What
You
Need
To
Know
About
Brain
Tumors





This booklet is about brain tumors. The Cancer Information Service can help you learn more about these tumors. The staff can talk with you in English or Spanish.

The number is 1–800–4–CANCER (1–800–422–6237). The number for deaf and hard of hearing callers with TTY equipment is 1–800–332–8615. The call is free.

Este folleto es acerca de los tumores cerebrales. Llame al Servicio de Información sobre el Cáncer para saber más sobre esta enfermedad. Este servicio tiene personal que habla español.

El número a llamar es el 1–800–4–CANCER (1–800–422–6237). Personas con problemas de audición y que cuentan con equipo TTY pueden llamar al 1–800–332–8615. La llamada es gratis.



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What You Need To Know About™ Brain Tumors

his National Cancer Institute (NCI) booklet has important information about brain *tumors*.* It discusses possible causes, symptoms, diagnosis, treatment, and followup care. It also has information to help patients cope with brain tumors.

Primary and Secondary Brain Tumors

A tumor that begins in the brain is called a **primary** brain tumor. In children, most brain tumors are primary tumors. In adults, most tumors in the brain have spread there from the lung, breast, or other parts of the body. When this happens, the disease is not brain cancer. The tumor in the brain is a **secondary** tumor. It is named for the organ or the tissue in which it began.

Treatment for secondary brain tumors depends on where the cancer started and the extent of the disease.

Information specialists at the NCI's Cancer Information Service at 1–800–4–CANCER can answer questions about primary and secondary brain tumors, and they can send NCI materials. Many NCI publications and fact sheets can be viewed on the Internet at http://cancer.gov/publications. People in the United States and its territories may use this Web

^{*}Words that may be new to readers appear in *italics*. The

[&]quot;Dictionary" section explains these terms. Some words in the

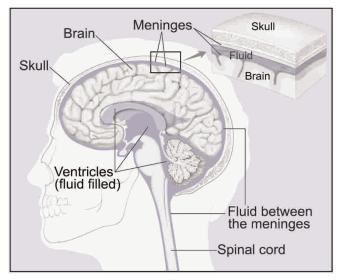
[&]quot;Dictionary" have a "sounds-like" spelling to show how to pronounce them.



site to order publications. This Web site also explains how people outside the United States can mail or fax their requests for NCI publications.

The Brain

he brain is a soft, spongy mass of *tissue*. It is protected by the bones of the skull and three thin *membranes* called *meninges*. Watery fluid called *cerebrospinal fluid* cushions the brain. This fluid flows through spaces between the meninges and through spaces within the brain called *ventricles*.



This picture shows the brain and nearby structures.

A network of nerves carries messages back and forth between the brain and the rest of the body. Some nerves go directly from the brain to the eyes, ears, and other parts of the head. Other nerves run through the spinal



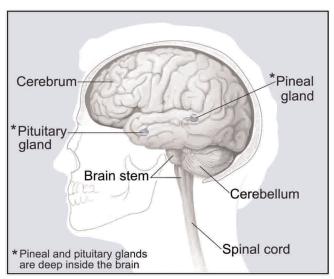
cord to connect the brain with the other parts of the body. Within the brain and spinal cord, *glial cells* surround *nerve cells* and hold them in place.

The brain directs the things we choose to do (like walking and talking) and the things our body does without thinking (like breathing). The brain is also in charge of our senses (sight, hearing, touch, taste, and smell), memory, emotions, and personality.

The three major parts of the brain control different activities:

- *Cerebrum*—The cerebrum is the largest part of the brain. It is at the top of the brain. It uses information from our senses to tell us what is going on around us and tells our body how to respond. It controls reading, thinking, learning, speech, and emotions.
 - The cerebrum is divided into the left and right *cerebral hemispheres*, which control separate activities. The right hemisphere controls the muscles on the left side of the body. The left hemisphere controls the muscles on the right side of the body.
- *Cerebellum*—The cerebellum is under the cerebrum at the back of the brain. The cerebellum controls balance and complex actions like walking and talking.
- Brain Stem—The brain stem connects the brain with the spinal cord. It controls hunger and thirst. It also controls breathing, body temperature, blood pressure, and other basic body functions.





This picture shows the major parts of the brain.

Understanding Cancer

ancer begins in *cells*, the building blocks that make up tissues. Tissues make up the organs of the body.

Normally, cells grow and divide to form new cells as the body needs them. When cells grow old, they die, and new cells take their place.

Sometimes this orderly process goes wrong. New cells form when the body does not need them, and old cells do not die when they should. These extra cells can form a mass of tissue called a growth or tumor.



Benign and Malignant Brain Tumors

Brain tumors can be benign or malignant:

- Benign brain tumors do not contain cancer cells:
 - Usually, benign tumors can be removed, and they seldom grow back.
 - The border or edge of a benign brain tumor can be clearly seen. Cells from benign tumors do not invade tissues around them or spread to other parts of the body. However, benign tumors can press on sensitive areas of the brain and cause serious health problems.
 - Unlike benign tumors in most other parts of the body, benign brain tumors are sometimes life threatening.
 - Very rarely, a benign brain tumor may become malignant.
- Malignant brain tumors contain cancer cells:
 - Malignant brain tumors are generally more serious and often are life threatening.
 - They are likely to grow rapidly and crowd or invade the surrounding healthy brain tissue.
 - Very rarely, cancer cells may break away from a malignant brain tumor and spread to other parts of the brain, to the spinal cord, or even to other parts of the body. The spread of cancer is called metastasis.
 - Sometimes, a malignant tumor does not extend into healthy tissue. The tumor may be contained within a layer of tissue. Or the bones of the skull or another structure in the head may confine it. This kind of tumor is called *encapsulated*.



Tumor Grade

Doctors sometimes group brain tumors by *grade*—from low grade (grade I) to high grade (grade IV). The grade of a tumor refers to the way the cells look under a microscope. Cells from high-grade tumors look more abnormal and generally grow faster than cells from low-grade tumors.

Primary Brain Tumors

Tumors that begin in brain tissue are known as *primary tumors* of the brain. (Information about secondary brain tumors appears in the following section.) Primary brain tumors are named according to the type of cells or the part of the brain in which they begin.

The most common primary brain tumors are *gliomas*. They begin in glial cells. There are many types of gliomas:

- Astrocytoma—The tumor arises from star-shaped glial cells called astrocytes. In adults, astrocytomas most often arise in the cerebrum. In children, they occur in the brain stem, the cerebrum, and the cerebellum. A grade III astrocytoma is sometimes called an anaplastic astrocytoma. A grade IV astrocytoma is usually called a glioblastoma multiforme.
- Brain stem glioma—The tumor occurs in the lowest part of the brain. Brain stem gliomas most often are diagnosed in young children and middle-aged adults.
- Ependymoma—The tumor arises from cells that line the ventricles or the central canal of the spinal cord. They are most commonly found in children and young adults.



 Oligodendroglioma—This rare tumor arises from cells that make the fatty substance that covers and protects nerves. These tumors usually occur in the cerebrum. They grow slowly and usually do not spread into surrounding brain tissue. They are most common in middle-aged adults.

Some types of brain tumors do not begin in glial cells. The most common of these are:

- *Medulloblastoma*—This tumor usually arises in the cerebellum. It is the most common brain tumor in children. It is sometimes called a *primitive* neuroectodermal tumor.
- *Meningioma*—This tumor arises in the meninges. It usually grows slowly.
- **Schwannoma**—A tumor that arises from a *Schwann cell*. These cells line the nerve that controls balance and hearing. This nerve is in the inner ear. The tumor is also called an acoustic *neuroma*. It occurs most often in adults.
- Craniopharyngioma—The tumor grows at the base of the brain, near the pituitary gland. This type of tumor most often occurs in children.
- *Germ cell tumor* of the brain—The tumor arises from a *germ cell*. Most germ cell tumors that arise in the brain occur in people younger than 30. The most common type of germ cell tumor of the brain is a *germinoma*.
- *Pineal region tumor*—This rare brain tumor arises in or near the *pineal gland*. The pineal gland is located between the cerebrum and the cerebellum.

Secondary Brain Tumors

When cancer spreads from its original place to another part of the body, the new tumor has the same kind of abnormal cells and the same name as the



primary tumor. Cancer that spreads to the brain from another part of the body is different from a primary brain tumor. When cancer cells spread to the brain from another organ (such as the lung or breast), doctors may call the tumor in the brain a *secondary tumor* or *metastatic* tumor. Secondary tumors in the brain are far more common than primary brain tumors.

Brain Tumors: Who's at Risk?

o one knows the exact causes of brain tumors. Doctors can seldom explain why one person develops a brain tumor and another does not. However, it is clear that brain tumors are not contagious. No one can "catch" the disease from another person.

Research has shown that people with certain *risk factors* are more likely than others to develop a brain tumor. A risk factor is anything that increases a person's chance of developing a disease.

The following risk factors are associated with an increased chance of developing a primary brain tumor:

- Being male—In general, brain tumors are more common in males than females. However, meningiomas are more common in females.
- Race—Brain tumors occur more often among white people than among people of other races.
- Age—Most brain tumors are detected in people who are 70 years old or older. However, brain tumors are the second most common cancer in children.
 (Leukemia is the most common childhood cancer.)
 Brain tumors are more common in children younger than 8 years old than in older children.
- **Family history**—People with family members who have gliomas may be more likely to develop this disease.



Being exposed to radiation or certain chemicals at work

- Radiation—Workers in the nuclear industry have an increased risk of developing a brain tumor.
- Formaldehyde—Pathologists and embalmers
 who work with formaldehyde have an increased
 risk of developing brain cancer. Scientists have
 not found an increased risk of brain cancer among
 other types of workers exposed to formaldehyde.
- Vinyl chloride—Workers who make plastics may be exposed to vinyl chloride. This chemical may increase the risk of brain tumors.
- Acrylonitrile—People who make textiles and plastics may be exposed to acrylonitrile. This exposure may increase the risk of brain cancer.

Scientists are investigating whether cell phones may cause brain tumors. Studies thus far have not found an increased risk of brain tumors among people who use cell phones.

Scientists also continue to study whether head injuries are a risk factor for brain tumors. So far, these studies have not found an increased risk among people who have had head injuries.

Most people who have known risk factors do not get brain cancer. On the other hand, many who do get the disease have none of these risk factors. People who think they may be at risk should discuss this concern with their doctor. The doctor may be able to suggest ways to reduce the risk and can plan an appropriate schedule for checkups.



Symptoms

he *symptoms* of brain tumors depend on tumor size, type, and location. Symptoms may be caused when a tumor presses on a nerve or damages a certain area of the brain. They also may be caused when the brain swells or fluid builds up within the skull.

These are the most common symptoms of brain tumors:

- Headaches (usually worse in the morning)
- Nausea or vomiting
- · Changes in speech, vision, or hearing
- Problems balancing or walking
- Changes in mood, personality, or ability to concentrate
- Problems with memory
- Muscle jerking or twitching (seizures or convulsions)
- Numbness or tingling in the arms or legs

These symptoms are not sure signs of a brain tumor. Other conditions also could cause these problems. Anyone with these symptoms should see a doctor as soon as possible. Only a doctor can diagnose and treat the problem.

Diagnosis

f a person has symptoms that suggest a brain tumor, the doctor may perform one or more of the following procedures:

 Physical exam—The doctor checks general signs of health.





- *Neurologic* exam—The doctor checks for alertness, muscle strength, coordination, reflexes, and response to pain. The doctor also examines the eyes to look for swelling caused by a tumor pressing on the nerve that connects the eye and brain.
- *CT scan*—An *x-ray* machine linked to a computer takes a series of detailed pictures of the head. The patient may receive an injection of a special dye so the brain shows up clearly in the pictures. The pictures can show tumors in the brain.
- MRI—A powerful magnet linked to a computer makes detailed pictures of areas inside the body.
 These pictures are viewed on a monitor and can also be printed. Sometimes a special dye is injected to



help show differences in the tissues of the brain. The pictures can show a tumor or other problem in the brain.

The doctor may ask for other tests:

- Angiogram— Dye injected into the bloodstream flows into the blood vessels in the brain to make them show up on an x-ray. If a tumor is present, the doctor may be able to see it on the x-ray.
- **Skull x-ray**—Some types of brain tumors cause calcium deposits in the brain or changes in the bones of the skull. With an x-ray, the doctor can check for these changes.
- *Spinal tap*—The doctor may remove a sample of cerebrospinal fluid (the fluid that fills the spaces in and around the brain and spinal cord). This procedure is performed with *local anesthesia*. The doctor uses a long, thin needle to remove fluid from the spinal column. A spinal tap takes about 30 minutes. The patient must lie flat for several hours afterward to keep from getting a headache. A laboratory checks the fluid for cancer cells or other signs of problems.
- *Myelogram*—This is an x-ray of the spine. A spinal tap is performed to inject a special dye into the cerebrospinal fluid. The patient is tilted to allow the dye to mix with the fluid. This test helps the doctor detect a tumor in the spinal cord.
- Biopsy—The removal of tissue to look for tumor cells is called a biopsy. A pathologist looks at the cells under a microscope to check for abnormal cells. A biopsy can show cancer, tissue changes that may lead to cancer, and other conditions. A biopsy is the only sure way to diagnose a brain tumor.



Surgeons can obtain tissue to look for tumor cells in three ways:

- Needle biopsy—The surgeon makes a small incision in the scalp and drills a small hole into the skull. This is called a burr hole. The doctor passes a needle through the burr hole and removes a sample of tissue from the brain tumor.
- Stereotactic biopsy—An imaging device, such as CT or MRI, guides the needle through the burr hole to the location of the tumor. The surgeon withdraws a sample of tissue with the needle.
- Biopsy at the same time as treatment—
 Sometimes the surgeon takes a tissue sample when the patient has *surgery* to remove the tumor.

 Sometimes a biopsy is not possible. If the tumor is in the brain stem or certain other areas, the surgeon may not be able to remove tissue from the tumor without damaging normal brain tissue. The doctor uses MRI, CT, or other imaging tests instead.

A person who needs a biopsy may want to ask the doctor the following questions:

- Why do I need a biopsy? How will the biopsy affect my treatment plan?
- What kind of biopsy will I have?
- How long will it take? Will I be awake? Will it hurt?
- What are the chances of infection or bleeding after the biopsy? Are there any other risks?
- How soon will I know the results?
- If I do have a brain tumor, who will talk to me about treatment? When?



Treatment

any people with brain tumors want to take an active part in making decisions about their medical care. They want to learn all they can about their disease and their treatment choices. However, shock and stress after a diagnosis of a brain tumor can make it hard to think of everything to ask the doctor. It often helps to make a list of questions before an appointment. To help remember what the doctor says, patients may take notes or ask whether they may use a tape recorder. Some also want to have a family member or friend with them when they talk to the doctor—to take part in the discussion, to take notes, or just to listen.

The doctor may refer the patient to a specialist, or the patient may ask for a referral. Specialists who treat brain tumors include *neurosurgeons*, *neurooncologists*, *medical oncologists*, and *radiation oncologists*. The patient may be referred to other health care professionals who work together as a team. The medical team may include a *nurse*, *dietitian*, *mental health counselor*, *social worker*, *physical therapist*, *occupational therapist*, and *speech therapist*. Children may need tutors to help with schoolwork. (The section on "Rehabilitation" on page 24 has more information about therapists and tutors.)

Getting a Second Opinion

Before starting treatment, the patient might want a second opinion about the diagnosis and the treatment plan. Some insurance companies require a second opinion; others may cover a second opinion if the patient or doctor requests it.



There are a number of ways to find a doctor for a second opinion:

- The patient's doctor may refer the patient to one or more specialists. At cancer centers, several specialists often work together as a team.
- The Cancer Information Service, at 1–800–4–CANCER, can tell callers about nearby treatment centers.
- A person with a brain tumor can request a consultation with a team of specialists in NCI's Neuro-Oncology Branch of the Warren Grant Magnuson Clinical Center at the National Institutes of Health in Bethesda, Maryland (301–402–6298).
- A local or state medical society, a nearby hospital, or a medical school can usually provide the names of specialists.
- The Official ABMS Directory of Board Certified Medical Specialists lists doctors' names along with their specialty and their educational background. Board-certified doctors have met specific education and training requirements and have passed an examination given by a specialty board. This resource is available in most public libraries. The American Board of Medical Specialties (ABMS) also offers information about board certification by telephone and on the Internet. The public may use these services to check whether a doctor is board certified. The telephone number is 1–866–ASK–ABMS (1–866–275–2267). The Internet address is http://www.abms.org.

Preparing for Treatment

The doctor can describe treatment choices and discuss the results expected with each treatment option. The doctor and patient can work together to develop a treatment plan that fits the patient's needs.



Treatment depends on a number of factors, including the type, location, size, and grade of the tumor. For some types of brain cancer, the doctor also needs to know whether cancer cells were found in the cerebrospinal fluid.

These are some questions a person may want to ask the doctor before treatment begins:

- What type of brain tumor do I have?
- Is it benign or malignant?
- What is the grade of the tumor?
- What are my treatment choices? Which do you recommend for me? Why?
- What are the benefits of each kind of treatment?
- What are the risks and possible *side effects* of each treatment?
- What is the treatment likely to cost?
- How will treatment affect my normal activities?
- Would a *clinical trial* (research study) be appropriate for me? Can you help me find one?

People do not need to ask all of their questions or understand all of the answers at one time. They will have other chances to ask the doctor to explain things that are not clear and to ask for more information.

Methods of Treatment

People with brain tumors have several treatment options. Depending on the tumor type and *stage*, patients may be treated with *surgery*, *radiation therapy*,





or *chemotherapy*. Some patients receive a combination of treatments.

In addition, at any stage of disease, they may have treatment to control pain and other symptoms of the cancer, to relieve the side effects of therapy, and to ease emotional problems. This kind of treatment is called *symptom management*, *supportive care*, or *palliative care*.

The doctor is the best person to describe the treatment choices and discuss the expected results.

A patient may want to talk to the doctor about taking part in a clinical trial, which is a research study of new treatment methods. The section on "The Promise of Cancer Research" on page 27 has more information about clinical trials.



Surgery is the usual treatment for most brain tumors. Surgery to open the skull is called a *craniotomy*. It is performed under *general anesthesia*. Before surgery begins, the scalp is shaved. The surgeon then makes an incision in the scalp and uses a special type of saw to remove a piece of bone from the skull. After removing part or all of the tumor, the surgeon covers the opening in the skull with that piece of bone or with a piece of metal or fabric. The surgeon then closes the incision in the scalp.

These are some questions a person may want to ask the doctor before having surgery:

- How will I feel after the operation?
- What will you do for me if I have pain?
- How long will I be in the hospital?
- Will I have any long-term effects? Will my hair grow back? Are there any side effects from using metal or fabric to replace the bone in the skull?
- When can I get back to my normal activities?
- What is my chance of a full recovery?

Sometimes surgery is not possible. If the tumor is in the brain stem or certain other areas, the surgeon may not be able to remove the tumor without damaging normal brain tissue. Patients who cannot have surgery may receive radiation or other treatment.

Radiation therapy (also called radiotherapy) uses high-energy rays to kill tumor cells. The radiation may come from *x-rays*, *gamma rays*, or *protons*. A large machine aims radiation at the tumor and the tissue close to it. Sometimes the radiation may be directed to the entire brain or to the spinal cord.



Radiation therapy usually follows surgery. The radiation kills tumor cells that may remain in the area. Sometimes, patients who cannot have surgery have radiation therapy instead.

The patient goes to a hospital or clinic for radiation therapy. The treatment schedule depends on the type and size of the tumor and the age of the patient. Each treatment lasts only a few minutes.

Doctors take steps to protect the healthy tissue around the brain tumor:

- *Fractionation*—Radiation therapy usually is given five days a week for several weeks. Giving the total dose of radiation over an extended period helps to protect healthy tissue in the area of the tumor.
- Hyperfractionation—The patient gets smaller doses of radiation two or three times a day instead of a larger amount once a day.
- Stereotactic radiation therapy—Narrow beams of radiation are directed at the tumor from different angles. For this procedure, the patient wears a rigid head frame. An MRI or CT scan creates pictures of the tumor's exact location. The doctor uses a computer to decide on the dose of radiation needed, as well as the sizes and angles of the radiation beams. The therapy may be given during a single visit or over several visits.
- 3-dimensional conformal radiation therapy—A computer creates a 3-dimensional image of the tumor and nearby brain tissue. The doctor aims multiple radiation beams to the exact shape of the tumor. The precise focus of the radiation beams protects normal brain tissue.
- **Proton beam radiation therapy**—The source of radiation is protons rather than x-rays. The doctor aims the proton beams at the tumor. Protons can pass through healthy tissue without damaging it.



These are some questions a person may want to ask the doctor before having radiation therapy:

- Why do I need this treatment?
- When will the treatments begin? When will they end?
- How will I feel during therapy? Are there side effects?
- What can I do to take care of myself during therapy?
- How will we know if the radiation is working?
- Will I be able to continue my normal activities during treatment?

Chemotherapy, the use of drugs to kill cancer cells, is sometimes used to treat brain tumors. The drugs may be given by mouth or by injection. Either way, the drugs enter the bloodstream and travel throughout the body. The drugs are usually given in cycles so that a recovery period follows each treatment period.

Chemotherapy may be given in an outpatient part of the hospital, at the doctor's office, or at home. Rarely, the patient may need to stay in the hospital.

Children are more likely than adults to have chemotherapy. However, adults may have chemotherapy after surgery and radiation therapy.

For some patients with *recurrent cancer* of the brain, the surgeon removes the tumor and implants several wafers that contain chemotherapy. Each wafer is about the size of a dime. Over several weeks, the wafers dissolve, releasing the drug into the brain. The drug kills cancer cells.



Patients may want to ask these questions about chemotherapy:

- Why do I need this treatment?
- What will it do?
- Will I have side effects? What can I do about them?
- When will treatment start? When will it end?
- How often will I need checkups?

Side Effects of Treatment

ecause treatment may damage healthy cells and tissues, unwanted side effects are common. These side effects depend on many factors, including the location of the tumor and the type and extent of the treatment. Side effects may not be the same for each person, and they may even change from one treatment session to the next. Before treatment starts, the health care team will explain possible side effects and suggest ways to help the patient manage them.

The NCI provides helpful booklets about cancer treatments and coping with side effects, such as *Radiation Therapy and You*, *Chemotherapy and You*, and *Eating Hints for Cancer Patients*. See the sections "National Cancer Institute Information Resources" on page 40 and "National Cancer Institute Booklets" on page 41 for other sources of information about side effects.

Surgery

Patients often have a headache or are uncomfortable for the first few days after surgery. However, medicine



can usually control their pain. Patients should feel free to discuss pain relief with the doctor or nurse.

It is also common for patients to feel tired or weak. The length of time it takes to recover from an operation varies for each patient.

Other, less common, problems may occur. Cerebrospinal fluid or blood may build up in the brain. This swelling is called *edema*. The health care team monitors the patient for signs of these problems. The patient may receive *steroids* to help relieve swelling. A second surgery may be needed to drain the fluid. The surgeon may place a long, thin tube (*shunt*) in a ventricle of the brain. The tube is threaded under the skin to another part of the body, usually the abdomen. Excess fluid is carried from the brain and drained into the abdomen. Sometimes the fluid is drained into the heart instead.

Infection is another problem that may develop after surgery. If this happens, the health care team gives the patient an *antibiotic*.

Brain surgery may damage normal tissue. Brain damage can be a serious problem. The patient may have problems thinking, seeing, or speaking. The patient also may have personality changes or seizures. Most of these problems lessen or disappear with time. But sometimes damage to the brain is permanent. The patient may need physical therapy, speech therapy, or occupational therapy.

Radiation Therapy

Some patients have nausea for several hours after treatment. The health care team can suggest ways to help patients cope with this problem. Radiation therapy also may cause patients to become very tired as treatment continues. Resting is important, but doctors



usually advise patients to try to stay as active as they can.

In addition, radiation therapy commonly causes hair loss. Hair usually grows back within a few months. Radiation therapy also may affect the skin in the treated area. The scalp and ears may become red, dry, and tender. The health care team can suggest ways to relieve these problems.

Sometimes radiation therapy causes brain tissue to swell. Patients may get a headache or feel pressure. The health care team watches for signs of this problem. They can provide medicine to reduce the discomfort.

Radiation sometimes kills healthy brain tissue. This side effect is called radiation *necrosis*. Necrosis can cause headaches, seizures, or even the patient's death.

In children, radiation may damage the pituitary gland and other areas of the brain. This could cause learning problems or slow down growth and development. In addition, radiation during childhood increases the risk of secondary tumors later in life. Researchers are studying whether chemotherapy may be used instead of radiation therapy in young children with brain tumors.

Side effects may be worse if chemotherapy and radiation therapy are given at the same time. The doctor can suggest ways to ease these problems.

Chemotherapy

The side effects of chemotherapy depend mainly on the drugs that are used. The most common side effects include fever and chills, nausea and vomiting, loss of appetite, and weakness. Some side effects may be relieved with medicine.

Patients who receive an implant (a wafer) that contains a drug are monitored by the health care team for signs of infection after surgery. An infection can be treated with an antibiotic.



Supportive Care

t any stage of disease, people with brain tumors receive supportive care to prevent or control problems and to improve their comfort and *quality of life* during treatment. Patients may have treatment to control pain and other symptoms of a brain tumor, to relieve the side effects of therapy, and to ease emotional problems.

These are common types of supportive care for people with brain tumors:

- **Steroids**—Most patients with brain tumors need steroids to help relieve swelling of the brain.
- Anticonvulsant medicine—Brain tumors can cause seizures. Patients may take an anticonvulsant medicine to prevent or control seizures.
- **Shunt**—If fluid builds up in the brain, the surgeon may place a shunt to drain the fluid. Information about shunts is under "Surgery" in the "Side Effects" section on page 21.

Many people with brain tumors receive supportive care along with treatments intended to slow the progress of the disease. Some decide not to have antitumor treatment and receive only supportive care to manage their symptoms.

Rehabilitation

ehabilitation can be a very important part of the treatment plan. The goals of rehabilitation depend on the person's needs and how the tumor has affected daily activities. The health care team makes every effort



to help the patient return to normal activities as soon as possible. Several types of therapists can help:

- **Physical therapists**—Brain tumors and their treatment may cause *paralysis*. They may also cause weakness and problems with balance. Physical therapists help patients regain strength and balance.
- Speech therapists—Speech therapists help patients who have trouble speaking, expressing thoughts, or swallowing.
- Occupational therapists—Occupational therapists help patients learn to manage activities of daily living, such as eating, using the toilet, bathing, and dressing.

Children with brain tumors may have special needs. Sometimes children have tutors in the hospital or at home. Children who have problems learning or remembering what they learn may need tutors or special classes when they return to school.

Followup Care

egular followup is very important after treatment for a brain tumor. The doctor checks closely to make sure that the tumor has not returned. Checkups may include careful physical and neurologic exams. From time to time, the patient may have MRI or CT scans. If the patient has a shunt, the doctor checks to see that it is working well. The doctor can explain the followup plan—how often the patient must visit the doctor and what tests will be needed.

The NCI has prepared a booklet for people who have completed their treatment to help answer questions about followup care and other concerns.



Facing Forward Series: Life After Cancer Treatment provides tips for making the best use of medical visits. It describes the kinds of help people may need.

Support for People with Brain Tumors

iving with a serious disease such as a brain tumor is not easy. Some people find they need help coping with the emotional and practical aspects of their disease. Support groups can help. In these groups, patients or their family members get together to share what they have learned about coping with the disease and the effects of treatment. Patients may want to talk with a member of their health care team about finding a support group. Groups may offer support in person, over the telephone, or on the Internet.

People living with a brain tumor may worry about caring for their families, keeping their jobs, or continuing daily activities. Concerns about treatments and managing side effects, hospital stays, and medical bills are also common. Doctors, nurses, and other members of the health care team can answer questions about treatment, working, or other activities. Meeting with a social worker, counselor, or member of the clergy can be helpful to those who want to talk about their feelings or discuss their concerns. Often, a social worker can suggest resources for financial aid, transportation, home care, or emotional support.

The Cancer Information Service can provide information to help patients and their families locate programs, services, and publications.



The Promise of Cancer Research

octors all over the country are conducting many types of clinical trials. These are research studies in which people take part voluntarily. Studies include new ways to treat brain tumors. Research has already led to advances, and researchers continue to search for more effective approaches.

Patients who join these studies have the first chance to benefit from treatments that have shown promise in earlier research. They also make an important contribution to medical science by helping doctors learn more about the disease. Although clinical trials may pose some risks, researchers take very careful steps to protect their patients.

Researchers are testing new anticancer drugs, doses, and treatment schedules. They are working with various drugs and drug combinations, as well as combinations of drugs and radiation therapy. They also are testing new methods and schedules of radiation therapy.

Patients who are interested in being part of a clinical trial should talk with their doctor. They may want to read *Taking Part in Clinical Trials: What Cancer Patients Need To Know.* The NCI also offers an easy-to-read brochure called *If You Have Cancer...What You Should Know About Clinical Trials.* These NCI publications describe how research studies are carried out and explain their possible benefits and risks. NCI's Web site includes a section on clinical trials at http://cancer.gov/clinical_trials. This section of the Web site provides general information about clinical trials. It also offers detailed information about ongoing studies of treatment for brain tumors. The Cancer Information Service at 1–800–4–CANCER can answer questions and provide information about clinical trials.



Dictionary

3-dimensional conformal radiation therapy:

A procedure that uses a computer to create a 3-dimensional picture of the tumor. This allows doctors to give the highest possible dose of radiation to the tumor, while sparing the normal tissue as much as possible.

Acrylonitrile (ak-ri-low-NYE-tril): A substance used to make plastics, rubber, and textiles. Workers exposed to this substance may be at risk of developing certain cancers (such as lung, brain, or prostate cancer).

Anaplastic (an-ah-PLAS-tik): A term used to describe cancer cells that divide rapidly and have little or no resemblance to normal cells.

Angiogram (AN-jee-o-gram): An x-ray of blood vessels; the person receives an injection of dye to outline the vessels on the x-ray.

Antibiotic (an-tih-by-AH-tik): A drug used to treat infections caused by bacteria and other microorganisms.

Anticonvulsants (an-tee-kon-VUL-sants): Drugs that prevent, reduce, or stop convulsions or seizures.

Astrocyte (AS-troe-site): A type of cell in the brain and spinal cord. An astrocyte is a star-shaped cell that supports nerve cells. It is a type of glial cell.

Astrocytoma (as-troe-sye-TOE-ma): A tumor that begins in the brain or spinal cord in small, star-shaped cells called astrocytes.

Benign (beh-NINE): Not cancerous; does not invade nearby tissue or spread to other parts of the body.

Biopsy (BY-op-see): The removal of cells or tissues for examination under a microscope. When only a sample of tissue is removed, the procedure is called an



incisional biopsy or core biopsy. When an entire lump or suspicious area is removed, the procedure is called an excisional biopsy. When a sample of tissue or fluid is removed with a needle, the procedure is called a needle biopsy or fine-needle aspiration.

Brain stem: The part of the brain that is connected to the spinal cord.

Brain stem glioma (glee-O-ma): A tumor located in the part of the brain that connects to the spinal cord (the brain stem). It may grow rapidly or slowly, depending on the grade of the tumor.

Burr hole: Small opening in the skull made with a surgical drill.

Cancer: A term for diseases in which abnormal cells divide without control. Cancer cells can invade nearby tissues and can spread through the bloodstream and lymphatic system to other parts of the body.

Cell: The individual unit that makes up all of the tissues of the body. All living things are made up of one or more cells.

Cerebellum (sair-uh-BELL-um): The portion of the brain in the back of the head between the cerebrum and the brain stem. The cerebellum controls balance for walking and standing, and other complex motor functions.

Cerebral hemispheres (seh-REE-bral HEM-iss-feerz): The two halves of the cerebrum, the part of the brain that controls muscle functions and also controls speech, emotions, reading, writing, and learning. The right hemisphere controls the muscles on the left side of the body, and the left hemisphere controls the muscles on the right side of the body.

Cerebrospinal fluid (seh-REE-broe-SPY-nal): CSF. The fluid flowing around the brain and spinal cord. Cerebrospinal fluid is produced in the ventricles in the brain.



Cerebrum (seh-REE-brum): The largest part of the brain. It is divided into two hemispheres, or halves, called the cerebral hemispheres. Areas within the cerebrum control muscle functions and also control speech, thought, emotions, reading, writing, and learning.

Chemotherapy (kee-mo-THER-a-pee): Treatment with anticancer drugs.

Clinical trial: A type of research study that tests how well new medical treatments or other interventions work in people. Such studies test new methods of screening, prevention, diagnosis, or treatment of a disease. The study may be carried out in a clinic or other medical facility. Also called a clinical study.

Craniopharyngioma (KRAY-nee-o-fah-rin-jee-O-ma): A benign brain tumor that may be considered malignant because it can damage the hypothalamus, the area of the brain that controls body temperature, hunger, and thirst.

Craniotomy (kray-nee-AH-toe-mee): An operation in which an opening is made in the skull.

CT scan: Computed tomography scan. A series of detailed pictures of areas inside the body taken from different angles; the pictures are created by a computer linked to an x-ray machine. Also called computerized tomography and computerized axial tomography (CAT) scan.

Dietitian: A health professional with special training in nutrition who can offer help with the choice of foods a person eats and drinks. Also called a nutritionist.

Edema (eh-DEE-ma): Swelling caused by excess fluid in body tissues.

Encapsulated (en-KAP-soo-lay-ted): Confined to a specific, localized area and surrounded by a thin layer of tissue.



Ependymomas (ep-en-dih-MOE-mahz): Brain tumors that may arise in the ventricles of the brain or in the spinal cord. Also called ependymal tumors.

Formaldehyde (for-MAL-duh-hide): Chemical used in the manufacturing and chemical industries, and by anatomists, embalmers, and pathologists. Workers exposed to formaldehyde may be at greater risk of leukemia and brain cancer.

Fractionation: Dividing the total dose of radiation therapy into several smaller, equal doses delivered over a period of several days.

Gamma rays: A type of high-energy radiation that is different from x-rays.

General anesthesia (an-es-THEE-zha): Drugs that cause loss of feeling or awareness and put the person to sleep.

Germ cell: The reproductive cells of the body. Germ cells are egg cells in females and sperm cells in males.

Germ cell tumors: Tumors that begin in the cells that give rise to sperm or eggs. They can occur almost anywhere in the body and can be either benign or malignant.

Germinoma (jer-mih-NO-ma): The most common type of germ cell tumor in the brain.

Glial cells (GLEE-al): Cells that surround nerve cells and hold them in place. They also separate nerve cells from each other.

Glioblastoma multiforme (glee-o-blas-TOE-ma multih-FOR-may): A type of brain tumor that forms from glial (supportive) tissue of the brain. It grows very quickly and has cells that look very different from normal cells. Also called grade IV astrocytoma.

Glioma (glee-O-ma): A cancer of the brain that begins in glial, or supportive, cells.



Grade: The grade of a tumor depends on how abnormal the cancer cells look under a microscope and how quickly the tumor is likely to grow and spread. Grading systems are different for each type of cancer.

Hyperfractionation: A way of giving radiation therapy in smaller-than-usual doses two or three times a day instead of once a day.

Imaging: Tests that produce pictures of areas inside the body.

Incision (in-SIH-zhun): A cut made in the body to perform surgery.

Local anesthesia (an-es-THEE-zha): Drugs that cause a temporary loss of feeling in one part of the body. The patient remains awake but cannot feel the part of the body treated with the anesthetic.

Malignant (ma-LIG-nant): Cancerous; a growth with a tendency to invade and destroy nearby tissue and spread to other parts of the body.

Medical oncologist (on-KOL-o-jist): A doctor who specializes in diagnosing and treating cancer using chemotherapy, hormonal therapy, and biological therapy. A medical oncologist often is the main caretaker of someone who has cancer and coordinates treatment provided by other specialists.

Medulloblastoma (MED-yoo-lo-blas-TOE-ma): A malignant brain tumor that begins in the lower part of the brain and that can spread to the spine or to other parts of the body. Medulloblastomas are a type of primitive neuroectodermal tumor (PNET).

Membrane: A very thin layer of tissue that covers a surface.

Meninges (meh-NIN-jeez): The three membranes that cover and protect the brain and spinal cord.



Meningioma (meh-nin-jee-O-ma): A type of tumor that occurs in the meninges, the membranes that cover and protect the brain and spinal cord. Meningiomas usually grow slowly.

Mental health counselor: A specialist who can talk with patients and their families about emotional and personal matters, and can help them make decisions.

Metastasis (meh-TAS-ta-sis): The spread of cancer from one part of the body to another. Tumors formed from cells that have spread are called "secondary tumors" and contain cells that are like those in the original (primary) tumor. The plural form of metastasis is metastases (meh-TAS-ta-seez).

Metastatic (MET-uh-STAT-ik): Having to do with metastasis, which is the spread of cancer from one part of the body to another.

MRI: Magnetic resonance imaging (mag-NET-ik REZ-o-nans IM-a-jing). A procedure in which a magnet linked to a computer is used to create detailed pictures of areas inside the body. Also called nuclear magnetic resonance imaging (NMRI).

Myelogram (MY-eh-lo-gram): An x-ray of the spinal cord after an injection of dye into the space between the lining of the spinal cord and brain.

Necrosis (ne-KRO-sis): Refers to the death of living tissues.

Needle biopsy: The removal of tissue or fluid with a needle for examination under a microscope. Also called fine-needle aspiration.

Nerve cells: Cells that receive and send messages from the body to the brain and back to the body. The messages are sent by a weak electrical current.

Neurologic (noor-uh-LOJ-ik): Having to do with nerves or the nervous system.



Neuroma (noo-RO-ma): A tumor that arises in nerve cells.

Neurooncologist (NOO-ro-on-KOL-o-jist): A doctor who specializes in diagnosing and treating brain tumors and other tumors of the nervous system.

Neurosurgeon (NOO-ro-SER-jun): A doctor who specializes in surgery on the brain, spine, and other parts of the nervous system.

Nurse: A health professional trained to care for people who are ill or disabled.

Occupational therapist: A health professional who helps people learn to manage their daily activities.

Oligodendroglioma (OL-ih-go-den-dro-glee-O-ma): A rare, slow-growing tumor that begins in brain cells called oligodendrocytes, which provide support and nourishment for cells that send nerve impulses. Also called oligodendroglial tumor.

Palliative care (PAL-ee-yuh-tiv): Care that prevents or relieves the symptoms of cancer or other diseases. Palliative care does not alter the course of a disease but can improve the quality of life. It attempts to meet the physical, emotional, spiritual, and practical needs of patients by helping to relieve pain, depression, or other problems. Also known as comfort care, supportive care, and symptom management.

Paralysis (pa-RAL-ih-sis): Loss of ability to move all or part of the body.

Pathologist (pa-THOL-o-jist): A doctor who identifies diseases by studying cells and tissues under a microscope.

Physical therapist: A health professional who teaches exercises and physical activities that help condition muscles and restore strength and movement.



Pineal gland (PIN-ee-al): A tiny organ in the brain that produces melatonin, a hormone that plays an important role in the sleep-wake cycle. Also called pineal body or pineal organ.

Pineal region tumors (PIN-ee-al): Types of brain tumors that occur in or around the pineal gland, a tiny organ in the brain.

Pituitary gland (pih-TOO-ih-tair-ee): The main endocrine gland. It produces hormones that control other glands and many body functions, especially growth.

Primary tumor: The original tumor.

Primitive neuroectodermal tumors (NOO-ro-ek-toe-DER-mul): PNET. A type of cancer that forms in bone or soft tissue. Also called Ewing's sarcoma.

Proton: A small, positively charged particle of matter found in the atoms of all elements. Streams of protons generated by special equipment can be used for radiation treatment.

Proton beam radiation therapy: A type of radiation therapy that uses protons generated by a special machine. A proton is a type of high-energy radiation that is different from an x-ray.

Quality of life: The overall enjoyment of life. Many clinical trials measure aspects of an individual's sense of well-being and ability to perform various activities to assess the effects of cancer and its treatment on the quality of life.

Radiation (ray-dee-AY-shun): Energy released in the form of particles or electromagnetic waves. Common sources of radiation include radon gas, cosmic rays from outer space, and medical x-rays.

Radiation oncologist (ray-dee-AY-shun on-KOL-o-jist): A doctor who specializes in using radiation to treat cancer.



Radiation therapy (ray-dee-AY-shun): The use of high-energy radiation from x-rays, gamma rays, neutrons, and other sources to kill cancer cells and shrink tumors. Radiation may come from a machine outside the body (external-beam radiation therapy), or from materials called radioisotopes. Radioisotopes produce radiation and can be placed in or near the tumor or in the area near cancer cells. This type of radiation treatment is called internal radiation therapy, implant radiation, interstitial radiation, or brachytherapy. Systemic radiation therapy uses a radioactive substance, such as a radiolabeled monoclonal antibody, that circulates throughout the body. Also called radiotherapy, irradiation, and x-ray therapy.

Recurrent cancer: Cancer that has returned after the tumor had disappeared. It may return at the same site as the original (primary) tumor or in another location.

Risk factor: Anything that increases a person's chance of developing a disease. Risk factors for cancer include a family history of cancer, use of tobacco products, certain foods, exposure to radiation or cancer-causing agents, and some genetic alterations.

Schwann cell: A cell of the peripheral nervous system that helps separate nerve cells.

Schwannoma (shwah-NO-ma): A tumor of the peripheral nervous system that arises in the nerve sheath (protective covering). It is almost always benign, but rare malignant schwannomas have been reported.

Secondary tumor: Cancer that has spread from the organ in which it first appeared to another organ. For example, breast cancer cells may spread (metastasize) to the lungs and cause the growth of a new tumor. When this happens, the disease is called metastatic breast cancer and the tumor in the lungs is called a secondary tumor. Also called secondary cancer.



Seizures (SEE-zhurz): Convulsions; sudden, involuntary movements of the muscles.

Shunt: A drainage tube. A surgeon implants or creates a shunt to divert blood or other fluid from one part of the body to another part. For example, a surgeon may implant a tube to drain cerebrospinal fluid from the brain to the abdomen. Or a surgeon may divert normal blood flow by joining two blood vessels together.

Side effects: Problems that occur when treatment affects healthy cells. Common side effects of cancer treatment are fatigue, nausea, vomiting, decreased blood cell counts, hair loss, and mouth sores.

Social worker: A professional trained to talk with people and their families about emotional or physical needs, and to find them support services.

Speech therapist: A specialist who evaluates and treats people with communication and swallowing problems. Also called a speech pathologist.

Spinal tap: A procedure in which a needle is put into the lower part of the spinal column to collect cerebrospinal fluid or to give drugs. Also called a lumbar puncture.

Stage: The extent of a cancer within the body, especially whether the disease has spread from the original site to other parts of the body.

Stereotactic biopsy (STAIR-ee-o-TAK-tik BY-op-see): A biopsy procedure that uses a computer and a three-dimensional scanning device to find a tumor site and guide the removal of tissue for examination under a microscope.



Stereotactic radiation therapy (STAIR-ee-o-TAK-tik ray-dee-AY-shun): A radiation therapy technique involving a rigid head frame that is attached to the skull; high-dose radiation is administered through openings in the head frame to the tumor while decreasing the amount of radiation given to normal brain tissue. This procedure does not involve surgery. Also called stereotaxic radiosurgery and stereotactic radiosurgery.

Steroids (STAIR-oydz): Drugs used to relieve swelling and inflammation.

Supportive care: Care given to prevent, control, or relieve complications and side effects and to improve the comfort and quality of life of people who have cancer.

Surgeon: A doctor who removes or repairs a part of the body by operating on the patient.

Surgery: A procedure to remove or repair a part of the body or to find out whether disease is present. An operation.

Symptom: An indication that a person has a condition or disease. Some examples of symptoms are headache, fever, fatigue, nausea, vomiting, and pain.

Symptom management: Care given to relieve the problems associated with a disease or its treatment. Symptom management improves the comfort and quality of life of people who have cancer.

Tissue (TISH-oo): A group or layer of cells that are alike and that work together to perform a specific function.

Tumor (TOO-mer): An abnormal mass of tissue that results from excessive cell division. Tumors perform no useful body function. They may be benign (not cancerous) or malignant (cancerous).



Ventricles (VEN-trih-kulz): Fluid-filled cavities in the heart or brain.

Vinyl chloride (VINE-uhl KLOR-ide): A substance used to make plastics. Exposure to vinyl chloride may increase the risk of liver, brain, and lung cancers; lymphoma; and leukemia.

X-ray: A type of high-energy radiation. In low doses, x-rays are used to diagnose diseases by making pictures of the inside of the body. In high doses, x-rays are used to treat cancer.



National Cancer Institute Information Resources

ou may want more information for yourself, your family, and your doctor. The following National Cancer Institute (NCI) services are available to help you.

Telephone

Cancer Information Service (CIS)

Provides accurate, up-to-date information on cancer to patients and their families, health professionals, and the general public. Information specialists translate the latest scientific information into understandable language and respond in English, Spanish, or on TTY equipment.

Toll-free: 1-800-4-CANCER (1-800-422-6237)

TTY: 1-800-332-8615

Internet

http://cancer.gov

The NCI's Cancer.gov[™] Web site provides information from numerous NCI sources. It offers current information on cancer prevention, screening, diagnosis, treatment, genetics, supportive care, and ongoing clinical trials. It also provides information about NCI's research programs and funding opportunities, cancer statistics, and the Institute itself. Cancer.gov contains CANCERLIT®, a database of citations and abstracts on cancer topics from scientific literature. Cancer.gov can be accessed at http://cancer.gov on the Internet.

Cancer.gov also provides live, online assistance through LiveHelp. Information specialists are available



Monday through Friday from 9:00 AM to 10:00 PM Eastern Time. LiveHelp is at **http://cancer.gov** on the Internet.

National Cancer Institute Booklets

ational Cancer Institute (NCI) publications can be ordered by writing to the address below, and some can be viewed and downloaded from http://cancer.gov/publications on the Internet.

Publications Ordering Service National Cancer Institute Suite 3036A 6116 Executive Boulevard, MSC 8322 Bethesda, MD 20892–8322

In addition, people in the United States and its territories may order these and other NCI booklets by calling the Cancer Information Service at 1–800–4–CANCER. They may also order many NCI publications on-line at http://cancer.gov/publications.

Booklets About Cancer Treatment

- Radiation Therapy and You: A Guide to Self-Help During Treatment
- Chemotherapy and You: A Guide to Self-Help During Treatment
- Helping Yourself During Chemotherapy: 4 Steps for Patients
- Eating Hints for Cancer Patients
- Understanding Cancer Pain
- Pain Control: A Guide for People with Cancer and Their Families
- Get Relief From Cancer Pain



- Taking Part in Clinical Trials: What Cancer Patients Need To Know
- La quimioterapia y usted: Una guía de autoayuda durante el tratamiento del cáncer (Chemotherapy and You: A Guide to Self-Help During Treatment for Cancer)
- El dolor relacionado con el cáncer (Understanding Cancer Pain)
- La radioterapia y usted: Una guía de autoayuda durante el tratamiento del cáncer (Radiation Therapy and You: A Guide to Self-Help During Treatment)
- ¿En qué consisten los estudios clínicos? Un folleto para los pacientes de cáncer (What Are Clinical Trials All About? A Guide for Cancer Patients)

Booklets About Living with Cancer

- Taking Time: Support for People With Cancer and the People Who Care About Them
- Facing Forward Series:
 - Life After Cancer Treatment
 - Ways You Can Make a Difference in Cancer
- Advanced Cancer: Living Each Day
- When Cancer Recurs: Meeting the Challenge



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