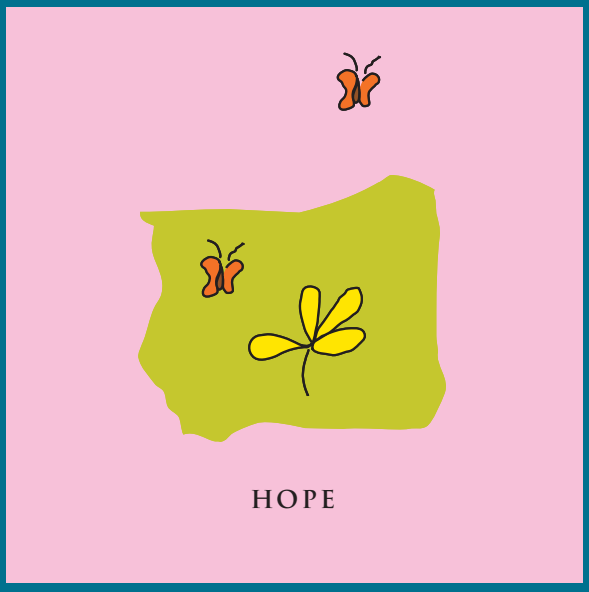
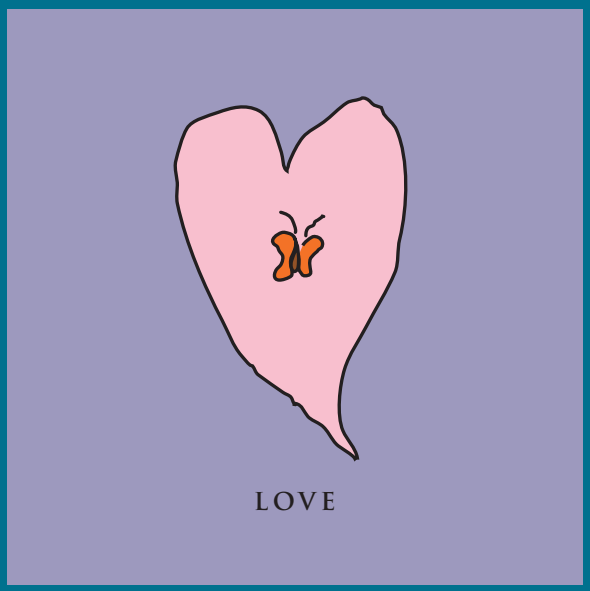
The Essential Guide to

BRAIN TUMORS





NBTF
NATIONAL BRAIN TUMOR FOUNDATION

Giving Help, Giving Hope®

NATIONAL BRAIN TUMOR FOUNDATION

THE ESSENTIAL GUIDE TO BRAIN TUMORS

The National Brain Tumor Foundation (NBTF) was founded in 1981 by brain tumor survivors, and their family members and friends. The National Brain Tumor Foundation is a nationwide non-profit organization serving people whose lives are affected by brain tumors. We are dedicated to promoting a cure for brain tumors, improving the quality of life and giving hope to the brain tumor community by funding meaningful research and providing patient resources, timely information and education.

"giving help, giving hope"

NATIONAL BRAIN TUMOR FOUNDATION

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DEDICATION

Karen Osney Brownstein and Elizabeth "Libby" Stevenson, conceived of and authored the original National Brain Tumor Guide in 1986 for brain tumor patients and their families. They created the Guide to offer a supportive and jargon-free resource to the brain tumor community across the country. The Guide continues to speak in very human terms to those confronting the trauma of their own medical crisis, letting them know that they are not alone, that there are vast resources available to them during a time of confusion and need.

Karen O. Brownstein

Elizabeth "Libby" Stevenson

As a member of the Board of Directors of the National Brain Tumor Foundation, Karen's tireless work—always laden with great wit and enthusiasm—was centered on the creation of the Guide. Karen—a teacher and author—survived her brain tumor, but was stricken with a lung disease that caused her untimely passing in 1989. Although her loss is irreplaceable, her spirit and her vision continue to thrive in this new updated version of the Guide.

Elizabeth "Libby" Stevenson served as the first Executive Director of the National Brain Tumor Foundation and later on the NBTF Board of Directors. Libby was diagnosed with a brain tumor in 1980 and survived her disease for over 20 years until she passed away in 2003. Her gracious manner and infectious smile served as an inspiration to all who met her and provided hope and compassion to other brain tumor survivors. She lived by her motto "always, there is hope" and was an ever-vigilant advocate for brain tumor patients.

The Essential Guide to Brain Tumors is proudly dedicated to these two pioneers in the brain tumor community—Karen Osney Brownstein and Libby Stevenson.

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ON THE COVER: Illustration by Scott Norris.
The artist was diagnosed in 1999 with a glioblastoma.
His screenprint is entitled "Hope, Faith, Courage, Love."

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INTRODUCTION

Why me? That's a natural question but I doubt if you'll ever get an answer. Why not me? The answer is because no one is immune. It is Me! This is where you are today. Take it one day at a time, face what you're up against, assemble your plan to combat it, and most of all, believe in yourself and your plan."

—Linda Kendall
Hemangioblastoma survivor, diagnosed in 1986
[Quote reprinted from *Search,* Fall 2000, Issue No. 4]

Linda Kendall

No one can prepare to be diagnosed with a brain tumor. It shatters your sense of well-being and personal security. It is common to experience a flurry of emotions and feelings when you receive the news that you have a brain tumor. One moment you may feel angry and overwhelmed, then dazed and numb the next. Many personal and practical questions come to mind: why me? Where will I turn for help? How will my family cope emotionally and economically? In a short time, you and your family are expected to make important decisions about your treatment and future, many of which are confusing and frightening.

Every question you ask and decision you make is important in determining what's best for you. That's why *The Essential Guide to Brain Tumors* has been designed to educate you, answer your questions, guide you through the treatment process and life after treatment, and encourage the participation and support of your friends and family. This *Essential Guide* is an informative resource to help you navigate new medical terminology, as well as offer emotional and practical advice for the challenges you may face. Because the *Essential Guide* is comprehensive, rather than focused on one particular type of tumor or treatment, you may find that some of the information does not pertain to your needs. *The Essential Guide to Brain Tumors* is not meant to replace medical advice, but to inform you and assist you in your quest for answers, information and support.

The Essential Guide to Brain Tumors begins with a look at how the brain functions. It then discusses a brain tumor diagnosis, tumor types, treatment options,

and survival tips. You will also learn about conventional and integrative treatments, symptom management and the latest research about potential causes. *The Essential Guide* offers information for caregivers and references to organizations that can provide additional information. Throughout the *Essential Guide* you will find personal experiences and helpful recommendations from brain tumor survivors.

FACTS ABOUT BRAIN TUMORS

- Each year over 190,000 people in the United States and 10,000 people in Canada are diagnosed with a primary or metastatic brain tumor.
- Brain tumors are a leading cause of death from childhood cancer, accounting for almost a quarter of cancer deaths in children up to 19 years of age.[1] Brain tumors are the second leading cause of cancer death in young adults ages 20–39.[2]
- Metastatic brain tumors (cancer that has spread from other parts of the body) occur in 10–15% of people with cancer and are the most common type of brain tumor.[3]
- In the United States, the overall incidence of all primary brain tumors is 14 per 100,000 people.[4]
- There are over 120 different types of brain tumors, making effective treatment very complicated.
- Brain tumors can be malignant or benign, and in either case can be life threatening.
- Because brain tumors are located at the control center for thought, emotion and movement, their effects can be devastating.
- At present, standard treatments for brain tumors include surgery, radiation therapy, and chemotherapy, used either individually or in combination.
- Brain tumors in children are different from those in adults and are often treated differently. Although as many as 69% of children will survive, they are often left with long-term side effects.[5]
- Enhancing the quality of life of people with brain tumors requires access to quality specialty care, clinical trials, follow-up care, and rehabilitative services. Improving the outlook for adults and children with brain tumors requires research into the causes of and better treatments for brain tumors.

Q: ***What is a brain tumor?***

A: A brain tumor is a mass of cells that have grown and multiplied uncontrollably. Primary brain tumors originate in the brain and rarely spread to other parts of the body. Metastatic (or secondary) brain tumors come from cancer cells in another part of the body. The diseased cells spread to the brain by moving through the bloodstream. This process is called metastasis.

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[1]Ries LAG, Smith MA, Gurney JG, Linet M, Tamra T, Young JL, Bunin GR (eds). *Cancer Incidence and Survival among Children and Adolescents: United States SEER Program 1975–1995,* National Cancer Institute, SEER Program, NIH Pub. No. 99-4649. Bethesda, MD, 1999.

[2]Jemal A, Murray T, Samuels A. *Cancer Statistics 2003.* January/February 2003. Vol. 53, No. 1. CA: A Cancer Journal for Clinicians. American Cancer Society. Pages 5–26.

[3]Yung A, Sawaya R, Curran W, and Fuller G. "Intracranial Metastatic Central Nervous System Tumors," Cancer in the Nervous System, Ed Levin. Churchill Livingston, Inc. 1996, page 243.

[4]CBTRUS Report.

[5]Jemal A, Murray T, Samuels A. *Cancer Statistics, 2003.* January/February 2003. Vol. 53, No. 1. CA: A Cancer Journal for Clinicians. American Cancer Society. Pages 5–26.

1. UNDERSTANDING THE BRAIN

The first step in understanding brain tumors is learning all you can about the brain: its structure and the role each part of the brain plays in our everyday thoughts and behaviors. Then you will better understand how different kinds of brain tumors can cause the associated symptoms.

THE CENTRAL NERVOUS SYSTEM

The essential components of the central nervous system (CNS) are the brain and spinal cord.

Brain

The brain is a soft, spongy mass of nerve cells and supportive tissue connected to the spinal cord. The brain of an adult weighs approximately three pounds. In the center of the brain are four connected hollow spaces called *ventricles*. The ventricles contain a liquid called *cerebrospinal fluid* (CSF) that circulates throughout the CNS. The brain controls our five senses in addition to our emotions, thoughts, speech, physical coordination, movement, and sensation.

Spinal Cord

The spinal cord is a long, cylindrical mass of nerves that extends from the brain stem down the length of the spine. The spinal cord controls movement and sensation.

The CNS uses billions of nerve cells, nerve fibers and supportive cells to relay messages to the rest of our body. The CNS is different from the peripheral nervous system (PNS). The PNS is made up of nerves that connect the CNS to the sensory organs, muscles, blood vessels, and glands.

The brain and spinal cord are protected by the skull, the spinal column, and the meninges.

Skull

The skull is a framework of eight cranial and 14 facial bones that protect the brain from being damaged. The cranium, the part of the skull that covers the brain, is made up of four major bones: the frontal, occipital, sphenoid, and ethmoid bones. There are four other bones in the cranium: two temporal bones, which are located on the sides and base of

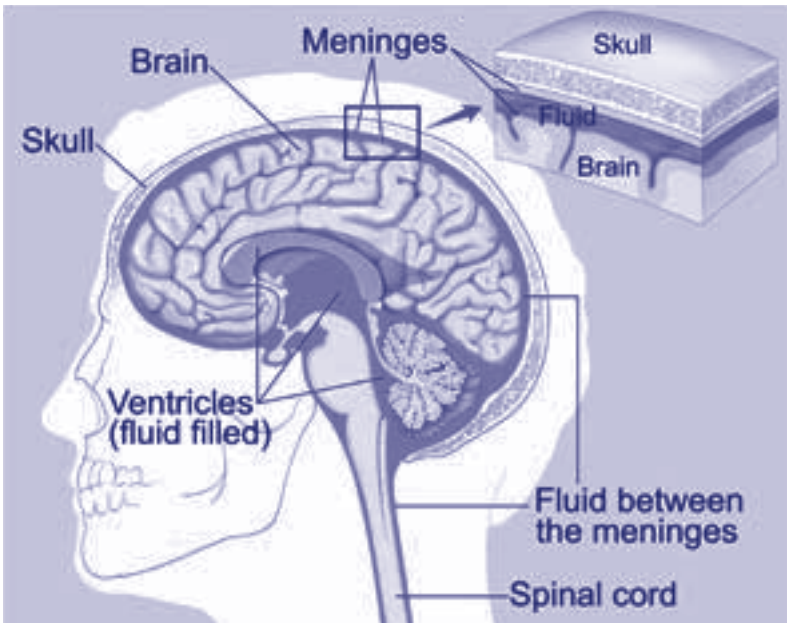


ILLUSTRATION COURTESY OF: National Cancer Institute, Bethesda, Maryland

the skull, and two parietal bones, which fuse at the top of the skull. The areas where the bones in the skull meet are called suture lines.

Spinal Column

The spinal column is composed of 33 irregular, spool shaped bones called *vertebrae* that are stacked one on top of the other. The spinal column is divided into five sections that extend from the base of the skull to the tailbone: the cervical, thoracic, lumbar, sacral and coccygeal. The spinal column protects the spinal cord.

Three membranes, or layers of tissue called meninges, surround the brain and spinal cord.

Meninges

There are three membranes called meninges that cover the brain and the spinal cord. The outermost layer, the *dura mater,* is a thick membrane. The second layer, called the *arachnoid,* and the third layer, called the *pia mater,* are thin membranes.

There are three spaces between the layers of the meninges. The space between the skull and dura mater is called the *epidural space.* The space between the dura mater and the arachnoid is called the *subdural space.* The space between the arachnoid and the pia mater is called the *subarachnoid space.*

Ventricles

The ventricles are four connected, fluid-filled cavities located in the center of the brain. The ventricles contain the *choroid plexus,* structures that produce *cerebrospinal fluid.*

Cerebrospinal Fluid (CSF)

Cerebrospinal fluid is a clear liquid that surrounds the brain and spinal cord. It cushions and protects them against injury. CSF circulates through the four ventricles and the subarachnoid space. The CNS has a closed circulatory system that drains into the bloodstream.

THE SECTIONS OF THE BRAIN

The brain is divided into sections, each of which controls a distinct aspect of human movement and behavior. A brain tumor can affect function (movement and/or behavior) depending on where in the brain the tumor is located.

Cerebrum

The cerebrum is the largest area of the brain. It has two sections called the right and left hemispheres. The right cerebral hemisphere typically controls the left side of the body, whereas the left cerebral hemisphere controls the right side of the body. Each hemisphere is further divided into four sections called lobes: the frontal, parietal, temporal and occipital lobes. Each lobe controls different behaviors and sections of the body.

The outer layer of the brain is called the cortex. It is made up of bodies of nerve cells known as *gray matter.* Much of the brain's activities occur in the gray matter. The internal layers of the cerebrum are made up of nerve fibers called axons or *white matter.* The white matter contains nerve fibers that allow communication between the brain and various parts of the body.

The cerebrum also houses many internal nerve structures, such as the thalamus, hypothalamus and pituitary gland. These structures are responsible for processing different messages being sent to the brain and for sending messages from the brain to other parts of the body.

Frontal Lobes

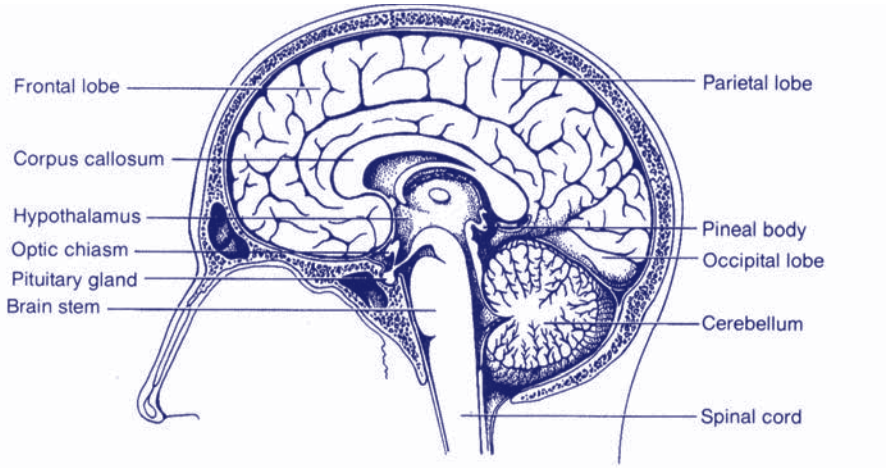
The frontal lobes make up the front portion of the cerebral hemisphere. The frontal lobes control many of the brain's activities including attention, abstract thought, problem solving, reasoning, judgment, initiative, inhibition, memory, parts of speech, moods, major body movements, and bowel and bladder control.

Parietal Lobes

The parietal lobes are in the upper central portion of the cerebral hemispheres. The parietal lobes process all messages being sent to and from the brain regarding physical sensations. The parietal lobes are responsible for interpreting the meaning of physical sensations to determine such factors as size, shape, weight, texture and consistency. They interpret spatial orientation and how we are aware of the parts of our own body. The parietal lobes also help us to make calculations, read and write.

Temporal Lobes

The temporal lobes form the lower portion of the cerebral hemispheres. The temporal lobes manage most auditory activities in the brain by translating words into meaning. There is also a



Cross-Section of Brain

ILLUSTRATION: Laurel V. Schaubert COURTESY OF: Charles B. Wilson, MD

small, important section of the temporal lobe that controls the brain's ability to form long-term memory patterns. The left temporal lobe controls language comprehension in most people. For this reason, the left temporal lobe is considered the dominant lobe

Occipital Lobes

The occipital lobes are in the back portion of the cerebral hemispheres. The occipital lobes control vision. The right occipital lobe processes what is seen out of the left field of vision, and the left occipital lobe processes what is seen out of the right field of vision.

THE INTERNAL NERVE STRUCTURES OF THE BRAIN

Thalamus

The thalamus is a pair of egg-shaped masses of gray matter located in the center of the two hemispheres, above the hypothalamus. The thalamus acts as a pathway for most of the messages that pass to and from the brain. It also is involved in our conscious awareness of pain, focusing of attention, certain aspects of speech/language, memory, motor and sensory functions, and the sleep/wake cycle.

Hypothalamus

The hypothalamus, located in the center of the brain, regulates automatic body activity such as heart rate, temperature, thirst, appetite, sleeping patterns, growth hormone, and physical expressions of emotions such as blushing, dry mouth, and sweating.

Pituitary Gland

The pituitary gland, also called the hypophysis, is found at the part of the brain between and behind the eyes. It is connected to the hypothalamus. The hypothalamus transmits messages to the pituitary gland, telling it to secrete the hormones that regulate growth, blood pressure, the thyroid, and gender-related functions (i.e. testosterone secretion, menstruation, and lactation). The pituitary gland also produces a hormone that controls the rate that water is secreted into the urine. This, in effect, controls the amount of water in the body.

Brain Stem

The brain stem, located at the base of the brain, includes three parts: midbrain, pons, and medulla oblongata. The brain stem contains the 12 cranial nerves, which control hearing, vision, sense of smell, and balance. The brain stem also contains pathways going from the spinal cord to the brain for messages related to movement and the senses. In addition, the brain stem controls involuntary functions, including breathing and heartbeat and our sleep/wake cycle. All functions controlled by the cerebrum pass through the brain stem.

Cerebellum

The cerebellum, located behind the brain stem, has many connections to the brain and the spinal cord. The cerebellum is responsible for coordinating muscle groups and controlling small movements and balance.

Corpus Callosum

The corpus callosum connects the left side of the brain to the right side of the brain. It is located in the center of the brain, surrounded by the cerebrum.

To learn more about the parts of the brain, visit the "Interactive Tour of the Brain" on the NBTF web site, www.braintumor.org.

2. DIAGNOSING A BRAIN TUMOR

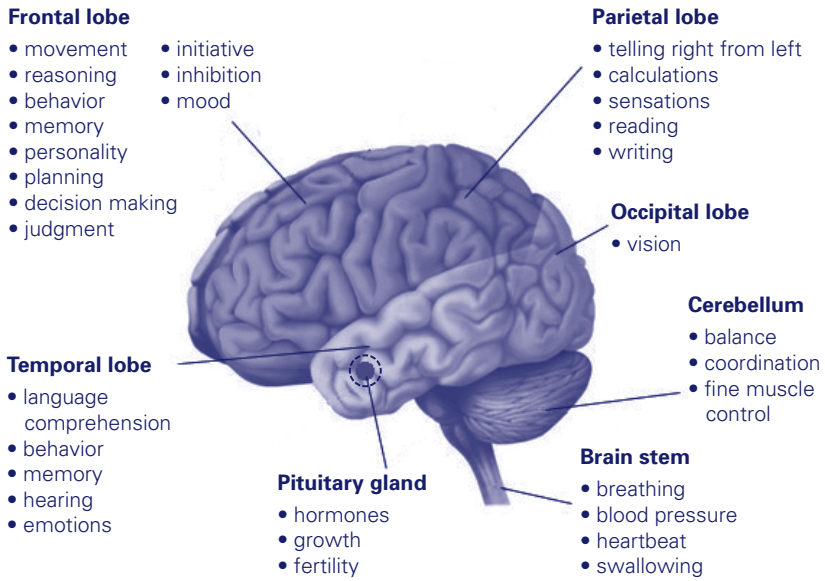
A brain tumor takes up space within the skull and interferes with normal brain activity. A tumor can cause damage by increasing pressure in the brain, shifting the brain or pushing against the skull, and invading and damaging nerves and healthy brain tissue. The location of a brain tumor influences the type of symptoms that occur. This is because different functions are controlled by different parts of the brain.

BRAIN TUMOR SYMPTOMS

A brain tumor can block the flow of cerebrospinal fluid (CSF) between the ventricles, causing a buildup of CSF and swelling, called brain *edema.* Edema can lead to symptoms including headaches, *seizures,* or *focal* deficits. Focal deficits include damage to sensory or movement abilities, problems in the ability to process information, personality changes, and speech disorders. A tumor of the spinal cord can block the communication between the brain and nerves throughout the body. This can lead to problems with movement or physical sensation.

The most common symptoms include:

- Headaches, which can be most severe in the morning
- Seizures or convulsions
- Difficulty thinking, speaking, or finding words
- Personality changes
- Weakness or paralysis in one part or one side of the body
- Loss of balance
- Vision changes
- Nausea or vomiting
- Confusion and disorientation



The doctor will perform a physical exam to detect the signs and symptoms associated with a brain tumor. This exam is called a neurological examination.

NEUROLOGICAL EXAMINATION

A neurological examination tests a person's physical and mental functions. The doctor will begin by taking a medical history and asking questions about:

- How the patient feels at the present time
- When the patient first noticed symptoms
- How often the symptoms occur
- Whether the symptoms are worsening
- The intensity and location of headaches
- Personality changes
- Changes in sense of touch, taste, smell, vision, or hearing
- What procedures or tests have already been performed
- What treatments or interventions have been prescribed

After asking questions to determine these conditions, the doctor will conduct a series of tests to measure the function of the patient's nervous system, and physical and mental alertness. This part of the exam includes checking the following functions:

- Eye movement and pupil reaction
- Hearing
- Smell
- Tongue movement and sensation
- Reflexes
- Balance and coordination
- Long- and short-term memory
- Judgment and reasoning
- Muscle strength
- Motor skills
- Gait
- Sensation
- Language
- Calculation

If responses to the exam are not normal, the doctor may order a brain scan or refer the patient to a neurologist or neurosurgeon, who will then order a scan.

SCANS AND IMAGING TECHNIQUES

A scan is a picture of the internal structures in the brain. A specialized machine takes a scan in much the same way a digital camera takes a photograph. Using computer technology, a scan compiles an image of the brain by photographing it from various angles.

Some types of scans use a *contrast agent* (or *contrast dye*), or a ferromagnetic substance such as *gadolinium.* This is injected into a vein and flows into brain tissue. Abnormal or diseased brain tissue absorbs more dye than normal, healthy tissue. The contrast agent allows the doctor to see the difference between normal and abnormal brain tissue.

TYPES OF IMAGING TECHNIQUES

Thanks to modern technology, several types of imaging scans are available to help diagnose brain tumors. Each type of scan is effective in capturing a different part and function of the brain. The patient may have more than one scan or different kinds of scans depending on the type and location of the tumor.

The most commonly used scan for detecting brain tumors is magnetic resonance imaging (MRI). There are two types of MRI scanning equipment: standard and open.

Magnetic Resonance Imaging (MRI)

An MRI is the standard imaging technique for suspected brain tumors. An MRI is a scanning device that uses magnetic fields and computers to capture images of the brain on film. It does not use x-rays. It provides pictures from various planes, which permits doctors to create a three-dimensional image of the tumor. The MRI detects signals emitted from normal and abnormal tissue, providing clear images of most tumors.

To prepare for a standard MRI scan, the patient will be asked to lie down on a long table, which slides through a long, cylindrical tube with a narrow opening. Although there is enough room for the patient's body inside the cylinder, the patient will not be able to move around. The scan takes approximately 15–45 minutes. During the scan, the patient will hear loud banging sounds, caused by the electronics within the machine. Patients may request earplugs to reduce noise. Some people find the MRI claustrophobic and ask for a sedative beforehand to relax. Other people request an open MRI.

An open MRI machine does not have a cylinder, so the patient is

not enclosed. The procedure lasts approximately 45 minutes. There is some discussion among doctors concerning the quality of the images of an open MRI compared to the standard or closed MRI.

Brain tumor patients will usually have more than one MRI procedure during the course of treatment. Here are some tips to help make the procedure more comfortable:

- Bring your favorite music CD
- Wear pants that have a comfortable, loose waist
- Wear short sleeves if you will be receiving a contrast agent injection
- Cover your eyes with a towel

There are several types of MRI scans. These techniques aid doctors before and during surgery in various ways.

> ***"I concentrate on my family and all the wonderful things we have been blessed with. I have come to know the technicians in the MRI area quite well, and when I enter the room, they hand me a plastic rosary. They know that's all I need to make it through."***
>
> **– Glioblastoma survivor**

Magnetic Resonance Angiography (MRA)

Magnetic Resonance Angiography generates an image of blood vessels and blood flow without the use of a contrast agent. It is less invasive than an arteriogram, a traditional blood-vessel exam that requires injecting a contrast agent. MRA is used to find the presence and position of the blood vessels leading to the tumor and determine whether or not these vessels have been displaced due to the tumor mass. This method is normally used before surgery to remove a tumor with a large supply of blood, or one that is in an area of the brain that has a large number of blood vessels.

Contrast-Enhanced MRA (CE-MRA)

Contrast-Enhanced MRA is a form of MRA that uses contrast agents to look at the movement of blood through the region of interest.

Flow Sensitive MRI (FS MRI)

Flow Sensitive MRI shows the flow of CSF through the ventricles and spinal cord. It is used when examining tumors in the spinal cord and at the base of the skull. It can also be helpful when removing tumors that cause *hydrocephalus.* Hydrocephalus is a condition marked by blockage of CSF pathways, leading to a buildup of CSF in the skull.

Functional MRI (fMRI)

Functional MRI provides instant images of brain activity by tracking the use of oxygen in the brain as it occurs. fMRI identifies the motor, sensory, and language centers of the brain, called the eloquent cortex. fMRI can help radiologists determine precisely which part of the brain is han-

Q: *What is the difference between a neurologist and a neurosurgeon?*

A: A neurologist is a medical doctor who specializes in diagnosing and treating illnesses in the brain and spine. A neurosurgeon is a medical doctor who performs surgery on the brain and spine.

Q: *What is a contrast agent?*

A: A contrast agent or contrast dye is a substance used to help detect a tumor by highlighting abnormal tissue in a scan.

Q: *What is the difference between invasive and non-invasive procedures?*

A: An invasive procedure involves a puncture or incision of the skin, or insertion of an instrument or foreign material, such as a contrast dye, into the body. A non-invasive procedure means that there is no puncture of the skin or insertion of foreign material into the body.

dling critical functions such as thought, speech, movement, and sensation. This information is important in planning surgery, radiation therapy, or other treatments.

Magnetic Resonance Spectroscopy (MRI Spect or MRS)

Magnetic Resonance Spectroscopy is a type of MRI that measures the levels of metabolites in the body. Metabolites are chemicals produced by living cells. The activity of metabolites in tumors is different from that of normal tissue. An MRS can detect patterns of activity that may help diagnose the type of tumor and evaluate tumor response to therapies. The types of metabolites commonly measured with an MRS are choline, lactate, and N-Acetyl-Aspartate (NAA). An MRS may also be used to determine the grade of a tumor and to distinguish active recurrent tumor cells from dead cells destroyed by radiation treatment, called *radiation necrosis.*

Other types of imaging techniques may also be used to help diagnose and treat brain tumors.

An MRI may not be an option for certain patients because the intense magnetic fields can damage some types of implanted medical devices. Patients should advise the doctor if they have a pacemaker, cardiac monitor, surgical clip, or facial tattoos.

Perfusion MRI

Perfusion MRI uses contrast agents to examine the flow of blood into the tissues. In some institutions, perfusion MRI is used to grade certain types of tumors.

Diffusion and Diffusion-Tensor MRI

These forms of MRI measure the diffusion (random motion) of water in the tissues. Since the diffusion of water along the nerve can be measured with this technique, it can be used in surgical planning to avoid injuring nerve bundles *(ganglia)* that have been shifted or displaced.

Computed Tomography (CT or CAT Scan)

Computed Tomography combines sophisticated x-ray and computer technology. Unlike other medical imaging techniques, CT has the ability to show a combination of soft tissue, bone, and blood vessels. CT is effective at examining bone and tissue calcification and hemorrhage. CT images can determine some types of tumors, as well as help detect swelling and bleeding. Usually, iodine is the contrast agent used during a CT scan. Patients who are allergic to iodine should inform their doctor before having a CT scan.

In preparation for a CT scan, the patient lies on a long table that slides into a round opening above his or her head. The CT circles around the patient's head, taking pictures of the brain from different directions. The scan makes a slight clicking sound as it moves. The information gathered is then sent to a computer, which translates it into pictures.

CT is a valuable diagnostic tool and its use has been increasing

Important Points About Diagnostic Tests

- Some people may have an allergic reaction to iodine, the contrast agent most commonly used for CT scanning. Allergic reactions can include rashes, a warm sensation, or in rare cases, difficulty breathing. If you know you are allergic to iodine, tell your doctor.
- Gadolinium, the contrast agent used with an MRI, may cause temporary headaches but has no other known side effects.
- Because an MRI uses magnetic fields, people who have metal implanted in their body in any form (including tattoos) should let the doctor know about it before scheduling the procedure.
- Medication can be given to help relieve the symptoms of anxiety or claustrophobia when having an MRI. Patients should let the doctor know their concerns before scheduling an MRI.

rapidly. However, CT scans involve exposure to *ionizing radiation.* This is a concern for people who have multiple CT scans and for children, because they are more sensitive to radiation than adults. It is wise for patients who have had frequent x-ray exams and parents of children who have brain tumors to keep a record of their x-ray history. If a patient changes health care providers, this information can help doctors make informed decisions. Many hospitals are reducing the dose of radiation given to children from adult levels to levels based on the weight of the child. This minimizes radiation over-exposure.

Positron Emission Tomography (PET)

Positron Emission Tomography is a supplementary test that can be used to gain additional information after an MRI. PET scans provide a picture of the brain's activity, rather than its structure, by measuring the rate at which a tumor absorbs glucose (a sugar). To do this, the patient is injected with glucose that has been labeled with radioactive markers. Then the PET scan measures the brain's activity and sends this information to a computer, which creates a live image. Doctors use PET scans to see the difference between scar tissue, recurring tumor cells, and cells destroyed by radiation treatment. PET is also used during brain mapping procedures *(see chapter 5)*. At this time, PET is not commonly found in most institutions because it requires using highly complex, expensive equipment, and can produce results that are difficult to interpret.

Angiography

Angiography is a common technique used to outline the position of blood vessels in the brain. A *catheter* is placed in the groin and fed up to *carotid* or *vertebral arteries* in the brain. A contrast dye is injected into the catheter, and x-rays follow its path through the blood vessels of the brain.

A doctor may decide that the patient needs to have a biopsy. This is the most accurate test for identifying the type and grade of a tumor.

BIOPSY

A *biopsy* is a surgical procedure in which a small sample of tissue is taken from the tumor site and examined under a microscope. The results help the doctor diagnose the type of tumor. The biopsy will provide information on types of abnormal cells present in the tumor.

There are two kinds of biopsy procedures: an open and a closed biopsy.

Open Biopsy

An open biopsy is done during a *craniotomy.* A craniotomy is a surgical procedure that involves removing a piece of the skull in order to get access to the brain. After the tumor is *debulked* or *resected,* the bone is usually put back into place. The patient is under anesthesia during this procedure.

Closed Biopsy

A closed biopsy (also called stereotactic or needle biopsy) is performed when the surgeon wants to avoid removing healthy tissue from the area surrounding the tumor, or when the tumor is in an area of the brain that is difficult to reach. The patient may be given a local anesthetic to numb the skin and a sedative medication and remain awake during the procedure. Or, the patient may undergo a general anesthesia, where he or she will be unconscious during the procedure. Guided by a CT or MRI that is performed prior to the procedure, the surgeon drills a small hole into the skull and passes a narrow, hollow needle through the

hole into the tumor to remove a sample of tissue.

Once a sample is obtained, a pathologist will examine the tissue under a microscope. Further tests or analysis may be performed on the tumor tissue. Then the pathologist will write a pathology report.

PATHOLOGY REPORT

A pathology report contains the analysis of brain tissue taken at the time of a craniotomy or needle biopsy. It provides the information to make a diagnosis of the tumor type. Sometimes the pathologist may not be able to make an exact diagnosis. This may be because more than one grade of tumor cells exists within the same tumor. If cells of only one grade are removed and classified during a biopsy, it is possible that the tumor grade will be misdiagnosed. This is called a sampling error. In some cases, the tissue may be sent to another institution for additional input.

Brain tumors grow because their cells divide to make more cells. The process of cell division is called *proliferation.* The percentage of cells that are actively dividing within the tumor are measured by a test called the *MIB-1 labeling index.* If no cells are actively dividing, the MIB-1 labeling index (LI) would be expected to be 0%. An MIB-1 LI of greater than 30% indicates that tumor cells are growing very rapidly. Several studies have shown that gliomas with an MIB-1 LI of 10% or less have a more favorable prognosis than those higher than 10%.

Q: ***Should a person consider getting a second opinion after receiving an initial diagnosis?***

A: Yes. A patient can get a second opinion to confirm the initial diagnosis and to compare the suggested courses of treatment. Some insurance companies require that a patient get a second opinion before undergoing major therapy. A second opinion should be obtained as soon as possible to avoid delaying treatment. Patients can ask their family physician to recommend other doctors. Patients may also call the National Brain Tumor Foundation to learn more about how to get a second opinion.

NBTF has a range of services available to patients and caregivers. We can provide a list of treatment facilities around the country, offer help and information, or make referrals to other helpful organizations. We can be reached by phone at 800-934-2873 or at www.braintumor.org.

3. KNOWN AND POSSIBLE CAUSES

Each year over 190,000 people in the United States and 10,000 people in Canada are diagnosed with a primary or metastatic (secondary) brain tumor. Many studies are looking into the causes of brain tumors, but the results have not been conclusive. Although the causes of brain tumors are not certain, there are many trends among people who get them. These trends include age, gender, geography, environmental influences, and behavioral patterns. Trends may provide some insight into the possible causes of brain tumors. This chapter will provide an overview of trends found in studies of brain tumor patients.

INCIDENCE RATES

According to the Central Brain Tumor Registry of the United States (CBTRUS), an estimated 43,800 new cases of primary benign and malignant brain tumors were expected to be diagnosed in 2005.* About 14 per 100,000 persons in the U.S. are diagnosed with a primary brain tumor each year, and about 7 per 100,000 are diagnosed with a primary malignant brain tumor. The incidence rate of primary tumors of children between ages 0 to 19 years is approximately 4 cases per 100,000. Gliomas make up almost half (49 percent) of all primary brain tumors. Meningiomas are the next most frequent type, making up 30 percent.

BRAIN TUMOR TRENDS

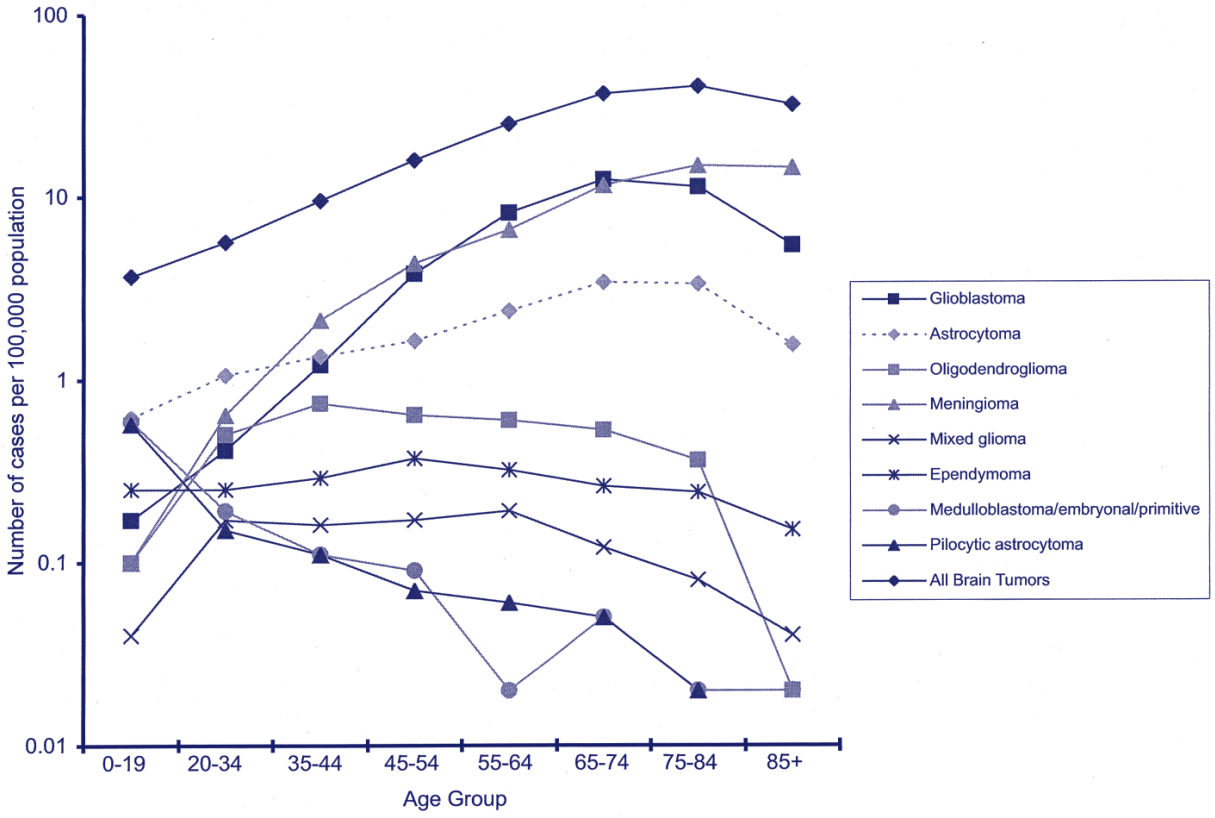
Age and Gender

The average age that an adult is diagnosed with a brain tumor is 54 years. The age and number of children diagnosed with brain tumors is distributed evenly between the ages of 0 and 19. Trends in age vary depending on the type and location of the tumor. This suggests that many different factors influence the different tumor types.

Rates for gliomas (*neuroepithelial* tumors) are almost 1.5 times greater in males as compared to females. Glioblastomas, lymphomas, and germ cell tumors are more common in males than in females. In contrast, meningiomas affect almost twice as many females as males. The findings of a recent study suggest that female hormones may have a protective

* These figures do not include metastatic brain tumors, which are the most common type of brain tumor.

Figure. 1. Incidence rates of primary brain tumors by major neuroepithelial tissue and meningeal histologic types and age group, CBTRUS, 1992–1998. The category All Brain Tumors includes some specific types not individually shown (tumors of cranial and spinal nerves, hemangioblastomas, primary lymphomas, germ cell tumors, and tumors of the sellar region). The Astrocytoma category includes diffuse astrocytomas, anaplastic astrocytomas, unique astrocytoma variants, and astrocytomas not otherwise specified.



effect against certain types of brain tumors. More investigation is necessary to account for gender differences. Tumors in cranial and spinal nerves and in the sellar region of the brain (the area just behind the eyes) occur equally in males and females.

Incidence and Mortality

According to the American Cancer Society, primary brain tumors are among the top ten causes of cancer-related deaths. In the United States, nearly 13,000 people die from primary brain tumors each year. Brain tumors are the second most common malignancy among children, involving one out of five, or 20% of pediatric cancer cases.

There was an increase in the incidence of primary malignant brain tumors in the 1980s and 1990s, particularly among children and the elderly. Several explanations have been offered to account for this. They include better diagnostic methods using CAT scans and MRIs, a greater availability of neurosurgeons, longer life expectancy, and improvements in medical treatments for elderly patients. Many researchers suggest some of the increase, particularly in childhood brain tumors, may be due to other, unknown causes. Environmental hazards are suspected, although no major risk factors have been clearly identified.

Another cause may have been a change in brain tumor classification in the mid 1980s. Some gliomas previously considered benign were changed to the status of malignant. This may have led to an increase in the number of brain tumors being registered. (Previous to the year 2002, benign brain tumors were not counted in cancer registries. The Benign Brain Tumor Cancer Registries Amendment, passed in 2002,

now mandates that cancer registries record all brain tumors regardless of their type.)

Geography and Ethnicity

There is a lot of variation in the trends of brain tumor patients along geographic and ethnic lines. Access to health care is one influential factor. Reported rates for primary malignant brain tumors tend to be higher in countries with more accessible and highly developed medical care, such as Northern Europe and the United States. Countries such as India and the Philippines have the lowest reported rates. This would seem to indicate that the difference is due to better diagnosis and reporting in more developed countries.

However, there is some evidence that cultural, ethnic, or geographic differences do play a role in the disease. The incidence rate for malignant brain tumors in Japan is less than half that in Northern Europe. In the US, gliomas affect more whites than blacks, but the incidence of meningioma is nearly equal among blacks and whites. These differences cannot be attributed only to differences in access to health care or in diagnostic practices. These and other findings suggest that further research about genetic differences needs to be done to explain variations in brain tumor incidence rates among different ethnic groups.

Survival and Prognosis

When diagnosed with a brain tumor, one of the first things a patient usually wants to know is "How long will I live?" The answer is never certain, and we encourage patients and families not to focus on statistics. No individual is a statistic; each person's prognosis is different.

Many brain tumors can be removed. Others can be kept under control for many years with treatment. Some brain tumor survivors don't experience *recurrence* while others do. For this reason, most brain tumors need to be monitored by periodic scans throughout the survivor's lifetime. The frequency of scans decreases as time goes by.

Survival is strongly related to a person's age and tumor type. On average, 20 percent of people diagnosed with a brain tumor in the U.S. will survive for five years. However, the five-year survival rate in children under age 14 with primary malignant brain tumors is 72 percent, much higher than average. People with glioblastoma multiforme consistently have the poorest survival in all age groups. For all people with meningiomas (including benign, atypical, and malignant), the five-year survival rate is 69 percent, but it is slightly lower for people with malignant meningiomas (54.6 percent).

Survival rates are strongly related to several factors. These factors include:

- **Age.** Among all brain tumor patients, children from three to 20 years of age and young adults from 20 to 44 years of age have higher survival rates than children under 3 and adults aged 45 or older.
- **Tumor type.** Brain tumors that grow slowly have a better prognosis than fast-growing tumors. Tumor progression from benign to malignant negatively affects survival.
- **Location.** This determines the type of symptoms a person may have, whether or not the tumor can be surgically removed, and how much of it can be removed.
- **Treatment.** Differences in the type of treatment and the patient's response to it also affect survival. At present, brain tumors are treated by surgery, radiation therapy and chemotherapy, used either individually or in combination.
- **Functional status.** People who are more functional at time of diagnosis do better than those who are more disabled. The Karnofsky Performance Scale (KPS) is a means of rating the patient's overall functioning level. KPS scores range from 100 to 0, where 100 represents normal functioning and 0 indicates the end of life.

KNOWN AND POSSIBLE CAUSES

To date, the only proven causes of brain tumors are rare hereditary syndromes, therapeutic radiation, and immunosuppression that gives rise to brain lymphomas. Yet these causes account for only a small percentage of cases. Although a lot of research has been done on the potential risk factors for primary brain tumors, most of the findings are uncertain. There is little agreement about the nature and extent of the risk factors. It is difficult to measure amounts of exposure to suspected risk factors and to define latency periods (the amount of time it takes for a brain tumor to develop after exposure to a risk factor).

The large number of different tumor types (more than 120) is another obstacle. However, studies have examined and continue to examine many factors that may cause brain tumors. Here are some of the findings:

Hereditary and Genetic Influences

Some hereditary syndromes, such as tuberous sclerosis, von Hippel-Lindau syndrome and neurofibromatosis types 1 and 2, are associated with a higher risk of developing brain tumors. Yet "genetic predisposition," as it is called, probably accounts for less than five percent of brain tumors. Other people may have what researchers call a "genetic susceptibility" for developing cancer. Genetic susceptibility means their bodies may not be as efficient at processing certain substances, removing *carcinogens,* or repairing damaged DNA. When exposed to toxic agents in the environment, they may more easily develop cancer. It seems likely that the majority of brain tumors are linked to interactions between genes and toxins in the environment, because such a small percentage of brain tumors are linked to heredity.

Molecular studies have found deletions (missing parts) or mutations (defects) of crucial genes that control the cell cycle. These are suspected to play a role in forming brain tumors. Many patterns of deletions and mutations have been identified in some tumor types. There is still much work to be done to systematically identify the molecular alterations in primary brain tumors and to develop methods to treat them.

Ionizing Radiation

Treatment of disease with therapeutic *ionizing radiation* (including x-rays) is a strong risk factor for brain tumors. Relatively low doses of radiation used to treat tinea capitis (ringworm) and skin hemangioma in children or infants have been associated with relative risks for nerve sheath tumors, meningioma, and glioma. One study showed a high rate of prior therapeutic irradiation among patients with glioblastoma. Another reported an increased risk of glioma or other brain tumors in patients who had undergone irradiation for acute lymphoblastic leukemia as children. Second primary brain tumors also occur more frequently than expected especially among patients treated with radiation therapy.

Exposure to Infections, Viruses, and Allergens

Several types of viruses have been shown to cause brain tumors in experimental animal studies. Since it is so difficult to design meaningful studies on humans, the topic has received little attention. There have been findings which raise the possibility that certain allergies and common infections (including chicken pox and shingles) may play a role in *preventing* brain tumors. More study is needed.

Head Injuries and Seizures

Serious head trauma has long been suspected as a cause of brain tumors. In fact, studies show a positive correlation between head trauma and meningioma, but a negative link to glioma. A history of seizures has been consistently associated with brain tumors, but since brain tumors are known to cause seizures, it is unclear if seizures and/or seizure medication can increase tumor risk. As for drugs and medications, there have been few studies of any links to adult brain tumors.

Diet

In animal studies, certain chemical substances known as N-nitroso compounds have been clearly identified as carcinogenic (causing cancer) to the nervous system. N-nitroso compounds are present in cured meats (nitrites), cigarette smoke, cosmetics, and many other sources. These compounds are also produced inside the human body as the digestive process breaks down food (including vegetables) and drugs. Given the great amount of exposure to these compounds and the variety of sources, it is extremely difficult to determine any individual's lifetime exposure.

Some studies of diet and vitamin supplementation seem to indicate that dietary N-nitroso compounds might influence the risk of both childhood and adult brain tumors. Researchers have observed in some studies that brain tumor patients (or their mothers) have generally consumed more cured foods than control groups. Avoiding cured food and eating more fruits and vegetables that are high in antioxidant vitamins may lessen the risk of developing cancer.

Chemicals in the Workplace and the Home

Some workers are exposed to carcinogenic or toxic substances

in the workplace. Researchers have attempted to pinpoint links to brain tumors, but gathering evidence is difficult. Workers are rarely exposed to one single chemical, and certain chemicals probably interact with others to increase or decrease risk. Therefore, researchers have been unable to make any definite links between brain tumors and specific chemicals, even those known to be carcinogenic.

There has been compelling evidence that workers in the production of synthetic rubber and polyvinyl chloride, and workers in certain parts of the petrochemical, petroleum, and oil industries are at greater risk for developing brain tumors. However, studies are contradictory and inconclusive. Increased risk was not found in adults who work in manufacturing of pesticides or fertilizers. However, four out of five studies of pesticide applicators have shown there is an increased risk for these professionals.

It is possible that parents exposed to carcinogens in the workplace might possibly increase the risk of cancer in their children. A mother's exposures might have a direct impact on the developing fetus, and a father's exposures before conception might damage his DNA. Higher risks of childhood brain tumors were reported for fathers working with, or working in industries involving: paper and pulp, solvents, painting, printing and graphic arts, oil or chemical refining, farming, metallurgy, and air and space. One theory is that chemical carcinogens from the workplace might remain on a parent's skin or clothing. When the parent goes home, his or her children might then be exposed to the carcinogens. However, there is no conclusive proof of this.

Studies of chemical exposures in the home have focused on the role of pre- and postnatal pesticide exposures in childhood brain tumors. A recent large study found increased risk in children exposed before birth to flea and tick pesticides. The authors of the study have urged further investigation of pesticide exposures during pregnancy.

Cellular Telephones and Radio Frequency (RF) Electromagnetic Fields

With the expansion of wireless communication technologies, radio frequency (RF) exposure is an important concern. It is important not to confuse RF fields with ionizing radiation, such as x-rays or gamma rays. Unlike ionizing radiation, RF fields cannot cause ionization or radioactivity in the body. Because of this, RF fields are called non-ionizing.

Concern over possible health effects of using cellular telephones has prompted studies looking at the relation between cell phone usage and an increased risk of brain tumors. The results of several studies suggest that there is no association. However, it may be important to continue study in this area because cell phone usage is becoming increasingly common. Many studies were conducted during a time when analog phones were the main type of cell phone, as compared to digital phones today. Total amount of phone use was lower, and the number of cell phone users was fewer then. Moreover, long-term studies are probably needed because some brain tumors may take a long time to develop.

The World Health Organization (WHO) suggests that individuals who are concerned about potential dangers of cell phone use may choose to do the following: limit their own or their children's RF exposure by limiting the length of calls, or use hands-free devices (headsets) to keep mobile phones away from the head and body.

Air Pollution

Certain toxic air pollutants are known to cause cancer in humans. Ultra fine particles, including diesel soot and other combustion products, are able to lodge deep in human lungs and even enter the

Q: *What causes cells to become tumors?*

A: Scientists believe that primary brain tumors develop when changes to the genetic makeup of cells allow abnormal cells to escape destruction by the immune system. Researchers also suspect that carcinogens, or poisons, may damage DNA in brain cells, leading to brain tumors. Studying how alterations in cell development occur will help to understand the causes of brain tumors and to identify similarities between different types of brain tumors.

bloodstream due to their microscopic size. A new study is investigating a possible link between brain tumors and air pollution.

DIRECTION FOR FUTURE STUDIES

There is a growing interest in understanding the causes of brain tumors. Progress in molecular research may lead to identifying new types of tumors. Advances in genetic research may shed light on what makes a person susceptible or resistant to developing a brain tumor. Developing new technologies, improving techniques for classification, using *molecular markers* more often, and keeping better records of the diagnoses and prognoses of primary brain tumors are all factors that will help us come to a better understanding of brain tumors and their causes. This knowledge could lead to strategies for preventing brain tumors, determining who might be sensitive to radiation therapy or certain drug treatments, and improving the survival rate of people diagnosed with malignant tumors. Clinical trials, research studies that involve people, are important means to search for answers to these types of questions.

Further studies are needed to explain gender and ethnic differences found among people diagnosed with gliomas and meningiomas. Studies are needed to find out why environmental factors and changes to DNA might increase vulnerability to brain tumors, and to help us understand the way that brain tumors develop. There is hope that further research can lead to prevention and a cure.

• • •

"Doctors may prescribe a regimen that may be effective, but they don't prescribe hope. I repeat: it's not science that has made a quantum leap in brain tumor survival, it's the brain tumor patients themselves. They have become empowered."

– Neuro-oncologist

Information for this chapter was adapted from the article "Epidemiology of Primary Brain Tumors: Current Concepts and Review of the Literature," published in Neuro-Oncology, *Volume 4, Issue 4, October 2002. The article was written by the following researchers, and we are very grateful for their assistance:*

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4. BRAIN TUMOR TYPES

To determine the course of treatment, the type of brain tumor must first be identified. This chapter discusses brain tumor types and how they are classified. Under each tumor type, you will find a list of the symptoms and treatment options that are typically prescribed. Many tumors share the same symptoms and treatments. Treatment is based on the tumor type and location. The three main treatment methods are surgery, radiation, and chemotherapy.

CLASSIFYING BRAIN TUMORS

In most cases, a brain tumor is named for the cell type of origin. Some brain tumors are named according to their location. Today, most medical institutions use the World Health Organization (WHO) classification system to identify brain tumors. The WHO classification, which is used throughout this guide, classifies brain tumors by cell origin and how the cells behave, from the least aggressive (benign) to the most aggressive (malignant). Some tumor types are assigned a grade, which signifies the rate of growth. There are variations in grading systems, depending on the tumor type. The classification and grade of an individual tumor help predict its likely behavior.

Although they may fall into a specific classification or category, brain tumors are specific to each individual. Brain tumors have vastly different characteristics and patterns of growth due to the molecular makeup of the individual tumor.

A series of criteria are used to make a diagnosis. One important criterion is *anaplasia*, the manner in which tumor cells grow with the loss of normal form or structure. The degree of anaplasia helps to forecast a tumor's growth potential. The most rapidly growing tumors have the highest degree of anaplasia. Tumor cells that show a lower degree of anaplasia are generally slow growing.

In addition to other criteria, some tumors are now examined for their genetic traits to evaluate the nature of the tumor. For example, certain patterns of mutations or chromosomal defects have been identified in certain tumor types.

Childhood Brain Tumors

Some tumor types are more common in children than in adults. The most common types of childhood tumors are medulloblastomas, low-grade astrocytomas, ependymomas, craniopharyngiomas, and brain stem gliomas. When childhood brain tumors occur in adults, they often occur in a different part of the brain than in children.

For more information about childhood brain tumors, call NBTF at 1-800-934-2873 to request information about the pediatric brain tumor organizations that exist. You can also find these resources on the web site at www.braintumor.org.

PRIMARY BRAIN TUMORS

Primary brain tumors originate in the brain itself. Primary brain tumors usually do not spread from the brain to other parts of the body. However, there are some exceptions to this rule.

Primary brain tumors are classified into two groups: glial tumors, which are called *gliomas,* and non-glial tumors.

GLIAL TUMORS

There are two types of cells that make up the nervous system: *neurons* and *neuroglia.* Neurons send and receive nerve messages. Neuroglia, otherwise known as *glial cells,* often surround the neurons. Glial cells play a supportive role by nourishing, protecting and supporting neurons. There are six kinds of glial cells; oligodendrocytes, astrocytes, ependymal cells, Schwann cells, microglia, and satellite cells.

A brain tumor that develops from glial cells is called a glioma. About half of all primary brain tumors and one-fifth of all primary spinal cord tumors form from glial cells. Gliomas tend to grow in the cerebral hemispheres, but may also occur in the brain stem, optic nerves, spinal cord, and cerebellum.

Gliomas are divided into subgroups depending on the origin of the glial cells. The most common type of glioma is an astrocytoma.

Astrocytoma

An astrocytoma develops from star-shaped glial cells (astrocytes) that support nerve cells. These tumors can be located anywhere in the brain, but the most common location is in the frontal lobe. Astrocytomas are the most common primary CNS tumor.

The physician, usually the neurosurgeon or neuro-oncologist, will discuss the type and location of an astrocytoma. The pathologist will assign it a grade. Astrocytomas are generally classified as low or high grade. Low-grade astrocytomas (grades I and II) are slow growing. High-grade astrocytomas (grades III and IV) grow more quickly. The main tumor type is listed for each grade. There are additional tumor types in each of these grades.

The WHO classification divides astrocytomas into four grades:

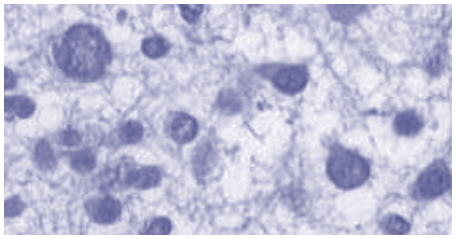
- Grade I Pilocytic Astrocytoma
- Grade II Low-Grade Astrocytoma
- Grade III Anaplastic Astrocytoma
- Grade IV Glioblastoma Multiforme (or GBM)

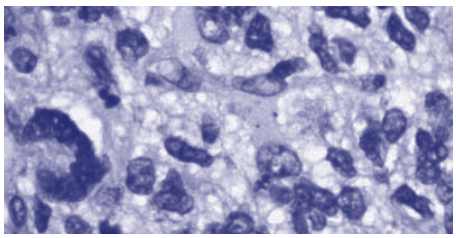
CHARACTERISTICS

The characteristics of an astrocytoma vary depending on the tumor's grade and location. Most people are functioning normally when diagnosed with a low-grade astrocytoma. Symptoms tend to be subtle and may take one to two years to diagnose. This is because the brain can often adapt to a slow-growing tumor for a period of time. High-grade tumors may present with changes that are sudden and dramatic.

SYMPTOMS

- Headaches
- Seizures or convulsions
- Difficulty thinking or speaking
- Behavioral or cognitive changes (related to thinking, reasoning, and memory)
- Weakness or paralysis in one part or one side of the body
- Loss of balance
- Vision changes
- Nausea or vomiting





Anaplasia in astrocytoma cells; grade II (left) and grade IV (right)

PHOTOS BY: David N. Louis, MD, Massachusetts General Hospital and Harvard Medical School COURTESY OF: Catherine L. Nutt, PhD, Massachusetts General Hospital and Harvard Medical School

Astrocytoma Grades:

• *Pilocytic Astrocytoma (Grade I)*

This tumor is also known as a juvenile pilocytic astrocytoma, or by the initials JPA.

CHARACTERISTICS

- Slow growing, with relatively well-defined borders
- Grows in the cerebrum, optic nerve pathways, brain stem and cerebellum
- Occurs most often in children and teens
- Accounts for two percent of all brain tumors

TREATMENT

Surgery is the standard treatment. If the tumor cannot be completely resected, radiation or chemotherapy may be given. Chemotherapy may be given to very young children instead of radiation therapy to avoid damage to the developing brain. Some of these tumors can progress to a higher grade, so it is important to be diligent about following up with the medical team after treatment.

• *Low-Grade Astrocytoma (Grade II)*

CHARACTERISTICS

- Slow growing
- Rarely spreads to other parts of the CNS
- Borders not well defined
- Common among men and women in their 20s–50s

TREATMENT

Treatment depends on the size and location of the tumor. The doctor will most likely perform a biopsy or surgery to remove the tumor. Partial resections or inoperable tumors may be treated with radiation. Recurring tumors may require additional surgery, radiation and/or chemotherapy.

• *Anaplastic Astrocytoma (Grade III)*

CHARACTERISTICS

- Grows faster and more aggressively than grade II astrocytomas
- Tumor cells are not uniform in appearance
- Invades neighboring tissue
- Common among men and women in their 30s–50s
- More common in men than women
- Accounts for four percent of all brain tumors

TREATMENT

Treatment depends on the location of the tumor and how far it has progressed. Surgery and radiation therapy, with chemotherapy during or following radiation, are the standard treatments. If surgery is not an option, then the doctor may recommend radiation and/or chemotherapy. Many clinical trials (experimental treatments) using radiation, chemotherapy, or a combination are available for initial and recurrent anaplastic astrocytomas.

• *Glioblastoma Multiforme (GBM) (Grade IV Astrocytoma)*

CHARACTERISTICS

- Most invasive type of glial tumor
- Commonly spreads to nearby tissue
- Grows rapidly
- May be composed of several different kinds of cells (i.e., astrocytes, oligodendrocytes)
- May have evolved from a low-grade astrocytoma or an oligodendroglioma *(see below)*
- Common among men and women in their 50s–70s
- More common in men than women
- Accounts for 23 percent of all primary brain tumors

TREATMENT

Standard treatment is surgery followed by radiation therapy. If surgery is not an option, the doctor may administer radiation therapy. Chemotherapy is sometimes given during or after radiation therapy or if the tumor recurs. Many clinical trials (experimental treatments) using radiation, chemotherapy, or a combination are available for initial and recurrent GBM.

Q: ***What is the difference between benign and malignant tumors?***

A: Benign tumors are slow-growing tumors that can be removed or destroyed if in an accessible location. Malignant tumors (brain cancer) are rapidly growing tumors that invade or infiltrate and destroy normal brain tissue. Tumors are graded to indicate how quickly they are growing. Low-grade tumors grow more slowly than high-grade tumors. Benign or malignant tumors can recur, which means they grow back after treatment for the initial tumor.

Brain Stem Glioma

CHARACTERISTICS

- Named for its location at the base of the brain
- Can range from low grade to high grade
- Occurs most often in children between three and ten years of age, but can occur in adults

SYMPTOMS

- Headaches
- Nausea
- Speech or balance abnormalities
- Difficulty swallowing
- Weakness or numbness of the arms and/or legs
- Facial weakness
- Double vision

Symptoms can develop slowly and subtly and may go unnoticed for months. In other cases, the symptoms may arise abruptly. A sudden onset of symptoms tends to occur with rapidly growing, high-grade tumors.

TREATMENT

Surgery may not be an option because the brain stem controls vital life functions and can easily be damaged. Radiation therapy can reduce symptoms and help slow the tumor's growth. Low-grade brain stem gliomas can have very long periods of remission.

Ependymoma

Ependymal tumors begin in the ependyma, cells that line the passageways in the brain where CSF is produced and stored. Ependymomas are classified as either supratentorial (in the cerebral hemispheres) or infratentorial (in the back of the brain). Variations of this tumor type include subependymoma, subependymal giant-cell astrocytoma, and malignant ependymoma. Ependymoblastoma, which occurs in infants and children under three years, is no longer considered a subtype of ependymoma. For ependymoblastoma, see primitive neuroectodermal tumor (PNET) below.

CHARACTERISTICS

- Usually localized to one area of the brain
- Develops from cells that line the hollow cavities at the bottom of the brain and the canal containing the spinal cord
- Can be slow growing or fast growing
- May be located in the ventricles
- May block the ventricles, causing hydrocephalus (water on the brain)
- Sometimes extends to the spinal cord
- Common among men and women in their 40s and 50s, and in children
- Occurrence peaks at age five and again at age 34
- Accounts for two percent of all brain tumors

SYMPTOMS

- Headaches
- Nausea
- Speech or balance abnormalities
- Difficulty swallowing
- Weakness or numbness of the arms and/or legs
- Facial weakness
- Double vision

TREATMENT

The doctor will perform tests to determine if it has spread to the spinal cord. Surgery followed by radiation therapy is the usual course of treatment. A shunt may be needed to treat hydrocephalus caused by blockage of the ventricles.

Mixed Glioma

A mixed glioma is often a combination of an astrocytoma and an oligodendroglioma *(see below).*

CHARACTERISTICS

- Composed of two or more types of glioma cells
- Graded according to the most aggressive type of tumor cells
- Common among men and women in their 20s–50s
- Accounts for one percent of all brain tumors

SYMPTOMS

- Headaches
- Seizures
- Weakness or paralysis
- Nausea and vomiting
- Visual problems
- Behavioral and cognitive changes

TREATMENT

Mixed gliomas are generally treated for the most anaplastic (cancerous) type of cell found in the tumor. For example, in the case of a tumor composed of an anaplastic astrocytoma and a low-grade oligodendroglioma, the treatment would be based on the anaplastic astrocytoma—the more aggressive of the two cell types.

Oligodendroglioma

This tumor type develops from glial cells called oligodendrocytes.

CHARACTERISTICS

- Occurs frequently in the frontal or temporal lobes
- Can be classified as low grade or high grade
- Common among men and women in their 20s–40s, but can occur in children
- More common in men than women
- Accounts for slightly less than three percent of all brain tumors
- May be associated with 1p or 19q chromosomal losses

SYMPTOMS

- Seizures
- Headaches
- Behavioral and cognitive changes
- Weakness or paralysis

TREATMENT

Treatment options depend on the grade of the tumor. If the tumor is low grade and symptoms are not severe, the doctor may decide to perform surgery, then "watch and wait" and evaluate tumor growth through MRIs. There is a malignant form called anaplastic oligodendroglioma and a mixed malignant astrocytoma-oligodendroglioma (oligoastrocytoma). The common treatment for these high-grade tumors is surgery followed by radiation therapy and/or chemotherapy. Both low- and high-grade oligodendrogliomas can recur. If a tumor recurs, the doctor will evaluate it for a second surgical procedure, radiation, and/or chemotherapy.

Gene expression studies are used to classify gliomas based on certain characteristics, or genetic profiles. Oligodendrogliomas can be identified by deficiencies in certain chromosomes named 1p and 19q. Genetic profiling of oligodendrogliomas provides a more accurate predictor of prognosis and treatment options than does standard pathology.

Q: ***What is resection?***

A: Resection is the surgical removal of a tumor. A total resection means all visible tumor, as seen by the neurosurgeon and detected on the scan, has been removed.

Even after a total resection, it is likely there are tumor cells remaining that will require further treatment.

A subtotal or partial resection means that some of the visible tumor remains. The term "debulking" refers to a partial resection.

Q: ***What does recurrence mean?***

A: Recurrence is a term used to describe a tumor that has grown back after being removed or stabilized. Recurrence commonly occurs in the same area as the original tumor, but may develop in another part of the brain or spinal cord.

After treatment, a brain tumor may disappear or remain in remission, a state in which the tumor cells stop multiplying. Remission can be temporary or permanent. It is not possible to predict whether or not recurrence will take place. Therefore, after receiving therapy the patient will need to have follow-up appointments indefinitely, usually with MRI imaging, even if the tumor was benign.

Optic Nerve Glioma

CHARACTERISTICS

- Named for its location on or near the nerve pathways between the eyes and the brain
- Can range from low grade to high grade
- Occurs most often in infants and children, but can occur in adults

SYMPTOMS

- Headaches
- Progressive loss of vision
- Double vision

TREATMENT

Surgery is standard treatment, usually followed by radiation therapy or chemotherapy. Chemotherapy may be given to very young children instead of radiation therapy to avoid damage to the developing brain.

Subependymoma

This tumor forms from ependymal cells, and is a variation of an ependymoma.

CHARACTERISTICS

- Slow growing
- Usually located in the fourth and lateral ventricles
- More common in men than in women

SYMPTOMS

- Headaches
- Nausea
- Loss of balance
- Sometimes no symptoms occur and tumor is detected incidentally

TREATMENT

Surgery will be performed when possible. Radiation therapy may be used if the tumor progresses or recurs. A shunt may be needed to treat hydrocephalus.

"During the six and a half years my son, Timothy, battled brain tumor disease, I learned many lessons and developed a variety of coping skills that helped me to care for him. We would sometimes joke about the fact that I was his unregistered nurse."

– Wendy Pizzi

NON-GLIAL TUMORS

The following tumor types develop on or in structures within the brain, such as nerves, blood vessels, and glands.

Acoustic Neuroma

An acoustic neuroma is also known as a vestibular schwannoma or neurilemmoma.

CHARACTERISTICS

- Grows on the sheath surrounding the eighth cranial nerve in the inner ear
- More common in women than men

SYMPTOMS

- Hearing loss in one ear
- Dizziness or vertigo
- Tinnitus (ringing in the ear)
- Tingling or numbness in the face
- Balance problems
- Coordination problems

TREATMENT

The tumor may be observed to monitor its growth, or surgery may be performed. The goal of surgery is the complete removal of the tumor without harming the seventh cranial nerve (which controls facial movement) or causing hearing loss. Radiosurgery may be an option. This focused, high-energy radiation prevents the growth of acoustic neuromas, but actual shrinkage of the tumor may never occur or may take several months.

Chordoma

CHARACTERISTICS

- Rare and low grade
- Occurs at the sacrum, near the lower tip of the spine, or at the base of the skull
- Originates from cells left over from early fetal development
- Invades the bone and soft tissues but rarely the brain tissue
- Can block the ventricles, causing hydrocephalus
- Can metastasize (spread) or recur

SYMPTOMS

- Double vision
- Headaches

TREATMENT

Surgery and radiation therapy are the common forms of treatment. Chordomas at the base of the skull can be difficult to remove. Surgical resection may be possible if the tumor is located in the spine.

CNS Lymphoma

CNS Lymphoma is a type of cancer that develops in the lymphatic system. The lymphatic system is a network of small organs called lymph nodes and vessels (similar to blood vessels) that carry a clear, watery fluid called *lymph* throughout the body. This fluid supplies cells called lymphocytes that fight disease and infection.

To correctly diagnose primary CNS Lymphoma, staging must be done. Staging is the process of using CT scanning to examine many parts of the body. Staging helps to confirm where the cancer originated and how far it has spread.

CHARACTERISTICS

- Very aggressive
- Usually involves multiple tumors throughout the CNS
- More common in people whose immune systems are compromised
- Often develops in the brain, commonly in the areas adjacent to the ventricles
- Can be primary (originating in the brain) or secondary
- Most common among men and women in their 60s–80s, but incidence is increasing in young adults
- Twice as common in men as in women
- Accounts for three percent of all brain tumors

SYMPTOMS

- Headaches
- Partial paralysis on one side of the body
- Seizures
- Cognitive or speech disorders
- Vision problems

TREATMENT

Radiation therapy, chemotherapy, and steroids are the most common forms of treatment. Surgery is rarely an option because there are usually multiple lesions. However, a biopsy at the start of steroid treatment can be critical to ensure the correct diagnosis.

Craniopharyngioma

CHARACTERISTICS

- Most common in the parasellar region, an area at the base of the brain and near the optic nerves
- Also grows in the regions of the optic nerves and the hypothalamus, near the pituitary gland
- Tends to be low grade
- Often accompanied by a *cyst*
- Originates in cells left over from early fetal development
- Occurs in children and men and women in their 50s and 60s

SYMPTOMS

- Headaches
- Visual changes
- Weight gain
- Delayed development in children

TREATMENT

Surgery is the most common treatment. Radiation therapy may be used.

Hemangioblastoma

CHARACTERISTICS

- Commonly located in the cerebellum
- Slow growing
- Originates from blood vessels
- Can be large in size
- Often includes a cyst
- Common among men and women in their 40s–60s
- More common in men than women
- Accounts for approximately one percent of all brain tumors
- Sometimes found in conjunction with von Hippel-Lindau syndrome, an inherited condition that may cause a tendency toward hemangioblastomas or kidney cancers

SYMPTOMS

- Headaches
- Nausea and vomiting
- Walking and balance problems

TREATMENT

Surgery is the standard treatment. Radiosurgery may be given to destroy multiple inoperable lesions.

Medulloblastoma

CHARACTERISTICS

- A type of primitive neuroectodermal tumor (PNET) *(see below)*
- Often located in the cerebellum or near the brain stem
- Can spread to the spinal cord through the CSF
- May obstruct the fourth ventricle, causing hydrocephalus
- Occurs most often in children under the age of ten, but may occur in adults
- Slightly more common in males than females

SYMPTOMS

- Headaches
- Early morning vomiting
- Lethargy or sleepiness
- Lack of coordination
- Double vision
- Behavioral or personality changes
- Signs of pressure seen behind the eye when examined with an ophthalmoscope

TREATMENT

Surgery is the standard treatment when possible. Chemotherapy is usually part of the treatment plan. Radiation of the brain and spine is often recommended in adults and children over three years of age. A shunt may be needed to treat hydrocephalus. This tumor may recur years later if not totally resected.

Meningioma

These tumors grow from the meninges, the layers of tissue covering the brain and spinal cord. Meningiomas are graded from low to high. The lower the grade, the lower the risk of recurrence and aggressive growth. The WHO classification divides meningiomas into three grades:

- Grade I, Benign Meningioma
- Grade II, Atypical Meningioma
- Grade III, Malignant (Anaplastic) Meningioma

CHARACTERISTICS

- May arise after previous treatment from ionizing radiation or excessive x-ray exposure
- Common among women and men in their 40s–50s, but can occur at any age
- Twice as common in women as in men
- Accounts for 27 percent of all primary brain tumors
- In very rare cases, can invade the skull or metastasize to the skin or lungs
- Women with meningiomas can experience tumor growth during pregnancy
- In rare cases, multiple meningiomas can develop at the same time

SYMPTOMS

- Seizures
- Headaches
- Nausea and vomiting
- Vision changes
- Behavioral and cognitive changes
- Sometimes no symptoms occur and tumor is detected incidentally

TREATMENT

If there are no symptoms, the doctor may monitor the tumor with MRIs. Otherwise, surgery is the standard treatment. If the tumor cannot be completely resected or if it recurs, radiation therapy may be given as well. Chemotherapy for unresectable, aggressive, atypical, or recurrent meningiomas is being tested through clinical trials. Follow-up scans are needed indefinitely, because meningiomas can recur years or even decades after treatment.

Pineal Tumor

A malignant form of pineal tumor is called pineoblastoma.

CHARACTERISTICS

- Named for its location in or around the pineal gland (near the center of the brain)
- Can range from low grade to high grade
- Can produce an excess of melatonin, a hormone that controls the sleep/wake cycle
- Can block the ventricles, causing hydrocephalus
- High-grade pineal tumors can spread to the spinal cord through the CSF
- Common types include germ cell tumors, pineal parenchymal tumors, and gliomas
- Occurs most often in children and young adults

SYMPTOMS

- Headaches
- Nausea and vomiting
- Fatigue
- Visual problems
- Memory problems

TREATMENT

Surgery is standard treatment when possible. Radiation therapy may be used as primary treatment in adults and children over three. Chemotherapy may be given to delay the use of radiation therapy in very young patients. Clinical trials using chemotherapy drugs are available for pineal tumors. A shunt may be needed to treat hydrocephalus caused by blockage of the ventricles. Treatment for high-grade (malignant) pineal tumors such as a pineoblastoma may involve radiation to the brain and spine to control spread through the CSF. Clinical trials using chemotherapy or biological therapy following radiation therapy are being investigated.

Pituitary Tumor

The pituitary gland produces hormones that affect growth and the functions of other glands in the body. Certain pituitary tumors secrete abnormally high amounts of their respective hormones and cause related symptoms. Other pituitary tumors do not secrete hormones, but grow and compress brain tissue, causing other symptoms.

CHARACTERISTICS

- Named for its location on or near the pituitary gland, located at the center of the brain behind and above the nose
- Can range from low grade to high grade
- May cause excessive secretion of hormones
- Common among men and women in their 50s–80s
- Accounts for six percent of all brain tumors

SYMPTOMS

- Headache
- Depression
- Vision loss
- Nausea or vomiting
- Behavioral and cognitive changes
- Cessation of menstrual periods (amenorrhea)
- Leaking of fluid from the breasts (galactorrhea)
- Hair growth in women
- Impotence in men
- Abnormal growth of hands and feet
- Abnormal weight gain

TREATMENT

If the tumor is large or compressing the optic nerve, standard treatment is surgery. This can be transphenoidal surgery, which gets access to the tumor by entering through the nasal passage *(see chapter 5)*. Radiation therapy may also be used. Some pituitary tumors may be treated with medication, and/or observed with MRI scans. Certain drugs can block the pituitary gland from making too many hormones. Follow up with an endocrinologist may be necessary to manage hormonal changes.

Primitive Neuroectodermal Tumors (PNET)

There are several tumor types in this category. Names of specific PNETs may be based on the tumor location. Examples include pineoblastoma (located in the pineal region), medulloblastoma (located in the cerebellum), and cerebral cortex PNET (located in the cerebral cortex).

CHARACTERISTICS

- Very aggressive and tend to spread throughout the CNS
- Grow from undeveloped brain cells
- Commonly include cysts and *calcification* (calcium deposits)
- Tend to be large
- Occur most often in young children

SYMPTOMS

- Can vary depending on location of tumor
- Weakness or change in sensation on one side of the body
- Morning headache or headache that goes away after vomiting
- Nausea and vomiting
- Seizures
- Unusual sleepiness or lethargy
- Behavioral or personality changes
- Unexplained weight loss or weight gain

TREATMENT

Surgery is the standard treatment when possible. In adults and children over three years of age, surgery may be followed by radiation therapy to the whole brain and spinal cord, and chemotherapy. In children under three years of age, surgery may be followed by chemotherapy or a clinical trial of chemotherapy to delay or reduce the need for radiation therapy.

Rhabdoid Tumor

CHARACTERISTICS

- Rare
- Highly aggressive and tends to spread throughout the CNS
- Often appears in multiple sites in the body, especially the kidneys
- Difficult to classify; may be confused with medulloblastoma or PNETs
- Occurs most often in young children but can also occur in adults

SYMPTOMS

- Vary depending on location of tumor in the brain or body
- An orbital tumor may cause the eye to protrude
- Balance problems may occur
- External tumors cause noticeable lumps; internal tumor symptoms vary based on location

TREATMENT

Whenever possible, surgery is performed to remove as much of the tumor as possible. This is usually followed by chemotherapy and radiation therapy. In children under three years of age, surgery may be followed by chemotherapy alone. Clinical trials are being studied using autologous bone marrow transplantation *(see glossary)* after high-dose chemotherapy for recurrent or multiple rhabdoid tumors.

Schwannoma

Also known as vestibular schwannoma and acoustic neuroma *(see acoustic neuroma).*

CHARACTERISTICS

- Arises from cells that form a protective sheath around nerve fibers
- Typically grows around the eighth cranial nerve, but can be found around other cranial or spinal nerves

SYMPTOMS

- Reduced hearing in the ear on the side of the tumor when eighth cranial nerve is involved
- Tinnitus (ringing in the ear)
- Balance problems
- Deficits depend on the nerve that is affected

TREATMENT

Surgery and radiotherapy are the most common forms of treatment. If the tumor is not completely removed, recurrence is likely.

METASTATIC BRAIN TUMORS

A metastatic, or secondary, brain tumor is one that begins as cancer in another part of the body. Some of the cancer cells may be carried to the brain by the blood, or may spread from adjacent tissue. The site where the cancerous cells originated is referred to as the primary cancer. Metastatic brain tumors are often referred to as *lesions.* Metastatic brain tumors are the most common brain tumors. There has been an increase in metastatic lesions as people are surviving primary cancers for longer periods of time.

CHARACTERISTICS

- The primary cancer is usually in the lung, breast, colon, kidney, or skin (melanoma), but can originate in any part of the body
- Most are located in the cerebrum, but can also develop in the cerebellum or brain stem
- More than half of people with metastatic tumors have multiple lesions (tumors)
- Common among middle-aged and elderly men and women

SYMPTOMS

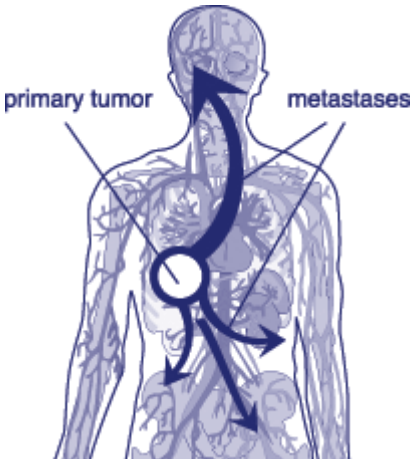
- Seizures
- Headaches
- Behavioral and cognitive changes
- Problems with coordination

TREATMENT

Surgery and/or radiosurgery are used if lesions are accessible and limited in number. Both of these treatments are commonly followed by whole brain radiation therapy (WBRT). In cases of multiple lesions, WBRT alone may be given. Chemotherapy specific to the brain-located metastatic tumor may be used.

RECURRENT TUMORS

A recurrent tumor is a tumor that has grown back after being removed, stabilized, or shrunken. Recurrence may occur in the same area as the original tumor or elsewhere in the brain or spinal cord.



Usually, symptoms that may indicate a tumor recurrence are those the patient had previously, such as leg or arm weakness or problems with coordination. The symptoms may return or become more pronounced. Headaches or seizures may occur if there is pressure on the brain.

Treatment options for a recurrence may be surgery, radiation, or chemotherapy. A combination of these treatments may be suggested. The physician will recommend specific treatments based on the size and location of the tumor or tumors, as well as the patient's functional status. Radiation therapy may be restricted if the patient has had previous radiation. Commonly, one treatment of standard focal radiation is the amount the brain can tolerate. Further radiation would cause severe cognitive damage. However, *radiosurgery,* an intense beam of radiation that focuses only on a specific area, may be an option *(see chapter 5).*

There are many clinical trials available for patients whose tumor has recurred. It is worth considering clinical trials as an option for treatment. The Internet is an excellent place to find clinical trial listings. See chapter 5 for more information on clinical trials.

A tumor recurrence can be quite traumatic for the patient and family. It brings back the feelings of having a life-threatening disease. While some people do very well, recovery from treatment after tumor recurrence may be more prolonged. Some people feel more tired and find that it takes longer to return to their normal routine. Fatigue may occur due to either an emotional reaction or physical aspects of the tumor. Patients and families may also experience depression. Seek assistance from a doctor or hospital social worker to get help dealing with the difficult emotions a recurrence can cause.

OTHER TUMOR-RELATED CONDITIONS

Cysts

A cyst is a fluid-filled sac that may encapsulate (surround) or be located next to a tumor. Based on its location in the brain, a cyst can cause symptoms such as headache, pain, seizures, or a neurological deficit. Cysts can be surgically removed or drained. If a cyst is not causing neurological difficulties, the doctor will conduct ongoing MRI and CT scans to observe its growth pattern.

Neurofibromatosis

Neurofibromatosis is a genetic disorder that can cause tumors in various parts of the nervous system. There are two types of neurofibromatosis. Type 1, the more common kind, usually occurs outside of the CNS. Type 2 occurs within the CNS. Type 2 neurofibromatosis causes multiple CNS tumors, including neurofibromas, multiple meningiomas, bilateral vestibular schwannomas, optic nerve gliomas, and spinal cord tumors. Symptoms include loss of balance, tinnitus, total hearing loss, facial pain or numbness, and headache. Surgery is the standard treatment.

Pseudotumor Cerebri

This condition is not a brain tumor, but its symptoms mimic a brain tumor. Pseudotumor cerebri most commonly afflicts obese adolescent girls and young women. Symptoms include headaches, blurred vision, dizziness, and a slight numbness of the face. The symptoms are caused by a buildup of CSF. Treatment is given to relieve the symptoms, particularly visual impairment. Treatment may include repeated lumbar punctures or medications to decrease CSF. In severe cases, a shunt may be needed.

Tuberous Sclerosis

Tuberous Sclerosis is a genetic disorder that causes numerous neurological and physical symptoms, including tumors of the CNS, eyes, and kidneys. Most cases occur in children under 20 years of age. About fifty percent of tuberous sclerosis patients develop brain tumors. Subependymal giant-cell astrocytomas are the most common type, but other tumor types are also associated with this condition. Most patients suffer from seizures. Treatment may involve inserting a shunt to prevent hydrocephalus. Surgery is another treatment option.

5. BRAIN TUMOR TREATMENTS

This chapter examines the standard treatments for brain tumors: surgery, radiation therapy, and chemotherapy. This chapter also describes biologic (gene) therapy, new treatments currently being tested in clinical trials, and complementary and alternative medicine (CAM).

Before receiving treatment, the patient's condition must be evaluated through clinical examinations and imaging tests *(see chapter 2)*. When possible, the doctor, patient, and family will discuss a treatment plan based on the type and location of the tumor, the patient's general health, medical history, and preferences.

In diagnosing and treating brain tumors, a multi-disciplinary treatment team, made up of various specialists, is generally considered the preferred approach.

The Treatment Team

- ***Neurologist*** A doctor specializing in the diagnosis and treatment of disorders and diseases affecting the CNS.
- ***Neuroradiologist*** A radiologist (an expert in imaging techniques) specializing in the interpretation of diagnostic images (scans) of the brain, spinal cord, and nervous system.
- ***Neurosurgeon*** A surgeon specializing in the diagnosis, treatment, and surgical management of disorders and diseases of the CNS.
- ***Neuropathologist*** A doctor specializing in the diagnosis of neurological disorders and diseases through microscopic examination of biopsied tissues (tumor cells).
- ***Neuro-oncologist*** An oncologist (cancer doctor) specializing in the treatment of cancers and tumors affecting the CNS.
- ***Radiation Oncologist*** A doctor specializing in the delivery of radiation therapy.
- ***Nurse Practitioner*** A registered nurse who independently performs physical exams, common diagnostic and laboratory tests and (in most states) can prescribe certain medications.
- ***Physician Assistant*** A certified health care worker who may perform physical exams, identify health problems, and plan treatment under the direction and supervision of a medical doctor.
- ***Neuro-oncology Nurse Specialist*** A registered nurse specializing in patient education (including symptom management) and support services for brain tumor patients.
- ***Neuropsychologist*** A licensed psychologist specializing in how the brain functions and the impact that brain damage has on one's abilities. *(Please note: although neuropsychologists are frequently not consulted until after treatment, it may be preferable to do so at diagnosis. That way, a more accurate evaluation can be made before treatment for comparison of changes that may occur after treatment.)*

In addition, the services of the following professionals may be beneficial:

- ***Medical Social Worker (MSW)*** A licensed social worker who assists patients and families with health-related problems and concerns. MSWs help locate appropriate health care, legal resources, and financial aid.
- ***Nutritionist*** A person who specializes in information about dietary needs.

continued on next page

The Treatment Team (continued)

- ***Physical Therapist*** A trained individual who helps patients restore function, improve mobility, relieve pain, and prevent or limit permanent physical disabilities.
- ***Speech Therapist*** A professional who helps people overcome problems understanding and producing language. Speech therapists also help with eating and swallowing difficulties caused by oral motor problems.
- ***Rehabilitation Counselor*** A specialist who helps people deal with the personal, social, and vocational effects of disabilities, and works toward increasing the client's capacity to live independently.
- ***Occupational Therapist*** An individual who helps clients to compensate for permanent loss of function by improving basic motor functions and reasoning abilities.
- ***Clinical Psychologist*** A licensed professional who can help patients and their families adjust to the effects of illness on their lives.
- ***Physiatrist*** or ***Physical Medicine and Rehabilitation Specialist*** A physician specializing in physical medicine and rehabilitation. Physiatrists specialize in restoring optimal function to people with injuries to the muscles, bones, tissues, and nervous system (such as stroke survivors).

TUMOR BOARD

Some medical centers offer the services of a tumor board. A tumor board is a *multidisciplinary* group of health care providers involved in the treatment and diagnosis of CNS tumors. Neurosurgeons, neurologists, radiation oncologists, pathologists, and other medical professionals may be part of a tumor board. This group meets and reviews the patient's MRI films and clinical and pathological information. The tumor board then discusses treatment options and makes a group recommendation regarding treatment.

Before receiving treatment, the patient commonly receives medication(s) to manage the symptoms of the tumor.

MEDICAL MANAGEMENT

Brain Edema

Brain tumors add mass within the skull. Tumors can interfere with the circulation of the brain's blood supply, causing swelling of the normal tissue surrounding them. This swelling is called brain edema. Brain edema causes increased intracranial pressure (pressure inside the skull) because the skull is a rigid container with no room for expansion. Increased intracranial pressure can cause *general symptoms* including headaches, seizures, nausea, vomiting, and blurred vision.

Brain edema can also cause *focal symptoms* by putting pressure on specific structures within the brain. Examples of focal symptoms include problems with language comprehension, speech problems, and weakness on the opposite side of the body from where the tumor is located.

Steroids (glucocortico-steroids) are drugs that reduce brain swelling. The most common steroid is dexamethasone (Decadron). Other steroids are prednisone and methylprednisolone.

Steroids and Their Side Effects

Steroids are prescribed to reduce inflammation and control swelling of the brain. Steroids can help relieve pre-surgery symptoms, which may increase the time to make treatment decisions. Steroids may be prescribed at diagnosis, or before or after surgery. These drugs do not kill tumor cells, but can improve a patient's condition. Steroids may be taken alone or combined with other forms of treatment. When the swelling is under control, then the dosage is gradually tapered off.

Steroids have a range of short- and long-term side effects. Short-term side effects include insomnia, facial swelling and flushing, increased sweating, increased appetite, moderate abdominal pain, nervousness, personality and mood changes, hoarseness, throat irritation, weight gain, water retention, and thirst. Some long-term side effects include muscle wasting (especially thigh muscles), peptic ulcers, glaucoma, fatigue, weakness, osteoporosis, impairment of the hip joint, diabetes, hypertension, and loss of bone calcification.

Some patients who take steroids for a few days or weeks do not experience side effects; others do. Steroids can cause both short-term and long-term side effects if taken over a long period of time, or

stopped suddenly without being monitored by a doctor. Patients should never stop taking steroids without the doctor's knowledge. Patients should discuss monitoring and all possible side effects with the doctor.

SURGERY

Surgery or *resection* is the primary form of treatment for brain tumors. The goal of surgery is to remove the tumor without causing damage to critical neurological functions. When only part of a tumor can be removed, it is possible that the tumor will recur. Therefore, the entire tumor is removed whenever feasible.

Debulking is another term used for a partial resection. Debulking attempts to remove as much of a tumor as is possible. It can alleviate symptoms and improve the effectiveness of other therapies, such as radiation therapy and chemotherapy. In general, radiation and chemotherapy treatments are used as secondary or adjuvant treatments for tumors that cannot be managed using only surgery. However, they may be used without surgery if the tumor is inoperable.

Prior to surgery, the neurosurgeon needs to determine the location of the tumor and plan the safest method of performing the operation. To do this, the patient will receive one or more of the following: a scan (MRI, CT or PET), and hearing, neuropsychological or speech tests. The patient will meet with the neurosurgeon to discuss the surgery, length of hospital stay, any pre-existing medical conditions, and possible risks of surgery. Patients should inform the neurosurgeon of all medicines being taken, including over-the-counter medications, herbs, and supplements. Patients may also meet with a neuro-oncologist or other members of the treatment team. It is helpful to prepare a list of questions and plan to keep a journal to record important information. Below are some sample questions.

1. Is my tumor benign or malignant?
2. What is the name, type, and grade of my tumor?
3. What are the treatment options?
4. What are the side effects of each treatment option?
5. Which treatment would you take if you had my tumor?
6. If I am more interested in quality of life than how long I live, which treatment would you recommend?
7. Are there any clinical trials for which I am eligible?
8. What questions are those clinical trials asking?
9. Do you have the equipment necessary to deliver stereotactic radiosurgery and fractionated stereotactic radiation therapy?
10. I wanted a second opinion from another neurosurgeon or radiation oncologist, whom would you recommend?
11. What factors do you look at to predict how I am going to do?

In some cases, surgery is urgent because of the tumor's location. The surgeon will obtain the patient's medical history and perform surgery as soon as possible.

Just before surgery, all or part of the patient's head will be shaved. If possible, the patient will discuss the type of anesthesia to be used with the anesthesiologist. An *intravenous (IV)* line will be placed in the arm to administer fluids and medications.

SURGICAL PROCEDURES

Craniotomy

Craniotomy is the surgical opening of the skull (cranium). During this procedure, the patient is usually under general anesthesia. The surgeon makes an incision through a section of the scalp. Then, using sophisticated surgical tools, a part of the skull is removed and the covering of the brain (dura) is opened to reach the tumor. As much of the tumor as possible is removed. The dura is sutured and the part of the skull is put back into place. Then the scalp is closed with staples or stitches. These are usually removed after about seven to 10 days.

Awake Craniotomy

Awake craniotomy, or surgery under local anesthesia, is a procedure in which the patient is allowed to return to consciousness after the brain has been exposed. With the patient awake, the neurosurgeon can perform *brain mapping.* Brain mapping is a procedure that allows the neurosurgeon to identify the *eloquent cortex,* the areas of the brain that control important functions such as speech, sensation, and movement. Once these delicate areas have been identified, the patient is put back under general anesthesia, and the surgery is completed.

Biopsy

A biopsy is a surgical procedure in which a small sample of tissue is taken from the tumor and examined under a microscope. The purpose of a biopsy is to diagnose a tumor; to find out its type and grade.

Stereotactic or Needle Biopsy

A stereotactic or needle biopsy is used to take tissue samples from tumors in hard-to-reach areas of the brain. The patient is usually awake during this procedure, but it can also be performed with the patient under anesthesia. A special frame called a static head frame holds the patient's head in place. A newer method, called "frameless" or computer-assisted image-guided brain needle biopsy, does not use a static head frame. After giving a local anesthesia, the neurosurgeon makes a small hole in the skull. A narrow, hollow needle is inserted through the hole to extract tumor tissue. After a needle biopsy, the patient is monitored for several hours in the recovery room. The patient may spend a few additional days in the hospital.

RISKS AND COMPLICATIONS OF SURGERY

A craniotomy is a major operation. Risks and complications of surgery can include bleeding, infection, brain edema, seizures, paralysis, and behavioral or cognitive changes. Some normal brain tissue may be damaged during surgery. This can lead to permanent impairment of the functions related to the injured area of the brain. For a short time after surgery, symptoms may appear to be worse than before surgery. However, most side effects of surgery usually decrease or disappear over time.

POST-OPERATIVE CARE

After waking up in a recovery area, the craniotomy patient will be moved to the intensive care unit (ICU). Heart rate, intracranial pressure, and other functions will be closely monitored. The patient may wear special stockings to prevent blood clots. He or she may be temporarily put on a machine called a ventilator that helps with breathing. Generally after spending anywhere from several hours to two days in the ICU, the patient will be moved to a regular room.

During recovery, breathing exercises are encouraged to keep the lungs clear. The health care team will work with the patient to get him or her up and around as soon as possible. This will help get the body's systems functioning again.

The doctor may give a referral to a rehabilitation program if necessary. Therapists can help with balance, strength, walking, talking, and other daily activities. Social workers, case managers, and discharge planners can help coordinate continued care before leaving the hospital.

OTHER SURGICAL PROCEDURES AND DEVICES

Embolization

Embolization is a treatment that cuts off a tumor's blood supply by clogging the small blood vessels that feed the tumor. A radiologist or neurosurgeon inserts a catheter through an incision in the skin of the groin. Guided by an x-ray, the catheter is advanced to the tumor site. An embolic agent is injected into the tumor. This may be a liquid or powdered substance, or more commonly, tiny metal coils. Embolization can reduce blood loss during brain surgery, shorten the length of time in surgery, increase the chances of a complete resection, and reduce the risk of damage to adjacent normal tissue.

Lumbar Puncture (Spinal Tap)

A lumbar puncture is a procedure that extracts CSF surrounding the spinal cord. A local anesthetic is given to numb the spine in the area where the needle is inserted. The CSF is examined to detect abnormal cells, an infection, or the presence of protein or blood.

Shunt

A shunt, or catheter, is a device consisting of a thin tube and a valve that controls the flow of fluid. A shunt is used to divert CSF from the brain into the abdominal cavity, where it is absorbed into the bloodstream. During a cerebral shunt procedure, the surgeon drills a small hole in the skull. One end of the shunt is inserted into a ventricle; the other end is tunneled under the skin to the abdomen. Then, excess CSF drains into the abdomen.

Ommaya Reservoir

An Ommaya reservoir is a surgically implanted catheter (tube) used to inject medicine or extract CSF from the ventricles. The catheter is attached to a small mushroom-shaped chamber (reservoir) beneath the scalp. A needle is inserted through the

skin and into the reservoir to administer medication and/or to obtain CSF samples.

Brain Mapping

Brain mapping is used during an awake craniotomy. It helps the neurosurgeon to avoid injuring delicate areas of the brain that may not be visible in a scan. In this procedure, small electrodes are used to identify the areas called the eloquent cortex that control speech, sensation, and movement. The patient is required to talk, count, and perform other basic tasks during brain mapping. The patient feels no pain, as there are no pain receptors in the brain. This part of the procedure typically lasts from 10 to 40 minutes. Brain mapping improves the accuracy of a craniotomy. It can also clarify the borders of a tumor and distinguish tumor tissue from necrosis (dead tumor cells), a cyst, CSF, and normal brain tissue.

Another technique to identify eloquent areas of the brain that control speech, sensation, and movement is a Functional MRI. A Functional MRI is done before surgery. *(See Chapter 2 for a detailed description of Functional MRI.)*

Intraoperative MRI

Intraoperative MRI is an imaging system that works in real-time to capture and display images throughout surgery. This technology allows the surgeon to pinpoint the tumor before the incision is made, and navigate it more precisely throughout the surgery to make sure that a more complete resection can be made. Some of the newer intraoperative MRIs have magnets that are as strong as 3 Tesla, which are optimal in obtaining a high-resolution image. Because of its location system, intraoperative MRI generally helps surgeons to make smaller incisions, which leads to less invasive procedures and as a result, a shorter recovery time for the patient. An MRI scan is often performed before patients leave the operating room so that the surgeon can verify the tumor resection, and it eliminates the need for the patient to have an immediate follow-up scan a few days after surgery.

Intraoperative Ultrasound Imaging

Intraoperative ultrasound imaging is a method used during surgery to gauge the depth, diameter or center, and edges of the tumor. It also helps to distinguish between the tumor, necrosis, a cyst, fluid buildup, and normal brain tissue. The device sends high-frequency sound waves to the brain. The waves bounce off the brain and are sent to a computer that transfers the information into a two-dimensional picture displayed on a television screen.

Microsurgery

Microsurgery involves the use of a high-powered microscope to magnify the operating area, thereby increasing precision. Microsurgery is a standard procedure in craniotomies.

Transphenoidal Surgery

Transphenoidal surgery is a method of surgery used to reach tumors in the sellar area, just behind the eyes. It accesses brain tumors through an incision made through the nostrils. Transphenoidal surgery is commonly used for pituitary tumors.

Stereotactic Surgery

Stereotactic surgery uses a scanning device to find the exact location of the tumor and the structures surrounding it. It sends the information to a computer, which produces a three-dimensional image of the brain. This technique helps the surgeon both plan the surgery with greater precision and arrive at difficult to reach areas during surgery. Stereotactic surgery is used in several capacities: to perform a biopsy, remove a tumor, implant radiation pellets or for other treatments. It helps the neurosurgeon navigate his or her way around during surgery, and minimize the length of surgery.

Photodynamic Therapy (PDT)

Photodynamic therapy is a cancer treatment in which patients are injected with a light-sensitive drug. This drug stays in malignant cells longer than in normal cells. The neurosurgeon performs laser surgery, shining a laser light directly on the tumor. A chemical reaction with the photosensitive drug destroys the cancer cells without harming surrounding normal tissue. PDT can be used in conjunction with other treatments, including surgery, radiation therapy and chemotherapy. The only common side effect is significant sensitivity to sunlight for about one month after treatment.

RADIATION THERAPY

Radiation therapy (RT) uses high-energy x-rays or other types of ionizing radiation to stop cancer cells from dividing. Radiation therapy may be used when surgery is not advised, or for tumors that cannot be completely resected. It may be used after surgery to destroy residual tumor cells and prevent or delay tumor recurrence. Radiation therapy can stop or slow the growth of inoperable tumors. Use of radiation therapy is avoided in children below the age of three because it damages the developing brain.

Ionizing radiation damages the basic building material in cells (DNA). Normal healthy cells can repair the damage better than tumor cells. Over time, irradiated tumor cells die. Thus, the results of radiation therapy may not be apparent until several months after treatment.

Two types of radiation therapy are *external beam* and *interstitial* radiation therapy. External beam radiation therapy involves machines called linear accelerators and cobalt machines. They direct radiation at the tumor from outside the patient's body. Interstitial radiation therapy (also called *interstitial irradiation* or *brachytherapy*) involves the surgical implanting of radioactive material directly inside the tumor.

CONVENTIONAL RADIATION THERAPY

Conventional radiation therapy delivers an external beam of radiation focused at an entire region of the brain containing the tumor. After resection, the area where the tumor was located and the surrounding margin is irradiated. The radiation is *fractionated* into many small doses and given over a period of time (usually five to seven weeks, excluding weekends). A typical daily dose of radiation therapy is 1.8–2.0 Gy (Gray). The total dose of a radiation treatment will vary depending on the tumor type, but ranges between 50–60 Gy. The doses may be hyperfractionated, or divided into more frequent, less intense doses.

Conventional radiation therapy can be either *focused* or *whole brain radiation therapy* (WBRT), depending on the location and size of the tumor(s). Focused radiation therapy aims x-rays at the tumor and area surrounding it. WBRT aims radiation at the entire brain. WBRT is used to treat multiple tumors and metastatic brain tumors.

Conformal Radiation

Conformal radiation is a type of conventional radiation treatment. A linear accelerator sends a high dose of radiation that has been modified by computer to match or conform to the shape of the tumor. The objective is to apply a uniform level of radiation to the tumor while reducing the amount of radiation that reaches other parts of the brain. Conformal radiation may be used to minimize injury to delicate structures such as the salivary glands, optic pathways, and brain stem.

Intensity Modulated Radiation Therapy (IMRT)

Intensity Modulated Radiation Therapy (IMRT), is a type of conformal radiation therapy. IMRT is designed to restrict the treatment beam to the tumor, regardless of its shape. The intensity of radiation is made to vary across the beam, so that a higher intensity reaches the thickest parts of the tumor. Multiple beams are used simultaneously and meet at the target point.

STEREOTACTIC RADIOSURGERY (SRS)

Stereotactic radiosurgery (SRS) is different than conventional

radiation therapy. SRS delivers a single, high dose of radiation in a one-day session. The dose can range from 2–30 Gy. Radiosurgery is not surgery, but like surgery, it is meant to be ablative: to destroy all the tumor cells in its path. Size and location of the tumor are important eligibility criteria for SRS. In an SRS procedure, a head frame is attached to the skull. Then CT or MRI scans are taken. With the aid of computer imaging, the location of the tumor is accurately calculated. The radiation is delivered directly to the tumor, often from several different directions. Newer methods of SRS do not use a head frame.

There are several types of machines that are used to administer radiosurgery: Gamma Knife®, LINAC, X-Knife®, SynergyS®, Trilogy®, CyberKnife®, Novalis® and cyclotron. The principles are the same, but they use different sources of energy and different methods to target the tumor.

Gamma Knife Radiosurgery

The Gamma Knife machine contains 201 sources of radioactive cobalt. It focuses a high dose of radiation to a small target area. The Gamma Knife is most effective for small tumors that are round or oval shaped. Gamma Knife can be used as a primary form of treatment, or as a secondary treatment after surgery.

LINAC Radiosurgery

Linear accelerator (LINAC) radiosurgery sends a single, high-energy x-ray that is designed by a computer to match the shape of the tumor and avoid healthy tissue. A linear accelerator is also used for Intensity Modulated Radiation Therapy (IMRT).

Proton Beam Radiosurgery

Proton beam radiosurgery is also called heavy particle radiation therapy. This method uses beams of charged protons (atomic particles) produced by a machine called a cyclotron. Similar to LINAC, the cyclotron sends a single beam that is designed by a computer to match the shape of the tumor. Proton beam radiosurgery is used to treat tumors at the base of the skull and tumors of unusual shapes.

STEREOTACTIC RADIOTHERAPY (SRT)

Stereotactic radiotherapy combines the precision of radiosurgery with fractionated radiation. SRT utilizes computer imaging to precisely locate the tumor. Then a series of low doses of radiation are given over several treatment sessions. Treatment may be given once or twice a day for several weeks. These fractionated doses add up to a larger total dose of radiation than would be given in a single SRS treatment.

SRT has some advantages over other types of radiation therapy. The precision of delivery and lower individual doses of radiation cause less damage to normal tissue. This allows SRT to be used in situations where single dose SRS cannot be applied safely. Some applications include: for tumors near the optic nerves, brain stem, or eyes; for some large tumors; and for pediatric patients.

BRACHYTHERAPY (INTERSTITIAL RADIATION THERAPY)

Brachytherapy is an internal form of radiation therapy. Brachytherapy involves the implantation of tiny, radioactive capsules or pellets directly into the tumor (interstitial) or into the tumor cavity (intracavity). The treatment lasts for several hours or days, after which the pellets may (or may not) be removed. Stereotactic surgery is used to implant the pellets by way of catheters.

A new method of brachytherapy utilizes radioactive liquid iodine in place of radioactive pellets. After surgery, a small, saline-filled balloon is implanted into the resection cavity. The balloon is connected to a small catheter and a reservoir that sits under the scalp. Five to 14 days after surgery, a needle is inserted through the scalp into the reservoir. The fluid in the balloon is aspirated out and replaced with radioactive liquid iodine. Because the dose is

> ***"I relax and remain positive with my thoughts. I just imagine myself in a peaceful place and let the machine do all the work. I don't focus on the fact that I am in a machine or even in a hospital. I just think of it as something that has to be done, and I know that it is all for my benefit and good health."***
>
> **– Pineal tumor survivor**

Q: *How is radiation measured?*

A: Radiation is measured by an international unit called Gray (Gy). Each dose of Gy represents a specific amount of energy that is absorbed by the body.

Q: *How does radiation destroy a tumor?*

A: Radiation works by damaging DNA. This damage stops cells from being able to divide, or reproduce. Over a period of time, tumor cells that received radiation will die when trying to divide.

in liquid form, it is very homogeneous and evenly distributed.

Brachytherapy is an invasive, inpatient procedure done under anesthesia. It is frequently used for tumor recurrence after previous radiation therapy. The advantages include avoiding exposure of vital structures outside the tumor, and a shorter length of treatment. However, many brachytherapy patients require follow-up surgery to remove necrotic tissue.

SIDE EFFECTS OF RADIATION THERAPY

Short-term side effects occur during or shortly after radiation treatment. Most can be treated or in some cases will decrease or disappear after treatment has been completed. The most common short-term side effects of radiation therapy are fatigue, loss of appetite, nausea, and short-term memory loss (loss of recently-learned information). Short-term memory loss usually subsides within two months after RT treatment is completed. Brain edema may occur and may be treated with steroids. Skin reactions (rash, redness, or irritation) and hair loss may occur in the area where the radiation is focused.

Some patients may experience long-term, or delayed, side effects. These may occur months or years after treatment. Delayed side effects can include varying degrees of memory loss, coordination problems, incontinence, and problems with reasoning and thinking. Loss of pituitary gland function can also occur. In the case of children, RT can result in delayed physical growth and/or delayed cognitive development and can cause learning disabilities.

Sometimes dead tumor cells form a mass in the brain. This is called *radiation necrosis.* Necrosis may look like a tumor on a scan and can cause similar symptoms (headache, memory loss, seizures, personality changes, and cognitive problems). A biopsy may be required to make a correct diagnosis. Surgery and/or steroids may be necessary to treat necrosis.

If a patient begins to have symptoms after radiation therapy and the tumor has not recurred, he or she may be experiencing delayed side effects. The patient should talk to the doctor about these symptoms and how to manage them. Currently, there is no definitive treatment for the long-term effects of radiation therapy, although in some instances surgery, steroids, anti-coagulants, or CNS stimulants may help alleviate symptoms.

CHEMOTHERAPY

Chemotherapy is the treatment of disease by means of chemicals (drugs) that have a toxic effect on tumor cells as they divide. Chemotherapy is given in cycles, which consist of "on" and "off" phases—days of treatment followed by periods of time between treatments. Cycles vary depending on the drug or drugs used. Chemotherapy is usually taken orally or by injection. It may be given alone or in combination with other treatments. Chemotherapy is usually a secondary therapy. It is also used to delay or replace radiation treatment in young children. Chemotherapy may be an important component of therapy for some "chemosensitive" tumors (e.g., CNS lymphoma, medulloblastoma).

The brain has a defense mechanism called the *blood brain barrier,* which keeps out harmful substances such as bacteria and chemicals. The blood brain barrier can also prevent some chemotherapy drugs from entering the brain. However, a technique called *blood brain barrier disruption* can be used to temporarily interrupt the barrier and allow chemotherapy drugs to pass through the blood vessels into the brain. In this procedure, a catheter is fed into the cerebral artery. A drug called mannitol is injected into the catheter. Mannitol dis-

rupts the blood brain barrier. While the blood brain barrier is open, chemotherapy is delivered through the catheter. The effects of mannitol wear off after a period of time.

Another new technique to deliver chemotherapy directly to brain tumors is the polymer wafer implant. Biodegradable wafers are saturated with the chemotherapy drug, BCNU. Several wafers are inserted into the tumor cavity after the tumor has been resected. The wafers are left there to dissolve over time. In this way, a concentrated dose of BCNU (approximately 100 times higher than that tolerated through IV) is able to bypass the blood brain barrier.

There are some cases where chemotherapy treatment is not used. Certain types of tumors do not respond to chemotherapy. Also, chemotherapy can be physically taxing. Patients should have overall good health in order to tolerate the side effects of these treatments.

SIDE EFFECTS OF CHEMOTHERAPY

Most chemotherapy drugs enter and affect the patient's entire system. Side effects are caused when the drugs damage normal cells that are dividing. Reactions can range from mild to severe. The side effects of chemotherapy vary depending of the type of drug that is used and the parts of the body or systems affected. Each patient's reaction to chemotherapy is unique. All side effects should be reported to the doctor. There are treatments available to alleviate many of the side effects, including rashes and nausea. In some cases, the type of chemotherapy drug may be changed.

If chemotherapy affects the bone marrow, it can cause *myelosuppression*. This is the term for the low production of blood cells. Red blood cells carry oxygen throughout the body, white blood cells fight infection, and platelets form blood clots to stop bleeding. Low red blood cell count or *anemia,* can cause fatigue, dizziness, chills, and shortness of breath. Low white blood cell count or *leukopenia,* can cause infection, fever, chills, sweating, diarrhea, sore throat, coughing, sores in the mouth, and/or a burning sensation during urination. Low platelet count can cause easy bruising, slow healing of cuts or scrapes, small red spots on the skin, pink or red urine, blackness or blood in stools, bleeding gums, nosebleeds, or heavy menstrual periods.

If chemotherapy affects the digestive system, it can cause *mucositis.* Mucositis means inflammation to the cells lining the mouth, throat, stomach and intestines. Inflamed mouth or throat can cause dryness of the mouth, tongue, and lips, burning or tingling sensations, or difficulty chewing or swallowing. Inflammation to the stomach and intestines can cause diarrhea, constipation, nausea, or vomiting.

Chemotherapy can weaken the immune system, a condition called *immunosuppression.* This makes a patient more susceptible to infections. Other side effects of chemotherapy include *neuropathy* (numbness and tingling in the arms or legs), skin reactions, hair loss, and fatigue. Some chemotherapy drugs can cause infertility, menopause, and kidney damage. Certain chemotherapy agents can increase the risk of developing blood clots. This condition is called *thrombophlebitis* or *deep vein thrombosis* (DVT). DVT requires medical treatment and can develop to a life-threatening condition. Notify your doctor immediately if swelling in the leg or arm, leg pain, or redness occurs. Do not rub or massage the area. *(See chapter 6 for more information about DVT.)*

CHEMOTHERAPY DRUGS

In general, the chemotherapy used to treat people with brain tumors is well tolerated. Newer *antiemetics* (antinausea drugs) have greatly reduced the nausea chemotherapy patients may have experienced in the past. Oncologists or oncology nurses will work with patients to minimize or prevent anticipated side effects. Listed at right are chemotherapy drugs commonly used, how they are taken, and some of their common side effects. Please keep in mind that the side effects any individual experiences may not match those listed. Uncommon side effects may indicate a serious problem, so it is important to inform the medical team of all side effects experienced.

The drug's generic name is followed in parentheses by its brand name.

CLINICAL TRIALS

Clinical trials are research studies conducted on humans. The studies are designed to determine the safety and side effects of new therapies, and the effectiveness of new and current treatments. Clinical trials usually undergo three phases

Chemotherapy Drugs

NAME	COMMON SIDE EFFECTS	
Carboplatin (Paraplatin) Taken by IV	• Nausea and vomiting (mild, delayed) • Hair loss	• Loss of appetite • Weakness (asthenia) • Fatigue
Carmustine (BCNU, BiCNU) Taken by IV or inserted during surgery by polymer wafer implant	INTRAVENOUS • Nausea and vomiting (mild) • Potential respiratory problems (smokers may not be able to receive a full course of treatment) • Fatigue • Myelosuppression • Pulmonary fibrosis	POLYMER WAFER IMPLANT • Seizures • Intracranial infection • Abnormal wound healing • Brain edema
Cisplatin (Platinol) Taken by IV	• Nausea and vomiting • Neuropathy • Weakness	• Fatigue • Hearing loss or ringing in ears • Kidney damage
Lomustine (CCNU) Taken orally	• Fatigue • Loss of appetite	• Nausea and vomiting • Myelosuppression
Methotrexate (Rheumatrex or Trexall) Taken orally, by injection, or intrathecally (injected directly into spinal fluid)	• Loss of appetite • Nausea and vomiting • Mouth sores • Fatigue	• Pulmonary fibrosis (inflammation and internal scarring of the lungs)
Procarbazine (Matulane) Taken orally	• Fatigue • Nausea and vomiting • Nervousness • Rash • Mouth sores, dry mouth • Abdominal pain • Constipation • Myelosuppression • Need to avoid foods high in tyramine* which cause increased blood pressure	*Tyramine is a normal substance in the body that helps support blood pressure. Tyramine is also found in certain foods, including: beer, red wine, vermouth, homemade bread, cheese, sour cream, bananas, red plums, figs, raisins, avocados, fava beans, Italian broad beans, green bean pods, eggplant, pickled herring, liver, dry sausages, canned meats, salami, yogurt, soup cubes, commercial gravies, chocolate, and soy sauce.
Temozolomide (Temodar) Taken orally	• Constipation • Nausea and vomiting • Fatigue	• Headache • Myelosuppression
Vincristine (Oncovin or Vincasar PFS) Taken by IV	• Jaw pain • Constipation	• Fatigue • Neuropathy

before reaching completion. Each phase answers a question about the safety and effectiveness of the treatment being tested. The differences between the phases are as follows:

- **Phase I trials** involve testing a treatment to determine a safe dosage and its side effects.
- **Phase II trials** involve testing a treatment for effectiveness.
- **Phase III trials** involve comparing a new treatment against a standard treatment for its effectiveness.

If a drug or treatment is showing statistically positive results, the clinical trial may end early, and the drug may be placed on the market more quickly.

Clinical trials follow a treatment plan, or *protocol*, and are conducted by various institutions such as hospitals, universities and research institutes. A group of patient advocates called the Institutional Review Board (IRB) examines the protocols to make sure they are designed and conducted with appropriate safeguards for the patients. There is an IRB at every institution that is conducting research.

People participate in clinical trials for a number of reasons: to try a new treatment method, to contribute to developing improved treatments, or to help find a cure. If a patient is considering participating in a trial, the trial he or she chooses will depend on the patient's tumor type, when it was diagnosed, treatments that have already been received, and the patient's state of health. Most trials have a series of criteria a patient needs to meet in order to participate.

There are both benefits and drawbacks to consider. Participants in clinical trials receive high-quality medical care. Participants are also among the first to benefit if a new approach is proven effective. However, a new treatment may not be better than or even as good as the standard treatment. There may also be unexpected side effects.

A patient should ask him/herself the following questions when deciding on a clinical trial:

1. Who is conducting the study? Is it conducted by an individual institution, or part of a national study?
2. Where is the study being done? Are there multiple locations? Is there a participating institution closer to home?
3. Does the center have a designated neuro-oncology (brain tumor) program?
4. What is the phase of the study? Has it been tested on people with brain tumors before?
5. What tests, treatments, and commitment of time does the study involve? Does it involve a hospital stay? If so, for how long?
6. What other choices are available? How does the study treatment compare to the alternatives?
7. What potential side effects may occur and how can they affect day-to-day life?
8. What does the treatment cost? Is any part of it provided for free?

Obtaining the answers to these questions can help a patient decide which treatment is right for him/her. When a decision is made to participate in a clinical trial, the patient or his/her representative will undergo a process called informed consent. Informed consent will explain the study's treatments and tests as well as possible benefits and risks. If a patient agrees, he/she or the representative will sign a consent form. A patient can decide to leave the trial at any time. During the trial, patients will be monitored closely and asked to report all symptoms of the treatment.

For a list of clinical trials call NBTF at 1-800-934-2873 or contact the National Cancer Institute (NCI) at 1-800-4CANCER (1-800-422-6237) or visit www.cancer.gov

"Be aware that the patient, family, friends, and loved ones will go through a range of emotions and reactions to a brain tumor diagnosis and treatment. These feelings will include denial, anger, acceptance, and even guilt. I feel strongly that it is part of your doctor's responsibility, not just to deliver the treatment, but also to help patients and their families cope with the disease."

– Radiation oncologist

Q: ***What happens after treatment is over?***

A: After treatment is over, most patients are usually monitored for tumor recurrence on a regular basis through MRI or CT scans. The doctor may decide to take scans every two to six months depending on the tumor type and patient's status.

BIOLOGIC/TARGETED THERAPIES

Biologic (also known as targeted) therapies offer an option for treatment for people who have tumor recurrence after surgery, radiation therapy or chemotherapy. Biologic therapies stimulate a person's own immune system to turn against the tumor. *Biological response modifiers (BRM)* are naturally occurring substances in the body that fight infections or diseases. The body normally produces small amounts of BRMs. Biologic therapies can cause the body to produce larger amounts of BRMs than normal.

Some of the new biologic therapies are: angiogenesis inhibitors, which interfere with the growth of blood vessels that feed the tumor; antisense therapies (proteins designed to block the function of another protein); and differentiators, which make cells less likely to divide. In addition, there are new chemotherapy treatments, gene therapy, growth inhibitors, and immunotoxin therapy.

BIOLOGIC THERAPY DRUGS

Isotretinoin (Accutane®) and thalidomide (Thalomid®) are currently being tested in clinical trials for use in brain tumor patients. These drugs are FDA approved for treatment of other medical conditions.

Both isotretinoin and thalidomide cause severe birth defects. Therefore, men and women receiving these drugs are required to use at least two forms of contraception, and women are required to take monthly pregnancy tests.

Other biologic therapy drugs continue to be developed and many are currently being tested in clinical trials, some in combination with previously approved agents (i.e. Irinotecan, BCNU). These trials include drugs such as bevacizumab (Avastin®), imatinib (Gleevec®) and erlotinib (Tarceva®).

OTHER BIOLOGIC THERAPIES

Gene Therapy

Clinical studies have identified certain genes as tumor suppressors. Tumor suppressors tell cells to die when their DNA becomes damaged. Cancer cells have damaged, mutated DNA. Instead of dying, they multiply uncontrollably. Gene therapy is a method to introduce a non-mutated gene into a tumor. This may be achieved by inserting the gene into a virus, and the virus acts as a carrier, or *vector.* The virus attaches to the tumor cells and transfers the gene into them. The transferred gene then acts as a tumor suppressor, causing the tumor cells to die. Surgery is often required to directly inject the viral vector carrying the non-mutated gene into the tumor.

Vaccine Therapy

This method attempts to use the patient's immune system to attack the tumor. Typically, a portion of the brain tumor is removed from a patient and processed in a number of ways to produce a vaccine. This vaccine of processed tumor tissue is then injected into the patient's skin. The patient's immune system recognizes the injected substance as foreign or abnormal, and specialized immune cells in the body learn to recognize the abnormal tissue. Those immune cells circulate around the body and if they come in contact with brain tumor cells, they direct other immune cells to try and kill the tumor cells. Vaccine therapy is still experimental and has not yet been proven to work in all patients, but much research is being conducted.

Immunotoxin Therapy

An *immunotoxin* is a poison linked to a part of the body's immune system, such as an antibody or protein. Immunotoxin therapy is a process of fighting cancer cells by introducing a toxin directly into tumor cells. The toxins are usually bacterial. Because of the risk of introducing toxins into normal brain tissue, the toxins are attached to other proteins that will selectively target only tumor cells. The goal of immunotoxin therapy is to target tumor cells and kill them without harming

> *"Every patient is a unique person in a unique environment..."*
>
> **– Neuropsychologist**

normal brain cells. Immunotoxin therapy is experimental. Research is ongoing and several different immunotoxins are being developed.

Convection-enhanced delivery is an experimental method to introduce immunotoxins into tumors. This method inserts immunotoxins into the brain by a small, pressurized pump. Convection-enhanced delivery is able to bypass the blood brain barrier. The treatment is usually administered over a period of several hours and is often completed during one sitting. Convection-enhanced delivery is currently being tested in clinical trials. It is a promising tool in the treatment of brain tumors.

COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM)

Standard or conventional therapy for brain tumor patients usually means surgery, radiation, and/or chemotherapy. *Complementary medicine* is used *in addition to* standard therapy. *Alternative medicine* is used *instead of* standard therapy. A simple definition of CAM is anything people do other than conventional therapies to maintain or achieve good health. *Integrative medicine* is a combination of conventional medicine with complementary and/or alternative therapies.

The goal of CAM is to enable patients to tolerate higher doses of standard therapy at closer intervals with fewer side effects. CAM also aims to increase the *quality of life* both during and after treatment. It is important to integrate CAM into conventional medicine *safely,* under the supervision of a CAM health professional.

MAJOR SYSTEMS OF CAM

There are countless CAM therapies available today. The major systems of CAM include: acupuncture, ayurveda, chiropractic, diet and nutrition, exercise, guided imagery, healing touch, herbal medicine, homeopathy, massage therapy, meditation, and nutritional supplements.

Acupuncture

Acupuncture, which was developed in China, involves the painless insertion of disposable, hair-fine needles into various points on the surface of the body. It may increase circulation, activate the immune system, relieve pain, and balance the central nervous system.

Acupuncture is primarily used to treat body pain, headaches, fatigue, nausea, vomiting, constipation, diarrhea, and insomnia. However, it is also quite useful in treating anxiety, depression, mood swings, weight loss, edema, neuropathy, muscle atrophy, and muscle weakness.

Acupuncture should not be used when the following conditions are present: a low platelet count (<15,000), a low white blood cell count (<1.0), thrombosis or embolism (blood clots), hemophilia, and/or the use of medications that increase bleeding (i.e., blood thinners such as Coumadin).

Ayurveda

Ayurveda, which was developed in India, consists mainly of specific dietary recommendations and customized herbal preparations. It is used to treat the same disorders as acupuncture. Like acupuncture, diagnosis is based on complex pulse analysis and a physical examination; however, needles are seldom used. It is difficult to find qualified practitioners because ayurvedic physicians are not yet licensed in the United States.

Chiropractic

Chiropractic involves the adjustment or manipulation of spinal vertebrae. This treatment may return balance to the CNS to enhance immune function and decrease inflammation. Chiropractic is primarily used to treat body pain, headaches, anxiety, insomnia, constipation, diarrhea, neuropathy, and muscle weakness.

Diet and Nutrition

The purpose of altering the diet is to provide additional energy for immune function. Basic alterations frequently include an emphasis on organic "whole" (unprocessed) foods, and avoidance of refined sugar, dairy, and/or acidic and spicy foods. Meat intake is minimized; however, fish may be substituted. There is a need to maintain adequate protein intake.

Several types of diets exist. They range from macrobiotics, which is based on Asian medical principles, to ayurvedic diet, which is based on Indian medical principles, to blood type diets, which are founded on Western medical principles. It is recommended that people read about the many approaches available and become educated, then find a licensed CAM professional to help make the right choice for their particular situation.

It is *not* recommended to alter the diet during chemotherapy or radiation treatments, when appetite is poor. It is more important for the patient to eat whatever food he or she can tolerate. Ask the doctor if a particular diet has any specific contraindications (things not recommended). For example, a diet high in antioxidants may have an adverse effect on radiation treatment and chemotherapy.

Exercise

The primary purpose of exercise is to enhance—rather than deplete—energy, strength, and vitality. The goal is to breathe properly and increase lung capacity, which in turn benefits the immune system. Exercise has some secondary psychological benefits as well.

Exercise can include walking, light weight lifting, or oriental practices such as Tai Chi, yoga, or qi gong. Tai Chi and yoga postures may enhance the immune system. Qi gong postures may improve specific physiological weaknesses. It is important to consult with a doctor before beginning any exercise regimen.

Guided Imagery

This involves using visualization, or mind over matter, and effectively enhances immune function. There are two types of guided imagery: *suggestive,* where the patient externally or internally guides the immune system to perform specific tasks, and *interactive,* where the patient is externally guided to communicate with the disease to gather information from the unconscious. The patient tries to understand why the disease is present, what it wants, and what it needs to make it go away.

Healing Touch

Healing touch involves the laying on of hands by a qualified practitioner. The goal is to detect and correct imbalances in body temperature and energy fields, known as *chakras,* through the practitioner's palms. There are several types of healing touch, including therapeutic touch and reiki.

Massage Therapy

Massage therapy involves manipulation of muscles and connective tissues of the body. Massage therapists apply pressure to the surface of the body primarily with their hands. Massage techniques affect various systems of the body, including the musculoskeletal, circulatory, lymphatic, and nervous systems.

Benefits of massage therapy can include stress reduction, increase in blood circulation and lymph flow, relaxation of muscles to relieve chronic pain, and improvement of range of motion in the joints.

Training requirements for massage therapists vary from state to state, but approximately 29 states in the United States presently license massage therapists.

Herbal Medicine

Herbal medicine utilizes plant and animal substances brewed into a tea or manufactured into powder or capsule form and taken orally. The goal is to enhance immune function of specific organs, for example, to decrease liver toxicity after chemotherapy. **In order to avoid unsafe herb-drug interactions, communication between the CAM provider and physician is strongly recommended.** It is also important for the patient to be monitored by a board certified herbalist and to use only quality-controlled herbs. The patient should always make sure that herbs prescribed conform to Good Manufacturing Practice (GMP) standards. GMP is the FDA's current requirement to regulate quality of herbal substances. Patients should tell their medical providers about any herbal medicines or supplements they are taking.

Homeopathy

Homeopathy involves the ingestion of modified or watered down viruses and bacteria believed to carry an energetic imprint of the original substance. This is similar to vaccination. The goal is to *gently* inform the body of a foreign presence so that the immune system will attack it. Homeopathy is used to treat most major symptoms and disorders. While homeopathic remedies are readily available, one should not attempt to self-treat. Licensed doctors of home-

opathy are common throughout the United States.

Meditation

This is a process of clearing the mind so that one can achieve relaxation. Meditation generally involves spending time sitting or lying comfortably and quietly and breathing deeply. It is extraordinarily effective for reducing stress. Meditation has been used for thousands of years with no adverse effects. There are various types of meditation including transcendental, shamanic, guided, and others.

Nutritional Supplements

There are a variety of substances (vitamins, minerals, etc.) that may strengthen the immune system and/or organ function. Two major types relevant to brain tumors are antioxidants (organic substances that counteract the damaging effects of oxidation in living tissue) and COX-2 inhibitors (drugs that block an enzyme which causes inflammation). However, some nutritional supplements have negative interactions with certain Western medicines and therapies. For example, antioxidants can reduce the effectiveness of radiation and/or chemotherapy treatments. Use of nutritional supplements requires supervision by a board certified herbalist or nutritionist. The doctor should be aware of any nutritional supplements a patient is consuming.

WAYS TO APPROACH CAM

There are three aspects to our being: body, mind, and spirit. A full program of healing must incorporate all three aspects, with a slant toward the patient's personality. To figure out the best approach, people should ask themselves three questions:

1. What kind of person am I?
   Three personality types are kinesthetic (or physical), intellectual, and spiritual.
2. What did I like to do prior to diagnosis (i.e., occupation and hobbies)?
   A kinesthetic or physical person might like cooking or exercise. An intellectual might prefer reading or psychotherapy. A spiritual person may enjoy meditation or practicing yoga.
3. How can I combine my talents to achieve my health goals?
   A physical person who wants to be more spiritual might try one of the various types of meditation. An intellectual who wants to be more physical could try reading exercise books, then exercising in a way consistent with what he or she learned about appropriate exercise. A spiritual person who needs to be more physical might try yoga or Tai Chi, since such exercises are essentially moving meditation.

Choosing a Practitioner

When a person is choosing a CAM practitioner, it is important to determine his or her validity. Look for licensed and/or board certified nutritionists and practitioners of acupuncture, homeopathy, and Oriental medicine. People can also ask their doctors for personal recommendations.

One way to test the knowledge and honesty of a practitioner is to ask a complex medical question to which the patient already knows the answer. Observe the practitioner's response. Patients should follow their instincts on how they feel about the practitioner.

6. SYMPTOM MANAGEMENT

The following chapter includes explanations of different symptoms and side effects that can be caused by a brain tumor or its treatments. Learning to manage symptoms will contribute to an overall better quality of life.

This chapter also discusses some of the various medications a doctor may prescribe to manage brain tumor symptoms and treatment side effects. Doctors and nurses can provide patients with guidance for coping with symptoms and side effects, and can also refer patients to other specialists within the health care system, including pharmacists, psychologists, and social workers.

PHYSICAL SYMPTOMS

Brain and spinal cord tumors can affect parts of the central nervous system that control movement, physical sensation, the five senses, and motor skills. Some physical symptoms may include:

- Hemiparesis (numbness, weakness, or paralysis on one side of the body)
- Difficulty with balance
- Visual and spatial disorders
- Bowel and bladder dysfunction

People with any of these symptoms may benefit from one of several forms of treatment available at rehabilitation centers. Physical and occupational therapists are experts in rehabilitation. Occupational therapists teach patients how to manage their side effects so that they can go about their lives and perform daily activities. Physical therapists help patients improve their walking, balance and strength. Every person with a brain tumor deserves to function optimally, so patients need to be evaluated for the appropriate rehabilitation and treatment.

If permanent mobility problems occur there are several options to continue with a good quality of life. Regular range of motion exercises to the affected limb and proper positioning help to decrease

Medication Tips

- To prevent harmful drug interactions, tell your doctor about any medications you may be taking, including over-the-counter drugs and herbal supplements.
- Medications should always be taken as directed.
- If you experience any side effects with any medication, report them to your doctor right away.
- Never stop taking medications without first talking to your doctor

pain and freezing of the limb(s). The exercises and positioning are commonly shown to the patient by a physical or occupational therapist.

In addition to exercises, there are many assistive devices to help with mobility, low vision, and functioning around the house. Handrails and grab rails, and bath or shower chairs are some of these assistive devices. There are several innovative assistive devices to help with eating and dressing, as well as aids for poor vision.

There are also assistive technology and accommodation products that can help maintain computer access and independence. Federal and state programs exist that link people with disabilities to services, technology, and funding to allow them access to assistive technology. For more information about federal and state programs and assistive technology resources, see the *2007 NBTF Resource Directory*, Section 6: Disability and Anti-Discrimination Organizations.

COGNITIVE AND BEHAVIORAL SYMPTOMS

A brain tumor or its treatment(s) can cause changes to a person's cognitive (thinking) abilities, behavior and/or emotions. Patients may experience difficulties with language use, attention and concentration, learning and memory, general intellectual abilities, executive functioning, and emotions.

- Language: difficulty speaking, writing, and/or reading
- Attention and concentration: being easily distracted, confused, and disoriented; difficulty doing more than one task at a time
- Learning and memory: short-term memory loss, slowed thinking
- Executive functioning: difficulty with problem solving, judgment, and multi-tasking (doing more than one thing at a time)
- Emotion and personality: depression, irritability, anxiety, mood swings, obsessive-compulsive tendencies, disinhibition, and withdrawal

The symptoms will vary depending on where in the brain the tumor is located and what method of treatment is received. These difficulties may affect a patient's ability to work or go about his/her daily life. This can cause a strain on both the patient and his or her family members.

Neuropsychological Testing

Neuropsychological testing is the method used to identify changes in the cognitive functioning of a patient. A series of tests conducted by a licensed neuropsychologist can assess the patient's emotional state, and mental and behavioral abilities. This evaluation helps to identify the areas of the brain that have been affected by the tumor. Although neuropsychologists are often not consulted until after treatment, it may be preferable to have a neuropsychological evaluation *before* treatment. That way, a more accurate comparison can be made of changes that may occur following treatment.

After analyzing the results of the tests, the neuropsychologist can make recommendations for rehabilitation, therapy, or medications to help patients regain as much function as possible. For example, stimulants such as methylphenidate (Ritalin) may improve cognitive function. A neuropsychologist may offer training in compensation techniques for the mental and/or physical abilities that cannot be fully regained. Neuro-oncologists or neurologists can give a referral to a neuropsychologist. Referrals can also be found in rehabilitation settings.

Q: *What is a neuropsychologist?*

A: A neuropsychologist is a licensed psychologist who has specialized training and experience studying how the brain functions. A neuropsychologist does testing and research to attempt to explain the relationship between brain activity and behavior, and to understand how functions within the brain influence thinking, learning and emotions. He or she studies the impact that brain damage has on a person's functioning and abilities. A neuropsychologist can help brain tumor patients and survivors evaluate changes resulting from their brain tumor or treatment, and can help develop a plan for rehabilitation.

"Knowing that you aren't alone has been, in my experience in talking with many other patients, the single most significant factor in improving a person's attitude, and taking away some of the fear."

– Libby Stevenson
Former Executive Director, NBTF

Cognitive Rehabilitation

Cognitive rehabilitation is designed to help people regain as much of their mental, physical and emotional abilities as possible. When full recovery is not possible, treatment includes compensation techniques. These are methods to develop other skills to make up for those that have been lost. Therapy can include tasks and exercises to strengthen sight, speech and movement. Compensation techniques include learning to live with memory loss by keeping calendars and organizers. If a patient experiences major behavioral and personality changes including impulsiveness, frustration, and frequent mood changes, he or she may benefit from counseling, anger management training, or medication. For people who experience serious loss of mental or physical abilities, cognitive rehabilitation therapy will be provided at home, work or school. Caregivers and/or family members will also be taught how to modify the patient's lifestyle to help compensate for difficulties.

HEADACHE

Headache is a common initial brain tumor symptom. The types and qualities of headaches patients experience depends on the type and location of the tumor. The typical brain tumor headache is described as severe, worse in the morning, and associated with other neurological symptoms such as nausea or vomiting. Many patients have tension headaches; a smaller number have migraine headaches.

Headaches are often due to edema, swelling of the brain caused by the tumor. Steroids such as dexamethezone may be prescribed to reduce edema. This decreases the headaches by relieving the pressure.

Surgical removal of the tumor will often relieve headaches as well. However, after surgery some patients may experience post-operative headache. This may be a tension headache with localized pain around the surgical site. Pain of this source is often relieved by analgesics (pain killers). Once the initial post-operative headache is relieved, most patients do not experience more headaches. The return of headaches can be a sign of recurrent edema or tumor growth. This may indicate the need to be evaluated for tumor recurrence.

Some patients will begin to experience headaches near the end of life. In these instances, *palliative* steps are taken to relieve symptoms and increase the patient's comfort.

Headaches are rarely persistent in brain tumor patients. When patients continue to have headaches, they need to be carefully evaluated and treated specifically for the pain in order to maintain a good quality of life.

SEIZURES

A seizure is a sudden attack or convulsion caused by an abnormal, uncontrollable burst of electrical activity in the brain. It can cause a range of reactions, from muscle contractions, staring, and tongue biting, to loss of consciousness.

Seizures are a common brain tumor symptom, occurring in 60% of all brain tumor patients. Seizures may be the first indication of an abnormal growth. Some people only experience one seizure while others suffer from reoccurring seizures, or epilepsy. Seizures are common with slow-growing gliomas, meningiomas, and metastatic brain tumors.

Seizures can be dangerous to patients, and certain precautions should be taken to avoid injury. For the sake of safety, people who experience uncontrolled seizures are restricted from driving a car or motor vehicle. There are many differences in the laws regarding

"I attribute my survival to being willing to take risks on unconventional therapies, being willing to think outside the box and being willing to say I want to try something different."

– Glioblastoma survivor

driving restrictions in the United States. Two basic approaches are used to determine if a person is allowed to drive: 1) the person must be seizure-free for a specific period of time (usually 3, 6, or 12 months), or 2) a physician or medical advisory board evaluates the person and makes a recommendation. The evaluation methods are not standardized, so they vary from one doctor to another.

Some states require doctors to report patients who experience seizures to motor vehicle agencies. Some patients may not tell their doctors about their seizures because they are afraid that they will lose their driving privileges. This is dangerous because the patients' seizures will go untreated. Whether or when driving privileges are restored depends on whether the seizures can be controlled. However, patients should report seizures in all cases. Check with your state department of public safety for more information regarding local laws.

There are two common types of seizures associated with brain tumors; partial (focal) and generalized seizures.

PARTIAL SEIZURES

Partial or focal seizures result from a tumor affecting one part of the cerebral hemisphere. There are two types of partial seizures: simple partial seizures and complex partial seizures.

Simple Partial Seizures

Simple partial seizures do not cause loss of consciousness. They can cause involuntary jerking, twitching, tingling or numbness in one part of the body, buzzing in the ears, chewing or lip smacking, sweating, and dilated pupils. The seizure can be short or may last for an extended length of time. An example of a focal seizure could be jerking of one arm, or a strange sensation in one hand.

Complex Partial Seizures

Complex partial seizures, associated with dysfunction of the temporal lobe, cause loss of consciousness. A patient may be aware of his or her surroundings but unable to speak before, during, or after the seizure. Additional symptoms that may follow this type of seizure are confusion and hallucinations (imagining sights, odors, and sounds). These seizures may last for several minutes before the patient returns to full awareness.

GENERALIZED SEIZURES

Generalized seizures are also called tonic-clonic or *grand mal* seizures. They begin with a sudden attack or loss of physical control that can cause flailing of arms and legs, loss of consciousness, then twitching and relaxing of muscles. Other symptoms include tongue biting, incontinence, and shallow breathing. The seizure usually lasts two to three minutes at the most, and will cease by itself. Afterward, the patient may experience limpness, sleepiness, headache, confusion, or sore muscles. Generalized seizures may or may not begin as partial seizures.

ANTIEPILEPTIC DRUGS (AED)

Medications that are used to control seizures have several names: antiepileptic drugs (AEDs), anticonvulsants, antiseizure drugs, and epilepsy drugs. A patient may be put on AEDs if he or she experiences a seizure or as a precautionary measure. If the patient has not experienced seizures or if the patient is seizure-free for an extended period of time, the AED may be tapered off. AEDs should never be stopped abruptly. The type and amount of medication is based on the level of seizure control needed and the side effects from the medication.

Some of the more common AEDs are phenytoin (Dilantin), carbamazepine (Tegretol), and valproate (Depakote).

Helping Someone Who is Having a Seizure

If someone is experiencing a seizure, stay with the person and allow the seizure to pass. Make sure the person is breathing. Remove harmful objects around him or her to prevent injury. Do not put anything in the person's mouth. If the person is having a grand mal seizure, try to protect the head from banging or getting bumped. Help the person lie on his or her side if possible. Call for emergency help if the person is having trouble breathing or is injured. Time the seizure. If the seizure lasts longer than five minutes or if a second seizure follows the first one, call for emergency help.

Patients who suffer from multiple seizures should keep a journal of when and for how long the seizures occur so that the doctor can identify a pattern. Seizures may be triggered by alcohol use, physical or emotional stress, other illnesses that put a strain on the body (such as colds or flu), or a change in medications that can alter levels of antiepileptic drugs.

Keep a list of all medications, including over-the-counter products. Keep track of symptoms that are possible side effects. These are important ways to help your doctors recognize possible drug interactions.

Some possible side effects of AEDs include loss of balance, jerking eye movements, itching, and skin rashes. **A rash is an allergic reaction, and the patient must be seen by a doctor immediately.** It is important to remember that side effects of these AEDs vary greatly from person to person. If side effects are a serious problem, a doctor may change a patient's medication. Other anti-epileptic drugs are available, including levetiracetam (Keppra), gabapentin (Neurontin), toiramate (Topomax), lamotrigine (Lamictal), and tiagabine (Gabitril). A patient should ask his or her doctor for more information about these medications.

One concern when taking AEDs is the possibility of interactions with other drugs. Many medications will either increase or reduce the effect of AEDs. Specifically, some chemotherapy drugs prescribed to brain tumor patients may interact with AEDs. The most commonly used AEDs are metabolized (absorbed) through a specific pathway in the bloodstream. Many other drugs are metabolized through the same pathway. The various drugs compete with each other. This changes the effectiveness of either or both drugs. Blood tests and other methods are used to monitor possible drug interactions.

FATIGUE

Fatigue can vary from a feeling of tiredness to total exhaustion. It can limit a person to accomplishing no more than one activity a day. Fatigue is not relieved by a good night's sleep. It can last for a short period of time or for many years. It can be the initial symptom of the brain tumor, and is a common side effect of surgery, radiation therapy and chemotherapy. Fatigue is considered one of the most debilitating symptoms and side effects of a brain tumor because it limits a person's degree of physical activity.

The most common way to manage fatigue is to understand how and when fatigue occurs and to plan daily activities according to energy levels. Most people experience high energy at certain times of the day. By becoming aware of personal energy level patterns, patients can perform their daily activities at these times. They can also learn to conserve energy and develop ways to use their limited amount of energy efficiently. Organizing their home and time, using devices such as grab rails and extension handles to assist with basic tasks, asking for assistance from others, and resting when necessary are some ways to manage fatigue.

Medical treatment for fatigue has shown varying results, depending on the cause. A low red blood cell count (anemia) is one cause of fatigue. For this, a patient may be put on medication to help produce more red blood cells. When a patient experiences severe fatigue, the doctor may prescribe a drug to stimulate alertness. Studies using methyphenidate or modifinal show varying results, but may be worth considering.

BLOOD CLOTS (THROMBOSIS)

Patients with glial tumors experience an increased production of clotting factor in their blood. This can cause deep vein thrombosis (DVT). DVT is a condition in which blood clots form, often in the legs. The clots block one or more veins, disrupting the blood flow.

Common signs of DVT are tenderness or pain in the calf, behind the knee, or in the thigh. There may be swelling in one leg, particularly the weaker leg, and/or pain in the leg where it is pressed or when the foot is flexed upwards towards the face. Another symptom is hemiparesis (partial paralysis), particularly in the affected leg. DVT can cause loss of mobility, resulting in being confined to bed for a short period of time.

"Finding little solutions that increase my stamina is satisfying and gives me some sense of control."

– Anaplastic Oligodendroma survivor

On rare occasions, blood clots in the leg may break loose and travel to the lungs, where they can block one or more blood vessels. This is called *pulmonary embolus (PE).* PE can happen suddenly and can be life threatening.

Symptoms of PE are shortness of breath, chest or back pain, an onset of fatigue, persistent cough, sweating, rapid heart rate, heart palpitations, anxiety or restlessness, and change of color in the lips or nails (they may become pale, blue, or purple).

Several methods are used to prevent DVT from occurring. After surgery, brain tumor patients wear pneumatic compression stockings, which stimulate the muscular action of the legs to keep the blood flowing. Post-surgery patients are encouraged to get out of bed and walk as soon as possible. Physicians may have nurses or physical therapists teach patients leg exercises while in the hospital. In addition, patients may receive a small dose of heparin or a heparin derivative to thin the blood and prevent the formation of blood clots.

DVT and PE may occur after hospitalization, especially due to decreased physical activity. Patients and caregivers need to be aware of the symptoms. Call the doctor immediately if any of the symptoms mentioned above are present.

OTHER SYMPTOMS

Nausea and Vomiting

Nausea and vomiting are common in patients with cerebellar or brain stem tumors and in patients undergoing chemotherapy. Antinausea medications called antiemetics are available for people who experience nausea and/or vomiting. A doctor can explain the options.

Constipation

Constipation is a common side effect of chemotherapy. The doctor or nurse will work with patients to address this problem. Adding fiber to the diet and increasing physical activity are common methods used to alleviate constipation. If there is no relief with this regimen, the doctor may prescribe laxatives. When constipation arises, ask the doctor or nurse to develop a plan so it will not alter quality of life.

Hormonal Changes

Changes in hormones and endocrine function may occur due to tumors in the hypothalamus, pituitary or pineal glands, or as a delayed effect of radiation therapy. Patients may experience changes in their estrogen, progesterone, testosterone, growth, thyroid, or steroid levels. This can be a disturbing, chronic problem that causes mood and personality changes and sexual dysfunction. These conditions require specialized treatment and monitoring by an endocrinologist.

Depression

Depression is common in people with brain injury, including tumor, stroke, or head injury. Symptoms can include decreased pleasure in usual activities, decreased concentration, apathy, withdrawal, and mood swings. While many of these symptoms can also be attributed to a tumor, depression can and should be treated. Treatments include anti-depressant medication and counseling with a psychologist, social worker, or clergy experienced in working with patients with life-threatening illnesses.

"I eventually came to the realization that the whole process was not just about avoiding pain and making my tumor go away, but was about enjoying and savoring **life.** *When I started living my life that way, amazing things happened."*

– Meningioma survivor

7. SURVIVORSHIP

Patients diagnosed with brain tumors go through a very difficult and life-threatening experience. This chapter examines what it means to be a brain tumor survivor.

The brain is the essence of who we are. It controls our thoughts, emotions, communication, movements, and organ functions.

A brain tumor diagnosis usually turns the patient's world upside down. For everyone involved, the brain tumor experience is a journey into an unknown land filled with uncertainty. Through the diagnosis, treatments and follow-up visits, there's much to learn and cope with physically, emotionally, and spiritually.

Patients may want to know when treatments will end, symptoms will stop, and when or if they will be healthy again. At some point, patients will usually ask the question, "Will I survive this disease?" and "When will I know that I'm a survivor?"

"SURVIVOR" DEFINED

What is the definition of a brain tumor survivor? Before the 1960s, the term "survivor" was primarily used for family members whose loved one died of cancer.* The definition changed when patients began living longer due to new radiation and chemotherapy treatments. The medical community began to use "survivor" to describe those who lived for at least five years after their diagnosis or the end of their treatment.

This definition is not accurate for patients who may live more than five years, but are not cured. Some patients may go into remission, requiring treatments many years later. It is wrong to suggest that some patients triumph, and others lose the battle against brain tumors. Treatments may fail the patient, but the patient never fails the treatment. This is why the National Coalition of Cancer Survivorship (NCCS) introduced the following definition of survivor, "From the moment of its discovery and for the balance of life, an individual diagnosed with cancer is a survivor."

You are a survivor—from the moment of your brain tumor diagnosis until long after treatment ends. How does that feel to you? It is important to know that not everyone takes on this definition. "Survivorship" is a dynamic process, and everyone deals with his or her brain tumor differently. You may feel uncomfortable calling yourself a survivor after your treatment ends, or you may wait until you are disease free. You may use the term when you feel some normalcy in your life, or avoid the term altogether.

STAGES OF SURVIVORSHIP

Brain tumor survivorship involves much more than the label "survivor." Survivorship is an ever-changing process, an experience of living with, through, or beyond brain tumor disease. The concept of survivorship includes everything in life that changes as a result of the diagnosis and its aftermath. Many patients struggle to make sense of the changes and to feel a sense of order in life. Fitzhugh Mullan, MD, a physician and

* Editor's Note: This chapter makes several references to cancer. That is because sources for this article included the National Coalition of Cancer Survivorship and the National Cancer Institute, as well as cancer patients and survivors. Not all brain tumors are malignant. However, because of the unique nature of brain tumor disease and its consequences, we feel that the information presented here is relevant to all brain tumor patients and survivors, including those with a benign diagnosis. Please keep this in mind as you read through the chapter. It may be helpful in places to substitute the words "brain tumor" for the word "cancer."

cancer survivor, wrote an essay entitled "Seasons of Survival: Reflections of a Physician with Cancer." In it, he inserts some structure into his cancer experience by proposing the following three survival stages.

Acute Stage

Acute stage includes the time from diagnosis through the beginning of treatment, when the focus is on the physical disease. Patients and caregivers struggle to navigate their situations and may rely heavily on their oncologists (or neurologists) for information. Supportive services like health care professionals and family support systems are widely available to help patients through this process.

Extended Stage

Extended stage begins when and if the patient responds to treatment. Patients and caregivers may feel positive yet uncertain. Fear of recurrence is often present. Recovery focuses on the physical, emotional, and psychological effects of treatment. Mixed emotional extremes are common. Medical services are no longer available on a regular basis. Patients and their families usually rely on community and peer networks for support.

Permanent Stage

Permanent stage refers to the long-term stage of survival, when a level of trust for health and life returns to the patient. The outside world praises the patient for his or her recovery. However, the patient must manage the long-term physical and psychological effects of the disease. Survivors may require continued care by specialists with knowledge about long-term and late effects of their disease and its treatments.

The process of brain tumor survivorship involves many feelings: anger, sadness, cognitive fatigue, the fear of seizures, and the hope that treatment will destroy the brain tumor and enable the patient to reclaim his or her life.

Survivorship can teach a new appreciation of the world, oneself, and others. The awareness of the impermanence of life can make it much more precious. And even when a cure is not possible, there may be an opportunity for healing. Treatments focus on the elimination of disease, while healing focuses on psychological and spiritual wellness.

INFLUENCES ON SURVIVORSHIP

There are several key factors that may be related to brain tumor survivorship:

- Physical factors including age, gender, type and stage of brain tumor, treatments, and progression of disease. Children older than age three tend to have a higher survival rate than infants, and adults below the age of 45 do better than older adults. Tumors that are slow growing generally have a better prognosis than aggressive tumors.
- Side effects such as cognitive disorientation, physical limitation, disfigurement, and disability. In general, less severe side effects allow for a better quality of survivorship.
- Psychological factors influenced by age, previous experience with illness, psychological strengths and weaknesses, coping mechanisms, prior history of depression, anxiety and other mental health issues, self-esteem, and personality traits like independence and motivation. These factors affect a person's outlook on life.
- Social factors including race, gender, ethnicity, religious orientation, education level, employment history, financial stability, available social support, and the patient's role in his or her family, such as being a spouse, parent, or child. Social factors affect a person's ability to get health care as well as the quality of care.

DEALING WITH EMOTIONS AND GRIEF

Brain tumor patients experience different types of loss throughout their journey: from the loss of hair, to the loss of various levels of cognitive functioning, the ability to take part in certain activities, relationships, self-esteem, and innocence. People affected by brain tumors often endure emotional pain and suffering from these losses. Relaxation activities like deep breathing, imagery, meditation, and light exercise can help ease stress. Survivors with severe emotional stress should consider seeking assistance from a mental health professional.

Intense emotional suffering caused by loss is called grief. Processing grief can be a long journey for patients and caregivers. Hidden grief can manifest itself in emotions like anger, guilt, anxiety, helplessness, and sadness. Everyone grieves in his or her own way. However, psy-

chologists believe that once grief is recognized, those mourning go through the following steps: accepting what has been lost, experiencing the pain associated with the loss, adjusting to the new environment, and moving on.

Several studies and surveys show that survivors need emotional support, especially reassurance. Many brain tumor patients welcome the opportunity to express themselves and share their experiences. Caregivers and friends can play an important role by educating their loved ones about the grieving process and by encouraging them to verbalize their feelings. Many patients and their families benefit from attending support groups. NBTF can help you locate a brain tumor support group in your area.

POST-TRAUMATIC STRESS DISORDER AND POST-TRAUMATIC GROWTH

Some brain tumor patients may perceive their diagnosis and its accompanying treatments as a traumatic event. Post-traumatic Stress Disorder (PTSD) is a term for an anxiety disorder that may result from a severe trauma. The diagnosis of a life-threatening illness or learning of one's child's diagnosis can be traumatic. Symptoms of PTSD include fear, helplessness, and horror, re-experiencing the event, avoiding reminders associated with the event, and increased stressful responses for at least one month.

Studies suggest that some childhood brain tumor survivors, their parents, and adult survivors experience PTSD. Brain tumors are unique from other traumatic stresses because of the neurological effects and the uncertainty of recurrence. If you think that you might have PTSD, you should consider seeing a psychologist who can provide you with a clinical diagnosis and professional assistance through your trauma.

Post-traumatic Growth (PTG) is a term for the positive life changes that can come from trauma. PTG is considered to be the opposite of PTSD. For some patients and caregivers, the brain tumor experience inspires them to question their beliefs, attitudes, life goals, and relationships. This period of re-evaluation, which can at first be traumatic, may ultimately create positive changes. Studies suggest that brain tumor survivors who endure trauma grow from their ordeal. Specific areas of PTG include appreciation of life, personal strength, and improved ability in relating to others.

A long-term glioblastoma survivor describes positive changes coming from his journey:

> "It was five years ago when I was diagnosed with a brain tumor and, based on statistics, given a rather dire prognosis. The irony is that I, like others in a similar situation, have come to refer to my disease as a gift because it was a wake-up call. And it was not, 'Hey, wake up, you're going to die.' It was, 'Hey, wake up, you are alive.' Wake up and recognize the preciousness of this moment and all the wonderful moments life so generously and graciously gives you."

REMAINING HOPEFUL

Brain tumor patients have a right to remain hopeful in the fight against their illness and its aftermath. Hope is a powerful concept and coping strategy that empowers patients to look beyond the moment and into the future.

One brain tumor patient expresses the importance he places on a positive outlook:

> "I have no question that the mind-body connection is very real and can affect the outcome of our illness. I do not intend my outcome to be translated as a cure. Some people will get better while others will have periods of remission. Whatever time remains—and I base this on many, many conversations with patients as well as my own experience—it will be higher quality if we engage our mind's ability to affect our attitude."

However, hope does not necessarily translate into being cured.

Kendra Peterson, MD, a neurologist with much experience working with brain tumor patients, explains:

> "It is important to explore what other things a patient hopes for, for example: freedom from pain or other physical symptoms, maintaining maximum independence for as long as possible, participation in a particular family event or gathering, making peace in a troubled relationship, dying with dignity or dying at home. What people hope for frequently changes throughout their lives and at the end of life, but rarely do they stop hoping."

SUPPORT GROUPS

A support group is a meeting of patients, family members, and others, who are dealing with the same issue or illness. Support groups are usually led or facilitated by a health professional, such as a social worker, psychologist, or nurse. Support groups can be in person (often held at a hospital) or online, where members communicate by email.

Support groups serve several functions. They give patients and families opportunities to talk with knowledgeable people, including health care professionals, who can educate them and provide information about their disease. Support groups let individuals know that they are not alone. They provide a chance to talk with people who are in or have survived similar situations. Support groups can offer emotional support and practical experience to help cope with the crisis of a brain tumor diagnosis. And support groups can smooth the transitions that patients and families must make as they deal with unfamiliar environments, such as hospitals and outpatient clinics.

Support groups are free of charge. Most of them have no requirements about regular attendance or participation. People can choose to come or not, stay as long as they like, and feel comfortable about participating or just listening to others in the group. Support groups are not all the same. Some can be intense and emotional, others fun and energizing.

Support groups are not for everyone—at least not consistently for everyone. It depends on the person and his or her particular feelings at any particular time. However, when a person and family have to face the diagnosis of a brain tumor, it is important to realize that everyone involved may benefit from having someone to talk with. It is often important to have a person who is not emotionally involved who can offer an outside perspective. The National Brain Tumor Foundation (NBTF) always recommends counseling, whether one-on-one or for the family. We and others across the country are helping professionals get support groups started, specifically for brain tumor patients, in a number of geographic areas. To see if there is a group in your area or for information about online support groups, call NBTF at 1-800-934-2873 or visit our website at www.braintumor.org.

Members of the Sacramento area Brain Tumor Support Group staff an information table at a resource fair.

MANAGING FOLLOW-UP CARE

Brain tumor patients need to receive the best quality of care available. Quality care may be found at local hospitals or may require travel to a well-known brain tumor treatment center, depending upon the diagnosis. Some patients do not want to receive treatments far from home. A second opinion from a major oncology center can confirm the best local treatment plan. See the NBTF fact sheet *Issues to Consider When Choosing a Brain Tumor Treatment Center* for more information.

Tips for Doctors' Appointments

Doctors' appointments can be very stressful for patients and caregivers. The exchange of information can be more difficult than most people realize. Here are some tips to help you get the most out of these important meetings:

- Take someone to medical appointments that can ask the doctor questions, understand what

was talked about during the appointment, and discuss it with you afterwards.

- Keep a notebook with questions and concerns, and write down notes from the meeting.
- Take a tape recorder and ask the doctor if you may tape the conversation.
- Request to meet with the doctor in a private room with the door closed. This is especially important for brain tumor patients, who may be more easily distracted than other people.
- Tell your doctor at the beginning of the meeting if you have several questions, and ask the most important questions first. Ask the doctor to schedule a longer appointment for next time if necessary. Ask when you can talk on the telephone about your immediate questions if there is not enough time during the meeting.
- Ask if your doctor works with a health care provider, such as a nurse practitioner or physician's assistant, whom you can contact if your doctor is unavailable.
- Express yourself clearly and directly, and ask for what you want or need. Let the doctor know when you have heard enough or want more information. Ask for additional resources on specific topics.
- Repeat what you heard the doctor say, and ask him or her to explain things in simpler terms if you don't understand.
- As a last resort, consider finding a new doctor if your needs are not being met.

NCCS has a free resource available called *Cancer Survival Toolbox*. It has information about communicating, finding information, making decisions, solving problems, negotiating, and standing up for your rights. Contact the NCCS at 1-877-NCCS-YES (1-877-622-7937), or visit www.canceradvocacy.org.

SPECIFIC QUESTIONS ABOUT FOLLOW-UP CARE

After treatment, patients need monitoring or follow up with a member of their medical team who knows the original diagnosis and treatment history. This person can determine how often and for how long follow-up care will be necessary.

Important questions to ask your neurosurgeon, neuro-oncologist, or neurologist about follow-up care:

1. How often should I see you or other members of my health care team for follow-up visits?
2. What follow-up tests should be done and how often?
3. What symptoms should I be concerned about?
4. Who should I contact if I develop those symptoms?

MEDICAL HISTORY AND RECORDS

Patients and their primary caregivers need to have basic knowledge about tumor type and treatment history. It empowers patients and their caregivers to make better medical decisions. This information can be organized in a notebook, portable file holder, or even a binder dedicated to medical history and records. It should be shared with new doctors.

Medical records patients should keep

- The type of brain tumor you were diagnosed with and copies of pathology reports
- Date of diagnosis and treatment history, including surgical reports, sites and levels of radiation, types and amounts of chemotherapy and any other drugs, lab reports, and doctor and hospital names with contact information
- MRI reports, and copies of scans if possible

Patients have the right to see and to get access to their medical records. The process of viewing medical records involves signing a release form. Fees may be charged for copies of records and scans. Get copies of films, disks, and reports as soon as possible. The best time to request these copies is when the tests are first given. Take your medical records with you to appointments. Keep duplicates for second opinions and in the event that your copies should get lost in the mail or elsewhere.

HEALTH INSURANCE, COSTS, AND FINANCIAL ASSISTANCE

Brain tumor treatments, tests, and doctors' appointments can be a financial burden for patients and their families. It is extremely important for patients to have health insurance that will offer some medical coverage.

Patients may want to ask a caregiver, family member, or close friend to help them manage their

health insurance. Having a designated health care advocate can make a big difference in the type and quality of care a patient receives. Because there are so many different types of health insurance plans, it is important for patients and their caregivers to understand the scope of their insurance coverage. Your insurance company can provide answers to questions about your policy and available coverage. Your state insurance office has information about how and where to get new insurance.

Sometimes coverage is denied by health maintenance organizations (HMOs) or employer-sponsored plans. There is usually an opportunity to appeal the decision by making claims such as medical necessity. Even simple claims that were processed incorrectly may require several phone calls and letters to resolve, which takes time and energy. At times like these it is especially worthwhile to have a caregiver, family member, or close friend who can assist with insurance issues. Patients may need to reserve their energy for taking care of themselves and getting stronger.

For more information, call NBTF and request a copy of our health insurance fact sheet, or download a copy from the web site at www.braintumor.org.

RETURNING TO WORK

The period after diagnosis and during treatment can involve changes when patients and their caregivers redefine expectations and family roles. Brain tumor patients may leave their jobs or reduce their work hours during this period. Later, many patients can and do return to work. Other brain tumor patients, however, cannot work at all, or can only handle some of their former responsibilities.

MAKING THE DECISION

Your capabilities, needs, and the advice from your physician and neuropsychologist should all be factors considered when deciding whether or not to return to work. Your physical and mental condition are also important. Your condition will be affected by the size, location, and type of tumor, as well as the treatments received. A neuropsychologist can anticipate problems you might have at work, and provide strategies to help you compensate. The biggest challenge you may experience when returning to work is that some tasks may be more difficult.

Strategies to help the patient prepare for returning to work and adjusting after starting:

- If necessary, seek cognitive training and assistance from a neuropsychologist.
- Consider going back to work part-time to start. Many patients make the mistake of going back to full-time work too quickly.
- When accepting a new job or going back to an old one, be honest about your needs and expectations.
- Organize your environment so that it helps you do your job well. You might want to arrange an enclosed workspace and use earplugs to avoid distractions. It might help to create checklists, keep a calendar of appointments, and employ auditory and visual cues such as appointment reminders from your computer or color-coded files.
- Relearn tasks through repetition and modeling.
- Prioritize work assignments.
- Understand your limitations and adapt.
- Work with your employer to make reasonable accommodations in the workplace.

AMERICANS WITH DISABILITIES ACT

The Americans with Disabilities Act of 1990 (ADA) prevents job discrimination for disabled individuals. If a person with a disability can perform the essential duties of a job, the employer cannot discriminate in the hiring process. By law, the employer must also make reasonable accommodations for people with disabilities.

FEDERAL AND STATE DISABILITY PROGRAMS

Temporary and permanent benefit programs offer financial assistance for those who cannot return to work. A hospital social worker or local social services agency can provide more detailed information and possibly assist with the application process.

Medicaid

Medicaid is a state-administered health insurance program for eligible people below a designated income level. It is jointly funded by federal and state governments. Each state has different eligibility requirements. For information

about Medicaid coverage, visit www.cms.gov or call your local Department of Social Services.

Medicare

Medicare is a federal health insurance program for eligible individuals aged 65 or older, people with permanent kidney failure, and disabled people under the age of 65. Disabled applicants must have been receiving Social Security Disability Insurance (SSDI) benefits for 24 months to qualify. The Medicare hotline has information about state counseling and assistance programs and about the Health Insurance Portability and Accountability Act (HIPAA) of 1996. HIPAA is a law that offers protections against employers who exclude employees from group coverage or who increase insurance costs because of an employee's medical history. Call 1-800-MEDICARE (1-800-633-4227), or visit www.medicare.gov or www.cms.gov for more information.

Social Security Administration

The Social Security Administration offers two programs for people with disabilities: Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). Both programs define a person with a disability as someone who is unable to perform any "substantial gainful activity" (work) because of a mental or physical impairment. The impairment must be 1) medically documented and, 2) considered terminal, or expected to keep the person from working for at least 12 months.

Social Security Disability Insurance (SSDI) is not based on need. SSDI is based on money deducted from a worker's paychecks. For more information about SSDI, call 1-800-772-1213, or visit www.ssa.gov/disability.

Supplemental Security Income (SSI) is a need-based program. Past contributions to the Social Security system do not affect eligibility. For more information about SSI, call 1-800-772-1213, or visit www.ssa.gov.

Department of Veterans Affairs

Veterans Health Administration offers eligible veterans and their dependents medical treatment based on financial need. Call 1-877-222-VETS (1-877-222-8387), or visit www.va.gov.

For more information on issues related to work and disability programs, call NBTF at 1-800-934-2873 and request a copy of *Returning to Work: Strategies for Brain Tumor Patients,* or download a copy from the web site at www.braintumor.org.

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This chapter was written with the assistance of Jeannine Walston, and we are very grateful for her help.

North American Brain Tumor Coalition

The North American Brain Tumor Coalition (NABTC) is a network of charitable organizations representing almost 200,000 patients, family members, and friends. NABTC is committed to eliminating brain tumors and improving the quality of life for those affected by brain tumors. NABTC represents the interests of its community by raising public awareness about this issue. NABTC advocates for increased research funding, access to specialized care, and other issues affecting the brain tumor community.

NABTC also participates in meetings and programs at the Food and Drug Administration (FDA), the National Institutes of Health (NIH), and other federal agencies. NABTC works with organizations representing patients with life-threatening illnesses to improve research and the delivery of health care. NBTF is a member of the NABTC. For more information about NABTC, visit www.nabraintumor.org.

8. SUGGESTIONS FOR CAREGIVERS

The caregiver plays an important and complex role. This chapter offers suggestions and insights in the hope that they may help the participants re-establish a sense of inner control, develop a new routine, and perhaps help create a new "norm" for the life of the brain tumor survivor. Caregivers can select the suggestions that are useful to them. Remember, there is no right or wrong approach to caregiving. It is important to always remain flexible and creative because the needs of a patient can vary depending on the situation.

What is a caregiver? A caregiver is a person who is responsible for attending to the needs of a dependent child or a frail, elderly, or disabled adult. Changes in our health care system have resulted in a shift of care from the inpatient context to the outpatient clinic. This means that caregiving requires more involvement and responsibilities from the care-receiver's family.

Everyone is an advocate for patient determination, believing that an illness need not make a patient any less competent. However, brain tumor disease often impacts both the physical and mental functioning of the person. Treatments can be physically debilitating, and a patient can become exhausted and vulnerable. Brain tumor patients can experience changes in mental functioning or behavior. When behavioral changes occur, a loved one may act in ways that are completely out of character and sometimes difficult to manage. Therefore, it is important to determine when to allow the patient to assert his or her independence and when to intervene.

TAKING CARE OF THE CAREGIVER

Quite often, loved ones are thrust into the caregiver role without preparation. Caregivers need to take care of themselves emotionally and physically so that they are able to provide the strenuous support and care demanded by the patient. As a caregiver, remember the basics: eat well, get enough sleep, and exercise.

Mitch Golani, PhD, a Los Angeles-based psychologist, defines the caregiver as a strengthened ally who provides comfort and strength through self-care and knowledge. He explains that caregivers should nurture themselves so that they can nurture the patient. In addition to the basics—eating well, getting enough sleep, and regular exercise—Dr. Golani

reminds caregivers of the importance of educating themselves and of setting limits.

Consider joining a support group. Support groups can provide an encouraging setting where caregivers are able to come together and share information, vent their frustrations, ask questions, and get new ideas. Support groups are helpful during all phases of the brain tumor journey—at diagnosis, during treatment and recovery, into survivorship, and beyond.

Seek help when you need a break. Help can be sought in friends, family members, therapists, spiritual advisors, or counselors. Having a support system is critical to prevent burn out.

A fundraising walk to support NBTF patient services and research programs.

GETTING AND MANAGING INFORMATION

Brain tumor patients often experience changes in mental functioning and/or behavior. For this reason, a caregiver may need to become his or her loved one's advocate and manage the patient's care. Here are some suggestions for information management.

- **Diagnosis**. It is essential to know the patient's tumor type and to get a written description of the treatment plan. This way, the caregiver or patient can clearly describe the diagnosis to other medical professionals.
- **Medications.** Keep a list of all medications used, including over-the-counter drugs. Ask the doctor about possible drug interactions. Write down all side effects and note when you informed the physician of any problems.
- **Communication.** Good communication with health professionals is essential. If something is not clear, ask for an explanation. Find out which staff member(s) can answer questions when the doctor is busy. Take notes at doctors' visits. Document the reason for the visit, the doctor's responses to questions, any procedures performed, and other vital information. Using a tape recorder can be very efficient. As a courtesy, ask your doctor first if it's okay to record the conversation.
- **Treatment.** Inquire about other treatment options. Find out how much time you can take to make a treatment decision. Get the names of specialists the doctor would seek advice from if he or she were the patient. Get a second opinion right away.
- **Medical Records.** Keep a chart for your loved one at home. Keep a copy of all scans, lab tests, and medical records. These will be helpful in getting a second opinion, if a complaint should arise, or if there are questions about the patient's medical history.
- **Resources and Referrals.** If you need financial help or assistance getting access to other resources, contact a hospital social worker. Hospital social workers are aware of local resources that might benefit you. Get the name of a helpful social worker and always talk with that person. He or she will become familiar with your case and can help things go more smoothly.
- **Insurance.** Challenge your insurance company and your doctors if you think your loved one is not getting the care he or she deserves. If this is difficult for you, find an advocate in a

Caregiver Checklist

- I eat three balanced meals a day
- I get at least seven restful hours of sleep a night
- I talk with or visit three friends or relatives weekly
- I get out or exercise at least once a week
- I keep my annual medical and dental appointments
- I take only the medications prescribed to maintain my health

family member, a hospital social worker, or through a patient advocate organization.

- **Advocacy.** When dealing with insurance companies, repeated follow up may be necessary to make sure claims get processed and paid. Insurance companies sometimes deny claims. When this happens, seek assistance from the medical team. The doctor can prove medical necessity. The medical center's billing department can also advocate for the patient.

SEEKING HELP

Caregivers have to figure out when something is beyond their expertise and when to call upon someone else for help. If the patient is seriously depressed, for instance, it may be best to seek treatment from a mental health professional.

For the patient, a neuropsychological evaluation can help understand the causes of neuropsychiatric symptoms such as depression, anger, and mood swings. The neuropsychologist can offer suggestions for possible treatments or other methods to manage the symptoms. For example, some rehabilitation services for head injury survivors may be applicable to brain tumor survivors as well.

Behavioral changes can be temporary, or the loved one may never be the same again. Such changes create feelings of loss and are a source of grief for the family. However, there are places to turn to for guidance on dealing with these changes. There is help available through professionals and peers, community resources, books and publications, and on the Internet. A doctor or medical social worker can offer referrals.

It is beneficial to develop a good working relationship with the patient's health care team. Find a nurse who can help your loved one get the best care possible. As the patient's advocate, a caregiver may ask the treatment team what to expect throughout the course of treatment. That is, what is typical in terms of the patient's response to treatment and what possible side effects may occur. Remember that it is important to respect and be considerate of the members of the health care team. They can become invaluable as providers and friends.

Spiritual questions may arise in times of crisis and suffering, as we seek meaning and comfort. Empathic listening and attention to these matters by the caregiver can be a great gift to the patient. However, these issues can be complex, and the caregiver does not necessarily have to be the only source of spiritual comfort. In the book, *Share the Care: How to Organize a Group to Care for Someone Who Is Seriously Ill,* authors Cappy Copossela and Sheila Warnock promote the wisdom of psychologist Stephen Levine, PhD. Dr. Levine, who blends existential philosophy with Buddhist tradition, explains that spiritual growth can lead to enormous comfort for the patient. A person's spirit may be healed even if his or her body is not. Turning to professional and lay clergy for advice can be a great source of comfort, but only if your loved one welcomes this.

Caregivers need to tend to their own spiritual needs as well. Caregivers can talk to a spiritual advisor or mental health professional concerning their own spiritual concerns or the desire to examine their faith or beliefs.

> *"During and after surgery, friends and family carried us through."*
>
> **– High-grade Oligoastrocytoma survivor**

IMPACT ON THE FAMILY

"We all had to find a new normal, make sacrifices, and face some realities that were difficult. The real challenge is understanding that some of these changes have enriched our lives."

—Mother of a 15-year-old pilocytic astrocytoma survivor

Illness is not a personal problem; it's a family affair. Caring for a loved one with a brain tumor can be a family's greatest challenge. It is essential that the family meets and talks about the situation and all the possible outcomes. Children need age-appropriate information about the illness and treatment. Young family members should be included in discussions to prevent them from feeling isolated and confused. Encourage input from all family members. If there are communication problems, it may be helpful to get a neutral person to facilitate the discussions. This can be a friend, social worker, or religious advisor.

It often falls on one family member to be the primary caregiver. However, no one person should have to take on all the responsibility of caregiving alone. When caregivers need a break, they can seek assistance from other family members or friends. Caregivers should recognize that some people are better able than others to handle certain tasks or levels of responsibility. If one person does not respond, ask someone else. When family or friends are not available, respite care or an adult day care center (if appropriate) may provide a break for the caregiver. If the patient's condition should decline drastically, or near the end of life, the caregiver and family will have to decide if the loved one can be best cared for at home, or if hospice or nursing home care is needed.

Dealing with legal and financial matters is a must. In the words of one caregiver, "Check your financial situation including wills and life insurance immediately upon diagnosis! In a tight family, the loss of the person does not need to be a loss or diminishment in their legacy or the personal, business, and ethical principles that he or she lived by." Keep records of all financial transactions, including investments, resources, creditors, debtors, and business transactions. Keep a record of where important documents are kept so they can be easily located when needed.

The end of life is not something we like to think about. However, planning ahead can help the patient and family avoid the burden of uncertainty and disagreements at this emotionally and physically stressful time. By filling out a legal document called a living will (or advance health care directive), patients can ensure that their wishes will be carried out if they should become unable to make decisions or to express themselves. A living will can give specific instructions and/or authorize a chosen person (called an agent) to make health care decisions for the patient. This legal document expresses a person's wishes for health care treatment at the end of life. A living will can be cancelled or replaced at any time. Everyone—regardless of his or her state of health—should have a living will.

Depression, anger, confusion, and mood swings are neuropsychiatric symptoms. Dealing with the neuropsychiatric symptoms that brain tumor patients often experience is one of the most difficult and stressful things for caregivers and families. Behavioral and personality changes in a loved one can be subtle or drastic. Speak with your doctor if you notice these types of changes. The symptoms may be treatable.

EMOTIONAL ISSUES

Caregivers and brain tumor patients alike may feel overwhelmed and confused when they first receive the diagnosis. They may experience a flood of feelings followed by an attempt to regain a sense of equilibrium. This process can be challenging. The book, *The Human Side of Cancer: Living with Hope, Coping with Uncertainty,* speaks to this. Authors Jimmie Holland, MD of Memorial Sloan-Kettering Hospital in New York, and Sheldon Lewis, editor of the International Journal of Integrative Medicine, emphasize finding

a balance between the psychological and the logistical. Caregivers may have to deal with being empathic and supportive on the outside while feeling heart-broken and despairing on the inside. Caregivers and brain tumor patients alike may experience a range of emotions upon diagnosis, including anger, fear, guilt, and grief.

Anger may arise for several reasons following news of a diagnosis. It may be anger about the diagnosis itself. It is natural to be angry and upset when one's life has been turned upside-down. Dealing with the hospital or treatment team may cause anger and frustration. The health care professionals encountered during and after treatment may not be as helpful and understanding as one would like.

Caregivers may be afraid of what the future may bring after learning about their loved one's brain tumor diagnosis. It is frightening to witness a loved one suffering from a serious illness.

If a child has been diagnosed, parents may feel guilty. They may think they might have done something to cause the brain tumor of that they could have protected their child. If an adult loved one has been diagnosed, caregivers may think that they should have recognized the illness sooner. Some of us may have learned to feel guilty when something goes wrong, regardless of the cause. Guilt is quite subjective.

Grief is a normal reaction to loss. Most people associate grief with the loss of a life. However, any change resulting in a loss will cause grief, including illness. Especially when there are changes in personality or mental functioning, loved ones must deal with the loss of the person that used to be. Grief is expressed in ways that are emotional, physical, and behavioral. Emotionally, grief can cause sadness, anxiety, frustration, and despair. Physically, it can cause exhaustion, insomnia, restlessness, and a change or loss of appetite. Human grief is a process that often follows a healing pattern. However, there is no timeline or smooth passage from one phase of grieving to another.

All feelings are normal. It is what we do with these feelings that counts. Being mindful of the ebb and flow of one's emotions is part of the process of adjusting to life after a brain tumor diagnosis. Recognize difficult feelings early on, accept them, and find a constructive way to deal with them. It is important to talk or write about these feelings. A Vietnamese proverb says, "A grief requires a hundred tellings." Caregivers and patients may need to examine their feelings again and again. Figuring out a way to express, manage, and accept difficult feelings requires constant attention and focus.

While caregiving is difficult, being a patient is not easy either. Patients want to be heard and to have choices. Honoring the patient's emotional needs takes skill. Caregivers may find it difficult to balance the patient's sense of independence with his or her need for help. However, whatever his or her level of functioning, there are almost always possibilities for patients to have choices. An experienced caregiver offered these words of wisdom: "Let your loved ones have a voice in their care. This is their body and their experience. It can be as simple as the color band-aid they wear or what time they go to physical therapy. Feeling important and like she is still a person, not just a patient, is one of the most important things to my daughter."

Caregiving is not an easy job, but a sense of humor can help you deal with the emotional ups and downs. Don't overlook the benefits of having fun. "It is really important that we change what we are doing once in a while," one caregiver suggested. "Take a road trip, a humor break, or eat breakfast at midnight. Play with the routine; get a new perspective." Humor is important to our psychological and physical health, and laughter is good medicine. It is a universal coping mechanism for dealing with stress.

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This chapter was written by Susan Weisberg, LCSW, and we are very grateful for her assistance.

GLOSSARY

accessible Located in an area that can be approached by surgery. Inaccessible tumors are located deep in the brain or beneath critical brain structures.

acuity Sharpness or clarity of hearing or sight.

adenoma A benign tumor that grows from or in a gland (ex. pituitary adenoma).

adjuvant A method, drug, or treatment used in addition to a primary treatment to increase its effectiveness.

AED See *antiepileptic drug.*

agnosia Impairment or lack of the ability to recognize objects or people. This symptom may occur with tumors located in the brain's parietal lobes.

agraphia Impairment or lack of the ability to write. This symptom may occur with tumors located in the parietal lobe of the dominant cerebral hemisphere.

alopecia Loss of hair. This is a common side effect of radiation therapy and some chemotherapy drugs.

alternative medicine Treatment used in place of conventional medicine.

analgesic A substance that reduces or relieves pain without causing loss of consciousness.

anaplasia The growth of tumor cells without form, structure, or orientation to one another, a characteristic of cancer cells. The degree, or grade, of anaplasia reflects the tumor's potential for growth. The fastest growing tumors have the greatest degree of anaplasia, and are the most malignant.

anesthesiologist A doctor specializing in the study and administration of drugs to decrease sensation and pain during surgery.

angiogenesis The formation of new blood vessels to support growing tissue.

angiogenesis inhibitor A substance that limits the growth of new blood vessels. This is one of the biologic therapies currently being studied. Also called *anti-angiogenesis therapy.*

angiogram A procedure used to diagnose and monitor blood vessels and brain tumors. The patient is injected with a contrast agent, and x-rays chart the flow of blood to the brain, revealing any abnormalities along the blood vessel pathways. Also called *arteriogram.*

anorexia Uncontrolled lack of appetite.

anosmia Loss of the sense of smell.

anterior Located toward the front (of the brain).

antibody A protein produced by specialized white blood cells (lymphocytes) in response to a foreign substance in the body (antigen). Antibodies are part of the immune system and fight infection and disease.

antiemetic Medication to help control nausea and vomiting.

antiepileptic drug (AED) Medication used to control seizures. Also called *anticonvulsant, antiseizure drug,* and *epilepsy drug.*

antigen A foreign substance that causes the immune system to respond and produce antibodies.

aphagia Loss of the ability to swallow.

aphasia Loss of the ability to speak, write, or understand spoken or written language. This symptom may occur with tumors located in the dominant cerebral hemisphere.

ataxia Loss of the ability to coordinate muscles in voluntary movement.

ataxic gait Loss of motor control of the legs, causing a clumsy walk.

BBB See *blood brain barrier.*

BCNU (carmustine) A chemotherapy drug used for treating malignant glioma.

benign Slow growing, not malignant or cancerous.

bilateral Occurring on both sides of the body or brain.

biologic response modifier (BRM) A substance that helps the body's immune system to resist or stop tumor growth.

biopsy A surgical procedure that involves removing a small amount of tissue and examining it under a microscope in order to determine the tumor type.

blood brain barrier (BBB) A natural defense the brain develops that prevents foreign substances from entering the brain through the blood.

bone marrow transplantation (BMT) A procedure in which bone marrow is injected into a patient after intensive chemotherapy treatment. *Autologous* transplants involve cells that have been taken from the patient, stored, and then reinfused following high-dose therapy. *Allogenic* transplants use marrow donated by another person. *Syngenic* transplants use marrow donated by an identical twin.

brachytherapy A form of radiation therapy in which small radioactive pellets or seeds are implanted directly into the tumor. Also called *interstitial radiation.*

BRM See *biologic response modifier.*

calcification A deposit of calcium.

CAM Complimentary and alternative medicine.

cancer Malignant tissue made of abnormal cells that divide uncontrolled. Cancer tends to invade and destroy normal cells, and spread to other sites.

carcinogen A cancer-causing substance or agent.

carmustine See *BCNU.*

carotid artery One of two major blood vessels that carry blood to the head.

case A person or group of people being treated in a study or clinical trial. The case group is compared to the control group.

CAT scan Computerized Axial Tomography scan. Also called *CT scan.* See computerized tomography.

catheter A hollow, flexible tube that is inserted into the body (or brain) to remove or introduce fluids.

cell The smallest structure of living tissue that can function independently. A cell contains a nucleus, cytoplasm and a membrane.

central nervous system (CNS) The brain, spinal cord, and cranial nerves.

cerebellum The part of the brain responsible for voluntary muscle movement. This structure is connected to the brain stem.

cerebral hemisphere See *cerebrum.*

cerebrospinal fluid (CSF) The clear liquid that surrounds the brain and spinal cord. CSF is formed in the four ventricles (cavities) of the brain. CSF circulates through the ventricles, the subarachnoid space, and the central canal of the spinal cord. Also called *cerebral spinal fluid* and *spinal fluid.*

cerebrum The large, rounded part of the brain in the top portion of the skull. The cerebrum contains two halves, or hemispheres. Each hemisphere is made up of four lobes: frontal, temporal, parietal, and occipital.

chemotherapy A treatment using chemical drugs to kill tumor cells. Chemotherapy is usually given by mouth (orally) or injected into a vein (intravenously). Chemotherapy can also be placed in the tumor cavity during surgery (polymer wafers), or infused in liquid form directly into the tumor using a small pump (convection-enhanced drug delivery).

choked disk See *papilledema.*

chromosome Structures in the nucleus of a cell that contain genes.

chromosomal loss A portion of a chromosome that is missing one or more genes.

clinical trial A research study conducted with patients to determine the safety and effectiveness of new treatments, or to improve existing ones.

CNS See *central nervous system.*

complementary medicine Treatment used together with conventional medicine (ex: using aromatherapy to reduce a patient's discomfort after surgery).

computerized tomography (CT scan) A method to diagnose and monitor brain tumors using x-ray and computer technology to produce an image, or scan, of the brain. Also called *CAT scan.*

contraindication Something that makes a particular treatment or procedure inadvisable.

contrast agent A material, or dye, that is injected into the bloodstream of a patient and accumulates in abnormal tissue. Contrast agents can highlight areas of MRI and CT scans, and angiograms. Common contrast agents include iodine and gadolinium.

control A group of people against whom a case study is being compared. The control group may be from the general population, unaffected by disease, or may be receiving standard treatment.

craniotomy Surgery involving the removal of a portion of the skull to get access to the brain. After surgery, the removed portion of skull is put back in place. When the piece of the skull removed during surgery is not replaced, the operation is called a craniectomy.

cranium The skull.

CSF See *cerebrospinal fluid.*

CT scan See *computerized tomography.*

cyst A membrane or sac filled with fluid.

debulk To remove part of the bulk of (a tumor).

deep vein thrombosis (DVT) See *thrombosis.*

deoxyribonucleic acid (DNA) The material in the nucleus of a cell that is the source of a person's inherited characteristics.

differentiation The process by which immature cells mature into normal cells. Differentiated cells perform specific functions and are not likely to divide. Differentiation also applies to the similarity between normal cells and cancer cells. Cancer cells that are well differentiated are similar to the original cell and are usually less aggressive.

diplopia The visual perception of two objects where there is only one; double vision. This symptom may occur with tumors located in the brain stem.

DNA See *deoxyribonucleic acid.*

dura mater The outermost layer of the three membranes in the meninges, which cover the brain and spinal cord.

DVT Deep vein thrombosis. See *thrombosis.*

dysarthria Inability to express or articulate words. This symptom may occur with tumors located in the medulla or the cerebellum.

dysphagia Difficulty swallowing. This symptom may occur with tumors located in the medulla.

dysphasia Inability to use language correctly or understand written or spoken words. This symptom may occur with tumors located in the dominant cerebral hemisphere of the brain, particularly in the frontal, temporal, and parietal lobes.

dysplasia Abnormal development of cells or tissue that can lead to cancer.

edema Swelling caused by an excessive accumulation of fluid in the cells or tissue.

electroencephalogram (EEG) A recording of the electrical activity in the brain. An EEG can be useful for monitoring seizures.

embolism The sudden blocking of an artery by a blood clot or foreign material in the bloodstream.

encapsulated Enclosed in or surrounded by a gelatinous covering or membrane. An encapsulated tumor is confined to a specific area and may be surrounded by a cyst.

endocrine dysfunction Disorders which involve the overproduction or underproduction of hormones by the pituitary gland. These hormones affect growth and the functions of other glands in the body.

endocrinologist A medical professional specializing in disorders of the hormone-secreting glands, including the pituitary gland.

epidemiologist A specialist in the population-based trends and patterns of diseases.

epithelium A type of membrane that covers the surface of an internal organ or lines a cavity inside the body.

etiology The study of the causes of diseases.

fatigue A condition of extreme lack of energy.

focal Limited to a single area.

Foley catheter A tube that is placed in the bladder to drain and measure the amount of excreted urine.

foramen An opening in a bone or membrane.

fractionated Divided into several small doses. A term used in radiation therapy.

gadolinium A contrast agent used in MRI scans.

gait Pattern of walking.

Gamma Knife A machine that focuses high-intensity radiation on a small target area. See *stereotactic radiosurgery.*

ganglia A mass of nerve tissue (gray matter) or a group of nerve cell bodies. Also called *nerve bundle.* Ganglia can refer to specific groups of nerves in the brain and spinal cord, such as basal ganglia.

gene A part of a cell formed from DNA that controls hereditary characteristics or the information to perform a specific function. Each gene exists at a specific location on a chromosome.

gene therapy Treatment that replaces or repairs abnormal genes that cause disease.

generic A drug not protected by a trademark; the scientific name of a drug.

genetic Related to heredity; having to do with the transfer of characteristics through the genes.

germ cell A reproductive cell (egg or sperm). Germ cell tumors can develop in the pineal region of the brain.

gland An organ that produces hormones.

glial cells Supporting tissue of the central and peripheral nervous system that exists between nerve cells and blood vessels. Glial cells in the central nervous system include oligodendroglial cells, astrocytes and ependymal cells. Also called *neuroglia.*

glioma A tumor formed from glial tissue.

gray matter The outer surface (cortex) of the brain that is made up of nerve cells and blood vessels.

hemianopia Loss of vision or blindness affecting one-half of the visual field in one or both eyes. Also called *hemianopsia.*

hemiparesis Muscle weakness or partial paralysis affecting only one side of the body.

heterogeneous Made up of more than one cell type.

histology The science of the microscopic structure of cells, tissues and organs in relation to their functions. Histopathology refers to the structure of abnormal or diseased tissue.

homogeneous Made up of one cell type.

hormone A substance produced by glands that is released into the bloodstream. Hormones affect the behavior and metabolism (physical and chemical processes) of other cells. Hormones also affect many body functions, including growth and maturation.

hydrocephalus An abnormal buildup of fluid inside the ventricles of the brain. Also called *water on the brain.*

hyperfractionated radiation A delivery method of conventional radiation therapy in which the radiation is divided into many doses of low intensity.

hypertension High blood pressure.

hyperthermia A treatment using heat produced by microwave sources to kill tumor cells.

hypothalamus A structure near the pituitary gland that has a role in the functions of the nervous system, hormonal processes, regulating body temperature, and sexual maturation.

immune system The body's natural defense system, consisting of certain organs and cells that protect against infection, disease, and foreign substances.

immunosupression Weakening or prevention of the natural biological defenses which protect the body against disease and illness.

ingest To take into the stomach for digestion; to eat.

inoperable Located in an area that is not accessible by surgery.

integrative medicine Treatment that combines mainstream medical therapies with CAM therapies for which there is scientific proof of safety and effectiveness.

interstitial irradiation A form of radiation therapy in which small radioactive pellets or seeds are implanted directly into the tumor. Also called *brachytherapy.*

intracranial pressure (ICP) Pressure inside the cranium, or skull. Increased ICP can be caused by a tumor or by excess fluid (edema).

intravenous (IV) Into a vein. Often refers to a method of delivering medication using a needle to inject the substance into the bloodstream.

invasive Any procedure that involves puncturing or cutting the skin, or inserting an instrument or foreign material into the body. Also refers to the ability of cancer to spread into normal tissue.

ionizing radiation A type of radioactive energy that can break chemical bonds or strip electrons from atoms, causing damage to the DNA in cells. Examples of ionizing radiation are gamma rays and x-rays.

irradiation The use of radioactive rays, including x-rays or gamma rays, to destroy tumor cells. Also called *radiation therapy.*

Karnofsky scale A performance measurement for rating a person's level of physical activity. It is used to evaluate a patient's condition.

laser A medical instrument that produces a powerful beam of light and can produce intense heat at close range. Used to vaporize tissue during surgery.

lateral Refers to location on the side or sides of the body or brain.

lesion Diseased or abnormal tissue; tumor.

leukopenia Low white blood cell count.

lumbar puncture A procedure in which a needle is inserted into the lower spine to withdraw cerebrospinal fluid. Also called *spinal tap.*

lymph A clear, watery fluid that contains white blood cells. Lymph circulates through the body via the lymphatic system and removes bacteria and certain proteins from the tissues.

magnetic resonance imaging (MRI) A scanning technique used to create high-quality images of soft tissue structures inside the human body. MRI is used to diagnose and monitor the growth of brain tumors.

malignant Rapidly growing, aggressive, invasive, or cancerous.

medulla The center area or inner portion of the brain.

membrane A thin layer of tissue that can function as a protective covering over a surface, the lining of a cavity, or a division between a space or an organ.

meninges Any of the three membranes that cover the brain and spinal cord. The meninges include the arachnoid, dura mater, and pia mater.

metastasis The spreading of a disease from an original site to another or other locations in the body.

metastatic brain tumor A type of brain tumor that comes from diseased cells in another part of the body. The tumor cells spread to the brain by moving through the bloodstream or the lymph system (metastasis). Also called *secondary brain tumor.*

MIB-1 labeling index A method of measurement used to estimate how slowly or quickly a tumor is growing. Also called *MIB-1 proliferation index.*

molecular marker A substance in the blood or body that helps to indicate the presence of a tumor or cancer. Also called *tumor marker.*

monoclonal antibodies (MAB) Antibodies made in the laboratory from a single type of immune system cell. These antibodies can identify substances on cancer cells or normal substances that may help cancer cells grow. The antibodies attach to the substances and kill the cancer cells or block their growth.

morbidity A diseased state, or complications resulting from treatment.

motor A muscle or nerve that produces or controls movement.

MRI See *magnetic resonance imaging.*

multidisciplinary Made up of individuals from different fields or specialties.

myelosuppression Weakening or prevention of the bone marrow's production of blood cells and platelets.

nasogastric tube A tube inserted through the nose into the stomach, to drain the contents of the stomach or to provide nourishment to a patient who is unable to swallow. Also called *feeding tube.*

necrosis Death of cells or tissue through injury or disease. Necrosis can be a side effect of radiation treatment.

neoplasm A tumor.

nervous system The entire grouping or functional unit of nerve tissue in the body made up of the brain, brain stem, spinal cord, nerves, and ganglia.

neuroepithelium The part of an embryo that develops into the nervous system. Neuroepithelium has qualities of both neural and epithelial cells.

neuroglia See *glial cells.*

neurologist A doctor specializing in the diagnosis and treatment of disorders and diseases affecting the brain, spinal cord and nervous system.

neuron A nerve cell that receives electrical signals (impulses) from other neurons and transmits impulses to muscles or other neurons.

neuro-oncologist A doctor specializing in the diagnosis and treatment of cancers affecting the brain, spinal cord and nervous system.

neuro-ophthalmologist A doctor specializing in the treatment of diseases of the eyes affected by the nervous system.

neuro-otologist A specialist in the diagnosis and treatment of disorders and diseases affecting the acoustic nerve, the ears, or hearing.

neuropathy Numbness or tingling in the hands or feet.

neuropsychologist A licensed psychologist specializing in the study of how the brain functions and the impact of brain damage on a person's behavior and abilities.

neuroradiologist See *radiologist.*

neurosurgeon A surgeon specializing in the diagnosis, treatment and surgical management of disorders and diseases of the brain, spine and nervous system.

***non per os* (NPO)** Nothing to eat or drink. (Nothing through the mouth, in Latin.)

nuclear medicine The branch of medicine specializing in the use of radioactive chemical elements for diagnosis and treatment of disease.

nucleus The center of a cell, which contains chromosomes and DNA and is essential to cell functioning.

oncogene A mutated gene that can transform a normal cell into a tumor cell. Also called *transforming gene.*

oncologist A doctor specializing in the treatment of cancer.

ophthalmologist A doctor specializing in the diagnosis and treatment of eye disorders and diseases.

otolaryngologist A doctor specializing in the diagnosis and treatment of disorders and diseases of the ear, nose and throat.

palliative Treatment intended to reduce pain and increase comfort, rather than to cure a disease.

papilledema Swelling of the part of the optic nerve called the optic disk. This can be caused by increased intracranial pressure. Also called *choked disk.*

paralysis The loss of motor function (the ability to move) in part or all of the body.

paresis Muscular weakness involving partial or incomplete paralysis.

pathologist A doctor who specializes in diagnosing diseases by studying tissue under a microscope.

***per os* (PO)** Orally. (Through the mouth, in Latin.)

pituitary gland A small, oval structure located at the base of the brain in the center of the head, behind the eyes. The pituitary gland secretes hormones which help control the body's other glands and regulate growth and metabolism.

placebo An inactive material that has no effect. A placebo may be used in an experiment to test the effectiveness of another substance or drug.

pleocytosis The presence of a greater number of cells than normal in the cerebrospinal fluid.

PNET Primitive Neuroectodermal Tumor.

positron emission tomography (PET) A medical imaging tool used to detect abnormal tissue. The patient is injected with a glucose-based contrast agent, which collects in diseased areas. The PET scan creates computer images of those areas.

posterior Located toward the back of the body (or brain).

primary brain tumor A tumor that originates within the brain.

procarbazine A chemotherapy drug used to treat malignant gliomas.

prognosis A prediction or projection about the probable outcome of a disease, or the prospects of recovery.

proliferation The reproduction or multiplication of cells.

protocol The treatment plan in a clinical study.

pulmonary embolus A condition in which blood clots in one part of the body break loose and travel to the lungs, where they can block one or more blood vessels.

pulmonary fibrosis A condition in which the air sacs of the lungs are gradually replaced by scar tissue.

quality of life (QOL) The level of comfort, enjoyment, and ability of a patient to pursue daily activities. QOL is often used in reference to treatment options.

radiation necrosis See *necrosis.*

radiation oncologist A doctor specializing in the administration of radiation therapy.

radiation therapy Treatment using high-energy, ionizing radiation to stop cancer cells from dividing. Also called *radiotherapy.*

radiologist A doctor specializing in the interpretation of x-ray films, scans, and images, including CT and MRI scans.

radiosurgery See *stereotactic radiosurgery.*

radiotherapy See *radiation therapy*

recurrence The regrowth of a tumor after treatment. This may be indicated by a return of symptoms.

remediation Specialized instruction for children to maximize their development, learning abilities, and quality of life, and to help make up for impairments caused by a brain tumor.

remission The reduction or disappearance of symptoms or of a tumor in response to treatment. Remission can be temporary or permanent.

resection The removal of a tumor by surgery.

secondary brain tumor See *metastatic brain tumor.*

seizure A sudden attack or convulsion due to an uncontrolled burst of electrical activity in the brain.

shunt A hollow tube or catheter surgically placed in the body to drain fluids. A shunt may be inserted in the brain to relieve increased intracranial pressure caused by blocked cerebrospinal fluid.

spinal fluid See *cerebrospinal spinal fluid.*

spinal tap See *lumbar puncture.*

standard treatment A proven, effective procedure to counteract disease. Standard brain tumor treatments are surgery, radiation therapy, and chemotherapy.

stem cell A primitive cell with the ability to differentiate (mature) into a specialized adult cell.

stereotactic radiosurgery (SRS) A type of radiation therapy that uses a large number of precisely aimed beams of ionizing radiation. The beams are aimed from many directions and meet at a specific point to deliver a single, high dose of radiation directly to the tumor. SRS avoids exposing normal tissue to radiation.

steroid A type of drug used to reduce swelling (edema) caused by tumors or treatment.

subcutaneous Under the skin.

suction The process of sucking or drawing out fluid by using negative pressure. A device such as a pump or valve can cause suction.

supratentorium The upper part of the brain.

systemic Affecting the body as a whole.

tentorium A fold of the dura mater that separates the cerebral hemispheres from the cerebellum in the back of the brain.

thrombosis A condition in which blood clots form, often in the legs. The clots block one or more veins, disrupting the blood flow.

tinnitus Buzzing or ringing in the ear. This symptom may occur with tumors located in or near the acoustic nerve.

tissue A group of similar cells united to perform a specific function.

tumor An abnormal mass of tissue that results from uncontrolled cell division. Also called *neoplasm* or *lesion.*

tumor marker A substance in the blood or body that helps to indicate the presence of a tumor or cancer. Also called *molecular marker.*

ultrasound A type of imaging technique which uses high-frequency sound waves to create a two-dimensional picture of soft tissue in the body.

vascular Referring to blood vessels.

ventricle A space in an organ through which fluid circulates. Ventricles of the brain contain CSF; ventricles of the heart contain blood.

vertebra One of 23 bones that make up the spine.

vertigo Dizziness, or an illusion of movement. This symptom may occur with tumors located in or near the acoustic nerve.

white matter Brain tissue made up of nerve cell fibers coated with myelin, a substance that conducts nerve impulses. White matter transmits information between the nerve cells in the brain and spinal cord.

whole brain radiation therapy (WBRT) A type of conventional radiation therapy that aims radiation at the entire brain. WBRT is used to treat multiple tumors and metastatic brain tumors.

NBTF PUBLICATIONS

- ***The Essential Guide to Brain Tumors*** An 80-page, easy-to-read booklet for newly diagnosed patients, long-term survivors, family members, and health professionals. *The Essential Guide* contains current information on diagnosis, treatment, and research, a glossary of terms, plus information on support groups and other resources.

- ***Understanding Brain Metastases: A Guide for Patient and Caregiver*** This 26-page booklet provides basic information on the diagnosis and treatment of brain metastases. It also contains a glossary and listing of resources. Produced in collaboration with the Lung Cancer Alliance.

- ***Understanding Glioblastoma Multiforme*** A 16-page brochure to help patients and caregivers understand more about the diagnosis and treatment of glioblastoma

- ***Coping with Your Loved One's Brain Tumor*** A brochure about how a brain tumor affects the family and practical suggestions to help cope with these changes.

- ***Resource Directory*** A comprehensive reference for patients and health care providers. The directory contains names and phone numbers of various organizations that offer services and products of particular interest to brain tumor patients, survivors, and their families.

- ***Returning to Work: Strategies for Brain Tumor Patients*** This pamphlet reviews brain tumor survivors' rights and offers suggestions to make the transition into the workplace.

- ***My Name is Buddy*** This is a true story for children about the diagnosis and treatment of Buddy, a golden retriever who had a brain tumor. Written by Dave Bauer in collaboration with NBTF.

- ***Brain Tumors: Understanding Your Care*** A 24-page brochure that describes brain tumor diagnosis, surgery, radiation therapy options, chemotherapy, continuing care and adjusting to daily life.

FACT SHEETS

- Childhood Brain Tumors Occurring in Adults
- Clinical Trials for Brain Tumors
- Clinical Trials: How to Get Access
- A General Overview of Complementary and Alternative Medicine Therapies
- How and Why to Get a Second Opinion
- How Tumors Affect the Mind, Emotion, and Personality
- Issues to Consider When Choosing a Treatment Center
- Pilocytic Astrocytoma in Adults
- Ten Questions to Ask Your Doctor
- Who Gets Brain Tumors and Why?

PUBLICACIONES EN ESPAÑOL (PUBLICATIONS IN SPANISH)

- ***Cómo enfrentar un tumor cerebral en un ser querido*** Un folleto sobre cómo un tumor cerebral afecta la familia y cómo enfrentar una nueva situación.

- ***Los tumores cerebrales: Cómo entender su tratamiento*** Un folleto de 24 páginas que describe el diagnóstico de un tumor cerebral, incluyendo información sobre la cirugía, las opciones de radioterapia, la quimioterapia, la atención médica continuada y el ajustamiento a la vida diaria.

HOJAS INFORMATIVAS EN ESPAÑOL (FACT SHEETS IN SPANISH)

- Cómo los Tumores Afectan la Mente, las Emociones y la Personalidad
- Preguntas Sobre Los Tumores Cerebrales

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