trials are carefully controlled research studies that are done to get a closer look at promising new treatments or procedures. Clinical trials are one way to get state-of-the-art cancer treatment. In some cases they may be the only way to get access to newer treatments. They are also the best way for doctors to learn better methods to treat cancer. Still, they are not right for everyone.

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. You can also call our clinical trials matching service at 1-800-303-5691 for a list of studies that meet your medical needs, or see “Clinical Trials” to learn more.

**Considering complementary and alternative methods**

You may hear about alternative or complementary methods that your doctor hasn’t mentioned to treat your cancer or relieve symptoms. These methods can include vitamins, herbs, and special diets, or other methods such as acupuncture or massage, to name a few.

Complementary methods refer to treatments that are used along with your regular medical care. Alternative treatments are used instead of a doctor’s medical treatment. Although some of these methods might be helpful in relieving symptoms or helping you feel better, many have not been proven to work. Some might even be dangerous.
Be sure to talk to your cancer care team about any method you are thinking about using. They can help you learn what is known (or not known) about the method, which can help you make an informed decision. See *Complementary and Alternative Medicine* to learn more.

**Help getting through cancer treatment**

Your cancer care team will be your first source of information and support, but there are other resources for help when you need it. Hospital- or clinic-based support services are an important part of your care. These might include nursing or social work services, financial aid, nutritional advice, rehab, or spiritual help.

The American Cancer Society also has programs and services – including rides to treatment, lodging, support groups, and more – to help you get through treatment. Call our National Cancer Information Center at 1-800-227-2345 and speak with one of our trained specialists on call 24 hours a day, every day.

The next few sections describe the various types of treatments used for brain and spinal cord tumors in children. This is followed by a description of the most common treatment approaches based on the type of tumor.

*The treatment information given here is not official policy of the American Cancer Society and is not intended as medical advice to replace the expertise and judgment of your cancer care team. It is intended to help you and your family make informed decisions, together with your doctor. Your doctor may have reasons for suggesting a treatment plan different from these general treatment options. Don't hesitate to ask him or her questions about your treatment options.*

**Surgery for brain and spinal cord tumors in children**

For brain and spinal cord tumors, surgery may be done for different reasons:

- To get a biopsy sample to determine the type of tumor
- To remove as much of the tumor as possible
- To help prevent or treat possible complications from the tumor

Before surgery, be sure you understand what the goal of the surgery is, as well as the potential benefits and risks.

**Surgery to remove the tumor**

In most cases, the first step in brain or spinal cord tumor treatment is for the neurosurgeon to remove as much of the tumor as possible while trying to limit any effects on normal brain or nerve function.

Surgery alone or combined with radiation therapy may control or cure many tumors, including some low-grade astrocytomas, pleomorphic xanthoastrocytomas (PXAs),
Children with infiltrating tumors (tumors that grow into surrounding areas), such as anaplastic astrocytomas or glioblastomas, cannot be cured by surgery alone. But surgery can reduce the amount of tumor that needs to be treated by radiation or chemotherapy, which might improve the results of these treatments.

Surgery may also help relieve some of the symptoms caused by brain tumors, particularly those caused by increased pressure within the skull, such as headaches, nausea, vomiting, and blurred vision. Surgery may also make seizures easier to control with medicines.

Surgery may not be a good option in some cases, such as if the tumor is deep within the brain, or if it has spread throughout a part of the brain that can’t be removed, such as the brain stem. If this is the case, other treatments may be used instead.

**Craniotomy:** A craniotomy is a surgical opening made in the skull. This is the most common surgery to remove a brain tumor. For this operation, the child may either be under general anesthesia (in a deep sleep) or may remain awake (with the surgical area numbed) for at least part of the surgery if brain function needs to be assessed during the operation.

Part of the head might need to be shaved before surgery. The neurosurgeon makes an incision in the skin over the skull near the tumor and then uses a special type of drill to remove a piece of bone from the skull. The opening is typically large enough for the surgeon to insert several instruments and view the parts of the brain needed to operate safely.

Many devices can help the surgeon see the tumor and surrounding brain tissue. The surgeon often operates while looking at the brain through a microscope. Imaging tests such as MRI or CT scans can be done before surgery (or ultrasound can be used once the skull has been opened) to help locate the tumor and its edges.

The surgeon will remove as much of the tumor as is safely possible. This can be done in several ways depending on how hard or soft the tumor is, and whether it has many or just a few blood vessels. One way is to cut it out with a scalpel or special scissors. Some tumors are soft and can be removed with suction devices. In other cases, a probe attached to an ultrasonic generator can be placed into the tumor to break it up and liquefy it. A small vacuum device is then used to suck it out.

The surgeon is very careful to avoid damaging normal brain tissue as much as possible. To lower the risk of removing vital parts of the brain, different techniques can be used, such as:

- **Functional MRI:** Before surgery, this type of imaging test (described in “How are brain and spinal cord tumors in children diagnosed?”) can be done to locate a particular function of the brain. This can be used to help preserve that region during the operation.

- **Intraoperative cortical stimulation:** During surgery, the surgeon can often detect the function of brain areas in and around the tumor by electrically stimulating them and
monitoring the response. This will show if these areas control an important function, helping the surgeon to avoid them.

- **Intraoperative imaging:** In some cases, the surgeon uses MRI (or other) images taken at different times during the operation to show the location of any remaining tumor. This might allow some brain tumors to be removed more safely and extensively.

After removing the tumor, the surgeon replaces the piece of skull bone and closes the incision. (If any metal screws, wires, or plates are needed to fasten the bone, they are usually made from titanium, which allows the child to get follow-up MRIs.)

After the operation, the child may have a tube coming out of the incision that allows excess cerebrospinal fluid (CSF) to drain from the skull. Other tubes may be placed to allow blood that builds up after surgery to drain from under the scalp. The drains are usually removed after a few days. An imaging test such as an MRI or CT scan is typically done 1 to 3 days after the operation to confirm how much of the tumor has been removed. Recovery time in the hospital is usually 4 to 6 days, but this depends on the size and location of the tumor and whether other treatments are given.

**Surgery to help with CSF flow blockage**

If the tumor blocks the flow of CSF within the head, it can cause increased pressure inside the skull (intracranial pressure, or ICP). This can cause symptoms such as headaches, nausea, vomiting, and blurred vision, and may even damage the brain or be life-threatening. Surgery to remove the tumor can often help with this, but there are also other ways to drain away excess CSF and lower the pressure if needed.

For example, the neurosurgeon may put in a silicone tube called a *shunt* (sometimes referred to as a *ventriculoperitoneal* or *VP shunt*). One end of the shunt is placed in a ventricle of the brain (an area filled with CSF) and the other end is placed in the abdomen or, less often, the heart (and would then be referred to as a *ventriculoatrial shunt*). The tube runs under the skin of the neck and chest. The flow of CSF is controlled by a valve placed along the tubing.

Shunts can be temporary or permanent. They can be placed before or after the surgery to remove the tumor. Placing a shunt normally takes about an hour. As with any operation, complications may develop, such as bleeding or infection. Sometimes shunts get clogged and need to be replaced. The hospital stay after a shunt procedure is typically 1 to 3 days, depending on the reason it is placed.

Another option to treat increased pressure in the skull in some cases is an *endoscopic third ventriculostomy*. In this operation, the surgeon makes an opening in the floor of the third ventricle at the base of the brain to allow the CSF to flow again. This operation is done through a small hole in the front of the skull. An advantage of this approach is that it does not require a shunt, but there is a chance that the opening made in the ventricle might close up again.
If the pressure inside the head needs to be relieved for a short time, an *external ventricular drain* (EVD) might be put in place to allow the excess CSF to drain out. The drain is a small tube. One end is put into a ventricle, and the other end is attached to a collection bag outside the body. Along with collecting the excess CSF, the drain can also be used to measure the pressure inside the skull, as well as to look for tumor cells, blood, or signs of infection in the CSF.

The drain can be placed either during surgery or during a procedure at the hospital bedside. It can be put in place to relieve the pressure in the days before surgery, or to help drain the fluid that collects after an operation. If the pressure inside the skull needs to be lowered for more than a few days, the doctor might need to change this to a VP shunt.

**Surgery to place a ventricular access catheter**

Surgery may also be used to insert a ventricular access catheter, such as an Ommaya reservoir, to help deliver chemotherapy directly into the CSF later on. A small incision is made in the scalp, and a small hole is drilled in the skull. A flexible tube is then inserted through the hole until the open end of the tube is in a ventricle, where it reaches the CSF. The other end, which has a dome-shaped reservoir, stays just under the scalp. After the operation, doctors and nurses can use a thin needle to give chemotherapy drugs through the reservoir or to remove CSF from the ventricle for testing.

**Possible risks and side effects of surgery**

Surgery on the brain or spinal cord is a serious operation, and surgeons are very careful to try to limit any problems either during or after surgery. Complications during or after surgery such as bleeding, infections, seizures, or reactions to anesthesia are rare, but they can happen.

Swelling in the brain is a major concern after surgery. Drugs called *corticosteroids* are typically given for several days after surgery to help lessen this risk.

One of the biggest concerns when removing brain tumors is the possible loss of brain function afterward, which is why doctors are very careful to remove only as much tissue as is necessary. Any symptoms of brain injury after surgery will depend mainly on the location and size of the tumor. If problems do arise, it might be right after surgery, or it might be days or even weeks later, so close monitoring for any changes is very important (see the section “Recovering from the effects of the tumor and its treatment”).

For more information on surgery in general as a treatment for cancer, see our document *Understanding Cancer Surgery: A Guide for Patients and Families*. 
Radiation therapy for brain and spinal cord tumors in children

Radiation therapy uses high-energy x-rays or small particles to kill cancer cells. This type of treatment is given by a doctor called a radiation oncologist. Radiation therapy may be used in different situations:

- After surgery to try to kill any remaining tumor cells
- As part of the main treatment if surgery is not a good option
- To help prevent or relieve symptoms from the tumor

Children younger than 3 years are usually not given radiation because of possible long-term side effects with brain development. Instead, they are treated mainly with surgery and chemotherapy. Radiation can also cause some problems in older children. Radiation oncologists try very hard to deliver enough radiation to the tumor while limiting the radiation to normal surrounding brain areas as much as possible.

Types of radiation therapy

Most often, the radiation is focused on the tumor from a source outside the body. This is called external beam radiation therapy (EBRT).

Before your child’s treatments start, the radiation team will take careful measurements to determine the correct angles for aiming the radiation beams and the proper dose of radiation. Your child may be fitted with a plastic mold resembling a body cast to keep him or her in the same position so that the radiation can be aimed more accurately.

In most cases, the total dose of radiation is divided into daily fractions (usually given Monday through Friday) over several weeks. For each session, your child lies on a special table while a machine delivers the radiation from precise angles. Each treatment is much like getting an x-ray, but the dose of radiation is much higher. It is not painful. Some younger children might need to be sedated to make sure they don’t move during the treatment. Each session lasts about 15 to 30 minutes, but most of the time is spent making sure the radiation is aimed correctly. The actual treatment time each day is much shorter.

Radiation therapy can damage normal brain tissue, so doctors try to deliver high doses of radiation to the tumor with the lowest possible dose to normal surrounding brain areas. Several techniques can help doctors focus the radiation more precisely:

Three-dimensional conformal radiation therapy (3D-CRT): 3D-CRT uses the results of imaging tests such as MRI and special computers to precisely map the location of the tumor. Several radiation beams are then shaped and aimed at the tumor from different directions. Each beam alone is fairly weak, which makes it less likely to damage normal tissues, but the beams converge at the tumor to give a higher dose of radiation there.
Intensity modulated radiation therapy (IMRT): IMRT is an advanced form of 3D therapy. In addition to shaping the beams and aiming them at the tumor from several angles, the intensity (strength) of the beams can be adjusted to limit the dose reaching the most sensitive normal tissues. This may let the doctor deliver a higher dose to the tumor. Many major hospitals and cancer centers now use IMRT.

Conformal proton beam radiation therapy: Proton beam therapy is related to 3D-CRT. But instead of using x-rays, it focuses proton beams on the tumor. Unlike x-rays, which release energy both before and after they hit their target, protons cause little damage to tissues they pass through and then release their energy after traveling a certain distance. Doctors can use this property to deliver more radiation to the tumor and do less damage to nearby normal tissues.

This approach may be more helpful for brain tumors that have distinct edges (such as chordomas), but it is not clear if it will be useful for tumors whose edges are mixed with normal brain tissue (such as astrocytomas or glioblastomas). There are only a handful of proton beam centers in the United States at this time.

Stereotactic radiosurgery/stereotactic radiotherapy: This type of treatment delivers a large, precise radiation dose to the tumor area in a single session (radiosurgery) or in a few sessions (radiotherapy). (There is no actual surgery in this treatment.) It may be useful for some tumors in parts of the brain or spinal cord that can’t be treated with surgery or when a child isn’t healthy enough for surgery.

A head frame is usually attached to the skull to help aim the radiation beams. (Sometimes a face mask is used to hold the head in place instead.) Once the exact location of the tumor is known from CT or MRI scans, radiation is focused at the tumor from many different angles. This can be done in 2 ways:

- In one approach, radiation beams are focused at the tumor from hundreds of different angles for a short period of time. Each beam alone is weak, but they all converge at the tumor to give a higher dose of radiation. The Gamma Knife is an example of a machine that uses this approach.

- Another approach uses a movable linear accelerator (a machine that creates radiation) that is controlled by a computer. Instead of delivering many beams at once, this machine moves around the head to deliver radiation to the tumor from many different angles. Several machines with names such as X-Knife, CyberKnife, and Clinac deliver stereotactic radiosurgery in this way.

Stereotactic radiosurgery typically delivers the whole radiation dose in a single session, though it may be repeated if needed. Sometimes doctors give the radiation in several treatments to deliver the same or a slightly higher dose, which can now often be done without the need for a head frame. This is called fractionated radiosurgery or stereotactic radiotherapy.
**Brachytherapy (internal radiotherapy):** Unlike the external radiation approaches above, in brachytherapy a radiation source is put directly into or near the tumor. The radiation it gives off travels a very short distance, so it affects only the tumor. This technique is most often used along with external radiation. It provides a high dose of radiation at the tumor site, while the external radiation treats nearby areas with a lower dose.

**Whole brain and spinal cord radiation therapy (craniospinal radiation):** If tests, such as an MRI scan or lumbar puncture, show the tumor has spread along the covering of the spinal cord (meninges) or into the surrounding cerebrospinal fluid, then radiation may be given to the whole brain and spinal cord. Some tumors such as ependymomas and medulloblastomas are more likely to spread this way, and therefore may require craniospinal radiation.

**Possible effects of radiation therapy**

Radiation is more harmful to tumor cells than it is to normal cells. Still, radiation can also damage normal brain tissue, especially in children younger than 3 years.

During radiation therapy, some children may become irritable and tired. Nausea, vomiting, and headaches are also possible but are uncommon. Spinal radiation causes nausea and vomiting more often than brain radiation. Sometimes dexamethasone (Decadron), a cortisone-like drug, can help relieve these symptoms.

Some weeks after radiation therapy, children may become drowsy or have other nervous system symptoms. This is called the radiation somnolence syndrome or early-delayed radiation effect. It usually passes after a few weeks.

Children may lose some brain function if large areas of the brain get radiation. Problems can include memory loss, personality changes, and trouble learning at school. These may get better over time, but some effects may be long-lasting. Other symptoms could include seizures and slowed growth. There may also be other symptoms depending on the area of the brain treated and how much radiation was given.

The risk of these effects must be balanced against the risks of not using radiation and having less control of the tumor. If problems are seen after treatment, often it’s hard to determine whether they were caused by damage from the tumor itself, from surgery or radiation therapy, or from some combination of these. Doctors are constantly testing lower doses or different ways of giving radiation to see if they can be as effective while causing fewer problems.

Normal brain cells grow quickly in the first few years of life, making them very sensitive to radiation. Because of this, radiation therapy is often not used or is postponed in children younger than 3 years old to avoid damage that might affect brain development. This needs to be balanced with the risk of tumor regrowth, as early radiation therapy may be lifesaving in some cases. It’s important that you talk with your child’s doctor about the risks and benefits of treatment.
Rarely, a large mass of dead (necrotic) tissue forms at the site of the tumor in the months or years after radiation treatment. This is called radiation necrosis. It can often be controlled with corticosteroid drugs, but surgery may be needed to remove the necrotic tissue in some instances.

Radiation can damage genes in normal cells. As a result, there is a small risk of developing a second cancer in the area that got the radiation – for example, a meningioma of the coverings of the brain, another brain tumor, or less likely a bone cancer in the skull. If this does occur, it is usually many years after the radiation is given. This small risk should not keep children who need radiation from getting treatment. It’s important to continue close follow-up with your child’s doctor so that if problems do come up they can be found and treated as early as possible.

For more on radiation therapy, see the Radiation Therapy section of our website, or our document Understanding Radiation Therapy: A Guide for Patients and Families.

Chemotherapy for brain and spinal cord tumors in children

Chemotherapy (chemo) uses anti-cancer drugs that are usually given into a vein (IV) or taken by mouth. These drugs enter the bloodstream and reach almost all areas of the body. However, many chemo drugs aren’t able to enter the brain and reach tumor cells.

For some brain tumors, the drugs can be given directly into the cerebrospinal fluid (CSF), either in the brain or into the spinal canal below the spinal cord. To help with this, a thin tube known as a ventricular access catheter may be inserted through a small hole in the skull and into a ventricle during a minor operation (see the “Surgery” section).

In general, chemo is used for faster growing tumors. Some types of brain tumors, such as medulloblastoma, tend to respond well to chemo.

Chemo is most often used along with other types of treatment such as surgery and radiation therapy. It may be used instead of radiation therapy in children 3 years and younger.

Some of the chemo drugs used to treat children with brain tumors include:

- Carboplatin
- Carmustine (BCNU)
- Cisplatin
- Cyclophosphamide
- Etoposide
- Lomustine (CCNU)
- Methotrexate
• Temozolomide
• Thiotepa
• Vincristine

These drugs may be used alone or in various combinations, depending on the type of brain tumor. Doctors give chemo in cycles. Each cycle generally lasts about 3 to 4 weeks and is followed by a rest period to give the body time to recover.

**Possible side effects of chemotherapy**

Chemo drugs attack cells that are dividing quickly, which is why they often work against cancer cells. But other cells in the body, such as those in the bone marrow (where new blood cells are made), the lining of the mouth and intestines, and the hair follicles, also divide quickly. These cells can also be affected by chemotherapy, which can lead to side effects.

The side effects of chemo depend on the type of drugs, the amount taken, and how long they are taken. Possible side effects can include:

- Hair loss
- Mouth sores
- Loss of appetite
- Nausea and vomiting
- Diarrhea
- Increased chance of infections (from having too few white blood cells)
- Easy bruising or bleeding (from having too few blood platelets)
- Fatigue (from having too few red blood cells or other factors)

Some of the most effective drugs against brain tumors tend to have fewer of these side effects than other common chemo drugs, but they can still occur. Most side effects tend to be short-term and go away once treatment is finished. Your child’s doctor and treating team will watch closely for any side effects. There are often ways to lessen these side effects. For example, drugs can be given to help prevent or reduce nausea and vomiting.

Along with the risks above, some chemo drugs can have other, less common side effects. For example, cisplatin and carboplatin can also cause kidney damage and hearing loss. Your child’s doctor will check your child’s kidney function and hearing periodically if he or she is given these drugs.
Be sure to ask your child’s doctor or nurse about medicines to help reduce side effects, and let them know if your child has side effects so they can be managed. In some cases, the doses of the chemo drugs may need to be reduced or treatment may need to be delayed or stopped to prevent the effects from getting worse.

For more information on chemotherapy, see the “Chemotherapy” section on our website, or our document A Guide to Chemotherapy.

Targeted therapy for brain and spinal cord tumors in children

As researchers have learned more about the changes in the inner workings of cells that cause cancer or help cancer cells grow, they have developed newer drugs that target these changes. These targeted drugs work differently from standard chemotherapy drugs. They sometimes work when chemo drugs don’t, and they often have different (and less severe) side effects. These drugs do not yet play a large role in treating brain or spinal cord tumors, but some of them may be helpful for certain types of tumors.

**Everolimus (Afinitor)**

For subependymal giant cell astrocytomas (SEGAs) that can’t be removed completely by surgery, everolimus may shrink the tumor or slow its growth for some time. This drug works by blocking a cell protein known as mTOR, which normally helps cells grow and divide into new cells.

Everolimus is a pill taken once a day. Common side effects include mouth sores, increased risk of infections, nausea, loss of appetite, diarrhea, skin rash, feeling tired or weak, fluid buildup (usually in the legs), and increases in blood sugar and cholesterol levels. A less common but serious side effect is lung damage, which can cause shortness of breath or other problems.

Many other targeted therapies are now being developed and studied in clinical trials. Some of these are described in the section “What’s new in research and treatment for brain tumors in children?”

**Other drug treatments for brain and spinal cord tumors in children**

Some drugs commonly used in children with brain or spinal cord tumors do not treat the tumors directly, but they may help lessen symptoms from the tumor or its treatment.

**Corticosteroids**

Cortisone-like drugs such as dexamethasone (Decadron) are often given to reduce the swelling that can occur around brain tumors. They are often given for a few days after
surgery, and might be used during radiation therapy as well. This may help relieve symptoms such as headaches, nausea, and vomiting.

**Anti-seizure drugs (anti-epileptics)**

Drugs may be given to lower the chance of seizures in children with brain tumors. Many different anti-seizure drugs can be used.

**Hormones**

The pituitary gland helps control the levels of many different hormones in the body. If the pituitary has been damaged by the spread of the tumor or by treatments (surgery or radiation therapy), your child may need to take pituitary hormones or other hormones to replace those missing.

**Treating specific types of childhood brain and spinal cord tumors**

The treatment options for brain and spinal cord tumors depend on many factors, including the type of tumor, its location, and how far it has grown or spread.

**Non-infiltrating astrocytomas (Pilocytic astrocytomas, subependymal giant cell astrocytomas)**

Many doctors consider these benign tumors because they tend to grow very slowly and do not grow into (infiltrate) nearby tissues. Pilocytic astrocytomas occur most often in the cerebellum in young children, while subependymal giant cell astrocytomas (SEGAs) grow in the ventricles and are almost always seen in children with tuberous sclerosis.

Most children with these astrocytomas can be cured by surgery alone. They may be given radiation therapy if the tumor is not removed completely, although many doctors will wait until there are signs the tumor is growing back before considering it. Even then, another operation to remove the remaining tumor may be the first option. The outlook is not as good if the tumor is in a place that does not allow it to be removed surgically, such as the hypothalamus or brain stem. In these cases, radiation therapy is usually the best option.

For SEGAs that can’t be removed completely by surgery, treatment with the drug everolimus (Afinitor) might shrink the tumor or slow its growth for some time.
Low-grade astrocytomas  
(Fibrillary or diffuse astrocytomas)

The initial treatment for these tumors is surgery if it can be done, or biopsy to confirm the diagnosis if surgery is not feasible. Because these tumors often grow into nearby normal brain tissue, they are hard to cure with just surgery. Usually the surgeon will try to remove as much of the tumor as safely possible. If the surgeon can remove it all, the child may be cured.

Radiation therapy may be given after surgery, especially if a lot of tumor remains. Otherwise, radiation may be postponed until the tumor starts to regrow. (Sometimes, a second surgery may be tried before giving radiation.) Radiation may also be used as the main treatment if surgery is not a good option because of the tumor’s location.

For children younger than 3, if the tumor can’t be removed completely or if it grows back, chemotherapy may be used to try to slow the tumor’s growth until they are older. They may then be treated with radiation.

Intermediate- and high-grade astrocytomas  
(Anaplastic astrocytomas, glioblastomas)

Surgery is often the first treatment for these infiltrating astrocytomas if it can be done, but patients with these tumors are almost never cured by surgery. In some cases only a needle biopsy is safe. When surgery is used, as much of the tumor is removed as possible, and then radiation therapy is given, often followed by chemotherapy.

If surgery can’t be done, radiation is the main treatment, again often followed by chemotherapy.

If the child is younger than 3, radiation may be postponed until they are older. Surgery may be repeated in some cases if the tumor comes back after the initial treatment.

Because these tumors are hard to cure with current treatments, clinical trials of promising new treatments may be a good option.

Oligodendrogliomas

If possible, surgery is the first option for oligodendrogliomas. Although surgery does not usually cure these infiltrating tumors, it can relieve symptoms and prolong survival. Many of these tumors grow slowly, and surgery may be repeated if it grows back in the same spot. Radiation therapy and/or chemotherapy may be given after surgery.

If surgery is not an option, chemotherapy, with or without radiation therapy, may be helpful. Oligodendrogliomas may respond to chemotherapy better than other brain tumors if the
tumor cells have certain chromosome changes. You can ask your child’s doctor about testing for these changes.

**Ependymomas and anaplastic ependymomas**

These tumors usually do not grow into nearby normal brain tissue. They can sometimes be cured by surgery if the entire tumor can be removed, but this isn’t always possible. If some of the tumor is left behind, a second operation may be done in some cases (often after a short course of chemotherapy).

Radiation therapy is recommended after surgery in most patients to try to prevent the tumor from coming back, even if it appears that all of the tumor has been removed.

The use of chemotherapy after surgery is still being tested in clinical trials. It might be recommended, but its benefit is still uncertain. It may be more helpful for anaplastic ependymomas. Very young children may be given chemotherapy after surgery to help avoid or delay the use of radiation.

Sometimes ependymoma tumor cells can spread into the cerebrospinal fluid (CSF). A few weeks after surgery, the doctor may order an MRI scan of the brain and spinal cord and test the CSF for tumor cells by doing a lumbar puncture (spinal tap). If tumor cells are found in the CSF or growing on the surface of the nervous system, radiation is typically given to the entire brain and spinal cord.

**Optic gliomas**

These tumors start in the optic nerves (the nerves leading from the eyes to the brain). They are often hard to operate on because these nerves are very sensitive and might be harmed by surgery. Depending on where the tumor is, removing it could lead to loss of vision in one or both eyes, so the benefits and risks of surgery have to be considered carefully. In some cases, a child might have already lost some vision because of the tumor itself. Sometimes surgery might not be needed, because these tumors can grow very slowly.

If treatment is needed and the tumor can be removed completely, surgery is often the preferred treatment. But in many cases (especially if the child has neurofibromatosis type 1) the tumor is likely to have spread too far along the optic nerves to be removed completely. Radiation therapy is preferred for these tumors if treatment is needed, although it can also affect a child’s vision (and can have other long-term side effects).

Younger children may get chemotherapy instead of radiation. Radiation could then be used later if needed as the child gets older.
Brain stem gliomas

Most of these tumors are astrocytomas, although a small number are ependymomas or other tumors. These tumors usually look a certain way on MRI scans, so the diagnosis can often be made without surgery or a biopsy.

**Focal brain stem gliomas:** A small number of brain stem gliomas are small tumors with very distinct edges (called focal brain stem gliomas). Some of these tumors grow so slowly that treatment might not be needed unless the tumor causes problems. If treatment is needed, these tumors can often be treated successfully with surgery. If surgery can’t be done, radiation therapy may be used to slow its growth. Radiation can also be used if surgery doesn’t remove the tumor completely.

**Diffuse brain stem gliomas:** Most brain stem gliomas grow diffusely throughout the brain stem, rather than as a distinct (focal) tumor. These tumors often start in the pons, where they are called diffuse intrinsic pontine gliomas (DIPGs). The brain stem is vital to life and can’t be removed, so surgery in these cases would most likely do more harm than good, and it is usually not attempted. Diffuse brain stem gliomas typically are treated with radiation therapy. Chemotherapy is sometimes added, although it’s not clear if it’s helpful.

Diffuse tumors are very hard to control, and they tend to have a poor prognosis (outlook). But in children with neurofibromatosis type 1, these tumors often grow slowly (or even stop growing), so these children tend to have a better outlook. Because these tumors are hard to treat, clinical trials of promising new treatments may be a good option.

**Primitive neuroectodermal tumors (including medulloblastoma and pineoblastoma)**

Primitive neuroectodermal tumors (PNETs) are all treated in similar ways, but medulloblastomas tend to have a better outlook than other types of PNETs.

**Medulloblastomas:** These tumors start in the cerebellum. They tend to grow quickly and are among those most likely to spread outside the brain (usually to the bones or the bone marrow). But they also tend to respond well to treatment.

These tumors can often block the flow of cerebrospinal fluid (CSF). This can lead to a dangerous rise in the pressure inside the skull, which might need to be treated right away with some type of surgery.

Children with medulloblastoma are often divided into 2 groups (see “How are brain and spinal cord tumors in children staged?”), with those in the high-risk group usually getting more intensive treatment than children in the standard-risk group. More recently, doctors have started to divide these tumors into 4 groups based on the gene changes within the tumor cells. These might also be used to help determine the best treatment.
Medulloblastomas are removed with surgery when possible, followed by radiation therapy to the area where they started. High doses of radiation are aimed at the area of the tumor. Because these tumors tend to spread to the cerebrospinal fluid (CSF), children 3 or older also may be given lower doses of radiation to the whole brain and the spinal cord (craniospinal radiation). Chemotherapy is usually given after radiation therapy, which might let doctors use lower doses of radiation in some cases. But if the tumor has spread through the CSF, standard doses of radiation will be needed.

For children younger than 3, doctors try to use as little radiation as possible. Chemotherapy is typically the first treatment given after surgery. Depending on how the tumor responds, chemotherapy might be followed by radiation therapy.

There are some reports that giving high-dose chemotherapy followed by an autologous stem cell transplant may be helpful for some children with medulloblastomas. Several clinical trials are now studying this. For more information on stem cell transplants, see our document Stem Cell Transplant (Peripheral Blood, Bone Marrow, and Cord Blood Transplants).

**Pineoblastomas and other PNETs:** These tumors also tend to grow quickly, and they are generally harder to treat than medulloblastomas (although treatment is often like that used for high-risk medulloblastomas).

Surgery is the main treatment for these tumors, but they usually are hard to remove completely. Still, surgery can relieve symptoms and may help make other treatments more effective. Children 3 or older are given radiation therapy after surgery. Because these tumors tend to spread to cerebrospinal fluid (CSF), radiation therapy is often given to the whole brain and the spinal cord (craniospinal radiation).

Chemotherapy may be given with radiation therapy so that a lower dose of radiation can be used. But if the tumor has spread to the CSF, standard doses of radiation will be required. Chemotherapy is also used to treat tumors that come back (recur).

For children younger than 3 years, doctors try to use as little radiation as possible. Chemotherapy is typically the first treatment given after surgery. Some studies have shown very good results using chemotherapy in young children. Depending on how the tumor responds, chemotherapy may or may not be followed by radiation therapy.

There are some reports that giving high-dose chemotherapy followed by an autologous stem cell transplant may be helpful for children with pineoblastomas and other types of PNETs. Several clinical trials are now studying this. For more information on stem cell transplants, see our document Stem Cell Transplant (Peripheral Blood, Bone Marrow, and Cord Blood Transplants).

**Meningiomas**

Surgery is the main treatment for these tumors. Children are usually cured if the surgery removes the tumor completely.
Some tumors, particularly those at the base of the brain, can’t be removed completely, and some are invasive and come back even though they were thought to be completely removed. Radiation therapy after surgery may control the growth of these tumors. Chemotherapy may be tried if surgery and radiation aren’t effective, but it is not helpful in many cases.

**Schwannomas (including acoustic neuromas)**

These slow-growing tumors are usually benign and are cured by surgery. In some centers, small vestibular schwannomas (also known as *acoustic neuromas*) are treated by stereotactic radiosurgery. For larger schwannomas where complete removal is likely to cause problems, as much as possible is safely removed, and what’s left is treated with radiosurgery.

**Spinal cord tumors**

These tumors are usually treated similarly to those of the same type in the brain.

Astrocytomas of the spinal cord usually can’t be removed completely. They may be treated with surgery to remove as much tumor as possible, followed by radiation therapy, or with radiation therapy alone. Chemotherapy may be used after surgery instead of radiation in younger children. It may also be used after radiation therapy in older children if the tumor appears to be growing quickly.

Meningiomas near the spinal cord are often cured by surgery. Some ependymomas can be cured by surgery as well. If an ependymoma can’t be removed completely, radiation therapy will be given after surgery.

**Choroid plexus tumors**

Benign choroid plexus papillomas are usually cured with just surgery. Choroid plexus carcinomas are malignant tumors that are only sometimes cured by surgery. After surgery, these carcinomas are usually treated with radiation and/or chemotherapy.

**Craniopharyngiomas**

Craniopharyngiomas grow very close to the pituitary gland, the optic nerves, and blood vessels that supply the brain, so they can be hard to remove completely without causing side effects. Some neurosurgeons prefer to remove as much of the tumor as possible, while others prefer to remove most of the tumor (debulking) and then give radiation therapy.

Partial surgical removal followed by very focused radiation therapy may cause fewer severe side effects than complete removal, but it is not yet clear if this approach is as good at preventing the tumor from growing back.
Germ cell tumors

The most common germ cell tumor, germinoma, can usually be cured by radiation therapy alone (after it is diagnosed by surgery or study of a cerebrospinal fluid sample). Chemotherapy may be added if the tumor is very large or if radiation doesn’t destroy it completely. To try to reduce side effects in children who have not yet reached puberty, some doctors use chemotherapy followed by a reduced dose of radiation as the main treatment. In very young children, chemotherapy may be used instead of radiation therapy. If other types of germ cell tumors are present, either mixed or not mixed with germinoma, the outlook is usually not as good.

Other types of germ cell tumors (such as teratomas and yolk sac tumors) are rarely cured by surgery. Both radiation therapy and chemotherapy are used to treat them, but in some cases this might not control the tumor completely. Sometimes these tumors spread to the cerebrospinal fluid (CSF), and radiation therapy to the spinal cord and brain is needed as well.

What should you ask your doctor about your child’s brain or spinal cord tumor?

It’s important for you to have honest, open discussions with your child’s cancer care team. They want to answer all of your questions, no matter how minor you might think they are. Here are some questions to consider:

- What kind of tumor does my child have?
- Where is the tumor located, and how far has it spread?
- Will my child need other tests before we can decide on treatment?
- Will we need to see other doctors?
- How much experience do you have treating this type of tumor?
- What are our treatment options? What do you recommend? Why?
- What is likely to happen if we chose not to have treatment right away?
- 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 will 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)?
• What will we do if the treatment doesn’t work or if the tumor comes back?
• What type of follow-up will my child need after treatment?
• Are there nearby support groups 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 second opinions concerning the diagnosis and treatment options, or about clinical trials for which your child may qualify.

Also keep in mind that doctors are not the only ones who can provide you with information. Other health care professionals, such as nurses and social workers, may be able to answer some of your questions. You can find out more about speaking with your child’s health care team in our document *Talking With Your Doctor*.

**What happens after treatment for brain and spinal cord tumors in children?**

After treatment, the main concerns for most families are the short- and long-term effects of the tumor and its treatment, and concerns about the tumor still being present or coming back.

It’s certainly normal to want to put the tumor and its treatment behind you, and to get back to a life that doesn’t revolve around the tumor. But it’s important to realize that follow-up care is a central part of this process that offers your child the best chance for recovery and long-term survival.

**Looking for tumor progression or recurrence**

In some cases, even with slow-growing tumors, some of the tumor may still remain after treatment. Even when childhood tumors are treated successfully, some might come back even many years later. (Your child’s doctor should be able to give you an idea of how likely this is.)
Imaging tests (CT or MRI scans), physical exams, and sometimes other tests will be done after treatment to help determine how successful it was. Whether the tumor was removed completely or not, your child’s health care team will want to watch your child closely, especially in the first few months and years after treatment to watch for tumor growth or recurrence. Depending on the type and location of the tumor and the extent of the treatment, the team will let you know which tests need to be done and how often.

During this time, report any new symptoms to your child’s doctor right away, so the cause can be determined and treated, if need be. Your child’s doctor can give you an idea of what to look for. If your child needs further treatment at some point, the doctor will go over the options with you.

Recovering from the effects of the tumor and its treatment

The tumor and its treatment might cause physical, mental, and emotional side effects, which can range from very mild to fairly severe. A child’s brain is often better able to adjust to changes than an adult’s, but it’s also more sensitive to treatments such as radiation. What’s more, some effects might be long-lasting or might not show up until years after treatment.

Once your child has recovered from treatment, the doctors will try to determine the extent of any damage to the brain or other areas. In a very young child this may take time. Physical exams and imaging tests (CT or MRI scans) will be done to determine the extent and location of any changes in the brain.

Several types of doctors and other health professionals might help look for these changes and help your child recover.

• A neurologist (a doctor who specializes in medical treatment of the nervous system) may assess your child’s physical coordination, muscle strength, and other aspects of nervous system function.

• If there is muscle weakness or paralysis, your child will be seen by physical and/or occupational therapists and perhaps a physiatrist (a doctor who specializes in rehabilitation) while in the hospital and/or as an outpatient for physical therapy.

• If speech is affected, a speech therapist will help your child improve talking and communicating.

• If needed, an ophthalmologist (a doctor who specializes in eye problems) will check your child’s vision, and an audiologist can check your child’s hearing. If problems with vision or hearing are found, your child may need some type of special education.

• Your child may also be seen by a psychiatrist or psychologist to determine the extent of any damage caused by the tumor and by treatment. The doctor will document your child’s development in areas such as general intelligence, speech and hearing, memory, and learning skills.
• If the tumor was in or near the base of the brain (such as a craniopharyngioma) or if radiation therapy was given to this area, the pituitary gland could be damaged, which could affect hormone levels. Symptoms can include fatigue, listlessness, poor appetite, cold intolerance, and constipation, which may point to low levels of cortisol and/or thyroid hormone. Other problems can include delayed growth and/or sexual maturation. Sometimes these symptoms may appear even before treatment, as a result of the tumor itself. If there is reason to think the pituitary has been affected, your child may be seen by an endocrinologist (a doctor who specializes in hormone disorders). Hormone treatments may be prescribed to restore normal hormone levels. For example, growth hormone can be given to help restore normal growth.

Late and long-term effects of treatment

A major concern of both parents and doctors is the potential for lasting effects from treatment, as well as effects that don’t show up until years later. Some of these, such as learning problems or delayed growth and development, were mentioned above. Others might include effects on the reproductive system as boys and girls get older or an increased risk of other cancers later in life. While doctors do everything they can to limit the chance of these complications, sometimes they may be an unavoidable part of making sure the tumor is treated properly.

To help increase awareness of late effects and improve follow-up care of childhood cancer survivors throughout their lives, the Children’s Oncology Group (COG) has developed long-term follow-up guidelines for survivors of childhood cancers. These guidelines can help you know what to watch for, what type of screening tests should be done to look for problems, and how late effects are treated.

It’s very important to discuss possible long-term complications with your child’s health care team, and to make sure there is a plan in place to watch for these problems and treat them, if needed. To learn more, ask your child’s doctors about the COG survivor guidelines. You can also view them on the COG website at www.survivorshipguidelines.org. The guidelines themselves are written for health professionals, so you might want to go over the information with the child’s treatment team. Information based on some of the guidelines, written for families of children with cancer, is also available (as “Health Links”) on the site.

For more about some of the possible long-term effects of treatment, see our document *Children Diagnosed With Cancer: Late Effects of Cancer Treatment.*

Social, emotional, and other issues in children with brain or spinal cord tumors

Children can develop social and emotional issues both during and after treatment. Factors such as the child’s age when diagnosed and the extent of treatment can play a role here.
Brain and spinal cord tumors and their treatment can sometimes affect how a child does some everyday tasks, including certain school, work, or recreational activities. These effects are often greatest during the first year of treatment, but they can be long-lasting in some children. It’s important that the treating center assess the family situation as soon as possible, so that any areas of concern can be addressed.

Some children and teens may have emotional or psychological issues that need to be addressed during and after treatment. Depending on their age, they may also have some problems with normal functioning and school work. These can often be helped with support and encouragement. Doctors and other members of the health care team can also often recommend special support programs and services to help after treatment.

Many experts recommend that school-age children and teens attend school as much as possible. This can help them maintain a sense of daily routine and keep their friends informed about what is going on.

Friends can be a great source of support, but patients and parents should know that some people have misunderstandings and fears about diseases such as brain tumors. Some treatment centers have a school re-entry program that can help in situations like this. In this program, a teacher (called a school liaison) working with the hospital can help pave the way for your child going (back) to school by talking with the teachers, explaining your child’s health issues, and discussing any special education techniques that might be needed. The liaison can also talk to the students about the diagnosis, treatment, and changes the child might go through, as well as answer questions from teachers and classmates. (For more information, see our document Children Diagnosed With Cancer: Returning to School.)

Centers that treat many children with brain and spinal cord tumors might have programs to introduce new patients to others who have already finished treatment. This can give patients and their families an idea of what to expect during and after treatment, which can be very important.

Parents and other family members can also be affected, both emotionally and in other ways. Some common family concerns during treatment include financial stresses, traveling to and staying near the treatment center, the possible loss of a job, and the need for home schooling. Social workers and other professionals at treatment centers can help families sort through these issues.

During treatment, children and their families tend to focus on the daily aspects of getting through it and beating the tumor. But once treatment is finished, a number of emotional concerns can arise. Some of these might last a long time. They can include things like:

- Dealing with physical changes that can result from the treatment
- Worrying about the tumor returning or new health problems developing
- Feeling resentful for having had a tumor or having to go through treatment when others do not
• Worrying about being treated differently or discriminated against (by friends, classmates, coworkers, employers, etc.)

• Being concerned about dating, marrying, and having a family later in life

No one chooses to have a brain or spinal cord tumor, but for many children and teens, the experience can eventually be positive, helping to establish strong self-values. Other children may have a harder time recovering, adjusting to life after the tumor, and moving on. It is normal to have some anxiety or other emotional reactions after treatment, but feeling overly worried, depressed, or angry can affect many parts of a young person’s emotional growth. It can get in the way of relationships, school, work, and other aspects of life.

With support from family, friends, other survivors, mental health professionals, and others, many people who have survived their tumor can thrive in spite of the challenges they’ve had to face.

**Keeping good medical records**

As much as you might want to put the experience behind you once treatment is completed, it is very important to keep good records of your child’s medical care during this time. This can be very helpful later on as your child sees new doctors. Gathering the details soon after treatment may be easier than trying to get them at some point in the future. There are certain pieces of information that your child’s doctors should have, even after the child has become an adult. These include:

• A copy of the pathology report(s) from any biopsies or surgeries.

• Copies of imaging tests (CT or MRI scans, etc.), which can usually be stored digitally (on a DVD, etc.)

• If your child had surgery, a copy of the operative report(s).

• If your child stayed in the hospital, a copy of the discharge summaries that the doctors prepared when your child was sent home.

• If your child got chemotherapy or other medicines, a list of the final doses of each drug your child received.

• If your child had radiation therapy, a final summary of the dose and field.

It is also very important to keep your child’s health insurance. Tests and doctor visits cost a lot, and even though no one wants to think of the tumor coming back, this could happen.
What’s new in research and treatment for brain and spinal cord tumors in children?

There is always research going on in the area of brain and spinal cord tumors. Scientists are looking for causes and ways to prevent them, and doctors are working to improve treatments.

Understanding gene changes in tumors

Researchers continue to look for the gene changes inside cells that result in brain and spinal cord tumors. The hope is that learning more about these gene changes may lead to better ways to treat these tumors.

For example, researchers have found that medulloblastomas can be divided into 4 main types, based on the different gene changes in the tumor cells. Some of these tumor types have a better outlook than others. Doctors are now learning how to use this information to help decide which children might need more or less intensive treatment.

More recently, researchers have identified some of the specific gene changes found in each type of medulloblastoma that might help the tumor cells grow. Some of these gene changes can be targeted with new types of drugs, which are now being tested in clinical trials. In the future, doctors may be able to develop other drugs that specifically target these gene changes.

Imaging and surgery techniques

Recent advances have made surgery for brain tumors much safer and more successful. Some of these newer techniques include:

- **Functional magnetic resonance imaging** (fMRI, described in “How are brain and spinal cord tumors in children diagnosed?”), which can identify the site of important areas of the brain and how close they are to the tumor.

- **Magnetic resonance spectroscopic imaging** (MRSI, described in “How are brain and spinal cord tumors in children diagnosed?”). In this approach, specially processed MRS information is used to make a map of important chemicals involved in tumor metabolism. This is being developed to help surgeons direct their biopsies to the most abnormal areas in the tumor and to help doctors direct radiation and evaluate the effects of chemotherapy or targeted therapy.

- **Fluorescence-guided surgery**. For this approach, the patient drinks a special dye a few hours before surgery. The dye is taken up mainly by the tumor, which then glows when the surgeon looks at it under special lighting from the operating microscope. This lets the surgeon better separate tumor from normal brain tissue.
• **Newer surgical approaches** for some types of tumors. For example, a newer approach to treat some tumors in or near the pituitary (such as some craniopharyngiomas) is to use an endoscope, a thin tube with a tiny video camera lens at the tip. The endoscope is passed through a hole made in the back of the nose, which allows the surgeon to operate through the nasal passages and limits the potential damage to the brain. A similar technique can be used for some tumors in the ventricles, where a small opening in the skull near the hairline serves as the point of endoscope insertion. The use of this technique is limited by the tumor’s size, shape, position, and by how many blood vessels it contains.

**Radiation therapy**

Several newer types of radiation therapy now let doctors aim radiation more precisely at the tumor, which helps spare normal brain tissue from getting too much radiation. Newer techniques such as stereotactic radiosurgery, 3-dimensional conformal radiation therapy (3D-CRT), intensity modulated radiation therapy (IMRT), and proton beam therapy are described in the section “Radiation therapy.”

The brain is very sensitive to radiation, which can lead to side effects if normal brain tissue receives a large dose, especially if the child is very young. Clinical trials have shown that in some situations, using chemotherapy can let doctors use lower doses of radiation therapy without lowering the chance that treatment will be effective. Doctors are now trying to determine if even lower doses of radiation can be used and still give the same results.

**Chemotherapy**

New approaches may help make chemotherapy (chemo) more useful against brain and spinal cord tumors.

**Adjuvant chemotherapy**

In some children and infants with brain tumors, chemo is given right after surgery to either delay radiation therapy (particularly in infants) or to decrease the radiation dose needed to treat the tumor. This is known as *adjuvant chemotherapy*. Some studies are looking at whether giving prolonged chemo can help avoid the need for radiation therapy at all in certain cases.

**High-dose chemotherapy and stem cell transplant**

One of the main factors that limits the doses of chemo that can be given safely is its effects on the bone marrow, where new blood cells are normally made. A stem cell transplant allows higher doses of chemo to be given than would normally be possible. First, blood stem cells are removed from either the child’s blood or the bone marrow and are stored in a deep freeze. The child is then treated with very high doses of chemo. The blood stem cells are then
thawed and infused back into the body, where they settle in the bone marrow and start making new blood cells.

Although some children with certain brain or spinal cord tumors (such as medulloblastomas) have responded well to this very intensive treatment, it can have serious side effects, and it is not yet known if it is effective enough to become standard. For now, most doctors consider this treatment experimental for brain and spinal tumors. Clinical trials are being done to determine how useful it is.

**Improving chemotherapy drugs**

Many chemo drugs are limited in their effectiveness because the tightly controlled openings in the brain capillaries, sometimes referred to as the *blood-brain barrier*, prevents them from getting from the bloodstream to some parts of the brain tumor. Researchers are now trying to modify some of these drugs by coating them with tiny layers of fat (liposomes) or attaching them to molecules that normally cross the blood-brain barrier, to help them work better. This is an area of active research.

**Getting chemotherapy directly to tumors**

Some newer approaches might help doctors get chemo directly to brain and spinal cord tumors.

For example, in one method called *convection enhanced delivery*, small tubes are placed into the tumor in the brain through a small hole in the skull during surgery. The tubing extends through the scalp and is connected to an infusion pump, through which chemo drugs can be given. This can be done for hours or days and might be repeated more than once, depending on the drug used. This technique can also be used to get other, newer types of drugs into the tumor. This is still an investigational method, and studies are continuing.

**Other new treatment strategies**

Researchers are also testing some newer approaches to treatment that may help doctors target tumors more precisely. The hope is to develop more effective treatments that cause fewer side effects. Although these treatment approaches are promising, most are still experimental at this time and are only available through clinical trials.

**Targeted drugs**

As researchers have learned more about the gene changes in tumor cells that help them grow, they have developed newer drugs that target these changes. These targeted drugs work differently from standard chemo drugs.
One example of such a targeted drug is everolimus (Afinitor), which may shrink or slow the growth of subependymal giant cell astrocytomas (SEGAs) that can’t be removed with surgery (see “Targeted therapy for brain and spinal cord tumors in children”).

Some types of medulloblastomas tend to have mutations (changes) in genes that are part of a cell signaling route called the hedgehog pathway. The hedgehog pathway is crucial for the development of the embryo and fetus, but it can be overactive in some medulloblastoma cells. Drugs that target proteins in this pathway are now being tested against medulloblastoma in clinical trials.

Many other targeted drugs are already being used to treat other types of cancer, and some are being studied to see if they will work for brain tumors as well.

**Angiogenesis inhibitors**

Tumors have to create new blood vessels (a process called angiogenesis) to keep their cells nourished. New drugs that attack these blood vessels are used to help treat some cancers, including some brain tumors in adults. Several drugs that impair blood vessel growth are now being studied for use against brain tumors in children.

**Hypoxic cell sensitizers**

Some drugs increase the oxygen content in the tumor, which makes tumor cells more likely to be killed by radiation therapy if the drugs are given before treatment. Studies are now looking to see if this affects treatment outcomes.

**Immunotherapy**

The goal of immunotherapy is to make the body’s own immune system fight the tumor.

Several types of vaccines are being developed against brain tumor cells. Unlike vaccines against infectious diseases, these vaccines are meant to help treat the disease instead of prevent it. The goal of the vaccines is to stimulate the body’s immune system to attack the brain tumor cells.

Early study results of some of these vaccines have shown promise, but more research is needed to determine how effective they are. At this time, brain tumor vaccines are available only through clinical trials.

Other types of drugs that affect the immune system, such as lenalidomide, are also being studied.
Therapeutic viruses

Researchers have done a great deal of lab work with viruses that reproduce only within brain tumor cells and then cause those cells to die, while leaving normal cells alone. Research using these viruses in humans with brain tumors is still in very early stages.

Additional resources for brain and spinal cord tumors in children

More information from your American Cancer Society

We have a lot more information that you might find helpful. Explore www.cancer.org or call our National Cancer Information Center toll-free number, 1-800-227-2345. We’re here to help you any time, day or night.

National organizations and websites*

Along with the American Cancer Society, other sources of information and support include:

Websites for parents and adults

American Brain Tumor Association
Toll-free number: 1-800-886-2282 (1-800-886-ABTA)
Website: www.abta.org

Has information about brain tumors in children and teens as well as adults, by web and phone. Also has lists of support groups across the US.

Children’s Brain Tumor Foundation
Toll-free number: 1-866-228-4673 (1-866-228-HOPE)
Website: www.cbtf.org

Offers information, counseling, and survivorship information, as well as online support from families who’ve been there. Books for kids and parents also available in Spanish.

National Brain Tumor Society
Toll-free number: 1-800-934-2873 (1-800-934-CURE)
Website: www.braintumor.org

Call or choose “information” on the website home page to get lists of treatment centers, learn about living with brain tumor, manage common problems, and find resources for caregivers and family members. Also has information in Spanish.
American Childhood Cancer Organization (formerly Candlelighters)
Toll-free number: 1-855-858-2226
Website: www.acco.org

Offers information for children and teens with cancer, their siblings, and adults dealing with children with cancer. Also offers books and a special kit for children newly diagnosed with cancer, as well as some local support groups.

Children’s Oncology Group
Website: www.childrensoncologygroup.org

Provides key information from the world’s largest organization devoted to childhood cancer research to help support children and their families from the time of diagnosis, through treatment, and beyond.

CureSearch for Children’s Cancer
Toll-free number: 1-800-458-6223
Website: www.curesearch.org

Provides up-to-date information about childhood cancer from pediatric cancer experts. Has sections on the Web site for patients, families, and friends to help guide them on how to support the child with cancer.

National Cancer Institute
Toll-free number: 1-800-422-6237 (1-800-4-CANCER)
Website: www.cancer.gov

Provides accurate, up-to-date information about cancer for patients and their families, including clinical trials information. Offers a special booklet for teen siblings of a child with cancer at: www.cancer.gov/cancertopics/when-your-sibling-has-cancer.

National Children’s Cancer Society, Inc.
Toll-free number: 1-800-532-6459 (1-800-5-FAMILY)
Website: www.children-cancer.org

Services include an online support network for parents of children with cancer, educational materials, and financial assistance for treatment-related expenses.

Websites for teens and children

Starlight Children’s Foundation
Toll-free number: 1-310-479-1212
Website: www.starlight.org

Website has animated stories and interactive programs to teach kids about chemo and procedures that may be done in the hospital; also provides a safe, monitored online support group for teens with cancer.
**Group Loop** (a subsite of the Cancer Support Community just for teens)
Toll-free number: 1-888-793-9355
Website: [www.grouploop.org](http://www.grouploop.org)

An online place for teens with cancer or teens who know someone with cancer to connect with other teens – away from the pressures of classes, responsibilities, and treatment schedules. Has online support groups, chat rooms, information, and more.

**Teens Living with Cancer**
Website: [www.teenslivingwithcancer.org](http://www.teenslivingwithcancer.org)

An online-only resource dedicated to teens coping with a cancer diagnosis and treatment. It focuses on teen issues and provides resources to support teens, their families, and friends.

**SuperSibs! powered by Alex’s Lemonade Stand**
Toll-free number: 1-866-333-1213
Website: [www.supersibs.org](http://www.supersibs.org)

Supports, honors, and recognizes brothers and sisters of children diagnosed with cancer so they may face the future with strength, courage, and hope. Alex’s Lemonade Stand is restarting SuperSibs in 2014 so there may be some delays with resuming support services.

*Inclusion on this list does not imply endorsement by the American Cancer Society.*

No matter who you are, we can help. Contact us anytime, day or night, for information and support. Call us at **1-800-227-2345** or visit www.cancer.org.

**References: Brain and spinal cord tumors in children detailed guide**


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