A RESOURCE GUIDE
FOR PARENTS OF CHILDREN WITH BRAIN OR SPINAL CORD TUMORS

5TH EDITION

COMPLIMENTARY COPY PROUDLY PROVIDED BY

Children's Brain Tumor Foundation

www.cbtf.org

1-866-228-HOPE

10 9 8 7 6 5 4 3 2 1

Copyeditor: Wade Iwata, LMSW, OSW-C
Cover design and layout: Regina Printing
Printed in the U.S.A.

This guide is dedicated
to the life and memory of

Jill Adlman
March 16, 1975–October 20, 1990

We hope it will be like her,
a light and an example to others
in their struggle against brain cancer.

ACKNOWLEDGMENTS

Fifth Edition

We would like to thank all of the parents, survivors, and professionals who contributed their compelling additions to the fifth edition of *A Resource Guide*:

Gina Baldacci, LCSW, Neuro-Oncology Social Worker, Children's Memorial Hospital

Donna Beach

Parent

Karen Capucilli

Parent

Mahmut Yaşar Çeliker, MD
Director, Pediatric Neuro-Oncology Team, Stony Brook Long Island Children's Hospital

Jennifer Click

Parent

Cheryl Coutts

Parent

Nicole Ellis, LSW
Social Worker, Division of Oncology, The Children's Hospital of Philadelphia

Barbara Jones, PhD

Associate Director and Co-Director of the Institute of Grief, Loss, and Family Survival – School of Social Work, University of Texas at Austin

John Ott

Parent

Stephen Sands, PsyD

Morgan Stanley Children's Hospital of New York – Presbyterian

Dawn Erin Scott

Parent

Charles Sklar, MD

Director, Long-Term Follow-Up Program, Memorial Sloan-Kettering Cancer Center

Gay Steinhorn
Parent
Zach Steinhorn
Survivor
Brooke Troiber
Survivor
Linda Wachtel
Parent, PES Chair
Brad Zebrack, PhD, MSW, MPH
Associate Professor, University of Michigan School of Social Work
Adjunct Associate Professor

We would like to thank the following individuals for their continued support of the Children's Brain Tumor Foundation *(names of Parent Education and Support (PES) committee members are italicized.*

Bonnie Aldman
Cristin Cunnington
Sylvia Cano
Lei Chen
Cheryl Coutts
Jason Fangusaro, M.D.
Janet Hawkins
Elana Ladas
Claudia Lusk
Gary McCann
Karen McKinley
Anita Nirenberg
Elyse Perez
Erin Puck
Morgan Sobel
Mark Souweidane, M.D.
Gay Steinhorn
Linda Wachtel
Susan Weiner
Akiva Zablocki

We would also like to extend a special thanks to the staff of CBTF; **Jessica Elder, Joe Fay**, **Kayla Giacin, Wade Iwata,** and **Stacia Wagner,** for all their hard work on this new edition of *A Resource Guide*.

We wish to express our thanks to the following people without whom this publication would not have been possible: **Bonnie Adlman** and **Varian Medical Systems.** We would also like to thank **Regina Printing Company** for helping us to design the front cover of the fifth edition of *A Resource Guide.*

TABLE OF CONTENTS

Foreward

The day my son was diagnosed with his brain tumor will always be with me. That was in 1987 before the beginning of the Children's Brain Tumor Foundation and my son was 19 months old. The only resources for help and information were from the doctors and nurses. It was years before the internet became part of our lives and crisis management.

Out of the need for information, the vision of a small group of dedicated parents and medical professionals, the Children's Brain Tumor Foundation was formed.

A great deal has changed since 1987 in the world of pediatric brain tumors.

What has remained the same however, is the pain and fear attached to hearing the devastating words that your child has a brain tumor.

To make a difficult journey a little bit easier, the first edition of the resource guide was printed in 1995. This book was the first in a series of patient education and support programs to help families navigate the greatest challenges that come with the diagnosis of a brain or spinal cord tumor.

I wish to give special thanks to all who have worked so hard to update and expand the information and usefulness of each edition of the resource guide. On behalf of the Board of Directors and the staff of the Children's Brain Tumor Foundation, it is with great pride that I present to you the fifth edition of the Resource Guide.

Linda Wachtel, Parent
CBTF Board of Directors
January 2012

CHAPTER

1

INTRODUCTION

Many thoughts have been running through your mind since your child was found to have a brain or spinal cord tumor. What does it mean? Where will you find help? How will you cope?

This guide was written for you—a parent of a young person with a brain or spinal cord tumor. In its pages, you will find information about the many services that are available. You are not alone, and there are many people who want to help. This guide will enable you to find them. You will also find, interspersed throughout this guide, gray boxes containing quotations from other parents and children in your family's situation—people who have been through what you are going through.

Your child's doctor will have explained the exact facts related to your child's tumor, but you may still be in shock. This book reinforces that teaching. It also addresses the most common questions about brain tumors in the young, combining medical information with practical suggestions. It considers the emotional impact on parents and other family members. What you learn here has been designed to help you cope with the stress of a chronic disease that may involve intensive treatments, frequent visits to the doctor and hospital,

interruptions in school and social activities, physical change, and—perhaps most frightening of all—uncertainty about the future.

It's important to remember that you are your child's best advocate. It's up to you to make sure that your child receives the best care our medical system has to offer. It's difficult to handle this responsibility alone, so you may want to enlist the help of a relative or friend who will encourage and support you.

You can't assume that everything necessary will be done. Learn to ask questions—and to listen carefully to the answers, preferably making notes. If you don't understand a word or medical term, ask your child's doctor or nurse for a better or simpler explanation. Find out what literature is available and read about your child's condition. If you're well informed, you'll feel more comfortable making decisions, asking questions of health care professionals, and you'll have less fear of the unknown. It often helps to have a family member or friend review the information with you or join you for the discussions with your child's doctors.

Many parents have found that keeping a medical journal can be helpful. By always carrying a notepad and a pencil, you will be able to write down the names and specialties of the many medical professionals you will meet. You can take notes on what they are telling you and make a list of questions that you might otherwise easily forget to ask. Keeping a journal of your child's day-to-day care, in which you take notes, record your child's progress, and note any concerns, can be an effective way to have all of the important information available at a glance. You can keep a list of all the professionals involved and how to reach them. Another section in your journal can list all medications and

their dosages, so you can easily monitor what treatment has been given and when. By keeping an account of your child's treatment, you can also notice any possible side effects that occur.

Try to arrange to collect copies of your child's scans (computed tomograph [CT] scans, magnetic resonance imaging [MRI] scans, and so on) and medical records. Extra copies can easily be made for you at the time the films are taken. You can also ask physicians to provide you with copies of all reports and to have them sent to your child's pediatrician. You and your child may need to see specialists in several locations, and sometimes files can get misplaced in busy medical centers. It is helpful to keep them together if you need to seek another opinion or if your child requires urgent care elsewhere.

Talking to other families in your situation may help—there is great comfort in knowing that you are not alone. You can arrange to meet them by asking your child's doctor or by contacting us, Children's Brain Tumor Foundation, at 866-228-HOPE (4673) or info@cbtf.org.

This handbook provides you with a general guide to childhood brain and spinal cord tumors, how to live with them, and how to cope. This guide does not offer all the answers. But by using it as a resource, you'll know where and how to ask for help.

CHAPTER

2

FACTS ABOUT THE BRAIN AND SPINAL CORD

As you read this page, you do many things simultaneously. Your eyes are moving from left to right; you are holding the book and turning its pages. You may be shifting in your chair. You may be aware of others in the room. You could also be listening to music and drinking a cup of tea or coffee, feeling the warmth of the cup in your hand. At the same time, you are thinking about what you are reading, filing away a few things in your mind for later consideration, and maybe making a mental note to talk to your child's doctor about something. Without a doubt, you are feeling many emotions.

What allows you to do all these things, all at the same time, is your brain, assisted by its link to the rest of the body, the brainstem and spinal cord. The brain is the control center of the body and mind, governing everything from movement, sensation, and speech to thought, emotion, and memory. Normal heartbeat, blood pressure, and other organ functions depend on the brain working properly. The spinal cord, in effect, is an extension of the brain, transmitting messages to and from the brain. It's like a relay station in an intricate, ordered, and continual pattern of electrical traffic.

Because the brain is divided into regions that control specific functions throughout the body, a tumor in a particular area of the brain is likely to have an impact on the actions that region governs. Knowing what goes on in what part of the brain will help you understand the impact of the tumor. We discuss these structures separately to help you better understand them, but they are really all interconnected and intertwined, working together at all times. A disruption in one part of the brain may cause disruptions in other parts as well.

Brain and Nervous System Basics

Together, the brain and spinal cord make up the **central nervous system (CNS)**. The network of nerves that connects the CNS to the arms, legs, eyes, ears, and other organs is called the **peripheral nervous system** (**PNS**). We are usually aware of our legs and arms moving and can generally control them. But other activities—such as blood circulation, breathing, digestion, and the work of hormones in our body—are carried out without our thinking about them. These are functions of the **autonomic nervous system**, which is controlled largely by the **brainstem**.

Because the brain and spinal cord are so vital to the body's function and survival, nature has provided some "protective armor". The first layer of protection is the skin of the scalp, which plays an essential role in fending off infection. Next are the bony structures of the skull and spinal column. The top of the skull, or **cranium**, surrounds the brain, keeping it from being crushed. Its rounded design gives the cranium added strength despite its relative thinness. The spinal cord is housed inside the hollow **vertebrae**, or spinal bones, of the neck and back. In addition, muscle groups strengthen and pad the spine.

Beneath the bony structures covering both the brain and spinal column are three layers of membranes, called **meninges**. The outer layer is the **dura mater**, a tough, translucent skin. Next is the spongy substance called **arachnoid**, which contains blood vessels. Closest to the brain surface is the **pia mater**, which contains major blood vessels and covers the brain's wrinkles and folds.

Cerebrospinal fluid (**CSF**) is a clear, watery substance that forms yet another protection for the brain and spinal cord, cushioning them from jolts and knocks, much as amniotic fluid protects a fetus. It also nourishes the brain while carrying away waste products. CSF is found between the pia mater and arachnoid layers of the meninges, as well as throughout the brain in cavities and tunnels called **ventricles**. CSF is constantly manufactured within the ventricle in the choroid plexus.

The body can be harmed when a brain tumor blocks the flow of CSF from a ventricle or if too much CSF is produced. If that happens, fluid builds up within the brain, which has very little room to expand inside the skull, resulting in raised intracranial pressure (ICP). The resulting condition is called **hydrocephalus**. A child may experience one or more of the following symptoms: headaches, vomiting, clumsiness, and drowsiness or lethargy.

You will also hear about the **blood–brain barrier**. Like the skull protects the brain from the outside world, the blood-brain barrier protects the brain from materials it doesn't want in the bloodstream. The blood–brain barrier is a layer of cells and is essential to the brain's survival and health. However, it also prevents therapeutic drugs and antibiotics from reaching tumors and infections in the brain. Researchers continue to look for ways around this barrier when it is standing in the way of

treatment. Currently, chemotherapy may be given through injection into the subarachnoid space to by-pass the blood-brain barrier, this is called **intrathecal chemotherapy**. Additionally, implantable wafers are being explored as a means of getting chemotherapy around the blood-brain barrier.

Cells of the Brain and Spinal Cord

Like all living tissue, the brain and spinal cord are made up of cells, which have characteristics and names unique to their function. The cells unique to the central nervous system are **neurons** and **neuroglia**. Neurons are the workhorses of the nervous system, sending and receiving signals to and from the brain through numerous connections. "Hundreds of billions" of neurons in the brain, with many times more interconnections, is as precise a figure as they can currently estimate. Each nerve cell is made up of a **nerve body**, with branches called **dendrites** and **axons** extending outward like a starburst (see Figure 1). These branches are responsible for transferring signals between cells. The axon typically carries signals from the neuron to other neurons or organs such as the heart, muscles, and lungs. The dendrites, usually found in large numbers on each neuron, receive signals from other neurons or sensory organs. Together these form a complex network of "wires" that carry nerve messages in pulsed signals to affect every human action, including thought, sensation, motor movement, respiration, and laughter.

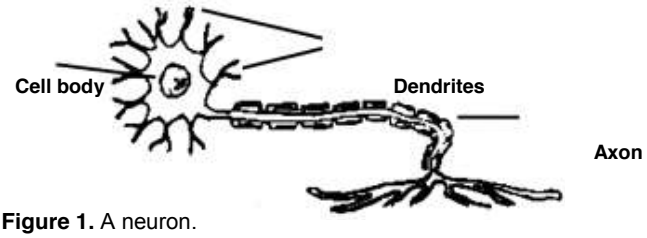

Figure 1. A neuron.

Unlike many other cells in the body, neurons cannot be replaced once they die. New experiments in animals have been able to regenerate limited neurons in limited areas. However, most dead neurons cannot be replaced. Nevertheless, the brain possesses an amazing ability called **plasticity**—which means it can often adjust to injury or loss of brain cells by making new interconnections which take over for the loss of others. Younger children, whose brains are still developing, seem to have the greatest ability to recuperate from this sort of damage. But scientists have found, since the 1990s, that even adult brains have enough flexibility to form some new connections in the brain. As you accumulate medical information about your child's situation, please keep this remarkable ability in mind.

Neuroglia are the second type of cell found in the brain. The literal meaning, "nerve glue," describes their supportive role. During fetal and infant development, certain neuroglial cells help guide the neurons to their final destinations in the brain and spinal cord. Others surround and nourish neurons while ingesting debris. There are many more neuroglial cells than neurons in the brain and neuroglia are involved in over half of all brain tumors.

Tumors arising from neuroglial or glial cells are referred to generally as **gliomas** but will often take their more specific names from the type of glial cell involved. The most common pediatric brain tumors involving glial cells are **cerebellar** and **hemispheric astrocytomas**, **brainstem gliomas**, **optic pathway gliomas**, **ependymomas**, and **gangliogliomas**. (See Chapter 3)

Brain tumors in children arising from neurons or their precursors include **supratentorial primitive neuroectodermal**

tumors (**PNETs**), such as **medulloblastomas** and **pineoblastomas**. (See Chapter 3).

Structures of the Brain

From the outside, the most obvious parts of the brain are:

- The two wrinkled **cerebral hemispheres** in the left and right halves of the upper brain (together called the **cerebrum**).
- The **cerebellum**, a smaller section attached to the lower back portion of the cerebrum, which coordinates movement and balance.
- The **brainstem**, which extends down from the center of the brain and in front of the cerebellum, to merge with the top of the spinal cord.

The brainstem controls our most basic functions, many of which happen without our thinking about them.

Three structures make up the brainstem:

- The medulla controls breathing, swallowing, blood pressure, and heart rate
- The pons (Latin for “bridge”) links the cerebrum to the cerebellum and medulla oblangata
- The midbrain governs basic vision and hearing.

Running down the length of the brainstem is the **reticular formation**, which is responsible for alertness or arousal. If a brain tumor distorts the reticular formation, a coma like state can occur.

There are twelve pairs of **cranial nerves**. Each cranial nerve exists as a pair, one nerve for the left side of the body and the other nerve for the right side. Most of them originate in the brainstem. They are identified by numbers (I through XII). These nerves control swallowing, facial movement, the senses (vision, taste, and hearing), and neck and shoulder muscles.

Major nerves carrying information to and from the rest of the body pass through the brainstem. The nerve axons cross over in the medulla so that the left side of the brain controls the right side of the body, and vice versa. Because of this, tumors on one side of the brain may well affect movement and sensation on the opposite side of the body. (An exception is in the cerebellum, where a side of the brain sends signals to the same side's arm and leg.)

Above the midbrain is the **diencephalon**, which includes the **thalamus** and **hypothalamus**. The hypothalamus is a regulatory center involved in many functions, such as hormone secretion (including that of the nearby pituitary gland), the autonomic nervous system, eating, sleeping, temperature, emotion, and sexual behaviors. Sitting above the hypothalamus, the thalamus serves as an information processor for much of what goes to and from the brain. A tumor in this region may cause hormone deficiencies that may alter growth, pubertal development, and handling of physical stress. In addition, tumors in this region can affect one's ability to regulate body fluids and appetite.

The cerebellum is the lower back of the brain, beneath the cerebral hemispheres and separated from them by a fold of dura mater called the tentorium. It is about one eighth the size of the cerebrum. The cerebellum is involved in fine motor coordination and balance, continually and automatically making allowances that let the body maintain its balance. If a tumor grows in the cerebellum, a person may stagger (ataxic gait) or make jerky movements. The person may be unable to judge distances or have control over hand movements.

The cerebrum is enormous in proportion to the rest of the brain. It is involved in sensory input, thinking, reasoning, learning, and memory—the functions we associate with intelligence. The cerebrum is proportionately larger in animals that seem to be able to take in sensory information and analyze it in some way. But only in humans is it so massive and complex.

The cerebrum is made up of right and left cerebral hemispheres, with a large groove called the **cerebral fissure** separating the two sides. Deep inside the brain, in the middle, is the **corpus callosum**, a bundle of nerve fibers connecting the halves of the brain, allowing information to move back and forth between the two sides.

The outermost tissue of the cerebrum is called the **cortex**, a deeply folded area made up of billions of cell bodies whose darkish cast gives it the name **gray matter**. The axons connected to the cell bodies extend below the cortex, forming **white matter**, which is the inner portion of the cerebrum. The convolutions of the cortex are formed by deep folds that result in a more compact structure, much like the folding of a road map. It is estimated that if the cortex were unfolded, its area would be three times larger than the surface of the brain. This folding

accomplishes an important conservation of space, which means many more nerve cells are concentrated in each unit of volume. This also means a disruption in any area may impact the millions of connections it has to other areas.

Like a road map, the cortex defines specific areas of function in the brain. Several large grooves, or **fissures**, outline four areas, or lobes, on each side of the brain: the **frontal**, **temporal**, **parietal**, and **occipital lobes**.

The frontal lobes are considered our emotional control center and home to our personality. The frontal lobes have much to do with the intellect and the ability to fit into a social group, helping us plan and prioritize, concentrate and recall, and exert control over our behavior. There is no other part of the brain where lesions can cause such a wide variety of symptoms (Kolb & Wishaw, 1990). Damage to the most forward section of the frontal lobes can cause changes in behavior, changes in the ability to read others reactions, changes in personality and lack of filter in behaviors, including sexual behaviors.

Toward the back of the frontal lobe is the **motor area**, a strip of brain with distinct sections controlling motor activity such as swallowing, chewing, talking, and movement of the hand, legs, toes, and so on. Doctors often need to map this area of the brain by using electrodes on the brain before surgery to make sure they know exactly where the functions are; otherwise, they might disturb or remove tissue that would affect those functions (see Figure 2).

Toward the front of the parietal lobes, a fissure in the brain that is responsible for the functions of logic, math, taste, pain, sensations of pressure, pain, and temperature, is the **sensory area**, a strip of cortex going up one lobe, over the cerebral

fissure, and down the other lobe. The sensory area is concerned with sensations coming in from the eyes, ears, nose, tongue, and other organs.

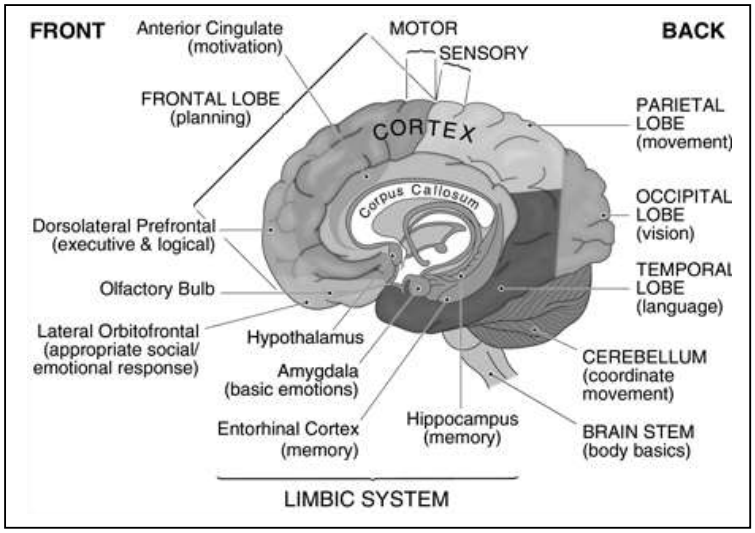

Figure 2. Your brain and what it does: a diagram of how the brain works. Functions of the Brain.

The occipital lobes are the visual center of the brain, making sense of information coming into the brain from the eyes. The left occipital lobe receives input from the right field of vision, and the right occipital lobe receives input from the left field of vision.

The temporal lobes are involved in a significant way with speech and language, hearing, and memory. The temporal lobes have additional complex features. The **amygdala** is located in

the temporal lobe and has a strong connection to mental and emotional reactions. It is also linked to fear responses and nervous reactions. It is believed to be associated with conditions such as autism and depression. The amygdala is connected to the **hippocampus**, which is known to be involved in the complex processes of forming, sorting, and storing memories.

This network of complex interconnections surrounding the top of the brainstem is called the **limbic system**. It links our basic functions and emotions to areas of the cerebrum that have to do with those higher levels of thought and understanding that we associate with being human.

Although the lobes have overall executive functions, they do not act alone, nor does any one process reside solely in a particular lobe. The brain's massive network of interconnections keeps communication going between the hemispheres and among the lobes, as well as among the structures below the cortex. The brain always functions as a whole.

Structures of the Spinal Cord

We discussed the spinal cord above and explained that it extends from the brain and has the same layers (meninges) and CSF surrounding it (see Figure 3). The spinal cord makes up two thirds of the CNS and is a pathway for nerve impulses. Sensory information (such as touch, temperature, pressure, and pain) is carried *to* the brain. Commands that relate to movement (motor function) and reflexes travel *from* the brain to all parts of the body.

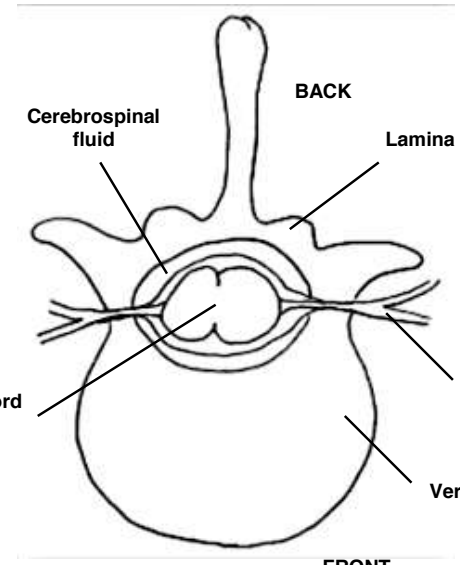

Figure 3. Cross-section of the spine.

The spinal cord is protected by the flexible, bony **vertebral column**, also called the spinal column. You can feel these separate, hollow bones (called vertebrae) along your back and neck. For identification purposes, these bones are grouped into sections, called levels, and are numbered (see Figure 4). Therefore, a spinal cord tumor might be described as occurring at either the cervical, thoracic, lumbar, sacral, or coccygeal level (for example, a tumor at C-3 or L-1) The 31 pairs of spinal nerves are attached to the cord by roots and branch out to different parts of the body through spaces in the vertebrae.

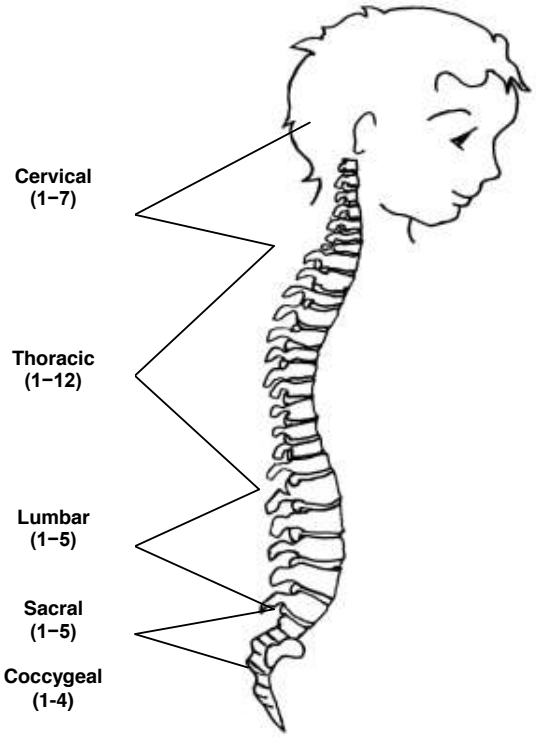

Figure 4. Side view of the spine showing vertebral levels.

Tumors can grow inside (intrinsic tumors) or outside (extrinsic tumors) of the spinal cord and put pressure on the spinal cord. Signs and symptoms result from compression because there is very little space for a tumor to grow. Spinal cord tumors produce two effects. Local (or focal) effects (such as pain, weakness, and sensory impairment) are due to growth in the immediate area, involving bone and spinal roots. Distal (or remote) effects are related to interference with the relay system of nerve impulses. Weakness, loss of feeling, or loss of muscle

control [**paralysis** (total loss) or **paresis** (partial loss)] below the vertebral level of damage can occur.

A thin, flat layer of membrane that is the bony arch of a vertebra, known as the **lamina,** may have to be removed (and replaced) during surgery to reach the tumor. If this is done, a child may occasionally need to be treated by an orthopedic specialist for an abnormal curvature of the spine.

CHAPTER

3

PEDIATRIC BRAIN TUMORS

Every year, about 4,150 children in the United States are found to have brain and spinal cord tumors. The past 20 years have led to a dramatic increase in the survival rate. This chapter provides an overview of the diagnosis and treatment of tumors in the brain and spinal cord (central nervous system, or CNS). Tumors can also arise in the spinal nerves (peripheral nervous system, or PNS) as well as the surrounding protective and supportive bones of the skull and spine.

Thanks to continued advances in computerized imaging, surgical techniques, radiation therapy, and chemotherapy, as well as newer approaches such as immunotherapy and gene therapy, the future of affected children continues to improve.

Although the cause of most brain tumors is not known, researchers are looking into environmental and genetic factors for clues. Unfortunately, there is little conclusive data on causes.

At a time when there is an explosion of medical information, families of children with brain and spinal cord tumors need up-to-date knowledge of recent advances and access to specialized treatment centers. Your own persistence in seeking information can be of great help to your child and your family. It is our goal to serve as a resource for families by providing information and support.

What Is a Tumor and What Makes Brain Tumors Different From Other Tumors?

A **tumor** is any abnormal mass in or on the body that is caused by the growth of abnormal cells growing and multiplying in an uncontrolled way. Doctors also refer to a tumor as a **neoplasm.**

Primary tumors are made up of cells unique to the organ or tissue where they start. **Secondary tumors** start somewhere else in the body and spread, or metastasize, to one or more sites. Most brain and spinal cord tumors in children are primary, meaning that they start in the CNS and are not the result of malignant cells spreading to the brain from another location in the body. A primary tumor in the CNS rarely spreads beyond the brain and spinal cord.

When a tumor grows slowly and does not spread, it may be called **non-malignant** or **benign**. In contrast, **malignant** tumors tend to be fast-growing (made of cells that divide and multiply very quickly) and can invade surrounding tissues. Malignant tumors with aggressive growth may travel and grow somewhere else within the CNS. Magnetic resonance imaging (**MRI**) scans of the whole CNS are sometimes needed to determine if this has occurred. The word *malignancy* generally means **cancer**. A common perception is that all malignancy and cancer is “bad” and that non-malignant is “good.” When we talk about tumors in the CNS, however, these definitions become blurred. A non-malignant tumor that grows slowly can be life threatening if it is in an area of the brain where it compresses structures that control the most vital body functions (like breathing or blood circulation). There are occasions where non-malignant tumors cannot be effectively

treated, and in some circumstances, non-malignant tumors may change over time to malignant tumors.

Due to the brain and spinal cord being enclosed in rigid containers (skull and spine); abnormal growths may be noticed simply because there is not enough room for them. Often the growth or tumor will cause increased pressure in the head or spine, which produces symptoms. Symptoms are often evident at an early stage of tumor growth.

How Are Brain Tumors Diagnosed?

Brain tumors are often difficult to diagnose because they are rare and therefore not the first thing a doctor is looking for. In addition, their signs and symptoms may mimic those of other ailments. Symptoms will also vary according to the exact location of the tumor. For example, many childhood brain tumors cause vomiting. However, there are other much more likely causes of vomiting. It is therefore not unusual that a child be seen several times and maybe by specialists before the proper diagnosis is made. Many symptoms are due to the effects of raised **intracranial pressure** (ICP), brought on by the tumor's size or location, blocking the normal flow of **cerebrospinal fluid** (CSF) from the brain. If the tumor has blocked the flow of CSF, the excess fluid builds up and causes a condition called hydrocephalus. Symptoms may include headaches (particularly in the morning), nausea, vomiting, poor coordination, seizures, drowsiness, and, in infants an increase in head size. Other symptoms of a brain tumor may include behavior changes, blurred vision, weakness in a limb or on one side of the body, speech problems, and difficulty with balance.

Parents (and pediatricians) often feel distraught they did not make the diagnosis earlier; however the delay in diagnosis often does not affect the outcome. The fact you were a proactive parent helped in getting your child diagnosed.

Spinal cord tumors can cause pain (especially when a child is sleeping). Tingling or weakness in the arms or legs and loss of bladder or bowel control may occur. The symptoms a child has are related to pressure of the tumor on a particular area of the spinal cord.

Once other diagnoses have been ruled out, the doctor will take a health history of your child and do several measures of neurological function. Often a neurologist is involved; he or she may order tests such as an **electroencephalogram** (EEG), a test that measures the electrical activity in the brain, a **computed tomography** (CT) scan, an x-ray device linked to a computer that produces cross-sectional images of the body, and a magnetic resonance imaging (MRI) scan. Sometimes the pediatrician will order these tests directly. These tests are generally noninvasive but may require **intravenous** (**IV**) injection of a special dye (usually gadolinium), also called contrast**,** that makes the tumor stand out on film. If your child is unable to lie very still for the scanning procedures, he /she may be given a sedative orally or intravenously. The doctor may be able to determine the type of brain or spinal cord tumor from CT or MRI results. Sometimes an exact diagnosis cannot be made until a sample of the tumor is actually sent to the pathologist for study under the microscope. The results from the pathologist will be important to formulate a treatment plan. Germ cell tumors can be diagnosed from a blood and CSF sample; tectal gliomas, diffuse pontine gliomas, and optic glioma are diagnosed by imaging and do not require biopsy in most cases.

What Brain Tumors Are Common in Children?

The sudden influx of medical terminology into your life can be intimidating. Health care professionals are familiar with such terminology through years of training and experience. But these terms are new to you, so ask your child's doctor to explain them. Some parents report that taking notes during visits with the doctor helped them keep track of medical terminology. There are many types of brain tumors and many names for them—often even more than one name for the same tumor. The descriptions that follow include only the most common types of brain tumors found in children, divided into two broad groups according to their location.

Most childhood tumors (more than 60%) are located in the **posterior fossa** (the back compartment of the brain). This area is separated from the cerebral hemispheres by a tough membrane called the tentorium. The posterior fossa includes the cerebellum, the brainstem, and the fourth ventricle. Tumors in this area include **medulloblastomas** (also called **primitive neuroectodermal tumors**, or **PNETs**), **cerebellar astrocytomas**, **brainstem gliomas**, and **ependymomas**. Although less common, other rare types of tumors have also been observed in this area, such as rhabdoid tumors and ganglioglioma.

The remaining 30% to 40% of CNS tumors occur within one of the two cerebral hemispheres or in the spinal cord. Tumors of the hemispheres include astrocytomas, oligodendrogliomas, craniopharyngiomas, choroid plexus carcinomas, ependymomas, supratentorial PNETs, pineoblastomas, and germ cell tumors.

The most common tumors of the spinal cord are astrocytomas and ependymomas.

Common Types of Brain Tumors

Medulloblastomas /PNET's
Alternative names: Primitive Neuroectodermal Tumor (PNET)

These are one of the most common malignant brain tumors found in children (20% of all pediatric brain tumors) and usually occur in children between the ages of 4 and 10 years old. Medulloblastomas occur more often in boys than in girls. These tumors typically arise in the middle of the cerebellum, interfering with the flow of CSF and causing hydrocephalus. Symptoms may include headaches, vomiting, unsteady walking, and pain in the back of the head. Medulloblastomas can spread to other parts of the brain through the CSF. Standard therapy for medulloblastoma consists of aggressive surgery followed by radiation to the entire craniospinal axis with boost to both the primary tumor site and focal CNS metastatic sites. Recently, adjuvant chemotherapy has also been shown to be beneficial.

Astrocytoma/Glioma:
Alternate Names: Anaplastic Astrocytoma; Glioblastoma Multiforme; Juvenile Pilocytic Astrocytoma(JPA); Pleomorphic Xantroastrocytoma (PXA); Desembryoplastic Neuroepithelial Tumor (DNET)

Astrocytomas arise in cells called astrocytes, while gliomas originate in glial cells, which are most often themselves astrocytes. Astrocytomas and gliomas are sometimes used interchangeably. There are two main types of astrocytoma's: high-grade and low-grade. High-grade tumors are aggressive, fast growing, and

easily spread. Low-grade astrocytoma's are usually localized and slow growing. Astrocytoma's are commonly found in the cerebellum, cerebral hemispheres, and thalamus or hypothalamus. Astrocytoma's account for the majority of pediatric brain tumors, with roughly 700 children diagnosed each year, with 80 percent of those diagnosed having a low-grade tumor. They can occur at any time in childhood or adolescence, and have the same symptoms as medulloblastomas. Treatment is surgical removal of the tumor, which in the case of total removal of the tumor can be curative. If the tumor has grown into the brainstem, radiation therapy or chemotherapy (depending on the child's age) is sometimes needed. Because radiation therapy can affect a child's growth and development, chemotherapy may be given to delay or eliminate the need for radiation.

Common Low-Grade Tumors are:

- Juvenile Pilocytic Astrocytoma
- Fibrillary Astrocytoma
- Pleomorphic Xantroastrocytoma
- Desembryoplastic Neuroepithelial Tumor

Common High-Grade Tumors are:

- Anaplastic Astrocytoma
- Glioblastoma Mulitforme

Brainstem Gliomas:

Approximately 10% of childhood brain tumors are brain stem gliomas, which most commonly affect children between the ages of 5 and 10 years old. Because of their location, brainstem gliomas may cause sudden dramatic symptoms, such as double vision, clumsiness, difficulty swallowing, and weakness. The brain stem is made up of the midbrain, pons, and medulla in the

posterior part of the brain. Tumors found on these structures are considered brain stem gliomas. The most common of these tumors are found in the pons region and are classified as **diffuse intrinsic pontine gliomas** (DIPG). Tumors found in the midbrain or medulla are most commonly referred to as focal brain stem glioma**.** In these cases, surgery is not usually an option. They are difficult to treat because the tumor cells grow between and around normal cells. It is usually impossible to remove a tumor in this area because it interferes with the functioning of this critical area of the brain. Radiation therapy, with or without chemotherapy, is the preferred option. Because of the rarity and poor prognosis of DIPG, children and their families are often encouraged to participate in clinical trials attempting to improve survival with innovative therapy.

Ependymomas:

Ependymomas make up roughly 6% of pediatric brain tumors and can occur at any time during childhood; however the majority are diagnosed before age 5. These tumors arise from the cells that line the passageways that produce and store cerebrospinal fluid. There are two types of tumors: supratentorial (in the top of the head) or infratentorial (in the back of the head). The majority of tumors in children occur as infratentorial tumors arising in or around the fluid filled-fourth ventricle.

Ependymomas cause symptoms such as; nausea, vomiting, problems with coordination, and hydrocephalus is often involved. Surgical removal of the tumor is the usual treatment of choice, followed by radiation therapy to the site of the resection.

Optic Pathway Tumors:

A small percentage (5%) of pediatric brain tumors involve the optic nerve, which sends messages from the eye to the brain. These are usually slow-growing and can be treated successfully with surgery, radiation therapy, or chemotherapy. Because visual pathways and/or the hypothalamus are affected, children with these tumors often have vision and hormone problems. Treatment options include surgery, radiation, and/or chemotherapy. Patients are evaluated based on age, extent of visual loss, and location of the tumor to decide on the treatment protocol. In patients who are asymptomatic and have smaller tumors, careful observation may be considered.

Craniopharyngiomas:

Nonglial growths, which account for 5%-13% of childhood brain tumors, usually impact growth because of their location near the pituitary gland. They may also affect vision due to their location. Treatment is often controversial because complete surgical removal may be curative but can also cause memory, vision, behavioral, and hormonal problems. Partial surgical removal plus radiation therapy is an alternative. Individuals who experience hormone problems will require life-long hormone replacement. Additionally, long-term follow-up care is often needed for vision issues.

Germ Cell Tumors:
Alternate names: Germinoma; Embryonal Carcinoma; Endodermal Sinus Tumor; Teratoma

A small percentage of childhood brain tumors (less than 4%) arise in the pineal or suprasellar regions. They are most often diagnosed around the time of puberty and are more likely to affect boys than girls. These tumors may respond favorably to chemotherapy and/or radiation therapy, following surgery. Germinomas of the brain are amongst the most radiation-curable of all tumors. The optimal treatment for those children with the more difficult mixed malignant germ cell tumors of the brain continues to be somewhat controversial. These tumors are far less sensitive to radiation therapy than germinomas, and are not cured by radiation therapy alone. The currently accepted treatment approach is to use several cycles of intensive chemotherapy, followed by radiation therapy.

Choroid Plexus Tumor:
Alternate names: Choroid Plexus Papilloma; Choroid Plexus Carcinoma

The choroid plexus is located within the ventricles of the brain and produces CSF. Choroid plexus papillomas (non-malignant) and choroid plexus carcinomas (malignant) account for 1% to 3% of pediatric brain tumors. These types of tumors usually arise in infants and may cause hydrocephalus. The treatment is typically surgery and, if the tumor is malignant, chemotherapy, and/or radiation therapy.

Ganglioglioma:
Alternate names: Gangliocytomas, Ganglioneuromas

These tumors arise in **ganglia**-type cells, which are groups of nerve cells. They represent 4% of all pediatric brain tumors. They most commonly occur in the temporal lobe of the cerebral hemispheres, the third ventricle, and less commonly in the spine. Treatment is typically surgery, and may include radiation if a full resection is not possible.

Atypical Teritoid/Rhabdoid Tumor (ATRT):

These tumors are rare, high-grade tumors that occur most commonly in children under the age of 2. They can be found in any part of the brain and tend to be aggressive and spread throughout the central nervous system. ATRT represents 1-2% of all pediatric brain tumors and was only recently classified as its own diagnosis within the past 10 years. Treatment tends to involve the surgical removal of the tumor followed by chemotherapy. Depending on the child's age and whether a recurrence has occurred, radiation therapy may be given.

Oligodendroglioma

Oligodendrocytes, a type of supportive brain tissue, are where these tumors occur. They are most commonly found in the cerebral lobes of the brain. These tumors tend to occur in young and middle aged adults, with a smaller population of children being diagnosed each year. While pure oligodendrocytes are rare, mixed gliomas, tumors made up of both oligodendrocytes and astrocytes are far more common. Treatment usually involves the surgical removal of accessible tumors. Biopsy alone will be done to confirm tumor type for

inaccessible tumors. Radiation therapy may follow, as well as chemotherapy for recurrent tumors.

Supratentorial Primitive Neuroectodermal Tumor (PNET)/Pineoblastoma:

Supratentorial PNETs and pineoblastomas account for approximately 5% of pediatric brain tumors. Their symptoms depend on location and proximity to the CSF spaces. Treatment involves surgical resection, radiation therapy to the brain and spine, and chemotherapy.

Specialists and Your Child's Treatment Team

After the initial diagnosis of a brain or spinal cord tumor, you may need to consult other specialists and doctors. Together with you, these professionals will take a team approach and map out a general plan of care for your child. This plan will be continually evaluated and revised as needed.

Larger medical centers may run clinics and have a formal meeting of these multidisciplinary team members, sometimes called a tumor board. Depending on your child's specific medical needs, you may need access to specialists or therapies at other facilities. Brain tumors are relatively rare, and children's medical needs are different than adults. Treatments and side effects for children may not be the same as those for adults. *Pediatric* specialists know the most about children's care.

Not all institutions have exactly the same kinds of doctors or specialists, and their exact roles may differ. If you keep in mind that the prefix *neuro-* relates to the brain and spinal cord and that

oncologists are doctors who study and treat cancer, the naming of these subspecialties will make more sense. The term *pediatric* in front of any of the subspecialties indicates the doctor works specifically with children. Please refer to the glossary in the back of *A Resource Guide* for detailed explanations of what each subspecialty title means.

Your child's team may include anyone else who might provide insight into how a treatment will affect your child's health and life—for example, your family's pediatrician, a child life specialist, social worker, clergy, or physical therapist. You and your child are the most important part of any meetings, and all comments, concerns, and feelings—both your's and your child's—should be considered.

When a brain or spinal cord tumor has been diagnosed in a child, it may be important to have surgery or begin aggressive treatment rather quickly. Therefore, if parents are interested in seeking an additional opinion, talk to your doctor about your concerns and have them help you find a specialist. Waiting too long could have a negative impact on your child's health. (In emergency cases, of course, action may need to be immediate and choices may be limited.)

It is important that you and your child feel you understand the treatment plan and feel comfortable with the treatment team. Because brain tumor treatments are rare and each treatment facility has varying experience in dealing with them you may choose to seek another opinion to increase this confidence level.

Getting a Second Opinion

Not everyone wants or requires a second opinion, but it is sometimes important and can be very reassuring. Your medical team should be helpful in assisting you with your questions regarding second opinions. Opinions may not, of course, be of equal value. All opinions should be obtained from pediatric facilities familiar with cases like your child's.

Ask your doctor about the best place to obtain a second opinion. Consider asking him/her to call and make the appointment for you. This may speed up the referral process. If you are unable to enlist the help of your child's doctor, take the initiative and make the appointments yourself.

Your medical team should assist you in gathering the medical information such as scan results, laboratory reports, and surgical pathology slides you may need for a second opinion. Most treatment centers will specify what records are needed for a second opinion. You are entitled to these records. Sometimes there is a fee for duplicating records. Keep a list of what you send, because some items will have to be returned. If the second doctor's opinion differs from that of the first doctor, a third opinion may be necessary.

At the second opinion appointment, take notes or ask if you can record the meeting. It may also be helpful to bring along a trusted family member or friend who will also hear what is said or take notes for you. At treatment decision time, which can be emotionally stressful, two sets of ears are always better than one!

My advice is to get more than one opinion on your child's condition. Looking back, I wish that I had taken the time to make sure that the hospital and the doctor had the tools and experience to make sure my daughter got all of the necessary testing and have the best team for her condition.

How Are Brain Tumors Treated?

Surgery

Treatment of brain or spinal cord tumors usually begins with surgery, also called **resection**, to remove all or part of the tumor. A surgery to remove only a small part of the tumor for diagnostic purposes is called a **biopsy**. A biopsy can also be helpful to determine if other types of treatment are less risky than resection. Some types of tumors, including DIPG and optic glioma, are not usually biopsied and tend to be treated after a diagnosis by MRI because of the possible surgical risks involved to the child. Although complete removal of the tumor (**gross total resection**) is often the treatment of choice, partial removal of the tumor (**subtotal resection**) will occasionally relieve a child's symptoms.

Modern surgical equipment and experience allows neurosurgeons to locate and remove tumors previously considered inaccessible. Advanced equipment also helps identify (and therefore avoid damage to) critical areas like cranial nerves or parts of the brain that control speech. Examples of these advances are operating microscopes with magnification and illumination, which allow surgeons to see structures in great detail, frameless stereotaxy provides a road map to structures in

the operating room, and ultrasonic aspirators allow tumors to be separated from normal brain tissue or the spinal cord.

Surprisingly, brain surgery is not particularly painful, as the brain itself has no pain sensation. It usually involves general anesthesia, causing the patient to be completely asleep for the operation. The head is held in a stable position and the scalp is injected with local painkillers. The scalp is opened and the skull bone is exposed. A trapdoor of bone is created and temporarily removed. The lining of the brain (dura mater) is opened and the brain or tumor is exposed. Once the tumor is removed, the dura mater is sutured closed, the bone is repositioned with titanium plates and screws, absorbable plates and screws, sutures, or fine wire. The scalp is then closed with sutures or staples.

Removal of the tumor often relieves some of the uncomfortable, dangerous pressure that an unwelcome mass in the brain or spinal cord causes. Surgery also establishes the diagnosis by obtaining portions of the tumor for the pathologists to examine. Pathologists can perform a frozen section procedure (also known as cryosection) at the time of surgery to help the surgeon determine the best course of action in the operating room. The frozen section is used to provide rapid microscopic analysis of the tissue and provides only preliminary results, as there are often many special stains and techniques that the pathologist will use to identify the tumor. Some tumor types, including astrocytoma and other gliomas, may be assigned a **grade** (high or low) that is based on its rate of growth and ability to spread.

After surgery, the patient will usually have a follow-up MRI scan done within the first 2 days. This will confirm the extent of tumor removal and provide a baseline image for future comparison.

On occasion, the surgeon, on the basis of the MRI scan findings, may want to return to the operating room to remove a portion of tumor that was not clearly seen at the time of the first surgery.

In some circumstances, resection alone may be curative. Other tumors may require additional therapy such as chemotherapy or radiation therapy.

Some tumor locations may cause a buildup of CSF. In these cases, the surgeon may place a **ventriculostomy** tube from the spaces of the brain to a drainage bag at the bedside. This allows the fluid pressure to be released while the brain swelling improves. These tubes cannot remain in place forever, because the surrounding tissues are prone to infection. Over the course of a week or so, the ventriculostomy tube drainage is "weaned" so the tube can be removed at the bedside. In a significant percentage of cases, however, a permanent device—called **ventriculoperitoneal shunt** (**VP shunt**)—must be placed to allow internal sterile drainage from the brain to the abdomen for the body to absorb the CSF. In certain situations, a third ventriculostomy is performed, in which a small connection is made between where the body makes CSF and where CSF is reabsorbed into the blood. This connection short-circuits the blockage.

Radiation Therapy

Radiation therapy involves aiming beams of X-Rays or gamma rays at the tumor in prescribed doses over a scheduled period of time. The rays kill the tumor cells by destroying their ability to divide and multiply. But radiation therapy, like surgery and chemotherapy, is a double-edged sword. It can harm normal tissue near the tumor, or along the path of the beam traveling in

and out of the body when targeted at the tumor, as well as, cells of the immune system. The side effects can include brain swelling, fatigue, hair loss, skin irritation, nausea, and vomiting. Newer radiotherapies include **intensity-modulated radiation therapy** (**IMRT**)**, proton-beam**, and **stereotactic** all of which are precisely focused therapies, as well as **conformal radiation** (CRT), which is a regionally focused therapy, and **hyperfractionated radiation**, which is a split-dosing therapy. CT and MRI scans can be combined in computerized treatment planning. The goal is to provide the maximum dose of radiation to the tumor cells while sparing all healthy cells and tissues around the tumor from harm.

Children must remain absolutely still during these treatments. Because babies and young children may be unable to cooperate, conscious sedation or general anesthesia can be given. Doctors hesitate to treat young children's brains with radiation therapy. Although it may be effective against the tumor, it can cause significant long-term side effects such as learning, developmental, and memory problems. Your child's doctor will discuss with you the risks, benefits, and alternatives to help you decide whether radiation therapy should be part of the treatment for your child.

When stereotactic radiosurgery is used, the patient's head is stabilized in a metal ring and a single dose of radiation is administered from a modified linear accelerator machine, **Gamma Knife**, or **X-Knife**. Stereotactic radiosurgery is usually *not* an alternative to conventional radiation therapy, though it may be recommended as a supplemental treatment. It is an alternative only in rare situations. This technique delivers a highly concentrated radiation dose with little injury to the adjacent brain tissue. Unfortunately, it is not useful for patients

with tumors that infiltrate the brain or tumors that are larger than a walnut.

Although most radiation therapy targets malignant tumors, doctors also may use radiation therapy on certain non-malignant tumors that are surgically inaccessible.

Chemotherapy

Chemotherapy is the use of certain chemicals to slow down or kill rapidly dividing tumor cells. Chemotherapeutic drugs are used before, during, or after surgery and radiation therapy. Like radiation therapy, they can also kill beneficial cells and have side effects such as nausea, vomiting, fatigue, infection, bleeding, and hair loss.

Chemotherapeutic drugs include many different medicines. They are used alone or in combination, depending on the type of tumor being treated. Some side effects are unique to certain drugs, such as nerve injury with vincristine, and hearing loss with cisplatin. Doctors carefully monitor the administration of these drugs to minimize side effects, and researchers are continually developing new drugs and adjusting dosage to improve and reduce harmfulness.

Chemotherapeutic drugs can be taken orally or intravenously through a vein in the arm or hand. If chemotherapy is going to take place over an extended period of time or will be given to a child whose veins are small or hard to access, doctors may suggest surgically implanting a device in a major vein, giving easy access to a vein without repeated needle sticks. Once implanted, the device can be used not only for

chemotherapy but also for antibiotics, fluids, blood transfusions, and for drawing blood for laboratory work.

Currently there are two devices commonly used for long-term access to the veins. Both are catheters inserted under the skin. The insertion is a minor surgical procedure that may require an overnight hospital stay or may be done as outpatient surgery. One end of the catheter is threaded into a large vein in the chest. The other end, into which the IV drugs will go, can either exit the chest through the skin (as with the **Broviac** or **Hickman**) or be left just under the skin (as with the Port-a-Cath), terminating in a little rubber reservoir into which the drugs are injected with a needle. A skin-numbing cream (**EMLA**) can be used over the reservoir to relieve the pain of a needle stick before the Port-a-Cath or Mediport is accessed.

If your child's doctor recommends a catheter, be sure to discuss with him or her, the benefits and risks of each type. The Broviac requires some special care at home; medical personnel will teach you what you need to know.

You can obtain more information about the short- and long-term effects of these therapies from your treatment center and in the information listed in Chapter 7 ("Survivorship"). Medications are available to relieve some of the uncomfortable immediate and short-term side effects. Long-term side effects may require follow-up care by other specialists. Consult your child's doctors about your child's specific needs and before treating any related health-problem on your own—even skin irritation.

Additional Treatments and Drugs

Excess fluid in the brain causes a variety of problems in brain tumor patients. As you have read, hydrocephalus results from excess CSF in the brain and leads to a variety of unpleasant symptoms. To relieve the buildup of CSF, doctors may surgically implant a flexible piece of narrow tubing into the brain and thread the other end of the tubing under the skin either into the abdominal cavity or through a vein to the heart. The CSF can then flow down the **shunt**, as it is called, away from the brain, and be absorbed into the body or filtered through the blood stream. Sometimes another CSF pathway can be established by a newer procedure called a third ventriculostomy. This procedure may avoid the need for a shunt.

If your child needs to have a shunt implanted, you will need to know the type of shunt, possible problems, and what symptoms to be aware of that may cause a possible problem. (More information on shunts can be obtained from the *Hydrocephalus Association*, listed in Chapter 11, "Resources.")

Some tumors cause the normal brain tissue around them to swell with excess fluid and inflammation. Surgery and radiation therapy can also produce swelling. Whatever the cause of the swelling, doctors routinely prescribe *Decadron* (dexamethasone), a steroid and anti-inflammatory drug that reduces swelling. This treatment usually brings dramatic relief to the child who has been having headaches, vomiting, and nausea due to swelling. **Steroids** are powerful medicines, but they may have side effects: increased appetite, high blood pressure, susceptibility to infection, facial swelling, acne, and fluid retention. In addition, children may have an artificial cheerfulness (euphoria) and experience an

emotional letdown or mood swings as the dose is decreased. Children taking Decadron may have an enormous appetite! It is very important to take these medications with food to avoid stomach irritation or bleeding. Antacids may be prescribed to help protect the stomach. The body's response to taking steroids is to stop its own production of steroids, so it's important that patients not discontinue this medicine abruptly. When the doctor wants the drug stopped, the dosage will be gradually tapered off.

Children undergoing chemotherapy or radiation therapy may face the discomfort of nausea and vomiting. There are drugs available to alleviate these symptoms called **antiemetics**. If you see your child developing nausea, speak with your child's medical team. There are different medications available, so you will be able to work with your child's doctors to find the best antinausea treatment for your child.

What Can We Expect in the Future?

New Treatments

Many children's tumor specialists are excited about treatments currently being researched and developed. They expect to see advances in several areas: less traumatic surgeries, new chemotherapeutic drugs and combinations of drugs that could effectively replace surgery and radiation therapy, chemotherapy with fewer side effects, treatments that marshal the body's own immune system to kill tumor cells, and gene therapy. Research must continue in specialized medical centers and children's hospitals, where health care professionals are experienced at taking care of a child undergoing these types of treatment.

The media is always describing seemingly miraculous cures and treatments, and well-meaning friends and relatives may overwhelm you with books and articles about alternative therapies. Remember that only you, along with a doctor or team that you have confidence in, can evaluate these choices and decide on a treatment plan for your child. You likely will hear opinions that will make you second-guess your own judgment. *Speak to your child's doctors openly and do not be afraid to ask whatever questions are on your mind***.**

Clinical Trials/Protocols

Your child's doctor or treatment team may recommend that you enroll your child in a clinical trial. This is a research study of new therapies (or experimental drugs and treatments). By studying a larger collected group of children in a **protocol** with very exact treatment guidelines, doctors are able to draw better conclusions about how effective a treatment is and work to improve it.

The *National Cancer Institute* (NCI) oversees a large cooperative group of over 240 hospitals—the **Children's Oncology Group** (**COG**)—which develops new treatments for children with brain tumors, shares information, and has common goals. You may be referred to a children's hospital or academic medical center for participation in a clinical trial.

Research is important for finding and providing new or improved treatments. Your child may be the first to receive new therapies before they are more widely available; they often become standard treatment. By evaluating new therapies for large numbers of children through COG, researchers can more

quickly and efficiently gather information about effective therapies.

Phases of Clinical Trials: Clinical trials are often described as being phase I, phase II, or phase III. Phase I trials are done to evaluate the side effects of a new treatment and to establish the proper dose. Different patients may receive different doses of the same medicine. Although doctors hope that the treatment may help the patient, that is not the main goal of a phase I clinical trial. After a phase I trial has been completed and the proper dose of the new medicine has been determined, a phase II trial may begin. In a phase II trial, all of the patients receive the same dose of the medicine and the goal is to see how effective the new treatment will be. If a phase II trial finds that the new treatment is very promising, a phase III trial may be done. In a phase III trial, patients are randomly given one of two different treatments. Randomly means that a computer (not the doctor or parent) decides which of the treatments a given patient will receive. A phase III trial is usually done to find out whether a new treatment is better than, worse than, or the same as the established treatment for a certain disease.

How to Find Clinical Trials: More information on how to access clinical trials can be found in Chapter 11 (“Resources”) of this guide.

CHAPTER

4

SUPPORTING YOUR FAMILY

Just like their parents, children often feel emotionally stressed in the face of serious illness. After diagnosis, childrens'—especially teens'—anxiety levels may already be high from whatever suffering the tumor has caused, from the loss of independence and physical ability or from the prospect of painful medical procedures. Although parents' shock, disbelief, and self-indictment at the time of diagnosis can hardly be contained, witnessing or sensing their parents' feelings can increase children's anxiety even more.

It is important to remember that your child has the same emotional needs as other growing children. At any age, your child needs reassurance. The suggestions that follow are appropriate for all children, but some may need to be tailored to fit the needs of the youngest patients:

- Reassure your child that a brain tumor is not caused by anything he or she did wrong and that neither the disease nor the treatments are meant as punishment.
- Be honest with your child from the time of diagnosis; however, be sensitive to what your child can understand at his or her particular age. Be honest and realistic when explaining procedures and treatments. Discuss all changes in treatment with your child. Nobody, not even your child,

expects you to know everything. If you don't know the answer to a question, don't hesitate to say, "I don't know." Truth supports trust.

- Don't be afraid to ask your child questions and encourage your child to ask you questions. Asking what he or she is thinking will not produce new fears but will provide an opportunity to express fears and worries that already exist. Discussions with your child about what he or she understands will give you a chance to clarify any unrealistic ideas and qualms your child has. He or she may have questions that catch you completely off guard. These questions may range from concerns with returning to school to much more involved issues such as possible long-term effects. It may be helpful to answer these questions as best as you can and enlist the aid of a doctor, nurse, child life specialist or social worker for those you are unsure of.
- Acknowledge your child's feelings. Listen without judging or rushing to reassure. Let your child know that it's okay to feel sad and cry. Encourage your other children to talk openly about their feelings. Family discussions are a good way to reduce anxiety and make it possible for family members to support one another.
- Let your child exert some control so long as it doesn't jeopardize health or interfere with treatment. Giving a child choices will alleviate some anxiety; it will also allow him or her to grow in spite of reduced independence and new obstacles.
- Don't be surprised if your child's behavior changes. He or she may be having trouble expressing feelings or may be afraid or unwilling to upset you. Children often keep their

feelings hidden because they do not want to upset their parents.

- Set limits! During this period, your child may challenge whatever limits you try to set. Although a tendency to let him bend the rules is natural, leniency may actually make a child more anxious and imagine that things are worse than they actually are. It will also make it more difficult to return to a "normal" routine.
- Be sensitive to the reality that young patients, just like adult patients, have good and bad days.
- Young children tend to be primarily concerned about separation from their parents. Oftentimes parents have commitments such as work or meetings that cannot be rescheduled. Reassure your child every time you leave that you love them and will be back as soon as you can. If you know what time that will be, say so.
- Encourage your child to keep in touch with friends and classmates while absent from school. It's also important that your child go back to school as soon as possible. This delivers an important message: "Despite the illness, I'm still a normal child with outside friends, interests, and responsibilities." (More information on School Transition in Ch. 6, "Education")
- Despite everything that's going on, your child is still the same lovable person you were raising before the tumor developed. The two of you need time every day to love and enjoy each other.
- Parents often dismiss their own health needs, both physical and emotional. When a child is diagnosed with a serious illness it's extremely important to take care of yourself if you

plan to be able to fully care for your child. The hospital social worker is available to discuss how you are feeling and to provide support as well as community referrals.

The Parent as Advocate

An advocate is a person who speaks in support of, or pleads the cause of, someone else. You are the best advocate for your child. Sometimes your child's voice will be heard only if you speak up.

> There have been countless times in which I remember my mother checking over every single drop of medicine I was given by a nurse, or information on every medicine I was prescribed. Asking, "now what is this?" and "how much of this is he supposed to be given?" Constantly checking over and over again, being overprotective isn't a bad thing.

It's important to keep a diary or journal of your child's health from day to day. Keep a record of any unexplained symptoms, such as fever or changes in behavior, along with any suspected side effects. If there are neurological, emotional, or physical changes in your child, a journal will help you describe these to your specialist. Note the date, time, and duration of these symptoms. These may simply be a mild reaction to a medication. A symptom does not necessarily have to be externally obvious to be serious. Any and everything you feel is important should be reported. You should never give your child any medication,

including Tylenol, vitamins, or holistic herbs, without discussing it with your child's doctor first.

In addition, parents often think of the questions they want to ask the medical team when the team is not available. Keep a list of your questions for your next meeting and bring it with you. These are some questions you might want to ask:

- What symptoms or side effects need to be reported to the doctor?
- What constitutes an emergency?
- How can I monitor healing or changes?
- Is there anything I can do to minimize side effects?
- Exactly what activities are allowed or restricted?
- What medication side effects are possible? How long will my child have to be on this medication?
- If you are interested in seeking alternative therapies, take information on the treatment to your medical team to discuss.

Listen carefully to the answers provided by your child's doctor and take notes. It's a good idea to make a habit of always carrying an iPad, laptop, or a notepad and pen. As mentioned earlier in this chapter, you may want to have a family member or friend go with you to discussions or meetings with the doctors—it's surprising how much information you can miss. You can also ask if a hospital professional is able to assist with note taking, while not always possible, sometimes they are able to help. Additionally you may want to ask the doctor if you may bring a tape recorder to meetings if no family member or friend can attend.

Keeping records of clinical visits and treatments can be helpful for your own reflection. Note things such as:

- Blood count levels
- Treatments administered at the clinic
- Medications prescribed or given/possible side effects
- The doctor's recommendations
- Your child's response to the treatment and medications

Be sure to keep track of authorization numbers, referrals, mileage, and expenses (in some instances these may be tax deductions). Also keep a separate list of the professionals involved with your child and how to contact them (by phone, fax, or e-mail).

Siblings

Parents whose child has a tumor are easily overwhelmed by everything that needs to be handled. They may be physically and emotionally drained from extended hospital stays and the intensity of caring for their sick child. Other children in the family may have unavoidably been deprived of emotional support when they, too, desperately need it. They may be carrying a heavy load of fear, grief, and confusion, coupled with anger, jealousy, and guilt. They may not want to upset you further and may keep painful feelings inside. There may be no one with whom to share these feelings. What's to be done?

You can begin to help by accepting the feelings of your healthy children as normal, understandable, and even justifiable.

After all, you have been much more involved with their sick brother or sister. At home, the sick child continues to need a great deal of attention. Brothers and sisters need special attention and love, too. Below are some ways a parent can involve siblings and help the whole family.

- Tell your other children, as soon as possible about the diagnosis. Explain the illness in ways that are age-appropriate, providing as much information as they can understand about their sister's or brother's condition. Often, hospital staff can aid in these discussions

- Discuss the plans for treatment and possible side effects their sibling might face. Prepare siblings for changes in appearance including hair loss and changes in weight. Talking about these changes ahead of time help to reduce fear for the siblings.

- Using the correct terms—*brain tumor* or *cancer*—will be helpful, because avoiding the terms can make the subject taboo. Often children's fantasies about what might be happening are more frightening to them than basic descriptions of reality.

- Assure siblings that they are in no way responsible for the tumor—and that cancer isn't contagious.

- Explain that the doctors don't know all the answers but that everyone is doing whatever he or she can to help their sick brother or sister.

- Set limits! During this period, your children may challenge whatever limits you try to set. Although a tendency to let them bend the rules is natural, leniency

may actually make a child more anxious and imagine that things are worse than they actually are.

- Take them to the hospital to visit or to the clinic during treatment, if you can. Be sure to find out what the minimum visitation age is at your child's hospital.

- Involving siblings in the care of the ill child can help them to feel useful, but keep tasks age appropriate. Younger children may want to bring a favorite toy to a sibling while older children may want to do more for the family, such as cooking a meal or cleaning.

> Dad told us that nothing we did or thought or said made my sister sick. He told us no one knows how or why people get brain tumors. He said a brain tumor is a serious illness, not like a cold, and it would need a lot of treatment to make it go away.

- Set aside time to spend with each sibling, as you are able.

- Encourage them to become involved in outside activities, and make a point of recognizing their accomplishments, rewarding them with praise, plenty of extra hugs, and thank-yous.

- Listening to them can ease feelings that their needs are being ignored because they're not sick.

- Don't hesitate to enlist the help of friends or relatives to transport them to their usual activities or just get them out of the house for some fun.

> Close friends watching my brother offered my parents opportunities to stay with me in the hospital night and day as well as during chemotherapy treatments.

Remember to alert teachers to what's going on at home—the family health crisis may make it difficult for siblings to keep up in school. It also may make a cooperative child unruly or a talkative one silent in class; behavior changes in the siblings of children with cancer are the rule rather than the exception. Let the teacher know when you see signs that may signal emotional upset. Ask the teacher to let you know if there are any problems with schoolwork or in the classroom. Be sure to keep the lines of communication open.

Fortunately most school-aged children don't know many people with brain tumors or cancer. Unfortunately, for this reason they know little about it as well and misconceptions are easily formed by children about a brain tumor and its symptoms.

> Not long after I was first diagnosed, in my brother's first grade class, one of his friends stood up and said he heard I was going to die. My brother stood up and set him straight and here I am 13 years later.

Most important, share your feelings with both your sick and healthy children. Letting them know that you, too, are concerned or sad or discouraged will make it easier for them to express their fears.

Nutrition

Good nutrition is an important part of your child's treatment. Try to deviate as little as possible from your child's normal diet. Your child's body needs to heal and gain strength in order to resume normal activities and undergo any treatments that may be planned.

Changes in or difficulties with nutrition can occur in children with tumors. After surgery, children may experience temporary nausea and vomiting simply from the procedure itself. Taking steroids can cause a dramatic increase in appetite. Children undergoing radiation therapy or chemotherapy often develop irregular eating patterns, nausea or complain their foods taste metallic, too salty, too sweet, or even have no taste. They may lose their appetite, have a feeling of fullness, or have diarrhea, cramps, constipation, or dry and/or sore throat or mouth. Cancer can place extra nutritional demands on the body and change how nutrients are used.

If any of these changes cause your child continuous appetite problems, call your child's doctor or nurse. They may prescribe antinausea medications (Zofran, for example). At this point, the heath care professional may arrange an appointment with a dietitian, who will become a member of your child's health care team. Nutritional supplements are occasionally recommended, but the best approach is usually a well-balanced diet worked out with an experienced dietitian to fit your child's needs and tastes.

When your child isn't eating well, you're less likely to overreact if you understand that there will be "off" eating days. Appetite will probably improve over time, and an "on" day is an opportunity for you to increase the nutritional value of the foods

you're preparing. Food is closely tied to emotions, so try to avoid confrontations over meals.

Some alternative treatments include special strict diets for which healing claims are made. Remember that eating favorite foods may be the only way to provide nutrition and pleasure during this time. Children may especially need the calories and protein that are forbidden by alternative treatments. Be sure to check with your child's doctor or nurse before giving your child vitamins, herbs, alternative supplements, or starting a new diet regimen. Certain compounds can interfere with cancer treatment and can cause harm.

Changes in Physical Appearance

For children (especially teenagers), self-esteem and self-confidence are often closely related to physical appearance. Changes in appearance may lead to an altered self-image. A common side effect of chemotherapy and radiation therapy is hair loss, which will occur in varying degrees from child to child and treatment to treatment. For the minority of children who receive whole-brain radiation, hair loss can be permanent. Although bald patches around surgical scars may attract unwanted stares or questions, the hair will usually grow back. Scars while more permanent, may in time come to symbolize healing or cure. To a child, the time it takes for hair to grow is likely to seem 10 times longer than it would to an adult.

Talk with your child about hair loss and how he/she would like to manage it. If they are interested in a wig, consider buying a wig after surgery but before any treatment begins, so that you can match your child's hair color. Check with your child's social worker for a list of local wig salons that cater to pediatric cancer

patients and some of the national groups that provide free wigs. You can also refer to Chapter 11 ("Resources") to find resources that offer these services. Insurance plans often reimburse for wigs, if a prescription is submitted. The prescription should read: Cranial prosthesis. Many children prefer instead to wear a baseball hat, bandana, or other colorful headgear.

> Talking with other brain tumor patients gave me a sense of acceptance and wellness as I moved along with my treatment.

> I have found, as a survivor, the importance of support groups and even chat rooms for those in treatment and even survivors. It is a vital coping tool to have these contacts so survivors and patients can feel connected. It is much easier, sometimes, to express certain feelings to someone who has been in your shoes or at least a similar predicament.

Taking steroids can cause children to gain weight and to have a puffy "moon" face and acne. You may want to talk about these changes ahead of time so that your child understands what to expect. These changes in appearance disappear once the steroids are stopped. Reassure your child (and yourself) that this look is temporary.

Again, allow your child to express concerns, anxieties, fears, and frustrations. Show him or her that you accept any physical changes, even if they are more upsetting to you than to

your child. Humor can be useful in talking about these changes and in encouraging conversation between your child and his or her peers. Your child's peers need to understand that your child is still the same person inside. It might also help for your child to meet and talk with other children who are experiencing similar problems.

Parents, Marriage, and Family

The tasks, obligations, and emotions related to having a child with a serious illness can strain even a strong marriage and family. If parents are divorced or separated, they will need to try to put their personal differences aside to help their child. Single parents may need even more support from the community and outside sources.

By now, you might have seen a few changes in your family relationships. Anticipate, expect, and accept that role changes will occur. Who does what in the family may change, and these new jobs may have to be negotiated. For example, who is the caregiver and who is the breadwinner may change, especially when health insurance is tied to employment status. No single role is more important than the other. Each job is needed for the family to function as a whole. Respect and accept your partner for what he or she does. It may help to include each other and other family members in everyday care of your child.

Everyone copes in a different way. There is no right way of coping with a child's serious illness. Try to recognize, accept, and honor your partner's style of coping even if it is different from yours. Some people need to talk. Others prefer introspection and quiet. Make time for yourselves as a couple, even if it's just 10

minutes a day. You can share feelings and maintain a relationship as partners.

Here are some suggestions to help you adapt and develop your coping skills:

- Gather information. Knowledge is critical to accessing expert care and ensuring quality of life. There will be less mystery, and you may gain a sense of having more control.
- Seek counseling when needed. Having a child with a serious illness can magnify other problems that were occurring prior to the diagnosis.
- Practice relaxation techniques such as deep breathing, meditation, and imagery.
- Work on and use your sense of humor. Studies show that laughter releases stress and improves the immune system.
- Expect that there will be stressful times. Anxiety is normal under the circumstances.
- Prioritize your worries. Although it is natural to focus on smaller, less frightening annoyances, save your energy for the big things.
- Write your feelings in a journal and let your partner read what you are feeling. Emotions can be less overwhelming and more easily understood when written, rather than shared “in the heat of the moment.”
- See chapter 8, “Support and Services in the Community,” for more information.

CHAPTER

5

During and After Treatment

Helpful Hints for Hospitalizations

Depending on what type of brain tumor your child has, you may be experiencing long hospital stays. A hospital environment can seem intimidating at first, but we hope the hints we provide here will help you and your child feel more comfortable. Don't hesitate to express any concerns, ask questions, or encourage your child to ask his or her own questions—children old enough to think of a question are probably old enough to ask it themselves. Information will give both of you a sense of control. Loss of control is often a big issue for children and teens while in the hospital, as their independence and freedom are significantly diminished. If you do not understand something, ask for further explanation until you do understand. Ask your team where additional literature is available.

When talking to your children giving correct, honest, and age-appropriate information about the diagnosis and how it will be treated will help with your children's adjustment. Honest communication with your children will serve your family well not only during hospital admissions but also throughout the entire treatment. Children may sense there is more going on and

make up explanations in their own minds. It is important to remember that young children will not demonstrate the same intellectual awareness or emotional reactions to events as adolescents or adults will. When you are able to, it may be beneficial to prepare your children in advance of upcoming hospitalizations. During hospitalizations, you may find it useful to connect with the hospital social worker, who is skilled at helping parents sort out their own feelings and finding appropriate ways to communicate with children.

> Knowing a few days ahead of time when it was time to return to the hospital for treatment or check-ups gave me time to prepare mentally and physically, and made me feel more comfortable with the return visits. In case of unanticipated hospital visits, my mom would let me know everything was okay and that I did not need to worry. She let me know that I just needed to be careful and let the doctors check me out.

Play is a wonderful outlet for children's fears and anxieties. "Medical play" with stuffed animals or dolls can help children learn about their own procedures and surgeries as well as provide a healthy outlet for frustration, anger, and anxiety. Medical play or directed play can be used educationally to demonstrate exactly what is going to happen. Because a lot of your child's anxiety currently is medical, you can use stories to direct his or her play and bring out what is on your child's mind. This will also give you insight into your child's worries, fears, and concerns. For example, a child may develop a unique relationship with a doll that has a brain tumor "just like I do." Drawing pictures or playing with medical equipment (safe, not

sharp or dangerous!) provided by the hospital staff can help relieve anxiety and fear and enable your child to express his or her understanding of what is happening. Providing a creative outlet for your child, of whatever age, can be very helpful. Videos and books may help to explain things to older children. Ask the hospital child life specialist to guide you in selecting helpful tools.

More Specific Hints:

- Ask for flexible visiting hours for parents.
- Ask what accommodations the hospital provides for parents staying overnight, such as recliner chair-beds, toiletries, bathing facilities for caregivers, laundry facilities, meals for parents, and available refrigerator space.
- Take a proactive role in your child's care by assisting with toileting, bathing, and eating. However, be aware that sometimes it may be necessary for you to step aside and let the nurse assist with these functions.
- Request that painful procedures be done in the treatment room if possible. Children need to have places where they feel safe, so pain should not be a part of their experience in their room or in the playroom.
- Take advantage of times when you can take a break, because both your mental health and your physical health are very important to your child's care. Identify a few friends and family members whom your child knows and feels comfortable with and whom you trust can be an important support, especially during extended hospital stays.

- Access hospital services that help children with adjusting to the hospital environment, their illness, and separation from their usual daily routines. Use the services of child life specialists and visit the playroom so your child can socialize with other children. Play can decrease fear and anxiety, which makes coping with feelings about medical procedures, hospital equipment, and personnel easier.
- Try to maintain some sense of connection to your child's school and peer group. Often school's will set up a hospital visit or send video messages between classmates and your child. Hospital-based teachers are available to help your child with schoolwork during extended hospital stays.
- Many hospitals now provide complementary medicine services such as yoga, massage therapy, mediation/guided imagery, music therapy, and Reiki, which promote wellness and relaxation. Ask your child's nurse whether these services are available at your hospital.
- If your child is confined to bed, arrange for a child life specialist to visit and bring activities to the bedside. Volunteers may also be available for reading, playing, or just for company.
- Check to see if there is a refrigerator in which you can store some of your child's favorite foods and snacks. Ask if your child can go to the cafeteria and choose his or her own meals.
- Try to arrange for your child to wear his or her own clothes as much as possible. Clearly label belongings with your child's last name, using permanent ink. Ask staff members if there is a washer and dryer available for your use.

- Try to arrange for treatments and procedures to be scheduled so your child has time to rest and be refreshed before visitors are expected.
- Inform visitors about the best time of day to visit. Some children feel better in the morning others, in the afternoon.
- Encourage family and friends to visit your child for brief visits for your child may require quiet time for their well-being and healing.
- Try to keep your child's daily routine as consistent as possible during the hospital stay. This can prove extremely reassuring to everyone and is particularly important for the youngest patients.
- If your child has a radio, iPod, DVD player, or laptop computer, bring it to the hospital (with earphones). Many institutions have portable stereos and CD players as well as DVDs and video games for patient use. Favorite videos, games, and music can be comforting.
- Bring things from home to make the hospital room more like your child's own room: stuffed animals, books, a blanket or comforter, family photos, posters, and so on. Items from home can be very comforting and make the hospital room more personal and cozy.
- Find out if there is a children's library or reading room in the hospital.
- Remember that members of your child's health care team are available to you and your family to answer any questions and provide support.
- Consider arranging for your child to talk with a hospital social worker or psychologist without your being present.

Even young children try to protect their parents from their fears.

- Encourage your child to keep in touch with friends and classmates while absent from school. It is also important that your child go back to school as soon as possible. This delivers an important message: "Despite the illness, I'm still a normal child with outside friends, interests, and responsibilities."

Neurosurgery

Your child's neurosurgeon will go over the precise details of what will take place during your child's surgery. It is important that you clearly understand what is going to take place. Not only are you going to be asked to give informed consent by signing the papers that give the surgeon permission to operate, but you are also going to need to understand for yourself and your child what will take place. By giving consent, you acknowledge that everything has been explained to you—and that you understand it. Preparing your child to undergo surgery can truly help with their adjustment after the operation, child life specialists are often available to help with surgery preparations.

Children often pick up information from overhearing parents and family members talking. Therefore, however young your child is, it is a good idea to discuss the surgery with him or her. It will help prepare your child for surgery if you explain what is going to happen in terms that are age-appropriate and understandable. You may want to utilize Children's Brain Tumor Foundation's *Parker's Brain Storm*, a children's book designed to explain brain tumor surgery to the youngest children. Children can become overwhelmed and anxious if they are given either too much

detailed information or too little information about a procedure or operation. It is also wise to address your child's questions and concerns. This allows less room for your child's vivid imagination to fill in the blanks. The hospital's child life specialist and social worker are trained to help you find good ways to talk with your child about surgery.

> It helped me when my parents told me that I would be going through a tough, demanding time but that my diagnosis and treatment was something that my parents and I would go through together, and that even though it would be hard, we would be stronger if we worked together.

Encourage your child to ask questions of the neurosurgeon, anesthesiologist, and nurses. Your child's concerns may be more immediate and very different from yours. You may ask about the length of surgery or technical procedures, but your child may be concerned with how he will feel when he awakens after surgery or how soon afterward he can eat. Children also tend to be much more straightforward than most adults are and may have surprising questions such as "What does a brain feel like?" for the neurosurgeon.

The length of the surgery itself is impossible to predict. Operating-room schedules can change because of emergencies. Because preoperative scans do not always accurately predict what the surgeon will find, the operation often feels additionally stressful for parents. You can inquire if you may bring your child into the operating room and wait until they have been sedated before leaving them. Once your child's surgery has begun, there

is usually a special waiting room where you can stay. Ask if you will be provided with surgical updates, often given by a nurse who comes to the waiting area, throughout your child's operation. Generally, the surgeon will meet you afterward and explain in detail what was done. Specific medical terms related to your child's particular operation will be explained by the doctor (and may be defined in the Glossary in this book). Although the type of tumor may be recognized by the doctor during surgery, the exact pathology cannot be determined until a tumor sample is sent to a lab for identification. It may take up to a week to get the pathology results; however, the surgeon may get a verbal preliminary report sooner.

After surgery, your child will probably be kept in the recovery room until the anesthesia wears off. You might want to inquire prior to surgery if you will be able to go into the recovery room to be with your child. Many institutions prefer that one or both parents be at the child's bedside when the child wakes after surgery. This can ease a child's fears and simply make him or her more comfortable. From the recovery room, the child is then usually moved to the pediatric intensive-care unit (PICU) or neurosurgical floor for precise monitoring.

It might be upsetting for you and your family to see IV tubes, drainage tubes, and machines attached to your child, but you can be a reassuring presence simply by talking to and touching your child. If you have questions about procedures or equipment (such as neurological checkups, follow-up scans, a catheter, sutures, hair removal, or bandages), *ask*! Right after surgery, some of your child's symptoms may be temporarily worse than before, because of swelling or the trauma of surgery. Nevertheless, remember that children can be amazingly resilient and that the healing process usually begins immediately.

If You Travel for Your Child's Treatment

Occasionally children must travel great distances to receive appropriate, specialized medical care. There are many resources that may be able to help you locate and utilize these services. You can find a full list in Chapter 11 ("Resources") of this guide.

Air Transportation

Many airlines have courtesy fares for a child and accompanying parent. Social workers may assist you and provide this information, but it may be helpful to contact each individual airline yourself. Remember to be persistent! It may be the supervisor of the supervisor who finally provides you with the details for a free flight. See Chapter 11 ("Resources") for flight resources

Lodging

Hotels

If you need to plan for accommodations, speak to the social worker or visitor services department at the hospital where you need to be. Some hotel chains provide rooms to a family at no charge if a child must go into the hospital for an early-morning or overnight procedure. Local hotels may give discount rates or provide guest rooms through the American Cancer Society. Your treatment centers website may offer local lodging resources as well.

Non-profit Housing

Being close to your child will no doubt be very important to you and will enable you to cope with your situation more easily. There are a growing number of national temporary housing facilities for families of children with life-threatening illnesses who are hospitalized far from home, including Ronald McDonald House. If you have to travel more than 2 or 3 hours to and from your medical facility, consider staying at non-profit housing like Ronald McDonald House.

Families may stay together and live in a comfortable home-away-from-home environment while their child is being treated. Families benefit from emotional support from staff members and volunteers as well as from other families who face similar situations. Your child will take comfort from knowing you are nearby.

There is usually a nominal fee for this housing, based on a family's ability to pay. Always ask if the fee is mandatory or if it can be waived. Non-profit housing resources are listed in Chapter 11 ("Resources"). Reservations should be made several weeks in advance by your child's pediatric social worker, however this is not always possible.

GOING HOME

Preparation and Transition

Going home can be exciting and joyous for the whole family. It can also be a hectic, fearful, and anxiety-filled period. Both you and your child may feel apprehensive when leaving the security of familiar doctors and nurses, even though they are only a phone call away. All of these emotions are normal responses to being discharged from the hospital.

The social work department of the hospital—or, in some cases, the nursing staff—can help you plan for your child's discharge home. If home care or other services are needed, advance coordination can ease the transition from hospital to home. If there is any medical equipment your child will need to have at home, the social worker or nursing staff will make the arrangements. Many times the medical equipment provider will offer training prior to leaving the hospital for your knowledge and comfort.

You want the transition to go as smoothly as possible. The days ahead of you may be filled with stressful moments. Schedules may need to be rearranged to accommodate clinic visits. Family members may be separated and siblings may feel neglected. In addition, everyone in the family may be feeling worried or tense.

> My brother and sister were very worried about me when I was going through treatment. My parents helped them feel less stressed by telling them honestly what was happening with me at the hospital. The hospital would not let my brother or sister visit me while I was an inpatient, which was hard for all of us.

It is important to continue life as normally as possible, yet under these circumstances, it is bound to be difficult. Your child needs to get back to some semblance of normal daily life. Whatever changes their condition may have produced in their lives, children with brain tumors still have the same social needs they had before their tumor was diagnosed, including maintaining social relationships with friends, attending school as often as possible, and being involved in their favorite activities.

Your encouragement and support in reestablishing such normal daily routines will really help. Overprotecting your child might send your child the message that you think he or she cannot handle a normal routine, whether emotionally or physically. This can create more distress in the long run. Treating your child as if she is fragile might keep her away from situations that provide opportunities to grow and develop normally. Sometimes when a family is going through such a stressful situation, it can be difficult for parents to determine what information or emotional support the child needs. Trying to find the right balance between protecting children and sharing information can be particularly tricky.

> We used a 'lights out' ritual for our family that was a routine time before bedtime that was open for any questions our children had. It helped us understand what was weighing on our children's minds each day, and we found they appreciated being in control of the conversation. This technique was especially helpful for the siblings who had lots of questions and felt pretty isolated from their brother's treatment. Sometimes the questions were very difficult for us to answer, but we felt it was okay to say we did not know the answer and we would get the answer from our son's doctor.

Consider connecting with a group of parents who are going through (or have been through) experiences similar to yours and your family's. Children's Brain Tumor Foundation has a *Family to Family (F2F) Program* that connects families sharing a similar experience across the nation. Resource organizations are listed within Chapter 11 of this book to connect you with groups that offer invaluable support, experience, and information.

Preparing to Leave the Hospital

It will help if you discuss ahead of time with your child's doctors what signs and symptoms you might normally expect to see during your child's recovery period. Keep this information with your other notes. Collect prescriptions for all medications you might possibly need. Ask the doctor what complications may occur. Discuss ahead of time what constitutes an emergency. Know how to reach all members of your child's health care team during and after office hours. Keep these important phone numbers with you at all times and make sure they are accessible to anyone caring for your child in your absence. Know where to take your child if an emergency occurs.

When to Call Your Child's Doctors

A parent's intuition is wonderfully reliable, so please call the doctor if you sense that your child's condition has changed or worsened; some situations can be life threatening. Report any obvious physical or behavioral changes even if the symptoms do not match any that have previously been highlighted by your child's medical team. Put aside such considerations as not wanting to bother the doctor, thinking your problem may have no urgency or waiting until morning. You know your child best, so do not hesitate to call medical professionals when you need answers

or notice an unexpected symptom. Sometimes the nurse will be easier to reach than the doctor and have more time to answer your questions.

You may never again take casually your child's complaints about a headache or dizziness. Nevertheless, common sense and basic medical knowledge will help you decide what to do. When in doubt, *call*!

Medical Expenses, Insurance, and Financial Assistance

Bills add up rapidly. Even if you have good insurance coverage, there will be nonmedical expenses such as phone calls, extra gas, tolls, meals away from home, childcare, and lost wages. (Keep receipts—some of these expenses may be tax deductible.) It will be important that you receive all the financial aid and insurance benefits that you are entitled.

Advice for Dealing with Your Insurance Company

- Educate yourself. Know about your child's illness and why referrals to specialists are needed. You will sound knowledgeable and thus will be more likely to quickly get the assistance you need.
- Get a copy of your policy and review it carefully. See exactly what services are covered and how the payment system works. See about purchasing additional coverage now, before it may be needed.
- Ask for a case manager at the insurance company who will always handle your case and answer questions. Ideally you will find someone who is sympathetic to your case and time

constraints. Do not waste time on someone who is not helpful or is uncooperative. Ask for a supervisor.

- Document every phone call. Write down the name of the person you speak to, the date and time, and the topic discussed.
- Fill out every form completely. Payment may be delayed or denied if the required information is missing. You may want to mail claims "return receipt requested" to ensure that someone of authority will have to sign for it.
- Many insurance plans and health maintenance organizations (HMOs) require that specialized tests, procedures, and treatments be pre-approved and authorized by a primary care provider (usually the pediatrician or doctor who provides routine medical care). You may need this authorization when you call to make an appointment with a specialist.
- Develop a good working relationship with the office staff of your child's primary care physician because authorizations must come from there. Try to personally meet the person who will be handling these and discuss the whole case with him or her.
- Keep a copy of every authorization you ever get! Follow up on authorizations and never assume that they are being handled. Consider telling specialists that you will get the necessary authorizations yourself. This may save money and problems later, because you are ultimately responsible for the bills.
- Sometimes the referral process to specialists or therapies is slow. You may have to emphasize the serious nature of your child's illness to get an earlier appointment or referral.

- Do not wait for someone at the doctor's office or insurance company to call you back. (Staff members can get busy. They may forget. It isn't their child.) Call back—every day if necessary. It's possible to be both persistent and polite (even though you may feel otherwise after spending hours on hold).
- You have a right to ask questions and to demand the best care for your child. Occasionally you may have to file appeals and grievances to obtain this care. Ask your child's doctor to help explain complicated situations to the insurance company. You may get help from your state legislator to intervene with your insurance company so that your child can get the service for which you are paying insurance premiums.
- *Be patient yet ever persistent with these companies!*

Financial Assistance

The pediatric social worker is a key member of your child's health care team. One of the things your social worker can do is to help you explore sources of financial aid for which your child or family may be eligible. The hospital financial office may also be able to help you make credit arrangements or see if you qualify for public or private sources of financial assistance. It's best to apply immediately, because *processing can take weeks*.

The following is a partial list of sources of financial and employment assistance:

Medicaid: Medicaid is a government program that provides insurance for low-income patients. Entitlements vary among states. Contact your local Department of Human Services or

Department of Public Assistance to find out whether your family is eligible and how to apply.

Supplemental Security Income: The Supplemental Security Income (SSI) program may provide some income for a child who is ill or has a disabling condition. Qualification is based on the parent's income. SSI will also entitle your child to Medicaid. Check with your local Social Security Administration office for an application. The federal telephone number is 800-772-1213.

State Catastrophic Illness Coverage: State insurance may be available if your private insurance plan does not include catastrophic coverage. Ask the social worker to help you find out if your state has this program. For additional information about financial assistance, see Chapter 11 (" Resources").

Family Medical Leave Act: Enacted in 1993, the Family Medical Leave Act (FMLA) requires employers to continue to provide health insurance coverage to an employee on medical leave for up to 12 weeks. This means that a parent of a child with a brain tumor can take up to 12 weeks of paid or unpaid (at the discretion of your employer) leave within a 12-month period. An employee who uses FMLA is guaranteed his or her job or equivalent job at equal pay and benefits level.

Follow-Up Treatment and Rehabilitation

Your child will probably be making regularly scheduled return visits to the neurosurgeon or other specialists to follow up on his or her progress. Your child may also need to return to the hospital for radiation therapy or chemotherapy as an outpatient. Professionals affiliated with support services may be monitoring you at home to provide help, but there are still other experts who

may have to be consulted. As you try to reestablish normal life, be aware that your child's health may have to be monitored for a very long time, by specialists such as these:

Neuroradiologist: One way that doctors monitor the effectiveness of your child's treatment is to conduct magnetic resonance imaging (MRI) or computed tomography (CT) scans at scheduled intervals. Everyone wants to make sure that the treatment did what it was supposed to do and that the tumor is not growing back. Always have previous scans available to the neuroradiologist, who is the physician who orders scans, so that they can be compared with the most recent one.

It is natural for parents and children to be anxious at these times. Watchful waiting can become intense. The results of these tests may even be uncertain. For example, it can be difficult or impossible to distinguish recurrent tumor from scar tissue. When doctors are in doubt, they will wait to do another scan or seek other opinions. Newer, more accurate diagnostic imaging techniques (such as functional MRI [fMRI], single-photon emission tomography [SPECT], and positron emission tomography [PET] scans) are available. Unclear reports do not necessarily mean disaster!

> I had been having several unclear MRI scans that were of definite concern to my doctors as well as my parents. After having my first PET scan, which was fairly new and out of state at the time, it was clear that this was merely scar tissue at the old tumor site and not a recurrence. Those unclear scans caused quite and uprising at my house, yet turned out to be nothing of concern.

The question "What if . . ." may always be lurking. Even a child whose medical situation is stable will need to be monitored when treatment stops and permanent remissions become cures.

Rehabilitation Therapist: Either the tumor itself or the effects of surgery or treatments may cause impairments in the use of arms or legs, in coordination, or in swallowing. Communication difficulties (language, speech, or understanding) may also occur. Some of these effects may be temporary, or other areas of the brain may take over that function. However, your child may need professional therapy to become as active and independent as possible. **Physical**, **occupational**, or **speech therapists** may help restore lost abilities. Children under the age of 3 years may benefit from an early intervention evaluation. (See Chapter 6, "Education," for further information.)

***Physiatrist*:** (or rehabilitation doctor) A specialist who can evaluate your child and make recommendations for a specific type of rehabilitation therapy. Physical therapists use motion and exercise to improve strength and movement. Occupational therapists evaluate and treat difficulties related to self-care and daily living. They can help develop new ways of doing things like getting dressed or eating, using special equipment if necessary. Children can have therapy as an outpatient, or occasionally a child will benefit from an inpatient intensive rehabilitation program. Therapy also can be delivered at home. The family may get involved in helping implement a rehabilitation program. Some therapies will also be built into a child's education plan.

Neuroendocrinologist: The pituitary, thyroid, and hypothalamus are glands in the brain that secrete hormones that control metabolism, growth, and sexual development. Sometimes

treatment for a brain tumor can alter their function and lead to medical problems, such as diabetes insipidus, early or delayed puberty, and growth problems. A doctor who specializes in endocrinology will be able to monitor the possible effects of surgery, radiation therapy, or chemotherapy on these glands with blood tests and growth charts. Your child's primary care physician typically will observe your child for normal growth and development. If there is a problem, your child can be referred to a specialist.

Pediatric Neurologist: A neurologist is an expert in diagnosing and treating disorders and diseases of the brain and spinal cord. Deficits and changes in your child's abilities or functioning can be identified, and new problems may be detected early. A pediatric neurologist typically checks reflexes, coordination, and the ability to perform fine motor skills, among other things. The findings of these tests will help assess the need for rehabilitative treatment and enable you to seek out other specialists, if needed.

Pediatric Neuro-oncologist or Oncologist: Pediatric neuro-oncologists and oncologists are pediatricians with specialized training in oncology or neuro-oncology (cancer as it relates to the brain and spine). They are uniquely trained to diagnose, treat, and monitor children with brain and spinal cord tumors. Often such an individual will coordinate your child's care, discussing treatment options with neurosurgeons and radiation oncologists. They often work with Children's Oncology Group (COG) institutions and thus have access to state-of-the-art therapies and national trials. In most instances, a clinical trial will be available for your child's disease. If not, your child's oncologist is likely to plan therapy on the basis of findings from earlier clinical trials.

As pediatricians, these physicians are attuned to normal childhood development and diseases. This background, along with extensive knowledge of cancer therapy, allows them to provide information about likely side effects of treatment (particularly as it relates to your child's developmental status) and to guide you to other subspecialists as needed. A number of major pediatric institutions have long-term follow-up programs for brain tumor survivors. The doctors who run these programs usually focus on screening and treating problems that may arise years after treatment has ended.

Pediatric Neuropsychologist: Treatment of a brain tumor in children may produce either short-term or long-term problems with learning and behavior. Because some problems become evident only as the child grows older, repeated neuropsychological testing (every two years) is essential to monitor progress and obtain appropriate assistance. Testing should be performed by a psychologist who is knowledgeable about pediatric brain tumors; a neuropsychologist will have additional training related to how diseases and treatments of the brain and central nervous system (CNS) affect psychological function.

Ideally, you should have your child tested prior to beginning any chemotherapy or radiation therapy, to provide the psychologist with a baseline. Some treatment protocols specify that testing be done at certain times. Otherwise, you, as your child's advocate, may have to push for this testing to be done and to be covered by insurance.

Results of these tests will be useful if you need to develop an individualized education plan (IEP) or 504 plan with your child's school. The pediatric neuropsychologist will be able to help with school issues and can also be an advocate for your

child. Remember, not all children will require school accommodations.

Pediatric Psychologist: Pediatric psychologists are trained to deal with the emotional and behavioral aspects of physical health. They can help with pain management, eating or sleeping problems, and social adjustment. For example, feelings such as grief and depression can often surface in a child who has a serious illness and should not necessarily be considered serious emotional problems. Misbehavior and even family difficulties can be normal reactions to the reality of the situation. These problems are common enough (during treatment and in the years that follow) that parents should take steps to lessen or prevent their effects. It is best to seek out a psychologist familiar with these kinds of situations.

Pediatric Oncology Nurse Practitioner/Specialist and Physician's Assistant: Pediatric oncology nurse practitioners and physician's assistants are highly trained health care team members who often work directly with your child's doctor and can be a wonderful resource for you. Both nurse practitioners and physician's assistants can help with medical procedures, including physical exams, under the supervision of a doctor. They often are the medical professionals who can simplify some of the medical jargon for you and coordinate the many tests and procedures your child will undergo.

Pediatric Oncology Social Worker: Pediatric oncology social work as a specialty discipline is committed to enhancing the emotional and physical well-being of children with cancer and their families. Practice is based upon a unique body of knowledge and expertise in the areas of bio-psychosocial care and the impact of life-threatening illness on normal child development and family life.

A pediatric oncology social worker can have many roles: provide support, counseling, education, and referrals to community resources, as well as act as case manager for children with brain tumors and their families. Pediatric oncology social workers help families manage day-to-day challenges associated with a brain tumor diagnosis and its treatment.

CHAPTER

6

EDUCATION

The location of a tumor and the treatment received can effect cognitive and/or sensory functions, and may result in temporary or permanent learning difficulties. Neurocognitive impairment may be acute and occur during the time of active treatment with recovery of function after the discontinuation of treatment. A common example in children is the loss of motor speed and coordination that occurs when receiving vincristine, a problem that usually lessens or resolves after treatment is completed. Neurocognitive impairment is also associated with long-term learning and functional problems that emerge long after treatment is completed, such as persistent memory, processing speed, attention, and academic skill deficits (Armstrong,D., Goldman,M., Sulc, W., Thompson, W., Cuadra, A. 2010). Changes in the way your child learns may be subtle and may become more noticeable as your child ages and more complex thinking is required. This chapter starts with returning to school and begins to touch on the cognitive effects which may be experienced. Testing specific to the needs of brain tumor survivors and yearly meetings with the school around your child's educational needs will assist in assuring he/she reaches his/her full academic potential.

> Don't rely on school system testing/evaluations. Get your own by independent evaluators and get them updated regularly.

Returning to School

In addition to education, children and adolescents receive a sense of identity and peer support from school. Long absences, changes in appearance, and changes in educational abilities can effect self-esteem, create depression and anxiety, and lead to frustration. The return to school helps to create a sense of "back to normal". Therefore, despite your concerns including exposure to germs or fear your child will be teased, returning to school as soon as possible is important. While your child is in the hospital, she should keep up with her schoolwork. States differ in their laws related to homeschooling during hospitalizations, but all states have provisions to assure their education continues. During treatment, ask the healthcare team about an estimated date your child can return, even if it is only for partial days. Many hospitals have an education coordinator or social worker who can help you with this.

Many children can continue to attend school while they are in treatment. However, they may be at risk for emotional and other educational problems. Providing open communication with the school and classmates will assist in clearing up some of the brain tumor misconceptions which they may have and help them gain an understanding of your child. If informed, teachers can deal successfully with challenges (e.g., self-image, relationships with peers) as they arise.

Before your child returns to school, you need to begin the communication process. Make sure the principal and other people involved with your child know your child's diagnosis, treatment and the effects of each. Ask the school who the primary contact person should be and plan a visit to discuss your child, his challenges, and

what his educational and social goals should be. Once this person is armed with knowledge of your child's illness and has created a plan with you, he can better update your child's teachers and the school nurse with medical updates. The more knowledgeable and familiar the school is with all aspects of your child's treatment and its impact, the more the school environment can be adapted to your child's special needs.

> The school my child attended did not permit students in the upper school to wear hats in class. They decided to make an exception only for him but failed to understand how extending the exception to all the students would have made my child feel a lot less awkward and different from his peers. The school believed they were accommodating my son but in actuality they were only further fostering the feelings of alienation he was feeling.

When your child returns to school, you want him or her to be treated as normally as possible. You will need the cooperation of both the school and the health care professionals working with your child. It is also important to remember your child may be afraid to return to school. Appearance changes and changes in learning and physical abilities make your child "different". Finding acceptance and understanding may be difficult. Look for changes in behavior and school performance as well as changes in peer relationships.

Ask your child's medical team for a hospital-school liaison who will provide ongoing information about medical/psychological issues to the school. Many hospitals

and schools have a return to school program. If they do not have a specific person, you may want to talk to your social worker and child life specialist about working with the school and classmates. The liaison can meet with you and your family and determine what is needed to return to school, help educate the school about your child's needs, and provide any written materials you may need. Additional support may be found through community based programs such as CBTF who have advocates with expertise in the educational needs of brain tumor patients and survivors.

Before your child returns to school, set up a meeting with your liaison and your child's educational team. This will include at least your child's teacher, school nurse, counselor and principal. This meeting will give you an opportunity to discuss any special requests or concerns you might have. Make sure to include a health care professional familiar with brain tumors. Here is a list of things you will want to make sure the school is aware of:

- Any medications your child needs to take (including time and how to give them)
- Any special devices the child will use and how to use them
- If your child has a port, central line or shunt, the school should be aware of it and know the warning signs of a developing problem
- Potential of seizures (if this is a concern)
- What may be a medical problem and what is not a medical problem

- How to handle any emergency including who to contact first
- Allergies, medicines or treatments your child can not have
- Medical contact numbers
- Social/behavioral issues
- Physical disabilities such as hearing loss, eye/hand coordination

To make the transition back to school an easy one, a school representative and/or your hospital liaison should be encouraged to prepare classmates by providing them with information about brain tumors and treatment, and answering any questions they may have. Pediatric brain tumor diagnoses are rare, so most people will have no brain tumor knowledge and may have many misconceptions. Let the teachers and classmates know what has changed and what hasn't changed. Explain what to expect, for example if your child now loses his balance or if her vision has changed, inform her classmates. Give them an opportunity to express their concerns and feelings. It is important to communicate to other students that brain tumors are not contagious, they do not make you less intelligent, and that radiation treatments do not make a child glow in the dark. The question of death may arise, and if it doesn't it will probably come up after you leave. You should think about how you are going to answer this question and can rely on the liaison to assist you. You may want to talk to your child about how involved he wants to be in the classroom presentation. It is very difficult for children to feel they are different from their peers. Letting them have some control over what is shared and what is not may help these feelings. The presentation may dispel misconceptions and encourage

acceptance. It is important during this transition time to check in regularly with your child not only about academic concerns, but about the relationships they are having with their classmates.

Fatigue and medical needs may warrant a slow, transitional phase. Perhaps attending only half-days, only having lunch, or going on a field trip with the class prior to a full-time return to school, can be helpful.

Things to Consider

Accommodations may be needed to meet physical changes, changes in the way your child learns, and potentially behavioral changes related to a brain tumor and its treatment. Cognitive changes will be discussed in the following section.

Some physical changes may include changes in vision, hearing, balance, and energy. Seating arrangements in the classroom may need to be adapted if your child experiences hearing or visual impairment. Classroom, playground, and gym accommodations may need to be made to assure your child's safety. If your child is experiencing fatigue, he may need playground or gym exemptions, a shortened school day, a locker closer to the classroom or an extra set of books at home to eliminate the need to carry them home. You may want to discuss modifying homework assignments with the classroom teacher. Medications, need for extra drinks throughout the day, and additional restroom breaks should all be addressed with the school. The hospital can assist with providing all needed documentation.

While these changes are necessary, the way in which they are implemented can assist in making your child feel more at

ease. No one wants to be singled out as the "brain tumor kid" or the one who receives special treatment.

Remember to keep an open line of communication with your child's school. While the school will be doing its best to make the necessary changes, they have probably had very limited experience with brain tumor patients. You should determine a regular meeting schedule and ask the school who your primary contact person should be. **The role the teacher plays is very significant to your child's developmental adjustment and recovery. Make technology your friend. Ask the teacher if you can establish a frequent email or texting relationship.**

During treatment or at times when your child's immune system may be compromised, **the teacher and/or school nurse must inform you of any communicable diseases** that any class member has contracted**,** such as chickenpox. If your child is still in treatment and has not had chickenpox, exposure to this virus can be dangerous and you should contact your physician immediately. (Chickenpox is worrisome primarily after chemotherapy; doctors rarely worry after radiation therapy.)

Cognitive and Emotional Changes and the Your Educational Rights

Recent studies suggest that childhood cancer survivors generally have similar high school graduation rates, but are more likely to require special education services than sibling comparison groups (Gurney, 2009). However, without the appropriate accommodations, the ability to meet academic potential is much lower. Brain tumor patients and survivors may face changes in their cognitive and physical abilities, as well as behavioral and emotional changes. Two thirds of brain tumor

survivors will have cognitive changes related to their tumor and its treatment. Cognitive changes in combination with physical changes, behavioral changes and changes in appearance such as hair loss or weight gain, may lead to teasing, bullying or social isolation. These situations may mean your child may now need academic accommodations and support. Many of these accommodations require the involvement of the special education department.

> I was lucky enough that as a senior in high school I merely needed the core requirements to graduate. I had missed half of my junior year and half of senior year. When I did finally transition back into school, I found that my greatest assets were the teachers and staff. I had an ISP set up due to physical learning problems, and they were there for me 100% of the way. If I had difficulty, I was able to work around it with their help. Their accommodations, support, and overall care were the reasons that I succeeded. I graduated in the top 15% of my class, and I can say that I owe my diploma to their efforts.

The first step is to identify whether there are special educational needs and what those needs are. To most effectively make a determination about learning changes and to give an accurate current picture of the student's abilities, a parent, a health care professional, or school personnel may request a neuropsychological evaluation. This testing is slightly different from the testing typically provided by the school system. The testing will look at the cognitive areas normally impacted by a

brain tumor as opposed to just evaluating IQ. The testing will diagnose your child's strengths and weaknesses and should assess attention and concentration, processing speed, visual-motor integration, fine motor speed, executive functioning and accuracy. It is important to provide the school with documentation as to the likelihood and type of learning challenges your child may face. A recent study found that less than 50% of recommendations from neuropsychological evaluations were implemented. The authors found that families need ongoing support and knowledge to implement the recommendations (Quillan, J. 2011). Because the recommendations may be difficult to interpret for both you and the school, you may want to work with an advocate who can help you and the school understand the recommendations. You can receive this documentation from the hospital neuropsychologist or by contacting CBTF. If you are trying to find an advocate a couple suggestions are:

- Check resources such as www.wrightslaw.com
- Ask other parents or the hospital social worker
- Contact the Protection & Advocacy organization for your state
- Check the Directory of Legal and Advocacy Resources

Cognitive changes may become more apparent as your child requires more advanced thinking. While cranial radiation may have a slight impact on IQ, this is not the primary academic challenge your child will face. Some of the common cognitive challenges faced by brain tumor survivors are:

- Difficulty paying attention
- Difficulty understanding and remembering visual information
- Reduction in processing speed.
- Problems planning and organizing
- Difficulty understanding what they read
- Difficulty adapting (affect, behavior and cognition) to changing demands of a complex environment
- Loss of memory

While your child may not be flunking classes, some observable changes may be:

- Going from an A student to a C student
- Increased hours spent completing of homework
- Increased frustration with school work and feelings of not understanding

If your child does have a physical, cognitive or emotional change which you believe requires some academic accommodations, you should schedule a meeting with the school psychologist or counselor to determine the best approach. Your child is protected by several federal laws which will assure she receives the necessary accommodations in the least restrictive setting. This means your child will continue in a classroom setting with non-impaired children whenever possible. Be sure to

provide the school with any neuropsychological testing from the start.

Certain federal laws require all public schools and some private schools to provide appropriate education and services to children with disabilities and special needs. The three main federal laws that apply to your child's school are the **Individuals With Disabilities Education Act** (**IDEA**) (http://idea.ed.gov/), **Section 504 of the Rehabilitation Act of 1973** (**Section 504**) (http://www2.ed.gov/about/offices/list/ocr/docs/edlite-FAPE504.html), and the **Americans with Disabilities Act** (**ADA**). The **ADA** is the most general of the three federal laws, and guarantees equal opportunity for people with disabilities, which may help in making sure your child gets the support he or she needs.

The **IDEA** applies to all public schools and covers children with one of 13 classifications of specified disabilities or special needs. A child with a brain tumor may be classified as hearing or visually impaired or traumatic brain injury. Occasionally schools do not view a brain tumor as a traumatic brain injury and may classify a child as other health impaired (OHI).

Under the IDEA, your child is entitled to an evaluation and a resulting individualized education plan (IEP).The IEP will establish your child's unique and individual educational needs and will document appropriate accommodations and services. The IEP is written by the educational team along with the parents, the child (if he is over 14), and any other advocates involved. Once your child has an IEP, the school *must* provide the accommodations and services that the plan spells out. The federal government gives money directly to school districts to cover eligible students.

The IEP will set specific goals for your child's education. It will include referrals to needed services such as occupational therapy, speech therapy or counseling. Here are some accommodations which may be included on an IEP:

- Use of a computer or audiobooks
- Written class notes
- Weekly assignments given ahead of time (assist with organization)
- Use of a calculator
- Extended testing time

The IEP can be changed during the school year through a formal meeting process and a yearly meeting will be held with all involved parties to assess progress and needs for the upcoming school year. Issues related to social integration can also be included in the IEP. Parents must be notified in writing of all educational meetings.

Section 504 applies not only to public schools but to any school that receives federal funds. As a result, many private schools are subject to the requirements of Section 504. Section 504 generally prohibits discrimination against a child or individual with disabilities. A child with special needs is entitled to appropriate educational accommodations to ensure that his or her education is comparable to that provided to non-disabled students.

As a general rule, every school is required to have guidelines for accessing special education services. Public

schools typically have guidelines that explain how the IDEA works in their particular school district. Private schools receiving federal funding are also required to follow the IDEA guidelines. If your child is enrolled in a private school, you may want to talk to the school about their ability to comply or contact your state's Office of Special Education and Rehabilitative Services for clarification of the rights of private school students.

Both IDEA and Section 504 give schools 30 days to perform the evaluation and then another 30 days to put a program in place. If you disagree with the classification, evaluation, or program provided for your child, IDEA and Section 504 entitle you to an impartial hearing.

Infants and toddlers (birth through age 3 years) who experience the trauma of life-threatening illness and treatments such as surgery, radiation therapy, and chemotherapy are entitled by federal law to early-intervention programs that try to head off developmental delays. These services do not depend on a family's ability to pay. According to a child's and a family's needs, the child may receive physical and occupational therapy, speech therapy, and special instruction. The family may be entitled to family services, such as training, counseling, or case management help to coordinate services.

A state's education department is typically responsible for children between ages 3 and 21 years, and a state's health department for children from birth to age 3 years. They refer parents or health care team members to early intervention services. After an assessment of a child younger than 4 years of age, an individualized family service plan (IFSP) will be developed by the early-intervention team, which must include the parent or guardian.

Getting your child the help he or she needs can be a complicated and frustrating experience. Remember that you are not alone and that there other families in your community who have children with special educational needs and have gone through this before you; they can help you. You may want to connect with families through the Children's Brain Tumor Foundation's Family 2 Family Network (F2F) The social workers at CBTF also have expertise in this area.

School Communication Form

There can often be a communication gap between the home and the many education staff members who work with your child.

> I remember when my child, due to his limited visual field, accidentally stepped on another student's painting drying on the floor of the hallway. A teacher passing by (not his own one), reprimanded him saying he was disrespectful of his peer's artwork. Had there been better communication among the entire faculty regarding his situation, this incident would have been dealt with in a more sensitive manner.

To ensure that each staff member is alerted to either your child's special needs or those of his or her siblings, a communication form can be developed between you and school personnel. A sample form is provided on the following page for your convenience. This form may be used for a child with a brain tumor or a sibling.

Parent–School Communication Form

A student in your school has been diagnosed with a brain or spinal cord tumor (or "A student in your school has a sibling who has been diagnosed with a brain or spinal cord tumor"). Because of the child's (or "child's sibling's") condition, he/she will need special considerations. It is of utmost importance that the following information be copied and distributed to all staff members who interact with this child. It is imperative that all staff (teachers, office workers, coaches, and so on) retain this document as a reminder so that they will be alert to and able to respond to any medical problems, educational changes or emotional concerns this student may encounter.

Student Name: _____ **Photo**:

Grade: _____

Homeroon Teacher: _____

Diagnosis: _____

Undergoing Treatment? **Yes:** ____ **No:** ____

Parent Name: _____ **Number**: _____

Medical Concerns:_____

_____

Emotional and Educational Concerns:

_____

_____

Limitations:

_____

_____

For further information, please contact:

_____

_____

SOME TIPS

If your child has to leave school/friends:

- Schedule a meeting with school principal, teachers, and anyone else who would be involved in your child's education
- Discuss all issues relating to child's health, educational plans moving forward, and how best to inform and educate child's classmates
- Have a presentation for child's classmates, to discuss child's illness, etc.
    - Ask child how much they wish to be involved in presentation and how much they would like disclosed to their classmates
    - Keep all information clear, simple and age appropriate
    - Key points to focus on:

      -Types of Symptoms (if classmates were aware) and what they may or may not mean (such as headaches, muscle pain, etc)

      -What treatment is the child undergoing to treat the brain tumor (describe simply)

- Explain the nature of the child's disease, that it is not communicable in any way, that the child is still the friend they have always known and will need them more than ever

- Explain the differences in child's appearance; hair loss, weight loss, puffiness

- Explain the differences in child's abilities: Cognitive abilities, balance, stamina—Explain why they now need help to do different things in a positive way without diminishing the child

- Most Importantly EMPOWER CLASSMATES to continue to be involved in child's life. Encourage them:
  - To visit
  - To Call
  - To send E-mail, letters
  - To Skype
  - To involve them in their lives (birthday parties, sleepovers, Halloween parties, etc)

- Be sure to keep classmates informed of child's progress, remind them to be involved, ask who has visited/called/emailed, what can they involve the child in (that will be safe and fun)

All of this will make the child's transition back to school much smoother, less isolating and less awkward for all involved. Classmates parents and child's teachers should be viewed as advocates and allies throughout the entire process to help the child re-acclimate and assimilate back into the academic world.

WHEN RETURNING

Parents

- Be involved in the school environment to help with the child's re-acclimation to school

- Discuss with older children how involved they would feel comfortable they're parents being at there school
- Younger children typically find their parents presence at the school very comforting; if the parents bring them lunch, stop by during a non-academic courses, just to make the child aware that they are around
- Be sure faculty is aware that child is returning and any fears the child may be having (about being treated differently, being left out because they can no longer do the things they used to)
- If teachers are informed and involved they can help to make a child feel more included, for example: if a child cannot perform an activity due to cognitive or physical ability, the teacher can send them on an error, or exclude a portion of the class by having them perform a different task.
- Returning to school can be scary for children and teenagers. They may be very self-conscious about their appearance and the way others are treating them.
- Make classmates AND THEIR PARENTS aware that child is back, make it a positive event

There is a wealth of resources available that can assist in many of the issues that you may face when your child returns to school. A list of resources is listed in Chapter 11 ("Resources") of this guide.

CHAPTER

7

SURVIVORSHIP

Due to the increased survival rates in the past 20 years, there are now about 28,000 survivors of pediatric brain tumors. With survival comes the potential for cognitive, medical, and emotional late effects. Problems which do not go away or show up months or even years after treatment are known as late effects. In addition to late effects, there is growing information on the on the “positive” changes many survivors and their families experience after the completion of treatment.

When treatment ends, most children and families are happy at the prospect of leaving the experience behind. While many fear leaving the sense of safety during treatment, moving to life after a brain tumor brings a sense of relief, happiness, and celebration. For many there also still remains a constant worry about the future including the possibility of recurrence. Over time, the focus may move from worrying about recurrence or a new tumor to concerns about school, relationships, employment and other potential medical problems. This chapter will talk about some of the potential late effects and what information you need in order to best advocate for your child.

Late effects and Risk Factors

Most survivors will need to be monitored for potential late effects. This follow-up is seen as preventative medicine. Yearly

monitoring will provide early detection. There are some risk factors related to an increased likelihood of potential late effects. These risks include the type and amount of treatment, type of tumor, its location, and age at diagnosis. In general, children who are treated at a young age (younger than 7 years) and those who receive the most intensive therapy (for example, high doses of radiation combined with high doses of several chemotherapy drugs) are at a higher risk of developing late effects. However, it is important to remember everyone is unique and no two people react in exactly the same way to a given treatment. Equally important is being *at risk* for a given problem does not necessarily mean a child will develop the problem.

Most hospitals will provide families with a comprehensive medical summary which should include future testing needs.

What Are the Most Common Types of Late Effects, and Can Anything Be Done About Them?

Late effects may be mild and easily treatable problems (such as an underactive thyroid) and on rare occasions, serious and life-threatening problems (a second, new cancer). Fortunately, many late effects can be treated and controlled. For many of these concerns, the outcome is best when the problem is detected early, often before any symptoms or signs are evident. The following are the most common delayed complications that have been observed in childhood brain tumor survivors.

Endocrine

The endocrine (or hormone-producing) system consists of several organs or glands (thyroid, adrenals, testicles, and ovaries) that are under the control of the pituitary gland, which is located in the brain, just behind the eyes. Each of these organs produces one or more substances or hormones that can affect

many important body functions. These endocrine organs can be damaged as a result of a tumor, surgery, radiation therapy, and, less often, by chemotherapy.

Endocrine problems may not develop until several years after the end of treatment; In fact, some hormone disorders have been known to appear 25 or more years after the completion of cancer treatment. Most problems can be easily diagnosed with routine blood tests and are treatable.

Pituitary Problems: The pituitary gland makes at least five different hormones, all of which can be affected by radiation therapy and surgery. Pituitary problems are most often seen in individuals who have been treated with radiation to the head and those whose pituitary has been damaged by a tumor and/or surgery. Most of the time, the problems are due to underproduction or deficiency of a hormone. However, accelerated production or overproduction of certain hormones can also occur.

Growth Hormone Deficiency*:* Loss of the ability to make normal amounts of growth hormone is the most common pituitary problem seen after radiation therapy to the brain. As its name suggests, growth hormone is essential for normal physical growth; children who are deficient in growth hormone grow slowly and are short when they reach adulthood. Growth hormone also affects bone strength, cholesterol levels, amount of body fat, and stamina. Treatment is available for children who are deficient in growth hormone and for selected adults with severe growth hormone deficiency. Children who also receive radiation to the spine may experience severe growth problems. Growth hormone therapy may improve growth, but it can't overcome damage to the spine caused by radiation treatments.

***Early Sexual Maturation**:* Young children treated with radiation to the brain tend to start their pubertal development at a younger age than the general population. This problem is seen more often in girls than boys. Early puberty, though not a serious medical condition, can lead to a shorter final height; specific drugs are available that can temporarily postpone puberty. Early puberty may also have an impact on the child in dealing with peers. The school should work closely with families to address the differences and assure the child is not being made fun of.

Obesity: Young adult survivors of childhood brain tumors may be at increased risk of becoming overweight and developing pre-diabetes or diabetes. Radiation to the brain appears to be an important risk factor, especially for girls treated at a young age. Young adult survivors who have a tendency to gain weight need to pay careful attention to their dietary habits and to incorporate a sensible exercise regimen into their regular routine. Survivors should also have their cholesterol monitored.

Thyroid Problems: The thyroid gland, a butterfly-shaped organ situated in the neck just above the collarbone, is often damaged by radiation to the neck, spine, or upper chest. The most common condition is hypothyroidism, which is an underactive thyroid. Symptoms of hypothyroidism can be subtle and often go unnoticed. Moreover, it may take more than 20 years after treatment for the problem to develop. Hypothyroidism can be treated with medication.

In addition to an underactive thyroid gland, prior therapy with radiation increases the chance of tumors of the thyroid. Fortunately, most of these tumors are benign and easily cured. A complete examination of the thyroid should be part of the yearly checkup for anyone who has received radiation to the neck region.

Testicles and Ovaries: The testicles perform two separate functions: (1) producing the male hormone testosterone, which is needed for sexual development (beard growth, muscle growth, and maturation of the sex organs) and (2) producing sperm. These two functions are affected very differently by cancer therapy. The male hormone–producing cells are rarely damaged by the treatments, except in males who have received high doses of radiation directly to the testicles. For men who produce low levels of testosterone, treatment with testosterone (injections or daily skin application of a gel) are available. The sperm-producing cells, however, are often damaged by a variety of chemotherapy drugs (such as cyclophosphamide, busulfan, thiotepa, CCNU) and low doses of radiation. A sperm analysis is required to determine if a male survivor is fertile.

The ovaries also perform two separate functions: (1) producing female hormones (estrogen and progesterone) and (2) producing eggs. However, in females, these two functions are affected equally by the treatments. Thus, when the ovaries are damaged, there is loss of both hormone production and egg production (fertility). This usually results in lack of menstruation. The ovaries are most often damaged when the treatments are given in late adolescence and after radiation to the pelvic area and high-dose chemotherapy. For women with loss of normal ovarian function, treatment with estrogen and progesterone is usually recommended. While such treatments are very beneficial, they do not affect or restore one's ability to make eggs and have children. Some women who continue to have regular periods after cancer therapy are at risk of entering menopause at a younger age than the general population. This is especially true of women who received radiation to the whole spine and those who were treated with the class of chemotherapy drugs known as alkylating agents (which includes cyclophosphamide, procarbazine, and thiotepa).

Many new techniques are now available to assist cancer survivors who experience infertility. All studies to date suggest that the children of cancer survivors are no more likely to have major problems than the children of people in the general population.

Neurocognitive Problems

Unfortunately, survivors of childhood brain tumors frequently develop problems in the areas of intellectual ability, academic achievement, memory, and attention. Although many different factors are probably responsible for these changes, the major risk factors include tumor location and surgery, age (younger than 7 years) at diagnosis, and treatment with radiation therapy.

Learning disabilities are particularly common among brain tumor survivors. Moreover, one can observe deterioration in function over time, particularly in children who were treated with radiation to the brain at a young age. Thus, it is extremely important to reassess cognitive functioning periodically in all survivors who are at high risk, as well as in survivors who are experiencing academic difficulties. This is done by administering a battery of tests known as neuropsychological tests.

Assessment is best accomplished by working closely with a pediatric neuropsychologist who has brain tumor experience. Most major medical centers will have trained neuropsychologists on staff, as will many schools. If problems are identified, the school must provide your child with appropriate services. Although this is now mandated by federal law, you and the members of the medical team may need to advocate for your child to get all the services to which he or she is entitled.

Learning problems are clearly among the most difficult and frustrating problems facing young brain tumor survivors, but new areas of research such as cognitive rehabilitation offer hope for the future.

Neurological and Neurosensory Problems

Neurological problems such as seizures and muscle coordination are relatively common among childhood brain tumor survivors. These sorts of disabilities often develop around the time of diagnosis or after initial surgery, but sometimes they first appear months or years after diagnosis. Injury caused by radiation to the brain can, on rare occasions, cause delayed neurological problems that may become apparent 10 or more years after treatment.

Neurosensory problems such as impaired vision and hearing may also develop, both early in the course of diagnosis and treatment and years after treatments are finished. Radiation can cause delayed visual problems through several different mechanisms. Direct damage to the eye nerves (optic nerves) can frequently result in visual changes years after treatment. In rare instances, previous radiation can produce cataracts in the eyes that can interfere with normal vision. If your child had surgery near the eye or eye nerves or had radiation to the head, regular visits to an eye specialist (ophthalmologist) are highly recommended.

Hearing difficulties are common after treatment for brain tumors and, in general, remain stable or even decrease in severity over time. Under certain circumstances, though, hearing problems have been shown to get worse or appear for the first time months to years after treatment ends. Children who receive treatment with the combination of the drug cisplatin and radiation to the brain appear to

be at the greatest risk for developing delayed hearing problems. Periodic hearing tests should be performed on all children at risk for hearing problems as well as for any child who is experiencing academic or learning difficulties.

Other Medical Late Effects

A small number of survivors can develop other disorders such as heart, lung, kidney, or skeletal problems (such as curvature of the spine). New tumors can also develop, but the overall risk is quite small, on the order of 1% to 3% of survivors at 20 years from diagnosis. Your child's risk of developing these problems will depend, in large part, on the treatments he received and his age at the time of the treatments.

Osteoporosis is a disorder resulting from too little new bone formation or too much bone loss, causing bones to become weak. Because some survivors have growth hormone deficiency resulting from treatment or high levels of thyroid hormone (hyperthyroidism which results from treatments such as radiation therapy to the brain, neck, or chest) they are at higher risk for osteoporosis. A diet high in calcium and the appropriate amount of Vitamin D may serve as preventative help. However, taking too much vitamin D may be harmful, so it’s best to check with a healthcare provider before taking any vitamin D supplements.

Social, Psychological, and Behavioral Late Effects

Some survivors struggle with challenging social, behavioral, or psychological outcomes at different points in their lives. Returning to school, moving to middle school or high school, and transitioning after high school are all times when being a brain tumor survivor may cause challenges in making and obtaining peer relationships. Research has indicated social isolation, being bullied, self-esteem, and difficulty in relating to peers their own

age as prevalent concerns for survivors. Research also indicated an increase in psychological distress for brain tumor survivors when compared to their peers.

Survivors may be at risk for poor educational attainment, less than optimal employment status, challenges in interpersonal relationships, and peer interactions. Overall, most survivors are psychologically healthy and satisfied with their lives and their future prospects. However certain groups of survivors may be at higher risk and this is especially true for brain tumor survivors. Other risk factors include: being female, having lower educational attainment, being unmarried, being unemployed or underemployed, lacking health insurance, or the presence of a current major medical issue or physical late effect. Adolescents treated for CNS tumors show increased risk for depression, anxiety, post-traumatic stress disorder, and attention deficit as compared to others. Treatments with cranial radiation or intrathecal methotrexate are specific risk factors. Despite the risk for adverse psychological and social late effects, most survivors do find meaning and form important relationships. There is increasing evidence that many survivors display **posttraumatic growth** after their early cancer treatment.

In addition, despite other health risks, many survivors engage in risky health behaviors such as lack of physical activity, tobacco use and excessive alcohol use.

While most of the late effects clinics provide comprehensive care including psychologists and social workers, survivors may also benefit from outside interventions. Possible solutions should be explored with the school social worker and psychologist as well as community based organizations which deal specifically with brain tumor survivors.

Ensuring That Your Child Gets Comprehensive Follow-Up Care

It is essential that you work closely with a health care provider or team that can assist you in coordinating the aftercare your child requires. This provider may be your child's pediatrician, the pediatric neuro-oncology team that treated your child, or the medical team at a **long-term follow-up clinic** (**LTFC**). These clinics are specialized clinics that work with survivors and their families to provide comprehensive care, education, and counseling. Many pediatric cancer centers have a designated late effects clinic on site to provide care to survivors once the treatment phase has finished. For an up-to-date list of clinics operating in the United States, please visit our website at www.cbtf.org or go to www.curesearch.org.

Maintain a copy of your child's medical history including:

- The date of diagnosis
- Names and total doses of all chemotherapy drugs
- Doses and sites of all previous radiation therapy
- Sites of all surgeries
- The start and stop dates for each treatment
- Any adverse reactions or complications related to treatment

This information can usually be obtained from the team supervising your child's cancer therapy. At the end of treatment, it's a good idea for you to ask your child's neuro-oncology team to review with you the treatments your child received as well as any late effects that might occur as a result of these therapies. If

appropriate, this may be the time to begin to arrange for follow-up treatment with specific specialists (for example, a neuropsychologist or pediatric endocrinologist). By charting your child's follow-up care early, at the end of planned therapy, it will help ensure a smooth transition from treatment to life after treatment.

> We created a medical data sheet to hand over to all new medical professionals we came into contact with. It was helpful that we maintained our journal even after treatment ended, for over the years, it is a quick and easy source to rely on.

CHAPTER

8

SUPPORT AND SERVICES IN THE COMMUNITY

Learning that your child has a life-threatening illness is devastating and plunges you and your family into a crisis that demands your immediate and full attention. You will be confronted with a series of new tasks and challenges. This is all new to you and it is okay to feel scared. Don't be afraid to ask for help!

Social workers and hospital staff are able to connect you with community resources and support groups that may be associated with different hospitals or private foundations related to brain tumors or children's cancer. You can find information on the Internet, from friends, or from newspaper lists of local meetings. When you contact national organizations, ask for referrals to local groups and have them send you any newsletters they publish.

You can also ask your child's doctor or treatment center to connect you with parents or children in a similar situation. The Children's Brain Tumor Foundation offers this service through our national Family to Family Program (F2F), which often can relieve the terrible sense of isolation. Remember that although some parents want to reach out to people, others prefer to rely on a few close family members or friends for support. There is no

"right" way to get through this time. Try to seek the type of help you need in the style that best suits you and your family.

For help in deciphering the medical information you are receiving, ask your doctor to set up a time with you to answer any medical questions you may have. Group support may help normalize concerns and fears by connecting you with others in a similar situation. Individual or family counseling can address issues you may not feel comfortable discussing with family, friends, or others around you. Different combinations of support, formal and informal, may be needed at different times.

There may be times of added emotional strain in the future. Your child may have a question or develop a new problem. Even coming off treatment and undergoing follow-up scans can be stressful. Prepare yourself by doing research on sources of support ahead of time which will enable you to know where to go when you need support. In this chapter, we list many national organizations that will be able to supply you with information. Your family's social worker can help you access local support services.

Asking for help sometimes makes people feel like a burden to others or selfish. The truth is, to be a support to someone else you must take care of yourself first. While your child may need the strength of your hugs, reassuring words, and love; you may need more. Caregivers can provide better care for their children when they in turn take proper care of themselves. Some ways to take care of yourself include: sleeping when your child sleeps, maintaining adequate nutrition, and building in some downtime for yourself.

Each family's support network is built differently. Many people draw strength from their extended family. Others find comfort from their religious community, neighbors, friends, child's school, employer, or a parent of another child who is ill. A good support system will enhance your family's ability to endure and allow you to take care of your individual needs.

Enlisting Help at Home

Priorities shift quickly and dramatically when there is a major illness in a family. When a child is ill, everyday needs and tasks take second place to the illness of the child. The rhythm of normal life is interrupted. Regular meals, laundry, and even employment take a backseat to doing what is necessary to ensure proper care for your child. Though family life continues (especially if there are siblings to care for), it may feel as if it just stops.

Depending on your circumstances, family members or close friends may offer to help. Accept these offers as gifts. Such assistance can help keep your home running smoothly during this crisis.

Sometimes (especially at first) too many phone calls and offers of help may be pouring in. Everyone will want to know "how is your child doing?" or "Did they get it all?". It helps to appoint one close friend or family member to coordinate all efforts in a particular category of tasks, such as cooking meals, caring for children, arranging for transportation, or taking phone calls. You might practice a (brief) standard response to people, such as "I'm feeling overwhelmed right now. But I appreciate your concern." Consider utilizing your voicemail or answering machine, even when you are home.

Many families now make use of the Internet to communicate. Some parents select one person to send out a group e-mail message that updates everyone on a regular basis. Others make use of resources such as *Carepages* (www.carepages.com) or *Caring Bridge* (www.caringbridge.com). Both are websites for families of children with a chronic or terminal illness. On the site, families create their own page that details their child's hospitalization, treatment, and/or overall health and wellbeing. You are then able to distribute the address of your page to other family members and friends. Everyone can read updates by accessing the page without disturbing the family.

This kind of assistance can be very valuable to you and your family because it will allow you to focus your energy on coping with your child's illness, decision making, and other changes that you will inevitably have to face.

Although some families are not comfortable accepting help, it is important to recognize that the recipient is not the only one who benefits from these offers of assistance. The person doing the offering and helping can feel supportive of you in a constructive way during this trying time. It may alleviate some of the helplessness felt by those close to you because it gives them a focus and outlet for their feelings, energy, and love. You will not be able to or be expected to repay them in equal measure.

Support Groups

When your child has a brain tumor, it can be very helpful to take advantage of a support group. Support groups provide a safe place to share with others, to be yourself, and to learn that the emotional ups and downs you are feeling are normal. A brain

tumor diagnosis and the loss of control and feelings which come with it including: anger, fear; sadness, frustration; and fatigue are not easy to deal with on your own. A support group can be a place to find comfort, identify and release feelings, and connect with others with a shared experience.

Although health care professionals can guide you and provide strategies for coping, sometimes only another parent who has experienced firsthand the exhaustion, stress, and anxiety related to having an ill child can provide the support you need. You can get guidance on how to deal with family issues and learn more about available medical care and new treatments. Each person will have discovered effective and often different and creative solutions for certain problems.

Sharing these experiences with others can aid and strengthen you. It can also lead to a greater understanding and acceptance of the difficult choices you have to make. You can learn to cope with the differences between you and those who *do not* have a child with a life-threatening illness. Your idea of what is “normal” will be different from what it was before. Learning from others will help you make choices that respect other family members and help you let go of demands that place undue stress on the family.

Recognize and respect your own special needs as a parent so that your energy is not consumed in presenting a façade, reacting to guilt, or compensating for a lack of understanding from people around you. Even if you do not feel comfortable talking in front of the group, you can listen and feel connected with others who face the same problems**.** Your journey will become more understandable and more acceptable.

Sibling support groups or other organizations such as SuperSibs! (www.supersibs.org) can help your other children in dealing with the difficulties they face. Siblings may resent the loss of attention from their parents or feel guilt or anger related to the special attention given to the ill child. Even children who seem to be handling it well may benefit from a group where they will meet children facing similar problems and find out that their feelings are normal under the circumstances. Kids need to share their feelings. Although the feelings can't be taken away, it helps to voice them. Sometimes children can speak more openly with strangers because there are no emotional ties.

Local cancer wellness programs for children, their parents, or other family members can be found by calling your local hospital, cancer center, or local chapter of the American Childhood Cancer Organization (www.acco.org). Groups connected to professional organizations will usually have a professional leader or child life specialist to facilitate a children's group. Sometimes groups for parents and children meet at the same location and time.

Computer Connections

There is a vast amount of medical information available on the Internet. You can use it to find out more about your child's illness or to help you decide where to seek a second opinion. You can communicate with other patients, their families, medical experts, and researchers. Because there is so much information, and because some of it can be inaccurate and misleading, you will have to carefully review it and decide what is actually worth pursuing. It is important to be careful when accessing information on the Internet. A medical center or a physician does not always post information. Be sure to check with your child's doctor if any questions arise about what you have read. Retrieving it can be overwhelming in

terms of time and emotion. Often a friend or relative can do the searching for you.

The information you gather (from this guidebook, literature from national organizations, or from the Internet) may be too technical or simply too much for you to handle at this time. You may want to set it aside until a later time. Remember to discuss information with your child's health care providers if you want to know how it might relate to your child's case.

Not everyone has a computer or access to one. Your medical center, a local library, or a friend may be able to provide you with Internet access.

Some of the major resources for brain tumor information are listed in the Resource chapter. Many individuals, groups, universities, and medical centers have their own web sites, and more sites are being added every day. It can be useful to go to the site of a major organization and simply click directly on the links.

Camps

Children with brain tumors are a lot like other children. After their experiences with surgery, radiation therapy, chemotherapy, medications, and endless tests, children's efforts to live the way they did before may lead to frustration. A camp experience can give the freedom to enjoy the pleasures that other children enjoy and to escape from the trauma of living with a brain tumor. At camp, children can breathe the fresh country air, engage in recreational activities with new friends, laugh, and simply be children instead of patients. Parents and siblings may welcome a

break, too, from the constant medical and emotional demands of a sick child.

Children's Brain Tumor Foundation sponsors special Brain Tumor camps specifically for children with brain tumors and their families. These camps offer an opportunity for children and adults to meet others sharing similar experiences. The combination of recreational activities, time away from the rigors of treatment and fun-family time may provide you with needed time to reconnect as family.

All oncology camps can meet the specific needs of your child during or after treatment and will require a medical release from your child's doctor. Generally there is no or minimal cost to attend these camps. These camps are staffed by trained counselors and other medical professionals. A camp near you can be found through the Children's Oncology Camping Association.

Wish-Fulfillment Agencies

Wish-fulfillment agencies help to grant the special wishes of a child with a life-threatening illness. Whether it is owning a television set, taking a trip to Disney World, attending a special event, or personally meeting with an athlete or entertainer, these organizations will help to provide your child with happiness and joy as they make your child's dream come true.

CHAPTER

9

Complementary Therapy and Healthy Eating

As a parent there may be times where you want more for your child than what is being offered by your child's clinical team through standard medical care. When used in addition, or as a compliment to, traditional treatment and surgery, complementary therapies and nutrition counseling may improve your child's ability to cope with and tolerate treatments as well as improve physical well-being. ***It is critical to always discuss with your child's team any additional therapies you may be considering. Anyone who practices complementary medicine should be licensed and certified.***

As complementary therapies begin to be more widely used and accepted, many of these modalities are being offered within hospital settings as part of their treatment plan. Insurance coverage for complementary therapies is not widely offered. Some policies cover a portion of these treatments, but many do not. The complementary therapies can be large out of pocket expenses. We recommend speaking with your team as to including your child's individual complementary treatment plan within their protocol in hopes to standardize fees.

Acupuncture

Acupuncture is a common practice in Chinese medicine, dating back more than 2500 years. Specially designed hair-thin needles of different sizes are inserted into acupoints, areas along the body that when manipulated help correct and rebalance the natural flow of energy in the body. Acupuncture is a painless method of reducing the nausea, fatigue, and anxiety that may be involved in the treatment of brain tumors. It may also improve blood-counts. Some children can have a fear of needles, but if your child is willing to try one acupuncture needle, they may be relieved to realize that an acupuncture needle does not hurt. You are your child's best advocate and will be able to determine the balance between the possible anxiety of starting acupuncture for your child and the therapy's proven positive effects.

> Acupuncture is a very effective therapy to minimize the side effects of treatment. It can help children to reduce nausea, anxiety, and improve their energy. It is a non-pharmaceutical option to improve your child's quality of life. If used appropriately, acupuncture can be painless.

> Before I had acupuncture on Thursday's (after treatment) I used to just lie on the couch and rest. Now on Thursday's, I can go to school and do everything. The needles do not hurt one bit.

Aromatherapy

Aromatherapy means “treatment using scents.” It is a holistic treatment of caring for the body with pleasant smelling botanical oils such as rose, lemon, lavender and peppermint. Essential oils are added into the bath or are massaged into the skin, inhaled directly or diffused to scent an entire room. Aromatherapy is used to relieve pain, care for the skin, alleviate tension and fatigue, and invigorate the entire body. Essential oils can affect the mood, alleviate fatigue, reduce anxiety, and promote relaxation. When inhaled, they work on the brain and nervous system through stimulation of the olfactory nerves. Your child may be sensitive to hospital sounds and smells while receiving radiation and chemotherapy treatment. Some bone marrow transplant units are using aromatherapy during bone marrow infusions to alleviate anxiety. This may be an easy and helpful way to help your child at the hospital, but experts suggest your child may not like the smell used while at the hospital in the future, so it is important to keep that in mind when picking an aroma.

Guided-Imagery and Visualization

Guided-imagery uses the power of a soothing voice and your child’s imagination to help your child’s coping with potentially anxiety producing or painful procedures. Using a peaceful image; such as lying in the warm sun, on a beach, while listening to lapping water and waves in the background while you softly stroke your child’s hand and arm, can lead your child into a calm state of mind, drawn completely into the image you have provided for them. Some children report guided-imagery can help them with nausea, anxiety, and lengthy MRI scans.

You can work with your child daily on visualizing their good cells over taking any brain tumor cells or the chemotherapy gobbling up the "bad cells" like within the Pac-Man game. Some children report feelings of empowerment and self-determination when using this technique, while other children have a hard time focusing on this activity on a daily basis. You will quickly learn what works for your child and what may be something that may cause more stress.

Healthy Eating

Seek the advice of a trained nutritionist or homeopathic practitioner who has experience working with patients diagnosed with cancer.

There can be a difficult balance between creating healthy eating habits for your child and your child's refusal to eat any food choice that is not their own. Dramatically changing a child's diet or lifestyle after their diagnosis of a brain tumor may result in resistance to eating at all. Lack of food could be counterproductive to your child's overall health and wellbeing. There may be times where you will need to give your child any food to maintain caloric intake rather than healthier choices. If you are interested in a healthy living approach to nutrition during and after your child's treatment, you may want to explore some of the colorful and creative cancer cookbooks such as Betty Crocker's "Living with Cancer Cookbook" which contains helpful nutritional information. Engaging your child in choosing and cooking meals may go a long way in establishing compliance with a healthier diet. Good nutrition is important for a healthy immune system. Explaining to your child that chemotherapy and radiation therapy help to treat their brain tumor but may take a

toll on their immune system, may engage your child's interest in their own health and wellbeing, empowering them to make healthier choices.

If you are interested in adding vitamins and supplements that may help your child's immune system through treatment, we advise you **always consult with your medical team**. You may also want to ask that a trained nutritionist be part of your child's ongoing treatment team.

Laughter and Humor

The average child laughs 400 times a day. Humor has both positive psychological and physical affects and may serve as a coping strategy for your child by reducing feelings of anxiety, nervous tension, anger and pain.

Some hospitals offer Clown Care Units in which the old adage "laughter is the best medicine" may ring true. Some clown care units utilize magic tricks, bubbles, laughter, and music to entertain, distract and heal.

Massage Therapy

Massage therapy can play an important role in supporting the well-being of your child through illness and recovery. Massage therapy involves touch and different techniques of stroking or kneading the muscles of the body. In can involve only part of the body or a full-body massage. A foot massage by a trained massage therapist while receiving chemotherapy may be extremely relaxing and can immediately reduce feelings of nausea. Research has shown that massage therapy can help decrease anxiety, depression, insomnia, physical discomfort,

pain, and help with symptoms of illness or side effects of medications.

Music Therapy

Music has the ability to assist with emotional, physical or spiritual health and to enhance quality of life. Music and sound promote relaxation and may assist in pain management as well as decrease anxiety, depression, and fear. It has also been shown to reduce nausea and vomiting during chemotherapy administration. The empowering experience of music therapy could prove to be the best part of your child's day at the hospital. Learning a new musical instrument, singing along with a favorite CD, or playing in a band with other children receiving treatment are all possibilities in the realm of music therapy.

> Children and adolescents going through medical treatment for cancer need to have moments of normalcy, empowerment, and opportunities to increase their self-confidence and self-expression. The universality of music can help these patients find that place and just be a kid.

Reiki

Reiki, or otherwise known as healing touch, is a gentle but powerful source of relaxation. This modality may prove helpful in stimulating your child's immune function, enhancing post-surgical healing, and relieving physical and emotional symptoms.

Yoga

In the ancient Sandskrit text of India, “Yoga” is defined as the union of the body and the mind. Yoga is a good kind of exercise for children as it is gentile, non-competitive, and works not only on the entire body but also the mind and the spirit. Children of all ages and physical abilities can practice yoga. Children can learn to stretch, breathe deeply, relax, and concentrate. Yoga builds stamina, stability and balance. It can help to improve digestion, elimination of toxins, and to keep your child healthy and happy.

> Not only can complementary therapies improve your quality of life, but they can empower you to feel more in control and pro-active in your own care. I have firsthand experience of the use of complementary therapies improving the quality of life and reducing my medical symptoms. It also gives the patient an opportunity to use every resource at their disposal for times when they are feeling their worst.

CHAPTER

10

Palliative Care, End-of-Life, and Bereavement

> The goal of palliative care is to minimize suffering by managing symptoms while maximizing quality of life

Hospitals and medical teams may offer a form of care called “palliative care” to promote comfort and reduce the stress and pain associated with intensive treatment. The goal of palliative care is to minimize suffering by managing symptoms while maximizing quality of life. This involves understanding and acknowledging issues such as pain management and nutritional requirements, as well as addressing psychosocial and/or spiritual needs presented by the patient and family. Palliative care can be offered in addition to curative treatment, or it can be chosen when curative treatment is no longer an option. Palliative care is provided by a team which includes the patient, family, and medical specialists who provide treatment for your child. Specialists include the doctors, nurses, social workers, and other professionals who are involved in the physical and psychosocial care of your child. Your oncologist may work on the palliative care team or in collaboration with the palliative care team, depending on how palliative care is delivered at your hospital. In addition to providing physical and emotional support for you and your family, the palliative care team is there to help you

understand treatment options and guide you through making difficult treatment decisions.

> The grieving process with a child with a brain tumor starts at the diagnosis. That's when the grief, anger, and searching begin. And they continue after.

End-of-Life Care

In the previous chapters, we shared information about different types of brain tumors and the treatment options available. Your child may have been on a treatment protocol for a cure, which may have included radiation therapy, chemotherapy, and surgery. However, there may come a time when all treatment options have been exhausted and your child's condition is not improving. At that time, you might want to explore with your child's medical team what medical options are available. Palliative care can be offered when curative treatment is discontinued to ensure that your child receives comfortable and compassionate care. Your doctor and medical team, along with your palliative care treatment providers, can work with you to discuss developing a plan of care to support your child through the dying process.

> When a child is first diagnosed with a brain tumor, the immediate concern is for the child's comfort, well-being, and recovery. No matter how much you may think you can prepare for the loss of a child, when it comes right down to it, you are never ready to say good-bye to your child.

Advance directives may be discussed with you to help inform and educate you about options you may have in deciding on end-of-life care for your child. An advance directive pertains to treatment preferences and the appointment of a surrogate decision-maker should someone no longer be able to make a decision independently. Throughout this time, it will be important to maintain an open and honest dialogue with your child's medical team about what your wishes are and what options are available. You will want to gain knowledge and understanding, which is critical in helping you to make the decisions that you want for your child. You may not feel ready for these conversations and find yourself reacting to the medical team. There may also be times when you need to initiate the conversation with your team. Doctors are dedicated to working toward a cure for your child, but they will benefit from knowing how you feel about palliative care and end of life options so they can work with you to determine the appropriate plan for you and your family.

> When asked if he wanted to go on any special trip, he said no. He was happy where he was, doing what he was. He, and we, knew we had done all humanly possible, with a sense of personal dignity.

Together with your family, you can work with the medical staff to formulate a plan that works for you at this most difficult time. The decision to move toward palliative care and discontinue curative treatment is a difficult one, filled with many emotions including fear, grief and anger, and the search for answers. It is a time filled with a lot to do and a lot to think about.

Hospice

At some point, discussion about hospice may be initiated by members of the medical team. Hospice is a philosophy that emphasizes and supports the physical, psychological, social, and spiritual needs of a child with a disease that is not responding to curative treatment. Hospice care is usually provided at home and sometimes may be offered in hospitals. Care is coordinated by a group of doctors, nurses, social workers, clergy, and volunteers who are specially trained to be available to patients and their families. There are many local hospice programs, and your child's doctor and social worker will help to arrange this referral. Insurance, including Medicaid, and private donations usually cover the expenses.

The loss of a child is a devastating and unnatural experience for any parent. It does not follow the expected course of life. The process of grief can be a long and painful one during which you may feel alone and forgotten by others who go on with their lives. You may want to seek assistance and support through this difficult time. If you would like assistance locating information and support services, the social workers at CBTF are available to help you determine what services may be helpful to you and your family. CBTF's website contains additional information on loss, grief and bereavement which is available to view and print. You may also contact CBTF to request a copy of this information. On this site you will see a description of the CBTF Loss, Grief and Bereavement Program. The goal of our national program is to connect bereaved families to a supportive community, provide supportive services for families, and offer therapeutic and educational information. CBTF offers different

types of support services to address varying needs identified by bereaved families:

- Individual Support and Counseling by Phone
- Referrals for Support Services
- Family-2-Family Mentor Program for Bereaved Families
- Jenna's Corner Online Community for Bereaved Families with Support Groups and Message Boards for Bereaved Parents and Teens
- Volunteer Opportunities for Bereaved Parents

> Hope has been my one and only link through the entire experience, from the time of my son's diagnosis, through all the treatments, the recurrence, more treatments, his dying, our emptiness, and where we are presently. Hope was, and still is, always there: hope he would survive, hope that we could pull through, hope that a beautiful new life awaits him, hope that we would be able to experience joy again, hope that my other son would become a productive member of society, and love life; hope that we will continue to live productively, hope that one day we will be together again. Even as we had to let go of that which means most to us, and watch our beloved child slowly be taken from us, we were able to hold on to that strong thread of hope in a future that would somehow be filled with beauty and meaning. And, we have not been disappointed.

CHAPTER

11

Resources

Children's Brain Tumor Foundation

The **Children's Brain Tumor Foundation** (**CBTF**), a national organization, was founded in 1988 by a group of dedicated parents, physicians, and friends to improve the treatment, quality of life, and long-term outlook for children with brain and spinal cord tumors through research, support, education, and advocacy on behalf of families and survivors.

Grants

CBTF is committed to finding a cure for pediatric brain tumors. Since its founding, CBTF has awarded grants to prestigious doctors and researchers at leading institutions throughout the United States for scientific research into the causes of and effective treatments for pediatric brain and spinal cord tumors.

Programs

Information and Referral: The provision of information and referrals is the service most often requested by parents, patients, and health care professionals around the United States. Many families use the **Patient Support** toll-free phone number: **866-228-HOPE (4673)**. Typically everything from community referrals for financial support to insurance coverage to information on

issues such as diagnosis, treatment, education, school reentry, bereavement, survivorship, and coping have all been covered. Callers are informed about CBTF's many programs and often use more than one service.

Family to Family Network: The **Family to Family Network** (**F2F**), CBTF's oldest support program, connects experienced parents who want to share their knowledge and understanding with parents who have either a child with a newly diagnosed tumor or a child with a recurrent tumor. In addition, many bereaved families receive support from a F2F volunteer who is also a bereaved parent.

A Resource Guide for Parents: CBTF provides this helpful book. If you are interested in receiving additional copies, or have questions about the contents in this book, please contact a CBTF social worker at 866-228-HOPE (4673).

Parker's Brain Storm: A child-friendly book that describes a little bear named Parker who is newly diagnosed with a brain tumor and is going to the hospital for surgery.

E-newsletter: Offers critical information about research, resources, fundraising, and events at CBTF.

Website: The CBTF website, **www.cbtf.org**, is a one-stop information source for families and health care professionals around the world.

Advocacy

Alliance for Childhood Cancer: The Alliance for Childhood Cancer, representing more than two dozen national patient advocacy groups and professional medical and scientific organizations, was established to advocate on behalf of the youngest victims of cancer. CBTF is a charter member. Patient advocates, many of whom are either cancer survivors themselves or are parents of children with cancer, are joined by oncology professionals representing the multidisciplinary spectrum of cancer care in a unique alliance that brings concerned parties together to advance the interests of children with cancer.
http://www.allianceforchildhoodcancer.org

LiveStrong Young Adult Alliance:
CBTF is a charter member of LiveStrong Young Adult Alliance. The Alliance is committed to promoting research and the investigation of the problem, serving as a voice for the issue and promoting effective solutions for the issues related to young adult cancer.
www.livestrong.org

Air Travel

The Air Care Alliance:
888-260-9707
www.aircareall.org

Angel Flight America:
877-621-7177
www.angelflight.com

Continental Care Force:
281-261-6626

Corporate Angel Network:
866-328-1313
www.corpangelnetwork.org

Delta SkyWish:
800-892-2757

LifeLine Pilots:
800-822-7972
www.lifelinepilots.org

Miles for Kids in Need:
817-963-8118

National Patient Travel Helpline:
800-296-1217
www.patienttravel.org

Camp Resources

Camp Mak-A-Dream
www.campdream.org

Children's Oncology Camping Association
http://www.cocai.org

Children's Oncology Services, INC
www.onestepcamp.org

Happiness is Camping
www.happinessiscamping.org

Complementary Therapies

American Cancer Society
http://www.cancer.org

American Music Therapy Association
www.musictherapy.org

National Center for Complementary and Alternative Medicine at National Institutes of Health
www.nccam.nih.gov

Cancerguide: Alternative and Complementary Therapies
www.cancerguide.org/alternative.html

Clinical Trials Resources

Center Watch
www.centerwatch.com

CureSearch for Children's Cancer
www.curesearch.org

National Cancer Institute
Direct search for clinical trials
www.clinicaltrials.gov

Virtual Trials
www.virtualtrials.com

Education Resources

Alliance for Technology Access
www.ataccess.org
The mission of the ATA is to increase the use of technology by children and adults with disabilities and functional limitations.

American Childhood Cancer Association
www.candlelighters.org
Educating the Child with Cancer: A Guide for Parents and Teachers
A book edited by Nancy Keene. An essential resource for families who have faced the childhood cancer diagnosis.

Assistive Technology News Portal
www.axistive.com
The web site provides new information and product reviews on assistive technology for learning disabilities.

Band-Aides and Blackboards
www.lehman.cuny.edu/faculty/jfleitas/bandaides/
This is a web site designed to help kids, teens, and adults understand about illness.

Cancervive
800-4-TO-CURE (800-486-2873)
www.cancervive.org
Cancervive is a national organization that provides support and advocacy for survivors of childhood and adult cancer. The group provides information, newsletters, books, and videos on survivor issues. Its *Teacher's Guide for Kids with Cancer* is an excellent resource.

DO-IT Pals
www.washington.edu/doit/Brochures/Programs/pals.html
Through the University of Washington, this is an online community of teen and young adults with learning disabilities preparing for college and careers. The Web site is monitored.

Family Center on Technology and Disability
www.fctd.info
The Family Center on Technology and Disability provides a wide range of resources on instructional and assistive technologies.

LD Online
www.ldonline.org
LD Online is dedicated to learning disabilities for parents, teachers, and other professionals.

Learning Disabilities Association of America
412-341-1515
www.ldanatl.org
This association of parents of children with learning disorders and interested professionals publishes pamphlets and books and makes referrals to local chapters.

National Center for Learning Disabilities
www.ncld.org
NCLD provides essential information to parents, professionals, and individuals with learning disabilities, promotes research and programs to foster effective learning, and advocates for policies to protect and strengthen educational rights and opportunities.

National Dissemination Center for Children with Disabilities
800-695-0285
www.nichcy.org
Central source for information on childhood disabilities including: IDEA, No Child Left Behind and research-based information on effective educational practices.

National Parent Network on Disabilities
(703)684-6763
www.npnd.org
A coalition of parent organizations and individuals united to serve children with special needs and their families.

Office of Special Education and Rehabilitative Services
800-872-5327
www.ed.gov/about/offices/list/osers/index.html
The Office of Special Education and Rehabilitative Services supports programs that assist in educating children with special needs and provides for rehabilitation of youth and adults with disabilities. It also supports research to improve the lives of individuals with disabilities.

Outlook-Life Beyond Childhood Cancer
www.outlook-life.org
Outlook –Life provides detailed information on the impact of cancer on school performance and learning.

PACER Center
www.pacer.org
PACER Center is a parent training and information center for families of children and youth with all disabilities from birth to 21 years old. Located in Minneapolis, it serves families across the nation as well as those in Minnesota.

Technical Assistance Alliance for Parent Centers (the Alliance)
888-248-0822
www.taalliance.org

Parent Training and Information Centers (PTICs) provide training and materials to help parents understand their child's special needs, the laws that protect and provide services to meet those needs, and their parental rights. These centers are found in every state. Call to locate the center nearest you.

Wrightslaw
www.wrightslaw.com
Provides updated and accurate information on; special education laws, education laws and advocacy for children with disabilities.

End-of-Life and Grief & Loss Resources

CBTF Loss, Grief and Bereavement Program
866-228-4673
http://www.cbtf.org/connections/loss-grief-bereavement

Children's Hospice International
800-2-4-CHILD (800-242-4453)
www.chionline.org

Compassionate Friends
877-969-0010
www.compassionatefriends.org

The Dougy Center for Grieving Children
866-775-5683
www.dougy.org

Information and Financial Aid Resources

American Cancer Society
800-ACS-2345 (800-227-2345)
www.cancer.org

CancerCare, Inc.
800-813-HOPE (4673)
www.cancercare.org

Cancer Fund of America
800-578-5284
www.cfoa.org

Cancer Information Service of the National Cancer Institute
800-4-CANCER (800-422-6237)
www.cancer.gov

Cancer Legal Resource Center
866-THE-CLRC (843-2572)
www.disabilityrightslegalcenter.org

The American Childhood Cancer Organization
855-858-2226
http://www.acco.org

Chai Lifeline
212-465-1300
www.chailifeline.org

The Children's Cause Cancer Advocacy
202-336-8374
www.childrenscause.org

Epilepsy Foundation of America
800-332-1000
www.epilepsyfoundation.org

Hydrocephalus Association
888-598-3789
www.hydroassoc.org

National Association for Parents of Children with Visual Impairments
800-562-6265
www.spedex.com/napvi/

National Children's Cancer Society
800-882-6227
www.children-cancer.org

National Hydrocephalus Foundation
888-857-3434
www.nhfonline.org

Patient Advocate Foundation
800-532-5274
www.patientadvocate.org

SuperSibs!
866-444-SIBS (7427)
www.supersibs.org

Technical Assistance Alliance for Parent Centers (the Alliance)
888-248-0822
www.taalliance.org

Lodging

Joe's House
877-563-7468
www.joeshouse.org
Joe's House is an online nation-wide lodging resource for cancer patients and their families who must travel away from home for medical treatment. The website lists cancer treatment centers and hospitals across the country with nearby lodging facilities that offer a discount.

National Association of Hospitality Houses
800-542-9730
www.nahhh.org
NAHH lists private homes that may be available during an extended stay.

Ronald McDonald House
www.rmhc.org
The Ronald McDonald House offers a place for parents and families who are travelling for their child's treatment to stay. They run at very little or no cost and there are chapters located nationwide.

Target House
www.stjude.org
The Target House is housing that is sponsored by St. Jude's Research Children's Hospital. It is available for families whose child's treatments are expected to last 3 months or longer.

Online Support and Information List Serve

Association of Cancer Online Resources
http://www.acor.org/support.html

Caringbridge
www.caringbridge.com

Children's Brain Tumor Foundation
www.cbtf.org

Pediatric Tumors Mailing List
http://health.groups.yahoo.com/group/Pediatricbraintumors/

Survivorship Resources

Beyond the Cure
800-5-FAMILY (800-532-6459)
www.beyondthecure.org

Children's Brain Tumor Foundation
866-228-HOPE (4673)
www.cbtf.org

Curesearch
800-458-6223
www.curesearch.org

Group loop
www.grouploop.org

National Cancer Institute-Office of Cancer Survivorship
800-4-CANCER (800-422-6237)
http://dccps.nci.nih.gov/ocs/

National Coalition for Cancer Survivorship
877-622-7937
www.canceradvocacy.org

Planet Cancer
www.planetcancer.org

Wig Resources

Locks of Love
www.locksoflove.org

Look Good, Feel Better program of the
American Cancer Society
www.2bme.org/2bMe.html

Wish-Granting Resources

The Dream Foundation
805-564-2131
www.dreamfoundation.com

Make-A-Wish Foundation
800-722-WISH (9474)
www.wish.org

Marty Lyons Foundation
212 977-9474
Fax: (212) 977-1752
www.martylyonsfoundation.org

CHAPTER

12

Glossary

~ A ~

absolute neutrophil count: Abbreviated as ANC. The percent of neutrophils multiplied by the total number of white blood cells. This number is used to define neutropenia.

acupuncture: An alternative treatment method where specially designed hair-thin needles of different sizes are inserted into acupoints, areas along the body that when manipulated help correct and rebalance the natural flow of energy in the body.

amygdala: Plays an important role in extreme states of excitement, aggression, fear, and anger. It is also believed to be associated with conditions such as autism and depression.

anaplasia: Cells or group of cells that grow without structure; a term often used to describe cancer cells.

anemia: Low number of red blood cells in the blood, reported as a low hemoglobin or low hematocrit.

anesthesia: Medication—intravenous, gaseous, local, or spinal—administered to provide pain relief and/or unconsciousness during surgery.

anesthesiologist: A physician specializing in the study and administration of anesthetic medications and the care of patients before, during, and after anesthesia.

anesthetist: A person who administers anesthesia—often a nurse with advanced training in this specialty.

angiography: A diagnostic procedure performed in the radiology department to visualize blood vessels after introduction of a contrast material (dye) into an artery.

anticonvulsant: Medication used to treat or prevent seizures.

antiemetic: Medication used to stop nausea and vomiting.

aphasia: Difficulty with understanding or expressing language, often but not exclusively due to damage in the cerebral cortex.

arachnoid: Spongy mid-layer membrane of the brain which contains blood vessels.

aromatherapy: Is a holistic treatment of caring for the body with pleasant smelling botanical oils. Essential oils are added into the bath or are massaged into the skin, inhaled directly or diffused to scent an entire room. Aromatherapy is used to relieve pain, care for the skin, alleviate tension and fatigue, and invigorate the entire body.

astrocytoma: A type of brain tumor that is commonly found on the cerebellum, cerebral hemispheres, thalamus, or hypothalamus.

ataxia (ataxic gait): Inability to coordinate movements or balance; clumsiness.

atypical Teratoid Rhabdoid Tumor (ATRT): These tumors are rare, high-grade tumors that occur most commonly in children under the age of 2. They can be found in any part of the brain and tend to be aggressive and spread throughout the central nervous system.

audiologist: A person who tests hearing.

autonomic nervous system: Controls functions of the body that are carried out without our thinking about them. This includes blood circulation, breathing, digestion, and the work of hormones in our body.

axon: A branch of the nerve body that typically carries signals from the neuron to other neurons or organs such as the heart, muscles, and lungs.

~ B ~

benign tumor: Slow-growing, non-malignant tumor that does not spread to other parts of the body.

biopsy: Examination of a small amount of tissue by a pathologist in an attempt to identify the tumor type.

blood–brain barrier: A protective barrier formed by blood vessels and glial cells that prevents some substances in the blood from entering the brain.

bone marrow transplant*:* A procedure in which healthy cells able to produce the components of blood are given to a patient to begin producing new blood cells for the patient. This is in contrast to a stem cell transplant by virtue of where the donor cells come from. Cells for bone marrow transplants are usually removed (or harvested) from the pelvic bone.

brachytherapy: A system of treatment in which radioactive substances are placed near or in the brain tumor.

brainstem: The bottom part of the brain that controls many of the automatic functions of the body (breathing, heartbeat, etc…)

brainstem glioma: A type of brain tumor found on the midbrain, pons, or medulla brain structures. They may cause sudden dramatic symptoms, such as double vision, clumsiness, difficulty swallowing, and weakness.

Broviac: A specific type of tubing that is placed through the chest wall into a large blood vessel used for accessing veins.

burr hole: A surgical small round hole made in the skull usually made for shunt placement and some other neurosurgical issues.

~ C ~

cancer: Cells with uncontrolled growth; a neoplasm.

CBC: Abbreviation for *complete blood count*.

central nervous system: Abbreviated as CNS. The CNS is the nervous system consisting of the brain and spine.

cerebellar astrocytoma: A non-malignant glial tumor of the cerebellum.

cerebral hemispheres: The two wrinkled areas in the left and right halves of the upper brain the form the cerebrum.

cerebellar mutism*:* A problem that most commonly occurs in some cases of surgery within the posterior fossa where the patient has extreme difficulty coordinating movements of the mouth. The patient may lose the ability to speak and eat. Generally, all patients with this problem recover functional speech.

cerebellum: The portion of the brain that coordinates movements and balance. The cerebellum is attached to the lower back portion of the cerebrum.

cerebral fissure: A large groove that separates the two cerebral hemispheres.

cerebrospinal fluid: Abbreviated as CSF. The clear fluid made in the ventricular cavities of the brain that bathes the brain and spinal cord.

cerebrum: Made up of the left and right cerebral hemispheres.

chemotherapy: Medications used to destroy tumor cells; may be given by mouth, intravenously, or intrathecally.

child life specialist: A professional who uses play therapy and develops activities to help children cope with the effects of illness and treatment.

Children's Oncology Group: Abbreviated as COG. A group of over 240 medical centers in North America with the primary objective of conducting clinical trials and ensuring that children have access to high-quality medical care.

choroid plexus tumor (Choroid Plexus Papilloma; Choroid Plexus Carcinoma): A tumor arising in the choroid plexus, the part of the ventricles in the brain that produces cerebrospinal fluid. This type of tumor usually arises in infants.

clinical trial: A research protocol used to try to identify the most effective treatment. Most children with tumors are participating in clinical trials. These are designated as phase 1, phase 2, or phase 3 trials.

cognition: A general term involving perceiving, recognizing, conceiving, judging, sensing, reasoning, remembering, and imaging.

computed tomography scan: Abbreviated as CT scan. An x-ray device linked to a computer that produces cross-sectional images of the body. Contrast dye may be injected into a vein to make abnormalities in tissue more evident.

conformal radiation: Abbreviated as CRT. A radiation therapy that uses computers to create a three-dimensional picture of the tumor so that multiple radiation beams can be shaped exactly (can conform) to the contour of the treatment area.

corpus callosum: A bundle of nerve fibers connecting the halves of the brain, allowing information to move back and forth between the two hemispheres.

cortex: The outermost tissue of the cerebrum where the deeply folded area made up of billions of cell bodies give it a darkish cast. It is also known as gray matter.

craniotomy: Any surgical opening into the skull (cranium).

cranial nerves: Twelve pairs of important nerves that originate in the brain and control special senses of hearing, taste, sight, and smell as well as facial, tongue, and eye movement and the skin sensation of the face.

craniopharyngioma: Nonglial growth that usually causes growth failure because of its location near the pituitary gland. It often affects vision.

cranium: The top of the skull.

cyst: A cavity, usually filed with a fluid, sometimes associated with tumors.

~ D ~

dendrite: A branch of the nerve body that receives signals from other neurons or sensory organs.

diabetes insipidus: A problem with water balance in the body due to a dysfunction of the pituitary gland that causes excess urine production and great thirst.

diencephalon: A part of the brain located above the midbrain which includes the thalamus and hypothalamus.

diffuse intrinsic pontine gliomas (DIPG): A brainstem glioma found in the pons region of the brain.

diplopia: Double vision.

dura mater: Tough outer membrane covering the brain.

dysarthria: Impairment of the ability to articulate words, a symptom that may occur with tumors located in the medulla of the brain.

dysmetria: A tremor or unsteadiness of the arms often tested by having the patient alternate pointing to his or her nose and then to the physician's finger.

dysphagia: Difficulty in swallowing. This symptom usually indicates a tumor involving the lower brainstem/cranial nerves.

dysphasia: Impaired speech with difficulty or inability to put words in their proper order, a symptom that may occur with tumors located in the dominant cerebral hemispheres, particularly the temporal and parietal lobes.

~ E ~

edema: An excessive accumulation of fluid in the cells or tissues that results in swelling.

electroencephalogram: Abbreviated as EEG. A test that measures the electrical activity in the brain, particularly in evaluating activity in areas that might indicate seizures.

electrolytes: Elements in the blood that affect cells and can be tested for by blood chemistry analysis. These include sodium, potassium, chloride, and bicarbonate.

EMLA: A skin numbing cream that is used to relieve the pain associated with a needle stick.

encapsulated: Refers to a tumor that is localized, or wholly confined to a specific area, surrounded by a capsule.

endocrinologist: A doctor who is trained to diagnose and treat disorders of the endocrine glands. (These glands secrete hormones that effect many body functions).

endotracheal tube: A breathing tube placed in the mouth that goes into the trachea.

ependymoma: Tumor that arises from cells that line the passageways in the brain where cerebrospinal fluid is produced and stored. Ependymomas are either supratentorial or infratentorial. Most ependymomas in children are infratentorial, located in or around the fluid-filled fourth ventricle.

~ F ~

frontal lobe: A groove in the brain that has much to do with the intellect and the ability to fit into a social group, helping us plan and prioritize, concentrate and recall, and exert control over our behavior.

functional magnetic resonance imaging: Abbreviated as fMRI. A scanning technique used to show brain function by demonstrating changes in the chemical composition of brain areas or changes in the flow of fluids.

~ G ~

gadolinium: The contrast material used for magnetic resonance imaging.

Gamma Knife: The brand name for a device that a surgeon uses to perform stereotactic surgery.

ganglia cells: Groups of nerve cells.

ganglioglioma: A type of brain tumor that most commonly occur in the temporal lobe of the cerebral hemispheres, the third ventricle, and less commonly in the spine. These tumors arise in the ganglia cells.

gastrostomy tube: Abbreviated as G tube. A tube used for feeding that goes through the abdominal wall and into the stomach.

germ cell tumor: Also known as germinoma, embryonal carcinoma, endodermal sinus tumor, or teratoma. Tumor arising in the pineal or suprasellar regions, above the pituitary gland. This type of tumor is most often diagnosed around the time of puberty and is more likely to affect boys than girls.

glial cell: A general name for cells of the central nervous system that nourish and support the nerve cells and the blood vessels that supply the nervous system. There are several specific types of glial cells: astrocytes, ependymal cells, and oligodendrocytes.

glioma: A tumor arising from glial cells or the supporting cells of the nervous system.

grade: When related to a tumor, it reflects the (high or low) potential for growth and degree of anaplasia.

granulocyte colony-stimulating factor: Abbreviated as G-CSF. A medication given by injection to stimulate white blood cell production.

gray: Abbreviated as Gy. A unit of measurement in radiation; can be used interchangeably with rad.

gray matter: A deeply folded area in the brain made up of billions of cell bodies whose darkish cast gives its name. It includes regions of the brain involved in muscle control, sensory perception such as seeing and hearing, memory, emotions, and speech.

gross total resection: Complete removal of a tumor as measured by the surgeon's observation (not by a microscope).

guided imagery: Uses techniques involving visualization of peaceful images guided with a soothing voice to help cope with painful or anxiety provoking procedures through relaxation.

~ H ~

hematocrit: A measurement of red blood cells in the blood; often used as the basis for decisions regarding transfusions.

hematoma: A collection of blood most commonly under the skin.

hemiparesis: Muscle weakness of one side of the body.

hemiplegia: Complete paralysis on one side of the body.

hemispheric astrocytoma (HCA): A type of brain tumor that occurs commonly within the cerebellum, but it may occur all over the central nervous system.

hemoglobin: A measurement of red blood cells in the blood; often used as the basis for decisions regarding transfusions. This number accounts for approximately one third of the hematocrit.

Hickman: A specific type of tubing placed through the chest wall and into a large blood vessel used for accessing veins.

hippocampus: Part of the brain that assists in the formation of memories from new experiences.

home care: A hospital department or organization designed to provided equipment, support, and nurses so that medical care can be undertaken at home.

hormone: A substance that the body produces that acts as a messenger to affect other organs.

hospice: Organizations that specialize in end-of-life care.

hydrocephalus: A buildup of abnormal amounts of cerebrospinal fluid within the brain's ventricular system that causes pressure on the brain.

hyper-: A prefix to medical words that means "high" or "elevated."

hyperfractionated radiation therapy: The administration of radiation therapy in smaller and more frequent doses to equal the total prescribed amount.

hypertension: Elevated (high) blood pressure.

hypo-: A prefix to medical words that means "low."

hypotension: Low blood pressure.

hypothalamus: A regulatory center involved in many functions, such as hormone secretion, the autonomic nervous system, eating, sleeping, temperature, emotion, and sexual behaviors.

hypotonic: Floppy; low muscle tone.

hypoxia: Low level of oxygen in the blood.

~ I ~

immune system: The body's defense system that protects it from harmful foreign substances such as bacteria and viruses.

immunotherapy: Using the body's own defense system (antibodies, white blood cells, and so forth) to combat a tumor.

infratentorial: The bottom portion of the brain (located in the posterior fossa under the tentorium) consisting of the cerebellum and brainstem.

intensity-modulated radiation therapy: Abbreviated as IMRT. A three-dimensional computer-aided radiation therapy that targets treatments at the tumor, decreasing damage to normal tissue.

intracranial pressure: Abbreviated as ICP. The pressure inside the skull, brain tissue, and cerebrospinal fluid.

intramuscular: Abbreviated as IM. Injection into a muscle.

intrathecal injection: An injection into the cerebrospinal fluid often used as a part of chemotherapy or pain management applications.

intravenous: Abbreviated as IV, also called contrast. Injection into a vein.

intubation: The placement of a tube in the trachea (windpipe) to assist with breathing.

invasive: Refers to something that invades tissue, including tumors, procedures, and medical specialties (such as invasive radiology, which often places intravenous catheters).

~ L ~

lamina: A thin, flat layer of membrane that is the bony arch of a vertebra.

laser: A technique using focused light to evaporate tumors during surgery

leptomeningeal: Most commonly used to describe spread of the cancer to the tissue lining around the brain.

leukocyte: A white blood cell.

limbic system: A network of complex interconnections surrounding the top of the brainstem that links our basic functions and emotions to areas of the cerebrum that have to do with those higher levels of thought and understanding that we associate with being human.

long-term follow-up clinic: Abbreviated as LTFC. A specialized clinic that works with survivors and their families to provide comprehensive care, education, and counseling.

lumbar puncture: Abbreviated as LP; also called a spinal tap. A needle penetrates the subarachnoid space of the lumbar spine and a sample of spinal fluid is withdrawn for laboratory examination. This procedure can also be used to inject dye prior to myelography or to administer medication.

~ M ~

magnetic resonance imaging: Abbreviated as MRI. A scanning technique used to diagnose and monitor brain tumors. With this technique magnetic fields, rather than radiation, are used to make a picture of an area of the body.

malignant: Tending to grow quickly and spread, causing harm to surrounding and/or distant tissue.

medulla: A structure of the brainstem that controls breathing, swallowing, blood pressure, and heart rate.

medulloblastoma: The most common malignant brain tumor in children, typically arising in the middle of the cerebellum, interfering with the flow of cerebrospinal fluid and causing hydrocephalus.

meninges: The covering membranes of the brain consisting of the dura mater, the arachnoid, and the pia mater.

meningitis: Infection or inflammation of the membranes (meninges) that cover the brain and spinal cord.

metastasis: The spread of tumor cells of disease from one part of the body to another.

midbrain: A part of the brain between the pons and the cerebral hemispheres in the brainstem that governs basic vision and hearing.

motor area: A strip of brain with distinct sections controlling motor activity such as swallowing, chewing, talking, and movement of the hand, legs, toes, etc.

~ N ~

narcotic: A class of medication used for pain management.

nasogastric tube: Abbreviated as NG tube. A tube from the nose into the stomach often used for feeding but sometimes used to remove gastric fluids.

nasojejunal tube: Abbreviated as NJ tube. A tube, used for feeding, that goes from the nose to the part of the intestines called the jejunum.

necrosis: Dead cells or tissue.

neoplasm: A tumor, either non-malignant or malignant.

nerve body: Makes up each nerve cell with branches called dendrites and axons extending outward.

neuroglia: During fetal and infant development, certain neuroglial cells help guide the neurons to their final destinations in the brain and spinal cord. Others surround and nourish

neurons while ingesting debris. Neuroglia are involved in over half of all brain tumors.

neurologist: A doctor specializing in the diagnosis and treatment of disorders and diseases affecting the brain, spinal cord, and peripheral nerves.

neurons: The workhorses of the nervous system, sending and receiving signals to and from the brain through numerous connections.

neuroendocrinologist: A doctor who specializes in endocrinology who will also be able to monitor the possible effects of surgery, radiation therapy, or chemotherapy on the endocrine glands.

neuro-oncologist: A physician who specializes in the treatment of cancer and tumors affecting the brain and spinal cord.

neuro-ophthalmologist: A doctor specializing in the diagnosis and treatment of eye problems that are a result of damage to the brain.

neuropsychologist: A psychologist who specializes in the effects that injury to or diseases of the brain and spinal cord have on emotions, behavior, and learning.

neuro-radiologist: A physician who orders scans, such as MRIs and CT scans, so that the effectiveness of treatment can be monitored.

neurosurgeon: A surgeon specialized in the diagnosis, treatment, and surgical management of disorders and disease of the brain, spine, and nervous system.

neutrophil: A type of white blood cell that fights infections. Neutrophils may also be referred to as segs or polys.

neutropenia: A low number of neutrophils in the blood, placing the patient at increased risk for infection.

non-malignant brain tumor: A slow-growing, benign tumor that does not spread to other parts of the body.

nurse practitioner or specialist: A specially educated nurse who provides direct care for your child in collaboration with your child's physician.

nystagmus: A particular movement of the eye.

~ O ~

occipital lobe: The visual center of the brain, making sense of information coming into the brain from the eyes.

occupational therapist: A specially trained person who deals with certain rehabilitation issues.

oligodendroglioma: A type of tumor that occurs in oligodendrocytes, a type of supportive brain tissue. They are most commonly found in the cerebral lobes of the brain.

Ommaya reservoir: A medical device implanted under the scalp that delivers medication directly into the ventricles.

oncogenes: Fragments of genetic material (DNA) that carry the potential to cause cancer.

oncologist: A physician who specializes in the treatment of cancer.

ophthalmologist: A doctor who specializes in the diagnosis and treatment of visual disorders and diseases.

optic pathway glioma: Brain tumors that involve the optic nerve. These tumors may lead to vision and/or hormone problems.

osteoporosis: A disorder resulting from too little new bone formation or too much bone loss, causing bones to become weak.

~ P ~

papilledema: Swelling of the optic nerve usually caused by intracranial pressure that can be seen on physical examination by looking at the back of the eye with an ophthalmoscope; not an uncommon finding with brain tumors.

paralysis: Total loss of muscle control.

paraparesis: Weakness of the legs only.

paresis: Partial loss of muscle control.

parietal lobe: A fissure (groove) in the brain that is responsible for the functions of logic, math, taste, pain, sensations of pressure, pain, and temperature.

pathologist: A doctor who specializes in the diagnosis of disorders and diseases by studying the tissues and fluids of the body.

peripherally inserted central catheter line: Abbreviated as PICC line. A type of intravenous catheter.

peripheral nervous system: The network of nerves that connects the central nervous system to the arms, legs, eyes, ears, and other organs.

physical therapist: A specially trained person who deals with certain rehabilitation issues.

physiatrist: A doctor who has specialized training in the field of physical medicine and rehabilitation (also called PM and R).

pia mater: The membrane closest to the brain's surface which contains major blood vessels and covers the brain's wrinkles and folds.

PICU: Abbreviation for *pediatric intensive-care unit*.

pineoblastoma: A sub-type of a supratentorial primitive neuroectodermal brain tumor of the cerebral hemisphere. Symptoms depend on location and proximity to the CSF spaces.

pituitary gland: An endocrine gland that is situated at the base of the brain and supplies hormones that control many vital processes.

plasticity: The brain's ability to adjust to injury or loss of brain cells by making new interconnections which take over for the loss of others.

platelet: A blood component that functions in blood clotting.

pons: A structure of the brainstem that links the cerebrum to the cerebellum and medulla oblongata.

port: A medical device implanted under the skin, usually in the chest wall, that allows access to the blood vessels to give medication and to draw blood.

positron emission tomography scan: Abbreviated as PET scan. A type of scanning used to measure activity of the brain.

postictal: A period of sleepiness, confusion, or agitation after a seizure.

posterior fossa: The portion or location in the brain that includes the cerebellum, brainstem, and fourth ventricle.

posterior fossa syndrome: A problem that sometimes develops after posterior fossa surgery that causes a patient to be very floppy and irritable. This can be accompanied by hemiparesis, mutism, and cortical blindness.

primary tumor: A type of tumor that is made up of cells unique to the organ or tissue where they start.

primitive neuroectodermal tumor: Abbreviated as PNET, a tumor arising in the posterior fossa of the brain. However, tumors with the same characteristics can also occur in other areas of the brain. This type of tumor tends to spread to other areas of the brain and spinal cord.

protocol: A written plan that specifies exact procedures to follow (related to clinical trials and therapies for brain tumors).

proton-beam radiation: A specific type of radiation therapy using particle beams of protons in a very confined area of the brain.

pulse oximeter: A medical instrument used to measure the oxygen level in the blood by a painless lighted probe.

~ R ~

rad: A unit of measurement used in radiation; can be used interchangeably with a unit called the Gray (Gy).

radiation oncologist: A physician who specializes in the treatment of tumors by radiation.

radiation therapy: Sometimes also called XRT or RT. A technique used to destroy tumor cells by exposing the affected tissue to radiation. This therapy usually consists of daily sessions for several weeks.

radiologist: A doctor who specializes in the interpretation of x-ray films and other imaging techniques.

reiki: An form of alternative healing that promotes relaxation and the relief of physical systems through a gentle touch.

remission: The decrease or disappearance of clinical symptoms of disease.

resection: Surgical removal of a tumor. *See also* gross total resection *and* subtotal resection.

reticular formation: Runs down the length of the brainstem and is the part which is responsible for alertness or arousal.

~ S ~

secondary tumor: A tumor that develops away from the original site. *See also* metastasis.

sedative: Medication used to make a patient sleepy or more relaxed; often used during medical procedures.

seizure: Also called a convulsion; excitation of neurons in the brain leading to involuntary muscle contractions or sensations.

sensory area: A strip of cortex going up one lobe, over the cerebral fissure, and down the other lobe. It is concerned with sensations coming in from the eyes, ears, nose, tongue, and other organs.

sepsis: An infection in the blood stream.

shock: A serious medical condition in which organs are not receiving adequate blood flow. It is usually associated with low blood pressure.

shunt: A plastic catheter with a reservoir and a valve used to relieve the increased intracranial pressure caused by hydrocephalus.

simulation: A confirmation procedure in radiation therapy to ensure that the marked location is accurate.

single-photon emission tomography: Abbreviated as SPECT. A new nuclear imaging technique that involves injection of a radioisotope (radioactive substance) that the blood then carries to the brain's tissues. Areas with more blood flow absorb more radioisotope. These areas are highlighted by colors, showing brain blood flow.

social worker: A health care profession who aids patients and families in multiple aspects of nonmedical care, including supportive counseling, financial aid, communication with physicians, and school issues.

speech and language pathologist: A therapist trained specifically in rehabilitative issues involving communication and eating.

spinal tap: *See* lumbar puncture.

stem cell transplant: A procedure in which healthy cells able to produce the components of blood are given to a patient to begin producing new blood cells for the patient. This is in contrast to bone marrow transplant by virtue of where the donor cells come from. Stem cells are removed (or harvested) usually from the peripheral blood.

steroids: Corticosteroids are medications used for many different complications due to treatments; including controlling the buildup of fluid and swelling of the brain before or after surgery, mimicking the effects of hormones which a patient might have lost the ability to make naturally, and they suppress inflammation, which can reduce the signs and symptoms of inflammatory conditions. Anabolic steroids are different and are used, on rare occasions, as appetite stimulants.

stereotactic radiosurgery: A single-dose focal radiation treatment in which many relatively weak doses of radiation are directed at a small target simultaneously, but from numerous points of the head.

stereotactic or **stereotaxis**: Computed tomography scanning and magnetic resonance imaging used to permit positioning (for surgery or radiation) in three dimensions so that a tumor can be located very precisely.

subcutaneous: Abbreviated as SQ. Under the skin; often referring to the way shots, such as granulocyte colony-stimulating factor or growth hormone, is given.

subtotal resection: Less than total surgical removal of a tumor.

supratentorial: The large top portion of the brain (above the tentorium) consisting of the cerebral hemispheres.

~ T ~

temporal lobe: A fissure (groove) within the brain that is responsible for memory, auditory processing, and sensory integration processes.

tentorium: A flap separating the cerebral hemispheres from the structures of the posterior fossa.

thalamus: Located as part of the diencephalon, this serves as an information processor for much of what goes to and from the brain.

thrombocytopenia: Low number of platelets.

tinnitus: Buzzing or ringing in the ear, a symptom common with tumors of the acoustic nerve. May also be a side effect of some medications.

tracheostomy: A hole made in the trachea in which a breathing tube is placed.

tumor: Abnormal growth. Tumors may be non-malignant or malignant (by cell type or location).

~ U ~

ultrasound: A technique using sound waves (to give a picture) that is used in the diagnosis of a wide variety of conditions.

~ V ~

ventricles: Small fluid-filled cavities within the brain; where cerebrospinal fluid is produced

ventriculoatrial shunt: Abbreviated VA shunt. Drains cerebrospinal fluid from the ventricles of the brain into the heart.

ventriculoperitoneal shunt: Abbreviated VP shunt. Drains cerebrospinal fluid from the ventricles of the brain into the abdominal cavity. *See also* shunt.

ventriculostomy: A hole made to allow cerebrospinal fluid to drain from the ventricles. This may be external (so the fluid flows into a drain outside the body) or internal (such as a third ventriculostomy).

vertebrae: Hollow spinal bones of the neck and back.

vertebral column: Also called the spinal column. It is made up of separate vertebrae along your back and neck.

vertigo: Dizziness with the sensation of spinning or moving.

vital signs: These are blood pressure, pulse, respiration, and temperature.

~W~

white matter: The axons connected to the cell bodies extend below the cortex.

~ X ~

X-Knife: The brand name for the device that a surgeon uses to perform stereotactic surgery.

~Y~

yoga: A form of alternative healing where balance, coordination, strength, and relaxation may occur through gentle stretching exercises.

References

Aukema, E.J., Last, B.F., Schouten-van Meeteren, A.Y. N., Grootenhuis, M.A. (10 September 2010). Explorative study on the aftercare of pediatric brain tumor survivor's: A parent's perspective. *Support Care Center,* 19, 1637-1646. doi: 10.1007/s00520-010-0995-6.

Bowers, D. Adhikari, s., El-Khashab, Y.M., Gargan, l., & Oeffinger, K. (2009). Survey of long-term follow-up programs in the United States for survivors of childhood brain tumors. *Pediatric Blood & Cancer*, 53, 1295-1301.

Building Mental Muscle. (2010)., [diagram illustration]. *Your brain and what it does: a diagram of how the brain works*. Retrieved 23 January 2012 from: http://www.brainwaves.com/brain_diagram.html.

De Luca, C.R., Conroy, R., McCarthy, M.C., Anderson, V.A., Ashley, D.M., (2009). Neuropsychological impact of treatment of brain tumors. Goldman, S., Turner, C.D., (eds.) *Late effects of treatment for brain tumors.* New York, NY: Springer Science and Business Media, LLC.

Reference

Ellenberg, L.M., Liu, Q., Gioia G., Yasui, Y., Packer, R.J., Mertens, A…Zeltzer, L.K. (1 November 2010). Neurocognitive report from the childhood cancer survivor study. *Neuropsychology.* 23(6), 705-717. doi: 10.1037/a0016674.

Gurney, J.G., Krull, K.R., Kadan-Lottick, N., Nicholson, H.S., Nathan, P.C., Zebrack, B…Ness, K.K. (10 May 2009). Social outcomes in the childhood cancer survivor study cohort. *Journal of Clinical Oncology.* 27(14), 2390-2395 doi:10.1200/JCO.2008.21.1458.

Moore, T. & Wagner, S. (2009). Caregiver and family issues for brain tumor survivors. Goldman, S., Turner, C. (Eds). *Late Effects of Treatment for Brain Tumors*, New York, NY. Springer.

Nathan, P.C., Patel, S.K., Dilley, K., Goldsby, R., Harvey, J., Jacobsen, C…Armstrong, F.D. (August 2007). Guidelines for identification of, advocacy for, and intervention, in neurocognitive problems in survivors of childhood cancer. *Archives of Pediatrics & Adolescent Medicine.* 161(8), 798-806. Retrieved from http://archpedi.ama-assn.org/cgi/content/abstract/161/8/798.

Nandagopal, R., Laverdiere, C., Mulrooney, D., Hudson, M.M., Meacham, L. (2008). Endocrine late effects of childhood cancer therapy: a report from the children's oncology group. *69* (28), 65-74. doi: 10.1159/000111809.

National Cancer Institute. Childhood Brain Tumors. Retrieved 23 January 2012 from http://www.cancer.gov/cancertopics/treatment/childhoodcancers.

Oeffinger, K.C. (10 May 2009). Health behaviors, medical care, and interventions to Promote healthy living in the childhood cancer survivor study cohort. *Journal of Clinical Oncology. 27* (14), 2363-2373. doi: 10.1200/JCO.2008.21.1441.

Schultz, K.A., Ness, K.K., Whitton, J., Recklitis, C., Zebrack, B., Robison, L.…Mertens, A.C. (2007). Behavioral and social outcomes in adolescent survivors of childhood cancer: A report from the childhood cancer survivor study. *Journal of Clinical Oncology*, 25, 3649-3656.

St. Jude Children's Research Hospital. (2012). Brain tumors. Retrieved 23 January 2012 from http://www.stjude.org/stjude/v/index.jsp?vgnextoid=567fbfe82e118010VgnVCM1000000e2015acRCRD.

Reference

Zeltzer, L.K., Recklitis, C., Buchbinder, D., Zebrack, B., Casillas, J., Tsao, J.C.I…Krull, K. (10 May 2009). Psychological status in childhood cancer survivors: a report from the childhood cancer survivor study. *Journal of Clinical Oncology*. 27(14). 2396-2404. doi: 10.1200/JCO.2008.21.143.

Embracing the challenge today gives hope for tomorrow.

VARIAN medical systems | A partner for life

Children's Brain Tumor Foundation

274 Madison Avenue, Suite 1004, New York, NY 10016
Phone: 212.448.9494 • Fax: 212.448.1022
Toll Free Patient Support Line: 866.228.HOPE (4673)
Email: info@cbtf.org • Website: www.cbtf.org