

# UNDERSTANDING AND COPING WITH YOUR CHILD'S BRAIN TUMOR

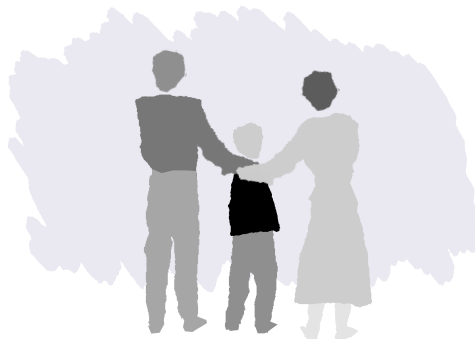
*A Guide For Families  
A Resource For Hope*



**NATIONAL BRAIN TUMOR  
FOUNDATION**

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# Understanding and Coping with Your Child's Brain Tumor

A Guide For Families  
A Resource For Hope

**Mary Alice Dragone, MS, RNC, PNP, CPON**  
**for the National Brain Tumor Foundation**

# Dedication

**T**his book is dedicated to the memory of Timothy Lawrence Pizzi (1983-1996), a young man who loved life and who loved people. During his six-and-a-half year battle with brain cancer, Tim rarely complained. Instead, he lived his short life to the fullest extent possible. He saw every challenge as an opportunity to grow closer to his God, enrich his family, contribute to his community, and further the cause of brain tumor patients and their families.

Tim once remarked that God probably allowed him to have a brain tumor so he could help others. That is the way he was, always thinking of his faith, family, and friends rather than himself. He battled his cancer bravely, and inspired many by his courageous example. This child was a soldier, in every sense of the word, involved in a war against brain cancer. Tim's personal battle is over, but those of us who fought with him continue in the war against this disease.

As in any war, the war against brain cancer involves many individual battles and some casualties. Victories come most often, though, to those leaders who can take all the soldiers at their disposal and form them into a team. This battle in which you now find yourself involves many people. As the parents of a child with brain cancer, your challenge is to take all these people and cause them to function as a team.

As your child's foremost advocate, you are the leader of that team. While it is important to be a bold leader, it is also necessary to be an informed leader. No leader is perfect, but the best leaders know how to rely on others for advice and support. Armed with both the courage to act and a willingness to listen and gather information, you can then lead your team. The concerted effort of the whole team—you, your child, your family, your community, your treatment team, and the team at the National Brain Tumor Foundation—will give you much reason to hope for the best for your child.

Tim showed our team that we can do more than just survive this battle; we can thrive as a family and as a community if we are willing to take charge of the things we can control and face those things that are beyond our control with courage, faith, hope, and even a sense of humor.

This guide will help you to take charge of the things you can control. It will provide you with information about the “ammunition” that is available to you in the fight against brain cancer. It also contains an extensive list of “allies” who can join you in your fight. It is our hope that Tim’s example and the example of so many who have battled brain cancer, many of whom have survived for many years, will deepen your faith, enrich your family, and strengthen your friendships so that you and your team can face the battle full of hope.

## ***Acknowledgments***

Timothy touched the lives of many people with his warmth, courage, and sense of humor. This guide was made possible in part by the generous gifts of the more than 230 people who loved Tim, and who wanted to help other children like him. Special thanks to Art Kern and Judy and Dennis Sweeney not only for their special generosity but also for their very special friendship and personal support. Finally, we are indebted beyond words to the National Brain Tumor Foundation for their steadfast support and monumental efforts on behalf of our family and brain tumor patients and families worldwide.

LARRY, WENDY, & CHRIS PIZZI  
NOVEMBER 1996

# Author's Acknowledgments

The author would like to thank the following people for their thoughtful review of this booklet:

- Michael Medlock, MD, Department of Neurosurgery, Georgetown University Medical Center
- Joseph Gootenberg, MD, Department of Pediatric Hematology/Oncology, Georgetown University Medical Center
- Barry Anderson, MD, PhD, Department of Pediatric Hematology/Oncology, Georgetown University Medical Center
- Leslie Nelson, MSW, LICSW, Department of Pediatric Hematology/Oncology, Georgetown University Medical Center
- Philip Cogen, MD, Department of Pediatric Neurosurgery, Children's Hospital National Medical Center
- Gregory Reaman, MD, Department of Pediatric Hematology/Oncology, Children's Hospital National Medical Center
- Roger Packer, MD, Department of Pediatric Neurology, Children's Hospital National Medical Center
- Margaret Oeller, parent

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# Introduction

**R**esearch and education continue to make progress toward the cure of childhood brain tumors. Just as important as these scientific endeavors is the advocacy for children provided by their families. Advocacy involves gaining knowledge, finding resources, and asking questions that will lead to optimal care, and therefore, optimal results. The information contained in this booklet is designed to help you become an effective advocate for the child you love. As you learn more, the hope you gain for the best possible outcome for your child can help you get through the rollercoaster of events and emotions surrounding diagnosis and treatment.

There is a great deal of information in this guide; some things are important for you to know now, some you will need to refer back to later, and some you will not need to apply to your particular situation. Many medical terms may be new to you. Refer to the basic neuroanatomy glossary at the back of the guide for clarification and definition of these terms. Read through each section of the guide and write down any questions which may arise. Address each section of this guide the same way you will need to face life with a child who has a brain tumor: one step at a time.

# **Diagnosis of Brain Tumors in Children**

## ***Why Can It Be Difficult to Diagnose Brain Tumors in Young Children?***

Diagnosis is difficult in young children for several reasons:

- ✓ Young children have a limited ability to describe symptoms characteristic of brain tumors, such as blurred vision or headaches.
- ✓ Some symptoms of brain tumors, such as vomiting or irritability, can occur in a variety of more common childhood illnesses.
- ✓ Other symptoms, such as behavioral changes, may be very subtle and develop over a long period of time.
- ✓ It can be challenging to perform a thorough neurological assessment and diagnostic tests such as CT or MRI scans on children who are frightened, not fully cooperative, or hard to sedate for procedures.

## ***What Are Common Symptoms of Brain Tumors in Children?***

Symptoms are often vague in children, especially in very young children who are not able to fully describe their symptoms. What differentiates these symptoms from those of routine childhood illnesses is that they persist and worsen over time.

### **General Symptoms That Apply to Many Tumors**

- Vomiting, usually occurring in the morning without nausea
- Headache
- Double vision or inability to focus on an object
- Head tilting to one side
- Increased size of head



- Different sized pupils, or pupils that do not react to light
- Unsteadiness, loss of balance, or tremors
- Weakness, particularly one-sided weakness
- Decreased coordination or motor skills
- Fatigue, sleepiness
- Irritability
- Change in behavior (different pattern or frequency of irritability or sleepiness, angry outbursts)

Some symptoms may develop as a result of the tumor location as it affects movement, sensation, the normal flow of *cerebrospinal fluid* (CSF), or other body functions:

- Optic gliomas and craniopharyngiomas (both are located near critical vision pathways, the *pituitary gland* and the *hypothalamus*): change in vision, abnormal eye movements (nystagmus), frequent thirst and urination, delayed or accelerated growth, headache
- Medulloblastomas and cerebellar tumors (located in the *posterior fossa* or *cerebellum*): clumsy, uncoordinated walking (ataxia), difficulties with speech, headache, vomiting
- Brainstem tumors (located in the *brainstem*): changes in walking, difficulty swallowing, speech difficulties, head tilt, one-sided muscle weakness, drooping eyelid, facial muscle weakness, crossed eyes or decreased vision
- Cerebral tumors (located in the *cerebrum*): seizures, abnormal sensation, one-sided weakness, speech difficulties

♦ **Note to Parents: Some of the terms shown in italics may be unfamiliar to you. These words are defined in a glossary at the end of this booklet.**

## **How Are Brain Tumors Diagnosed?**

Your child's doctor relies on special imaging procedures or scans to locate and identify tumors in the brain and spinal column. Two commonly used devices are the CT (Computerized Tomography) scan and the MRI (Magnetic Resonance Imaging) scan. CT scanning uses x-rays with computer guidance to create images of the brain while MRI scanning uses radio waves and a magnetic field to create images. A contrast dye, given intravenously, is frequently used during scanning to help the doctor identify abnormal tissue. Very young children often require sedation to remain still for the duration of the scans. Although the scans are not painful, the testing can be noisy and the child is held in a confining space.

There are some specific steps you can take which will make your child's testing experience a more positive one:

- ✓ Ask if there are any open MRI machines in your area. These relatively new machines are better for children, because there is no confining space.
- ✓ Ask the radiologist if you can remain with your child during the test.
- ✓ Ask the radiology department to make two copies of these scans, one for the doctor, and one for you to keep for your records. This will be especially helpful if you need to send scans to a specialist or to another doctor for a second opinion.
- ✓ Ask the technician if the MRI is equipped with a tape-playing system. If this setup is available, ask your child what he or she would like to listen to during the scanning process. Be sure to bring a "backup" tape, in case you experience "technical difficulties."

The results of these scans will be interpreted by a radiologist and given to your doctor. If a tumor is evident, the doctor often orders a biopsy to confirm the specific tumor type. Brain stem gliomas, however, are generally diagnosed by scans alone.

# Understanding Tumor Types

Tumors are described by the type of cell involved, their location, and the degree of malignancy.

## Type of Cell Involved

The type of tumor is defined by the cell of origin, for example:

**Glial Cells:** Gliomas are composed of glial cells which make up the connecting or structural tissue of the brain. Glial cells lie between nerve cells and the blood vessels that supply the nervous system. The three types of glial cells are ependymal cells, astrocytes, and oligodendroglial cells.

- Ependymal cells line the fluid-filled cavities of the brain (*ventricles*) and spinal cord (central canal). Tumors made up of these cells are called ependymomas.
- Astrocytes get their name from their starlike shape. They are part of the structural tissue of the brain. Tumors made up of these cells are called astrocytomas. This is the most common type of brain tumor found in children.
- Oligodendroglial cells are also part of the structural tissue of the brain. Tumors made up of these cells are called oligodendrogliomas.

Some tumors may be made up of more than one type of glial cell. They are called mixed gliomas.

**Primitive or Undifferentiated Cells:** A Primitive Neuroectodermal Tumor (PNET) is made up of primitive cells much like those involved in the early development of the nervous system. These cells tend to grow quickly and spread easily within the brain and spinal cord. Medulloblastomas, located in the *posterior fossa*, are one type of PNET.

## Location

The name of the tumor often defines its location. For example:

- Cerebellar Astrocytoma: This tumor is located in the *cerebellum* and is made up of astrocytes.

- **Brain Stem Glioma:** This tumor is located in the *brain stem* and is made up of glial cells.
- **Optic Nerve Glioma:** This tumor is located on the optic nerve and is made up of glial cells.

Ask your doctor to show you a model or picture of the brain and explain where the tumor is and how it could affect that part of the brain. After you have had time to process this information yourself, explain it simply and honestly to your child.

## **Degree of Malignancy and Tumor Grade**

A tumor is any new growth of tissue that forms a mass. The degree of malignancy and “grade” of a tumor are based on the degree of differentiation (maturity) and aggressiveness (growth rate) of the cells involved. Commonly used terms such as “benign” or “malignant” are used to describe brain tumors. Other terms are also used to describe the cells and characteristics of brain tumors.

**Benign:** A tumor is benign if its relatively normal appearing cells grow slowly, do not invade normal tissue, and do not spread to distant sites. However, tumors composed of “benign” or slow growing cells can occur in critical areas of the brain. This tumor may cause serious damage, be life-threatening, or be difficult to surgically remove. Thus, “benign” may not always be “good.” Benign tumors may also be referred to as low grade or well differentiated.

**Malignant:** A tumor is malignant if the cells grow quickly and aggressively and there is invasion of normal tissue. Unlike malignant tumors in other areas of the body, brain tumors rarely spread outside the brain and spinal cord. However, malignant tumors have the ability to spread from their area of origin to other areas of the brain and spine through the cerebrospinal fluid. Malignant tumors may also be referred to as high grade, poorly differentiated, or anaplastic.

# Choosing Your Child's Treatment

There are many centers of excellence in this country where your child can be cared for by a team that specializes in treating pediatric brain tumor patients. Do not assume that highly competent care cannot be provided in your local area. The following suggestions are intended to help you find a treatment team that best meets your child's (and your) needs.

## General Suggestions

- Get second opinions.
- Ask about referrals from:
  - Brain tumor organization hotlines (see Resource section at the end of this booklet);
  - Support groups in your area; and
  - Your child's primary care provider.
- Contact the children's hospital and the university medical centers in your area to ask for recommendations of local pediatric oncology, pediatric neurosurgery, and radiation oncology departments. The National Brain Tumor Foundation can also recommend specialists nationwide.
- Review the literature and look for the names that come up repeatedly in reference to your child's particular type of tumor or its treatment. You can access this literature in several ways:
  - Search the Internet (see Resource section at the end of this booklet).
  - Ask your local county librarian (main library) or nearest medical school librarian to do a Medline search on your child's particular type of tumor. A Medline search will provide you with abstracts of articles that list the authors, give a description of the study, and often list the institutions where authors practice. You can then request copies of

### ***There's Not Always Time***

In many cases, at the time of diagnosis there is very little time for thorough research or careful consideration of treatment team members because treatment decisions must be made quickly, especially with regard to surgery.

the full articles that interest you.

—Ask the medical school librarian to see the latest conference reports from medical and consumer organizations/associations dealing with brain tumors. Check for speakers and their institutions.

- When you contact a nationally known expert, you may want to send a copy of your child's scans, diagnosis, and pathology report. Once this individual has reviewed your child's case, he or she may call you to discuss any questions you may have about your child's treatment up until this point and to offer any opinions he or she may have concerning further treatment. He or she may also recommend colleagues in your local area who are skilled in the management of pediatric brain tumors.

## ***Typical Members of a Treatment Team and Their Functions***

The following is a list of treatment team members for any brain tumor patient. You may wish to select team members who also specialize in pediatrics.

- ✓ Neurosurgeon: Specialist in techniques to biopsy and remove brain tumors
- ✓ Oncologist/Neuro-oncologist: Specialist in therapies (including chemotherapy) used to treat tumors/brain tumors
- ✓ Radiation Oncologist: Specialist in the use of radiation therapy to treat tumors
- ✓ Neurologist: Specialist in the functions of the nervous system
- ✓ Endocrinologist: Specialist in the functions of the endocrine system (physical growth, sexual development, functioning of the glands of the body)
- ✓ Neuropsychologist: Specialist in assessing learning and development who can design and coordinate educational plans to help your child reach his or her full potential
- ✓ Nurse Practitioner/Clinical Nurse Specialist: Nurse with an advanced degree who often works with the Oncology, Neurosurgery, or Radiation

Therapy teams to treat children with brain tumors, manage side effects of treatment, educate their families, and manage their care

- ✓ Social Worker: Professional who helps families meet their physical and emotional support needs
- ✓ Art Therapist/Child Life Specialist: Professional who uses art and/or play therapeutically to help children cope with the effects of diagnosis and treatment

## ***Communicating with Specialists***

There are no absolute “right” answers to the following questions. To find the “best” specialist for your child, you will want to assess the individual’s overall expertise and treatment style. You do not need to make this decision alone. Your child’s primary care provider is an excellent resource to discuss the options available to your child for care. Don’t forget to check with your insurance company to ensure that a particular specialist will be approved by your plan. Last but not least, trust your instincts.

### **Some Suggestions for Dealing with Specialists**

***Advocacy involves informed questioning.***

- Do not be afraid to ask questions.
- Write questions down ahead of time and ask them at the beginning of your meeting, not at the end.
- Do your homework so you can ask informed questions. Take advantage of the resources mentioned in this guide to develop your questions. I understand that some children are treated with radiation more than once a day. Is that an option for us? is a better question than. What are our options?
- Be gently persistent, but also realistic. Doctors must balance scientific objectivity with compassion and hopefulness. In the end, though, you want his or her candid objectivity.
- Do not expect your child’s doctor to predict the future. Accept “best guess” answers to some questions.

## Specific Questions To Ask Specialists

- How many children with brain tumors have you treated in the past year? Past 5 years?
- How many children with \_\_\_\_\_ (your child's specific type of brain tumor) have you treated in the past year? Past 5 years?
- Are you Board Certified (indicates passage of a specialty certification examination) in your specialty area?
- Are you a specialized pediatric \_\_\_\_\_ (oncologist/neurosurgeon/neurologist/radiation oncologist) ?
- How would you describe your treatment style? Would you describe it as aggressive or conservative?
- [For Radiation Oncologist] Does your department sedate children for radiation therapy? If yes, what methods are used? If not, what other methods are used to help children remain still during treatment?
- What are the major risks associated with the treatment you provide?
- Would you see yourself as being the coordinator of the treatment team?  
IF YES, ask:
  - How will care be coordinated (joint clinics, conferences, interdisciplinary team)?
  - How will information be communicated to me?
  - How are long-term side effects monitored?
  - How is psychosocial support provided?
  - How will the child's return to school be facilitated?
  - Are nurse practitioners, clinical nurse specialists, social workers, or art/play therapists part of the team?
  - How is neuropsychological testing arranged?
- IF NO, ask which specialist he/she would recommend as coordinator of the team.



## Issues for You To Evaluate After the Meeting

- Were your questions regarding risks of surgery, neurological outcomes, number of cases done, etc., answered honestly without sounding defensive?
- Did the specialist fully attend to your questions? Was there good eye contact? Was he or she able to tune in to your concerns with sincerity?
- Do you have the confidence in this individual that is necessary when entrusting the life of your child to his or her care?

# Treatment Methods

**Y**our child's age, symptoms, tumor type, tumor location, and prior treatment history will all influence the decision to pursue various treatment options. The basic options include, but are not limited to, surgery, radiation, and chemotherapy. Before beginning any course of treatment, your child's doctor will order a series of tests that will establish a baseline of information from which he or she can later judge the effects of the treatment. These tests may include, but are certainly not limited to: MRI/CT, EEG, speech evaluation, neuropsychological testing, blood tests (including endocrine function), and tests of vision and hearing. Changes in these areas, whether positive or negative, may affect your decision to continue a particular treatment.

## Surgery

The purpose of surgery is to biopsy the tumor to determine its type and to remove as much of the tumor as is possible without risking damage to important parts of the brain.

### Options

- ✓ A biopsy involves taking a sample of the tumor so that a specific diagnosis can be made. A biopsy most often takes place during the removal or resection of the tumor.
- ✓ Complete surgical resection is the attempt to remove the entire tumor. Your child's doctor will perform a CT or MRI scan after the surgery to determine how much of the tumor was actually removed.
- ✓ A partial (subtotal) resection removes only part of the visible tumor.
- ✓ When tumors are in highly critical areas of the brain, removing the tumor may pose too great a risk to your child. In cases where surgery may not be an option, chemotherapy and/or radiation may become the primary treatment. In other cases where the tumor is very slow growing, your child's treatment team may delay surgery and use frequent scans to follow the growth of the tumor.

## Tools Used in Surgical Procedures:

- **Ultrasonic Aspirator (Cavitron):** This device uses sound waves to cause vibration. The vibrations break tissue into small pieces that can be suctioned (aspirated) away.
- **Laser:** A laser is a surgical cutting tool that vaporizes small amounts of tissue. It is a very precise instrument. However, a laser may not be the instrument of choice in a specific surgery because it can cause heating of surrounding tissue, is relatively slow in action, and does not stop bleeding well.
- **Stereotaxy:** This technique gives very precise, three-dimensional information about the location of a tumor. It involves the use of a scanning device, sometimes with a frame around the head. Stereotaxy may be used for needle biopsies, placement of implants, and some microsurgery.
- **Cranial Nerve Monitoring:** This technique helps the surgeon locate the cranial nerves and avoid damage to them during surgery.
- **Neuroendoscopy:** A technique that allows for work within the *ventricles* and sometimes in the spinal canal. A neuroendoscope is a tube that has a small video camera and possibly other instruments attached to its tip.

## Shunting

Tumors can sometimes cause hydrocephalus, which is the blocking of the flow of *cerebrospinal fluid* (CSF) from the *ventricles* to the spinal canal. The resulting pressure that builds up in the child's head is referred to as *increased intracranial pressure*. While this condition can be life-threatening, it can be relieved by surgically placing a special tube, known as a *shunt*, to divert the extra CSF. The most common type of shunt in children is the ventriculo-peritoneal (VP) shunt that carries CSF from the ventricles to the peritoneum (abdomen) where it is reabsorbed.

Shunting may be required before or after tumor removal. It is most commonly needed in younger children with cerebellar or infratentorial tumors. These shunts can sometimes become blocked or infected. The symptoms the child experiences can often mimic the presenting symptoms of the child's tumor and can frighten the family. Ask your child's neurosurgeon

about potential problems, the expected duration of shunt placement, and anticipated revisions due to growth.

## Possible Complications

Surgery can lead to a number of possible complications, but your child's treatment team will take steps to ensure that your child has as few problems as possible. They may recommend certain medical treatments, both before and after surgery, to reduce complications, such as:

- steroids, to reduce swelling;
- diuretics, to reduce intracranial pressure;
- antibiotics, to prevent infection; and
- other medications, to prevent or treat seizures.

After surgery, the treatment team will carefully monitor your child for complications, including the following:

- Infection and bleeding after surgery.
- Neurological damage from manipulation of cranial nerves or other critical areas of the brain. Sometimes this cannot be avoided because tumor removal may occur very close to cranial nerves and other critical areas of the brain. Rehabilitation services such as occupational, physical, and speech therapy may be necessary to reduce the impact of neurological damage.
- Posterior fossa syndrome (also called cerebellar ataxia, cerebellar mutism, or pseudobulbar syndrome) can occur in children undergoing surgery in the *posterior fossa* (*cerebellum* and *brain stem*). After surgery, these children may have difficulty walking (ataxia) and may not be able to speak (mutism). This condition may begin within hours or days of the surgery. It usually resolves itself, sometimes in just a few days and sometimes after a few months. Physical, occupational, and speech therapy can help in the recovery process.

## ***Radiation Therapy***

Radiation therapy may be used by itself or in combination with other therapies for the treatment of brain tumors. It may be used in place of surgery when a tumor occurs in an area in which it is very difficult to operate, such as the brain stem. It may be prescribed following surgery, to attack cells that could not be surgically removed safely. It may also be administered in conjunction with certain chemotherapy drugs.

### **How Does Radiation Therapy Work?**

Many brain tumors are radiosensitive, which means that the cancer cells can be destroyed by radiation therapy. The challenge radiation provides is to deliver it in such a way that it does minimal damage to healthy cells and maximum damage to tumor cells. There is also a limit to the amount of radiation an individual can receive in his or her lifetime, so doctors are careful in determining dosage and total amounts to be given. Necrosis (tissue death) from radiation can sometimes appear months, or even years, after treatment, so doctors are very cautious in their use of this therapy.

### **What Makes Brain Tumors Radiosensitive?**

Rapidly dividing cells in tumors have unstable DNA (the material in the cell that tells it how to grow). This DNA is susceptible to damage from ionizing radiation. Normal cells can also be damaged, but they can repair themselves. The repair mechanisms of cancer cells are not very effective, so cancer cells tend to not grow back.

### **Techniques**

Prior to radiation, a child will undergo “simulation,” during which small, often permanent markings are made on the scalp that will assist the technician in directing the radiation to the tumor during treatment. There are several techniques for delivering radiation therapy to the brain:

- Focal techniques are directed toward a precise location.
  - Traditional: Treatment is given for a very brief period of time on a daily basis (often 5 days a week for approximately a month). Hyperfractionated radiation involves two or more daily treatments. These daily treatments are important because cells are sensitive to

radiation only during part of their life cycle. Frequent treatments damage more cancer cells. However, it is important that several hours pass between treatments so that normal cells may have a chance to repair themselves. Hyperfractionation allows for a higher dose of radiation to be used without increased side effects.

- Radiosurgery: This treatment focuses radiation precisely on the area of a brain tumor in order to destroy the tumor. CT or MRI scanning defines the exact location of the tumor. The Gamma Knife and linear accelerator (LINAC) are two devices that deliver this type of treatment. Its use is sometimes limited by tumor type, size, and location.
- Brachytherapy: This technique involves the implantation of radioactive seeds or pellets into the tumor area. It is used infrequently in children.
- Craniospinal axis irradiation is a technique that focuses the treatment beams more broadly on both the brain and the spine. This technique is used in tumors that have spread or are likely to spread to the *cerebrospinal fluid*.

## Future trends in radiation therapy

- Nonconformal therapy  
This is irradiation in a 3-dimensional field.
- Radiation boosts with Gamma Knife, LINAC, or brachytherapy
- Development of radiation sensitizers  
These are drugs that increase the effectiveness of irradiation. Among the drugs being investigated are BUdR, IUdR, and hydroxyurea. BUdR and IUdR can also label those tumor cells which are most likely to grow and spread. These drugs can help determine the aggressiveness of a tumor and monitor the progress of treatment.
- Boron neutron capture  
This involves giving medicines that put boron (a chemical element) into tumor cells which are then bombarded by slow neutrons. Several irradiation events occur, causing more damage to tumor cells.
- Repair of irradiation effects on normal cells using neurotrophins or, possibly, fetal tissue transplantation

## Possible Complications/Side Effects

The risk of complications from radiation therapy depends upon several factors, including the following:

- the total dose of irradiation
- the area treated
- the age of the child
- the type of radiation therapy received
- the type of tumor
- the extent and effect of tumor resection surgery
- the type of chemotherapy used

Ask your child's radiation oncologist about complications that may be possible in your child's case.

## Common Side Effects During Treatment

Your child may or may not experience one or more of the symptoms listed below. Should these symptoms occur, there are many ways to decrease or control their impact. Examples of supportive treatments are the use of wigs and caps, anti-nausea medications, pain medication, and steroids.

- ✓ Hair loss in the area where radiation therapy was given (often grows back following completion of therapy)
- ✓ Redness/dryness of skin
- ✓ Mild sore throat, if craniospinal irradiation received
- ✓ Nausea with or without vomiting
- ✓ Temporary decrease in blood counts
- ✓ Fatigue
- ✓ Postirradiation or Somnolence syndrome: This condition is the result of swelling of brain tissue following irradiation of the entire brain. It can occur from 1 to 3 months after irradiation, and may last from seven to ten days. Symptoms include lethargy, sleepiness, decreased appetite, vomiting, and low grade fever. Steroids often alleviate these symptoms.

## Possible Long-term Side Effects

Radiation can be very effective in destroying tumor cells. It can, however, also affect healthy cells. Some of these effects are noticeable immediately, while others do not manifest themselves for quite some time.

Growth delay. A child's growth may be affected by the following:

- irradiation of the *hypothalamus* and *pituitary gland*
- irradiation scatter to the thyroid gland  
Scatter refers to irradiation that unintentionally affects tissue lying on the edge of the focused irradiation field.
- poor nutrition from a decreased appetite
- spinal irradiation, which affects growth by slowing the growth of spinal bones (vertebrae)

Each child's response to radiation therapy will differ. Some children will experience several of the long-term side effects that are described above and on the following pages, while others may not experience any.

Growth delay may be treated with nightly injections of growth hormone. Some people fear that the use of growth hormone may cause a tumor to recur by spurring its own growth as well as the height of the child. To date, there is no evidence that the use of growth hormone causes tumors to recur any more frequently than if the hormone had not been used.

However, the decision to use growth hormone should be made in consulta-

tion with the brain tumor treatment team and a pediatric endocrinologist. The use of growth hormone does not restore height lost when the spinal cord is irradiated.

Precocious (early) or delayed sexual development. Altered sexual development may result from irradiation in the area of the pituitary gland or hypothalamus. Precocious sexual development is defined as breast development or pubic hair in girls under 8 and pubic hair and testicle enlargement in boys under 9. Symptoms of delayed sexual development include no breast development in girls by age 13-14, no testicular enlargement in boys by age 15-16, sexual development that stops, and menstrual periods that



stop occurring. These conditions may be treated by hormonal suppression (in the case of precocious puberty) or hormone replacement (in the case of delayed puberty).

**Altered thyroid function.** The thyroid gland controls the body's metabolism. Its function may be altered by direct irradiation of the hypothalamus or pituitary gland, or from "scatter" to the thyroid gland during craniospinal irradiation. Possible symptoms include growth failure, cool "spotty" skin, and constipation. A child's doctor can easily diagnose altered thyroid function through blood tests and may use daily oral replacement therapy to treat it.

**Diabetes insipidus.** This can occur from irradiation in the area of the pituitary gland. Decreased levels of antidiuretic hormone (ADH), produced by the pituitary gland, may lead to diabetes insipidus, the inability to concentrate urine. Symptoms may include frequent thirst and urination. It is treated with DDAVP nasal spray or tablets, which supplement the ADH produced by the pituitary gland.

**Adrenal insufficiency.** Adrenal insufficiency can lead to life threatening shock if untreated during times of stress, especially during illness or surgery. Symptoms may include vomiting and lethargy that occur suddenly and in the presence of other signs of illness (cold, flu, etc.). A child's doctor would diagnose it by measuring blood cortisol levels, and treat it with small daily doses of cortisol.

**Cognitive losses.** Learning disabilities may occur in children who have had cranial irradiation, but effects may not be apparent for two to three years after receiving radiation therapy. Early diagnosis through neuropsychological testing is essential, so that those who are involved in the child's education can determine which services the child needs to reach his or her highest potential. See section on "Returning to School" on page 34.

**Dental.** Radiation therapy to the teeth may cause teeth to develop improperly. However, radiation therapists take special care to block the teeth during cranial irradiation. Early and regular dental visits are strongly encouraged.

**Eye.** There may be a risk of cataracts after cranial irradiation. However, great efforts are taken to block the eye from irradiation effects. Regular

evaluation by an ophthalmologist is recommended.

When treating very young children, the treatment team may recommend that radiation therapy be delayed to reduce the risk of significant damage to developing normal brain tissue. Instead, the team may use chemotherapy to reduce tumor size or prevent recurrence until radiation may be more safely used.

## Chemotherapy

Many different chemotherapy drugs are used to treat pediatric brain tumors. Some are given at home, while others must be given in the clinic or hospital. The effects that these drugs have on brain tumors are measured by MRI/CT scans. The effects that these drugs have on healthy cells are measured by regular blood tests.

### How Does Chemotherapy Work?

Chemotherapy involves the use of drugs that damage rapidly multiplying cells found in brain tumors. Low grade or slow growing tumors are generally resistant to chemotherapy.

The presence of a *blood-brain barrier* has made chemotherapy less effective against brain tumors than other types of cancer.

### **The Blood-Brain Barrier**

There is a tight barrier between blood vessels and the brain tissue they serve, which protects the brain from harm. the purpose of this barrier is to keep harmful chemicals from getting through to brain tissue. As a result, chemotherapy particles must be very small to get through to the tumor:

A fatty or lipid layer makes up part of the blood-brain barrier. Chemicals that dissolve in water can't get through. Chemotherapy particles must be dissolvable in fat (lipid soluble) in order to get through to the tumor:

Chemotherapeutic agents are chosen based on the life cycle of the tumor cell. A child's doctor may select different drugs to damage the tumor cell in different parts of its life cycle. The frequency of chemotherapy treatment is also determined in part by the life cycle of that particular tumor cell. Some types of chemotherapy may be given daily, some weekly, or every 3 weeks. The level of a child's healthy blood cells may also be a factor in determining frequency of chemotherapy treatment.

## Clinical trials/studies/protocols

In order to make the most progress in treating childhood brain tumors, doctors coordinate their efforts through clinical trials. Clinical trials, also called studies or protocols, involve the use of specific drugs to treat specific types of tumors. Doctors evaluate these treatments and try to decide how to improve survival rates and reduce side effects. Each study or protocol builds on those that have gone before it. The two primary pediatric cancer research groups of doctors and hospitals from all over the country are the Children's Cancer Group (CCG) and the Pediatric Oncology Group (POG). Although many different hospitals belong to each organization, the groups share their findings with each other. Some studies or protocols are based only at one hospital that is trying a new treatment. Your child's treatment team will provide you with the protocol options available to your child. Check the "Resources" section at the end of this guide for more information about available protocols nationwide.

There are three types of clinical trials available to children with brain tumors:

- ✓ **Phase I Trials:** These trials focus on determining the toxicity (side effects) and proper dose of a particular drug. Usually, there is some information on the toxicity of this drug in adults before it is used in children. There is usually preclinical (laboratory or animal model) evidence of the drug's effect on a specific tumor.
- ✓ **Phase II Trials:** These trials focus on determining how different tumor types will respond to an investigational drug and what percentage of patients will benefit. Prior studies have already shown the investigational drug to be effective in some patients and side effects have been determined.

- ✓ **Phase III Trials:** These trials compare two or more treatments against each other to increase the rate of cure and to decrease the toxic effects of treatment. One treatment uses the current best known standard of care and the other involves some new change to that standard treatment regimen.

## **How Is Chemotherapy Given?**

Most chemotherapeutic agents are given intravenously (IV) or by mouth (PO). When chemotherapy is given by IV for extended periods of time or when the agents being used are very irritating to the veins, a venous access device might be recommended.

- One type of device (Hickman or Broviac catheter) consists of internal and external parts. The internal part is made of a silicone tube that is tunneled under the skin to the large blood vessels near the heart. The external part, also a silicone tube, is used to draw blood and give medications. Parents flush the catheter daily to keep it patent or open. A dressing over the exit site of the catheter is changed several times each week.
- Another type of device (Port-a-cath, Infus-a-port, or Mediport) is implanted completely beneath the skin. Access is achieved by puncturing the skin above the reservoir with a specially designed needle. This device is flushed once each month and does not require a dressing. It is most helpful in children who do not require frequent access for blood draws or treatment.

These devices can spare a child the painful needle sticks that are often associated with chemotherapy. The internal catheter, in particular, also allows the child to resume a somewhat “normal” life-style, even during treatment. However, complications that may occur with these devices include infection, blockage of the catheter due to clot formation, and damage to the external part of the catheter. Discuss the benefits and risks associated with these devices with your treatment team.

## Common Chemotherapeutic Agents

- Vincristine: Given by IV (intravenously or into a vein)
- Carboplatin and Cisplatin: Given by IV
- Nitrosureas: Carmustine (BCNU) (Given by IV) and Lomustine (CCNU) (Given by mouth)
- Procarbazine: Given by mouth. Certain foods must be avoided when taking this medication.
- Cytosin and Ifosfamide (Alkylating agents): Given by IV
- Etoposide (VP-16): Given by IV

## Future Trends in Chemotherapy

- The use of chemotherapy as a complementary or adjuvant therapy in tumor types previously treated only with surgery and irradiation
- High dose chemotherapy with autologous bone marrow or stem cell transplant  
High doses of chemotherapy are given to destroy the tumor, and the child's own bone marrow or stem cells are given back intravenously to rescue the child by replacing the normal blood cells that were destroyed by the chemotherapy.
- Administration of chemotherapy intrathecally (into the spinal canal) or intraventricularly (into the ventricles of the brain)
- New agents such as RMP-7 (opens the *blood-brain barrier* to increase the concentration of drug into the tumor area), tamoxifen, temozolamide
- New drug delivery systems such as small pumps or wafers placed on the tumor that deliver chemotherapy directly to the tumor
- Use of agents to increase cell maturation (maturation agents) and decrease the blood supply to the tumor (antiangiogenesis agents)
- Targeted drug therapy using monoclonal antibodies (Moabs)  
If Moabs that are specific to brain tumors can be identified, they could be used to deliver chemotherapy directly to the tumor.

- **Gene therapy**

This experimental method uses viruses to insert genes into brain tumor cells. This makes a tumor cell susceptible to being destroyed by antiviral agents given intravenously.

- **Biologic Response Modifiers**

Interferon and interleukins are substances that work with the immune system against the growth of tumor cells. Lymphocyte activated killer cells (LAK) are immune system cells that may be activated to find and destroy tumor cells.

## **Possible Complications/Side Effects**

### **GENERAL SIDE EFFECTS**

Chemotherapy damages rapidly dividing cells. Unfortunately, some good normal cells are damaged along with the bad tumor cells. Unlike tumor cells, however, normal cells do repair them-selves. Each child reacts differently to each chemotherapy drug. Some children experience severe side effects, while others do not. Many of these side effects can be managed by various control measures. Some complications, such as bone marrow suppression and hair loss, are the result of damage to “good” cells.

- **Bone marrow suppression**

A child’s bone marrow produces red blood cells, white blood cells, and platelets. About 7 to 14 days after many chemotherapeutic agents are given, these cells decrease in number significantly. The effects of bone marrow suppression can be managed in the following ways:

—Anemia (low number of red blood cells) may be treated with red blood cell transfusions or with erythropoietan (a protein that stimulates development of red blood cells).

—Thrombocytopenia (low platelets) may be treated with platelet transfusions.

—The duration and severity of low white blood cell counts may be reduced through the use of growth factors (GCSF) that stimulate the bone marrow to make certain types of white blood cells.

- **Hair loss**

This may occur within days to weeks of the beginning of chemotherapy.

Some suggestions to help deal with this side effect include:

- talking to your child about how he or she feels about the loss of his or her hair. What would he or she like to do about this change in his or her appearance?
- cutting a child's hair short before it begins to fall out.
- sleeping with a surgical cap on to collect hair that comes out during sleep.
- letting the child pick out caps and scarves to wear (some caps even have false pony tails attached).
- giving older girls the choice of wearing a wig (these can be very expensive and may be uncomfortable for young children to wear).

Hair begins to grow back when chemotherapy ends and may come back in a slightly different color or texture.

- Nausea / Vomiting ( occurs with most IV chemotherapy except Vincristine)

A child's doctor or nurse can give medications that are very effective at controlling this side effect. These medications work best when given before the chemotherapy and then a few times afterward. Some chemotherapy that is taken by mouth can be given at night to lessen the effect of nausea. Some children do develop such a decreased appetite during chemotherapy that their nutrition must be supplemented with intravenous hyperalimentation (protein and carbohydrates) and intralipids (fat) given over 12 to 24 hours each day.

## DRUG-SPECIFIC SIDE EFFECTS

The side effects listed below are not an exhaustive list. Please consult your child's treatment team regarding specific side effects of each chemotherapy agent that will be used.

- ✓ **Neurologic changes:** Numbness, drooping eyelid, change in walking with foot drop, constipation, hoarseness, seizures, and jaw pain can occur most often with the use of Vincristine but can also occur with Cisplatin.
- ✓ **Hearing:** High frequency hearing loss can occur with Cisplatin and, less frequently, with Carboplatin. Regular hearing tests are performed so that drug doses may be adjusted to prevent significant hearing loss.
- ✓ **Bladder irritation and bleeding:** This problem is associated with Cytosin and Ifosfamide. It is most often prevented by giving adequate amounts of fluid and by supplementing the chemotherapy with MESNA, which helps to protect the bladder.
- ✓ **Kidney toxicity:** Loss of blood salts or electrolytes (potassium, phosphorus, calcium, magnesium, etc.) can occur with Carboplatin, Cisplatin, and Ifosfamide.
- ✓ **Low plasma sodium levels:** This effect may occur with the use of Vincristine.
- ✓ **Allergic reaction:** This effect may occur with VP-16 given intravenously. When this agent is given, vital signs are carefully monitored and the medication is given slowly.
- ✓ **Secondary cancers:** There is some increased incidence of leukemia in persons who have received VP-16.
- ✓ **Sexual development/fertility:** Higher doses of Cytosin and Ifosfamide can be associated with decreased fertility. If sexual development is affected, a child's doctor may recommend hormone replacement.



# Social and Emotional Support

**C**hildren with brain tumors and their parents can greatly benefit from social and emotional support during and after treatment. Here are a few suggestions to help you get the support you need.

## *Advice for Parents*

- Talk to other parents of brain tumor patients. The National Brain Tumor Foundation has a list of parents who are more than willing to talk or listen to other parents who are facing brain tumor disease.
- Allow people to help you. Give friends specific ways to help you when they ask, such as making meals, accessing the Internet for specific information, baby-sitting for your other children, mowing the lawn, or meeting you for short breaks while at the hospital.
- Designate someone at home and/or work who can serve as the information “go-between” for family, friends, and coworkers. Many people will want to know how things are going for you and your child, but keeping all these people updated can be stressful. Use these “go-betweens” to relay information for you.
- Join a support group. Groups may be organized formally, through local hospitals or chapters of organizations like Candlelighters, or informally in clinic waiting areas and inpatient units. Call the National Brain Tumor Foundation to find out about support groups near you.
- Ask the social worker at your treatment center about specific services (parking, financial assistance, and resource groups), as well as counseling and support services.
- Be aware of the special needs of any other children you may have. Siblings of a brain tumor patient often have social and emotional needs introduced by the intrusion of the disease into the family.
- Maintain some social contacts outside your brain tumor world. Church, synagogue, and club activities are important to your emotional well-being.

## Advice for Your Children

- ✓ Help your child (and others) to remember that he or she is a child, and not just a brain tumor patient. Try to maintain some kind of normalcy in your child's life.
- ✓ Help your child find support from his or her peers.
- ✓ Look into age-appropriate local support groups that may be available through the hospital or local chapters of organizations.
- ✓ Consider sending your child to a local or regional summer camp for children with cancer. These camps are usually staffed by doctors and nurses who specialize in treating children with cancer, and by trained camp personnel who direct activities.
- ✓ Allow your child the opportunity to openly express his or her feelings about diagnosis and treatment.
- ✓ Ask people at your child's treatment center how children's coping skills are evaluated. Assessment and intervention may be available through the social worker, art therapist, or child psychologist.
- ✓ Remember that your child's physical needs are accompanied by social, emotional, and spiritual needs. His or her treatment will have the best outcome if all needs are considered as part of the treatment.

*“Things get much easier once there has been time for acceptance of the situation and once there has been time to develop trust and confidence in the treatment team. The value of a good relationship with the treatment team including the social worker cannot be overstated.”*

—PARENT OF A CHILD WITH MEDULLOBLASTOMA

# Returning to School

**A**ny illness has an impact on a child's education. Frequent or prolonged absence from the classroom may disrupt the learning process. How a child is feeling on any given day will also affect his or her academic performance. The attitude of the child's teacher and peers toward to child who is ill may also affect his or her behavior and performance in school.

A child with a brain tumor may face the additional challenge of physical changes in the structure of the brain, which affect the thought and learning processes. It is important to identify these changes and to adopt teaching and learning strategies that capitalize on the child's strengths and compensate for the child's weaknesses. These strengths and weaknesses can best be identified by neuropsychological testing.

## ***Neuropsychological Testing***

Neuropsychological testing measures cognitive skills (memory, learning, language), motor skills, and social skills. It is used to help schools plan for optimal educational interventions. Child Development Centers associated with major medical centers generally have neuropsychologists who are skilled not only in administering testing but also in making recommendations for optimal functioning of the child. Many insurance companies require a letter of necessity from your child's doctor to cover this service. Once a child's educational needs have been identified, those involved in meeting these needs must decide upon a plan of action to ensure that these needs are met. The "plan" is called an Individualized Educational Plan (IEP).

## ***Individualized Educational Plans (IEP)***

Federal law mandates that the state and local school systems provide resources and adaptive educational programs to children with disabilities. Once a child is diagnosed with a brain tumor, he or she qualifies for special educational assessments and resources under the category "Other Health Impaired" (OHI). The results of these assessments and the anticipated use of these resources are outlined in detail in the child's

Individualized Educational Plan (IEP). An IEP provides not only evaluation for special education services but also for occupational therapy, physical therapy, speech therapy, and counseling. The IEP requires the setting of specific goals for your child with a plan to meet those goals. It also involves regular assessment of progress.

Several factors can affect a child's return to school:

- The location of the tumor and the effects of surgery, radiation, and/or chemotherapy may have an impact on learning and/or physical abilities.
- Absence from school for treatments may cause a child to fall behind his or her peers academically.
- School personnel may be fearful of a child's health status.
- Resources for adaptive education to meet a child's needs may be limited or hard-to-access.
- Limited access to specialized testing may delay the identification of areas of support needed for a child to optimize his or her learning.

## ***Preparing for Your Child's Return to School***

School attendance allows children to grow both socially and academically. Prior to a full return to school, the social worker or school liaison on your child's treatment team can help your child to participate in school activities to the best of his or her current ability and energy. This can be done through partial attendance, hospital-based schooling, or "home-bound" tutoring. When your child is able to return to school more fully, there are several steps you can take to ease that transition:

- ✓ Talk to your child about how he or she feels about returning to school. What concerns or questions does he or she have about returning to the classroom? How can you together best address those concerns or find answers to those questions?
- ✓ Identify people who work within the local school system who can help to meet the goals established in your child's IEP. Providers of educational services may include a special education coordinator, speech and hearing specialist, visual specialist, school nurse, social worker, counselor, or psychologist. Many of these specialists service more than one school sys-

tem, and may only be available on a part-time basis. Make sure you have a clear understanding of the services to which your child is entitled by law!

- ✓ Determine which member of the treatment team will be your child's advocate as you work with the educational system. This individual may be your child's social worker, nurse practitioner or nurse specialist, neuropsychologist, or physician.
- ✓ Meet with school representatives and outline your child's diagnosis, care received, abilities, and disabilities.
- ✓ Identify special needs related to the school environment, e.g., distance to classrooms, stairs, mobility in the rain (crutches or wheelchair), desk location within the classroom.
- ✓ Arrange a meeting for all those involved in accomplishing the goals outlined in your child's IEP. Decide what measures will be taken to meet these goals and how progress will be measured. In addition to those individuals mentioned above, your child's teacher(s) and school principal should also be included in this meeting. Decide what steps should be taken, should problems arise. Define lines of communication and areas of responsibility. Provide a forum for these people to ask questions, as well as to provide information.
- ✓ Identify the expectations you have for your child's return to school (full day classes versus half day with home tutoring, adaptive physical education classes, speech therapy, etc.). Identify the expectations that the school has for your child's return to school.
- ✓ Educate school personnel with written materials related to childhood brain tumors and return to school. Be sure to address how often your child is likely to be absent from school, any limits you may wish to set for your child in his or her activities, any medical emergencies that may have to be dealt with in the classroom, and how much your child generally needs to be encouraged to perform to the best of his or her ability. If your child is not immune to the chickenpox, it will be important for you to be aware of any exposure your child may have to this illness at school. Children whose immune systems are impaired can get serious complications from chickenpox if they are not immune. Your treatment

team can send a letter to the school describing how to notify you in case of an exposure.

- ✓ Ask your child if he or she would be willing to have the medical center nurse/social worker/school liaison visit the school. This visit could include a discussion by your child and his or her treatment team member of any changes in the child's appearance (hair loss, weight gain) or behavior since he or she was last in school, the diagnosis, treatment received, any emergency care that might be needed, and how classmates and school staff can be supportive of this child. A visit with your child's classmates can also be very helpful in relieving their fears or addressing their concerns and answering their questions.

# Parents As “Unregistered” Nurses: One Mom’s Perspective

**A**n unregistered nurse is responsible for coordinating all care for his or her child and ensuring that all the child’s needs are met, whether these needs are medical, physical, mental, emotional, social, or spiritual. Since you are always on call, you should always have the following “equipment” with you:

- ✓ a listening ear for your child  
What questions or concerns does he or she have at this time? What appropriate information can you give that will answer these questions and address these concerns without causing unnecessary fear in your child?
- ✓ comfort toys, family pictures, audio tapes, stuffed animals and snacks that bring a touch of the familiar to what may otherwise be a strange place
- ✓ activities, small games, books, a blank tablet and crayons, or a deck of cards to help pass the time while waiting for appointments or tests

You will also need to have:

- a basic knowledge of your child’s disease
- a written list of symptoms to watch for that would necessitate calling the doctor or making a trip to the hospital
- a single card that briefly lists your child’s medical history. The card should include the date of the original diagnosis, dates of scans and their results,

*“During the six and a half years my son, Timothy, battled brain tumor disease, I learned many lessons and developed a variety of coping skills that helped me to care for him. We would sometimes joke about the fact that I was his “unregistered” nurse. I write this chapter in hope that our experiences will better equip you to help care for your own child.*

—WENDY PIZZI

dates of surgeries, radiation treatments, amount of radiation given, dates of chemotherapy treatments, list of drugs administered, list of current medications, list of allergies, and names of medical treatment facilities where care has been administered. This will make the interviews you have with every doctor, resident, and nurse who needs this information so much easier.

- a basic knowledge about the operation and care of your child’s shunt or catheter (if applicable)

Understand what exercises or activities should be avoided. Know what size and type needle should be used to access your child’s catheter (if necessary), as well as the amount of saline and heparin required to flush it. (Some unregistered nurses I’ve met carry these special needles with them at all times, in case of emergency, or to save time during the hospital admittance procedure.)

- a list of your child’s doctors names, addresses, telephone numbers, fax numbers, and e-mail addresses  
Know which doctor is your child’s primary physician.
- a list of important telephone numbers, addresses, insurance information, and your child’s social security and hospital numbers
- paper and pen to write questions you may have or information you wish to keep

You can keep many of these items, along with a calendar, in a small three-ring binder. Put your name and telephone number in a prominent place inside the cover of this notebook. “Equipment” like this can sometimes be misplaced, and is very difficult to replace!

If you find your nursing shift includes time you spend in the hospital with your child as an inpatient, you may also want to ask your doctor for the following:

- ✓ A copy of the protocol he or she plans to follow if your child is undergoing chemotherapy treatment
- ✓ A description of the drug(s) to be administered  
Learn all you can about the drug and the delivery method. Ask the doctor or pharmacist for the drug sheet and read it carefully. Detailed descriptions of most chemotherapy drugs are readily available on the



Internet as well. Pay particular attention to the part of the drug sheet that tells you about how the drug is administered. Remember that the side-effects (contraindications) listed are possible side-effects. Each child will experience different effects and different degrees of effects.

- ✓ A prescription for anti-nausea medication as needed in your patient's orders

This will save much time and anxiety if your child becomes ill in the middle of the night.

The unregistered nurse must develop skills in two specific areas if he or she is to perform this job to the best of his or her ability. The first skill is effective and efficient communication. As an unregistered nurse, you must strengthen the ties of communication that exist among those who are involved in the care of your child. You should clearly communicate your needs, and those of your patient, to members of the treatment team. You must ask questions, listen to answers, seek information, tap into available resources, do some creative problem solving, when necessary, and work together in cooperation with the medical community. Bonds of communication must be solid, so that when you encounter a crisis or an emergency situation you can continue to provide the best care possible for your child.

Different forms of communication occur in the medical environment. Doctors, nurses, and technicians need to give information to and receive information from their patients and the unregistered nurses. You need to find a way to disseminate this information to your family/community/support system, especially in a time of crisis. Do not expect your physician or nurse to address each of your extended family members and friends. Do not expect yourself to fill this role either! Establish clearly defined lines of communication, enlisting specific individuals who will be responsible for relaying information. This will save the time and emotional energy you will need to spend on your immediate family and on yourself.

My primary communications were with Timothy and the treatment team members with whom he came in direct contact. My husband, Larry, was basically responsible for all other areas of communication. He would contact key people in our family and community with medical updates or information, as it became available. These key people would then become contact points for others in the family and community who were also

interested in our situation. He would also maintain good communication ties among the various doctors who were treating Tim, keeping each of them informed and updated as well.

As Tim's unregistered nurse, I had to adjust the level of communication with him as he matured. When he was six years old, Tim had no concept of brain tumors, surgery, chemotherapy, radiation, or hospitalization. He only knew that his left hand would shake. I had to explain to him, as simply as possible, that there was something inside his head that was causing his left hand to shake, and that the doctors were going to try to fix the problem. After listening to Tim, I detected his two primary concerns: would the hospital have food he would like to eat, and could he have his little stuffed dog, Ketchy, with him during his hospitalization. Once I answered these two questions for him, Tim did not have any further concerns. (I did, but I tried not to transmit these to Tim!)

As Tim matured, he expressed more interest in his medical condition. He had more specific questions and a need for more information. Larry and I always shared with him whatever information we had available to us, the results of his MRI scans, and the various treatment options that were available to him. He was always an integral part of the decision making process, including the decision to stop treatment altogether.

The second skill that an unregistered nurse needs is consideration of others. Keep in mind the fact that interactions with a child with a brain tumor and his or her family may be difficult for some people. They may not know what to say, what to expect, or how to respond. The tool our family used to ease this problem was humor. During the six-and-a-half year course of his illness, Tim became famous for his puns, jokes, and "groaners." He wielded humor with the skill of a professional comedian. Wherever he went, Tim would tell people jokes. Humor helped people to see past Tim's limitations and made him approachable and even endearing. It helped to break down many walls and to build many bridges.

Remember that the people with whom we are working are just that: they are people, with lives and problems of their own. Like you, they have good days and bad days, and they do make mistakes. They also, like you, appreciate honesty, courtesy, encouragement, friendship, and support as they attempt to do their best in working with you to care for your child.

In considering the needs of others, we deliberately forged relationships and established lines of communication with Tim's treatment teams. Larry worked diligently and successfully to link Tim's California team with his Kansas team, keeping both groups updated on current issues and encouraging communication between them.

Whenever possible, I tried to consider Tim's needs above all others. There were at least three occasions when I, as Tim's unregistered nurse, had to intervene on his behalf and be his advocate within the constraints imposed by the hospital.

- The first incident involved daily blood draws during Tim's initial twenty-eight day hospitalization. As it became increasingly difficult to find a good vein from which to draw blood, I finally asked the nurses on the floor to check with Tim's primary physician to determine whether these daily tests were still necessary. They were not.
- The second occurrence involved the use of a strobe light during routine EEGs. Tim did not mind any aspect of the test except the strobe light, so I simply asked the doctor if we could omit this portion of the test, since we had already determined that Tim had constant seizure activity in his brain. She agreed to this request as well.
- The third incident occurred when Tim had to stay alone in ICU while he was receiving a chemotherapy that required close monitoring. This first round of this drug was very difficult for Tim, because he really wanted his "unregistered nurse" to stay with him while he was in ICU. Before the second round was to begin, I asked the charge nurse if there was any way I could stay with Tim in ICU. She managed to find a space in one of the ICU bays which would allow me to stay with Tim.

I made each one of these requests politely and firmly of people with whom I had already established good lines of communication. I considered Tim's needs first, and tried my best to meet them within the parameters established by the hospital.

As an unregistered nurse, you must also be considerate of yourself and your personal needs. Take the time to care for yourself. Come up with some creative strategies to ensure you meet your basic needs for food, exercise, sleep, fresh air, and some sort of support system. When you do meet these needs, you will be better able to care for your child and meet his or her needs.

Pre-position people in your life who are able to assist you in time of need. Keep a list of people who are willing to help you with childcare, meals, errands, laundry, telephone calls, correspondence, grocery shopping, or whatever other needs you may have. These people usually cannot fill your role as the unregistered nurse, but they can be helpful with many other jobs. Friends are most often anxious to do something, to feel that they are somehow contributing to caring for your child. Allow them to share in your workload.

As the unregistered nurse, you and your team must have alternatives to use if the current plan does not appear to be working. In Tim’s case, our alternate plans included surgery, radiation, stereotactic radiosurgery, various chemotherapies, and Hospice care at home. Each of these courses of action had to be carefully considered and planned accordingly. During the course of each action, we would develop contingencies and “what ifs” to consider,

### **A Personal Note from Wendy Pizzi**

*“My job as Timothy’s unregistered nurse has come to an end. I thank my son for the many lessons he has taught me about the important things in life. It was a joy and a privilege to be his unregistered nurse and to have the opportunity to share with other parents some of the skills and techniques I have learned through caring for this special child. This career as an unregistered nurse was challenging, yet fulfilling. It is my hope that our experiences will make your job a bit easier and that you will be better equipped to face the challenges that lie before you. God bless you!”*

should the current plan fail. We always had a specific direction we were heading and plans for how we were going to get there. It was important, however, that we not project our plans too far into the future. Such “paralysis of analysis” can lead to unnecessary fear and frustration.

When your alternate plans include hospitalization, you must remember that within the medical community, and especially during hospitalization, there are specific rules you must follow. It is to your advantage to become familiar with these rules before you inadvertently break them, and to follow them to the best of your ability. When it does become necessary to question a particular rule, always present your request to the individual who is in charge or who has the authority to grant your request. Again, remember to reinforce those lines of communication and be considerate of others. It is amazing how far a little kindness and common courtesy can extend!

The medical world is constantly changing. New technologies are introduced, new treatments are discovered, and new techniques are implemented every day. The unregistered nurse must take advantage of available resources to provide the best care for his or her child. This guide will provide you with much of the information you will need in deciding how to best care for your child. Use the information, investigate the resources, develop good communication skills, and be considerate of others. These simple steps will make your job so much easier.

# Basic Neuroanatomy Glossary

## *Blood-brain barrier*

A tight barrier between blood vessels and the brain tissue they serve that protects the brain from harm. The purpose of this barrier is to keep harmful chemicals from getting through to brain tissue.

## *Brainstem*

The lowest part of the brain. It connects the cerebellum to the spinal cord. It is the pathway for the cranial nerves and also controls heart beat, breathing, and blood pressure.

## *Central nervous system (CNS)*

Includes the brain, spinal cord and the nerves that arise from the brain and spinal cord.

## *Cerebellum*

The lower part of the brain. It controls balance, posture, and coordination needed for walking and speaking.

## *Cerebrospinal fluid (CSF)*

The fluid that bathes the brain and spinal cord. It is made within the ventricles of the brain and circulates through these ventricles, the subarachnoid space, and the spinal canal.

## *Cerebrum*

The upper part of the brain. It is made up of two halves or hemispheres. The left hemisphere controls the actions of the right side of the body. The right hemisphere controls the actions of the left side of the body. Each hemisphere is made up of 4 lobes that have specific functions:

- Frontal lobe: thinking, memory, behavior, muscle movement, expressive speech, personality
- Temporal lobe: hearing, learning, memory, vision, music
- Parietal lobe: sense of touch, posture, pressure, and motion; reading; receptive speech; concept of body image
- Occipital lobe: reading, vision

### *Hypothalamus*

Brain tissue located above the pituitary gland. It helps control body temperature, fat and sugar metabolism, and how water is held onto by the body. It is also the “control center” for the pituitary gland, controlling which hormones are released.

### *Increased intracranial pressure*

The pressure that can build up in the head when a tumor blocks the flow of *cerebrospinal fluid* (CSF) from the *ventricles* to the spinal canal.

### *Pituitary gland*

A small gland, about the size of a pea, located near the center of the head underneath the brain. It releases chemicals called hormones that control the other glands of the body. These hormones affect growth, metabolism, sexual development, and other important body processes.

### *Posterior Fossa*

The back area of the brain containing the cerebellum, fourth ventricle, and brain stem. This is the most common place for brain tumors to occur in children.

### *Shunt*

A special tube surgically placed in the brain to divert the flow of cerebrospinal fluid (CSF). The most common type of shunt in children is the ventriculoperitoneal (VP) shunt that carries CSF from the ventricles to the peritoneum (abdomen) where it is reabsorbed.

### *Tentorium*

The tissue that separates the cerebrum from the cerebellum. “Infratentorial” refers to areas below the tentorium (cerebellum, brain stem). “Supratentorial” refers to areas above the tentorium (cerebrum).

### *Ventricles*

The four chambers found in the center of the brain. They make and contain cerebrospinal fluid.

# **BRAIN STEM**

motor and sensory  
pathway to  
body & face

vital centers  
cardiac  
respiratory  
vasomotor

# **CEREBELLUM**

balance  
posture

motor coordination  
including eye  
movements

# **CORPUS CALLOSUM**

transmission of messages from  
one side of the brain to the other

# **FRONTAL LOBE**

attention  
abstract thought  
problem solving  
emotion  
judgment  
inhibition  
generalized &  
mass movements  
movements  
muscle movements  
supplementary  
motor skills  
sexual urges

behavior  
reflection  
creative thought  
intellect  
initiative  
coordinated  
movements  
some eye  
skilled movements  
sense of smell  
physical reaction

# **HYPOTHALAMUS**

hormonal body processes

moods motivational states  
sexual maturation temperature  
regulation

# **OCCIPITAL LOBE**

reading

vision

# **OPTIC CHIASM**

optic nerves - vision

# **PARIETAL LOBE**

appreciation of form through touch

(stereognosis)

tactile sensation

response to internal stimuli

(proprioception)

sensory combination & comprehension

some language & reading functions

some visual functions

# **PINEAL BODY**

unknown

# **PITUITARY GLAND**

hormonal

body processes

physical maturation

growth -

height & form

sexual maturation

sexual function

# **SPINAL CORD**

source of sensation & movement

# **TEMPORAL LOBE**

auditory memories

visual memories

some hearing

some vision

pathways

other memory

music

fear

some language

some speech

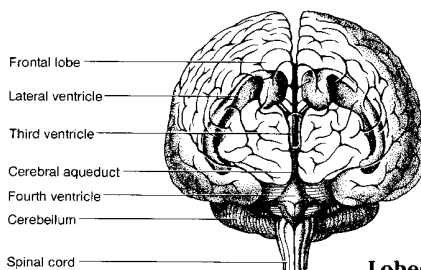
some behavior

# **VENTRICLES & CEREBRAL AQUEDUCT**

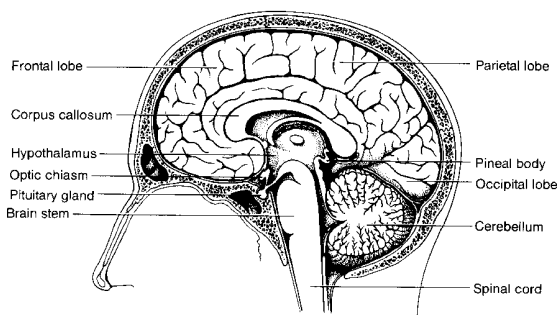
contain the cerebrospinal fluid that  
bathes the brain and spinal cord

*Illustrations by Laurel V. Schaubert,  
Biomed Arts Associates,  
San Francisco, California.  
Courtesy of Charles B. Wilson, M.D.*

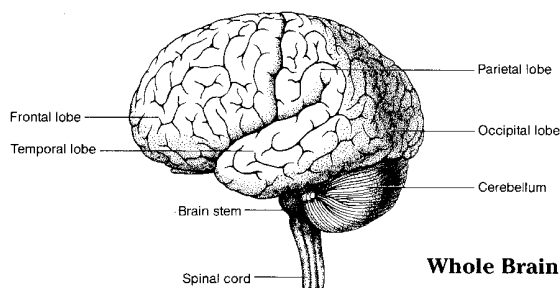
## **Anatomy and Functional Areas of the Brain Illustrated**



**Lobes of the Brain**



**Cross-Section of Brain**



**Whole Brain**



## Resources

**T***he National Brain Tumor Foundation provides a variety of support services, as well as information about adult and pediatric brain tumors, clinical trials, and related issues. For more information, contact:*

National Brain Tumor Foundation  
414 Thirteenth Street, Suite 700  
Oakland, CA 94612  
800-934-CURE or 510-839-9777  
<http://www.braintumor.org>

## Internet Resources

**National Brain Tumor Foundation Web Site**  
<http://www.braintumor.org>

**“Clinical Trials and Noteworthy Treatments for Brain Tumors”**  
<http://www.virtualtrials.com>

A listing of U.S. clinical trials by tumor type and geographic location. Designed and maintained by Dr. Al Musella, DPM.

### **BRAINTMR Mailing List**

A worldwide e-mail bulletin board for support and the sharing of information about personal and/or professional experiences related to brain tumors. To subscribe to the list, send an e-mail message to [listerv@mitv-ma.mit.edu](mailto:listerv@mitv-ma.mit.edu); leave and subject line blank, and type “subscribe braintmr” followed by your first and last name. There is no charge to join.

**The National Cancer Institute/CANCERNET**  
<http://www.cancernet.nci.nih.gov>

Provides information on cancer, treatments, clinical trials, statistics, and support. Also, by sending an e-mail to [cancernet@icicb.nci.nih.gov](mailto:cancernet@icicb.nci.nih.gov) (leaving subject blank) and typing “help” as the message you will receive the PDQ (Physician’s Data Query) Information for Health Care Professionals.

## **ONCOLINK**

**<http://www.cancer.met.upenn.edu>**

Provides cancer information and support, articles clinical trials lists, and access to PDQ and CANCECNET publications. Maintained by the University of Pennsylvania. For brain tumor information, choose “Disease Oriented Menus,” then “Central Nervous System Cancers,” then “Brain Tumors.”

## **National Childhood Cancer Foundation**

**<http://www.nccf.org>**

Provides location of Children’s Cancer Group (CCG) participating institutions and available protocols by diagnosis.

## Organizations

Acoustic Neuroma Association  
P.O. Box 12402  
Atlanta, GA 30341  
(404) 237-8023  
[www.anausa.org](http://www.anausa.org)

The Brain Tumor Society  
124 Watertown Street, Suite 3H  
Watertown, MA 02472  
(800) 770-8287  
[www.tbts.org](http://www.tbts.org)

American Brain Tumor  
Association  
2720 River Road , Suite 146  
Des Plaines, IL 60018  
(800) 886-2282  
[www.abta.org](http://www.abta.org)

Candlelighters Childhood  
Cancer Foundation  
7910 Woodmont Ave., Suite 460  
Bethesda, MD 20814  
(800) 366-2223  
(301) 657-8401  
[www.candlelight.org](http://www.candlelight.org)

American Cancer Society  
1599 Clifton Road, NE  
Atlanta, GA 30329  
(800) ACS-2345  
[www.cancer.org](http://www.cancer.org)

The Children's Brain Tumor  
Foundation  
274 Madison Avenue, Suite 1301  
New York, NY 10016  
(212) 448-9494  
[www.childrensneuronet.org](http://www.childrensneuronet.org)

The Brain Tumor Foundation for  
Children, Inc.  
1835 Savoy Drive, Suite 316  
Atlanta, GA 30341  
(770) 458-5554  
[www.btfcgainc.org](http://www.btfcgainc.org)

Childhood Brain Tumor  
Foundation  
20312 Watkins Meadow Drive  
Germantown, MD 20876  
(301) 515-2900

Brain Tumor Foundation of  
Canada  
111 Waterloo St., Suite 100  
London, Ontario N6B 2R4  
CANADA  
(519) 642-7755

The Epilepsy Foundation  
of America  
4351 Garden City Drive, Suite 500  
Landover, MD 20785  
(800) 332-1000  
[www.efa.org](http://www.efa.org)

Pediatric Brain Tumor Foundation  
of the U.S.  
315 Ridgefield Court  
Asheville, NC 28807  
(800) 253-6530  
[www.pbtfus.org](http://www.pbtfus.org)

Hydrocephalus Association  
870 Market Street, Suite 705  
San Francisco, CA 94102  
(415) 732-7040  
[www.hydroassoc.org](http://www.hydroassoc.org)

Pituitary Tumor Network  
Association  
16350 Ventura Blvd. #231  
Encino, CA 91436  
(805) 499-9973  
[www.pituitary.com](http://www.pituitary.com)

National Brain Tumor Foundation  
414 Thirteenth Street, Suite 700  
Oakland, CA 94612  
(800) 934-CURE  
[www.braintumor.org](http://www.braintumor.org)

Community Alliance for Special  
Education  
(support and advocacy for  
school issues)  
1031 Franklin Street Suite B5  
San Francisco, CA 94109  
(415) 928-2273

National Neurofibromatosis  
Foundation, Inc.  
95 Pine Street, 16th Floor  
New York, NY 10005  
(800) 323-7938  
[www.nf.org](http://www.nf.org)

Neurofibromatosis, Inc.  
8855 Annapolis Road, Suite 110  
Lanham, MD 20706  
(301) 577-8984  
(800) 942-6825



**NATIONAL BRAIN TUMOR  
FOUNDATION**

**GIVING HELP, GIVING HOPE®**

**INFORMATION LINE: 800-934-CURE**

# Notes