

# Finding Your Way:

A RESOURCE GUIDE FOR FAMILIES  
IMPACTED BY A CHILDHOOD BRAIN  
OR SPINAL CORD TUMOR

SEVENTH EDITION

[WWW.CBTF.ORG](http://WWW.CBTF.ORG)



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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.*



We want to thank all contributing authors, including the thousands of families who have given us insight over the past 35 years.

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Parent of a pediatric brain tumor patient

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**Visit <https://cbtf.org/> for additional resources.**

## Foreword

The day I heard the words “your son has a very large brain tumor” will always be with me. That was in 1987, and my son was only 19 months old. I am proud to say, today he is 37 years old and a long-term survivor.

In 1988, the need to fund meaningful pediatric brain tumor research was urgent. A small group of dedicated parents and medical professionals came together to initiate the birth of the Children’s Brain Tumor Foundation (CBTF). As CBTF marks the milestone of its 35th anniversary, we pause to consider the progress in treatment of pediatric brain tumors and support that’s available. Yet, there is still so much more to be done.

To empower parents, in 1995 CBTF created the first edition of the resource guide. The CBTF resource guide was the first tool in what expanded to become a continuum of the most innovative patient education and support programs helping families nationwide. Today, CBTF continues as leaders, remaining dedicated to funding research and providing expansive programs helping families navigate the greatest challenges from the moment of diagnosis through long-term survivorship or bereavement.

Thank you to all who have worked so hard to update and expand each edition of the resource guide, provide the range of CBTF programs, and fund groundbreaking research. On behalf of the Board of Directors and the staff of CBTF, it is with great pride that I present the seventh edition of *Finding Your Way: A Resource Guide for Families Impacted by a Childhood Brain or Spinal Cord Tumor*.

**Linda Wachtel, Parent**  
CBTF Board of Directors  
March, 2023

## Chapter 1 Introduction

This guide was written by a community of people impacted by brain tumors who are here to support you and help you feel not alone. You did not ask to join this community but can now rely on it for support. Feel free to contact the Children's Brain Tumor Foundation at 212-448-9494, email [info@cbtnf.org](mailto:info@cbtnf.org) or visit our website at [cbtnf.org](http://cbtnf.org) to further connect with others, learn more about our programs or seek answers to your questions.

A brain or spinal cord tumor diagnosis impacts the entire family forever. This guide is meant to clarify the medical terminology, offer practical tips for your personal, medical and educational life and provide guidance for your journey during and after diagnosis and treatment, including information on palliative care and bereavement.

Access to understandable medical information is readily available. Knowledge is power, but not all information on the Internet is accurate or trustworthy. Below are tips on locating reliable information, as **the Internet has both reliable and unreliable information.**

- If you use a search engine, begin with the information below the sponsored line or sites that do not say ad in front of it. Consider who is writing the information. A site ending in .edu means it is part of an educational system, .org usually indicates it is a non-profit organization, and .gov indicates it is part of a government site, whereas .com or .biz means it is part of a for-profit site. In the United States, educational and government websites usually contain accurate and up-to-date information. Most non-profit websites have

accurate information, but check the date of the last update on the site.

- When visiting a sponsored website, determine if the purpose is to sell something. If the site is trying to sell you a product or service, you should question its accuracy.
- Look at the source. If it is documented from scientific sources, it can be considered reliable. Personal stories and blogs may provide information and valuable tips; however, each brain tumor diagnosis is unique, and people write from their perspectives.
- Search for additional information that supports what you learned.
- Check online (<https://whois.domaintools.com/>) to see who owns a domain and where they are based.
- Avoid sites that offer scientific breakthroughs, require payment upfront, require you to disclose personal information, offer testimonials without scientific proof, or offer a money-back guarantee.

When your child is diagnosed with a brain tumor, you are thrown into a medical world you may not know. Always rely on your medical team for answers to medical questions and accurate information. Here are tips for tracking and getting medical information.

- Do not be afraid to ask questions. You are your child's best advocate.
- Ask your medical team the best way to communicate (email, text, phone) and who your contact person should be.



- Ask if your hospital has an online patient portal where you can ask questions.
- Write down your questions between treatments and bring the list with you to appointments.
- Ask your social worker to assist you if you need help communicating with your medical team. Your social worker can set up a team meeting and assist in building trust and a communication system that works for everyone.
- Listen actively. Take notes in a journal or through an electronic method, which you can keep throughout treatment. Ask the doctor to write down important points for you. Bring a friend to take notes. Ask the team if you can record important meetings. Make sure the team is aware of how much information you would like to receive and how you and your family want to receive the information.
- If there are cultural differences or language barriers, communicate them with your team. Let them know who should receive information.
- If your child is a minor, determine what meetings you would like them to attend and whether or not you want to include siblings.
- If your child is old enough, make sure they can ask questions. For teens and young adults, there may be questions they are uncomfortable asking in front of you. Consider letting them have time without you in the room.
- Be open and honest with your medical team. Communicate your needs and any alternative medical decisions you are considering.

- Keep your pediatrician updated and design a communication method to ensure they are kept up to date. This will assist with the transition in the future.
- Take advantage of the many specialists on the team and know each of their roles. The impact of a childhood brain or spinal cord tumor diagnosis goes far beyond medical treatment.

## Chapter 2 Brain Tumor Basics

The brain is the organ that controls all our body functions. The multiple ways the parts of the brain are connected and work together create the complex effects a brain tumor may have. 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 most likely new to you, so ask your child's doctor to explain them. The below glossary can hopefully be a helpful first step.

### Anatomy

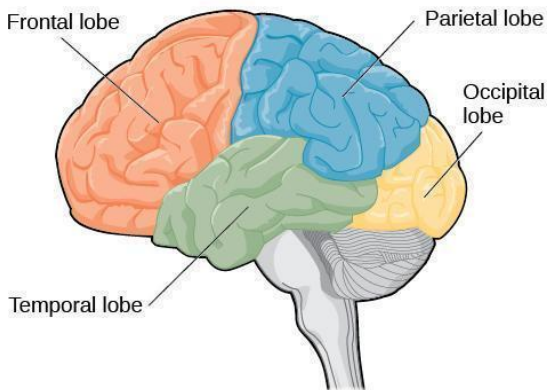
Central Nervous System (CNS)—the brain and spinal cord.

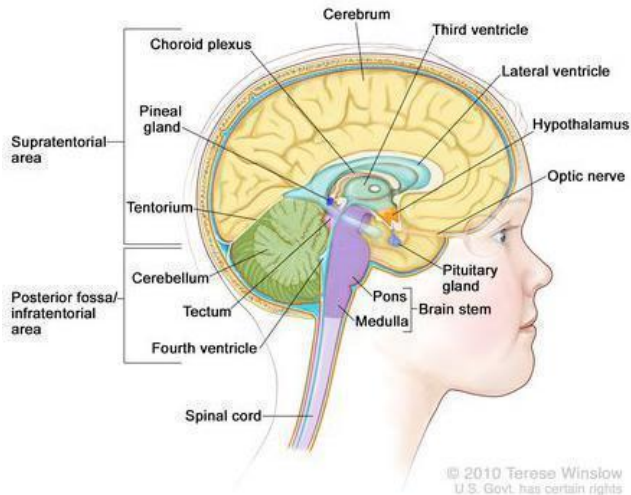
Peripheral Nervous System (PNS)—nerves that connect the brain and spinal cord to the rest of the body.

Cerebral Spinal Fluid (CSF)—a clear, watery substance that your brain and spinal cord sits in. Provides nutrients and cushioning for your brain and spinal cord.

Intracranial—inside the cranium, inside the brain.

Major parts of the brain include the cerebrum (upper part), cerebellum (lower part), and brainstem. Other important structures that brain tumors can affect include the pituitary gland, optic nerve, and spinal cord.





Cerebrum—made up of the left and right hemispheres of the brain. The two hemispheres are connected by a bundle of nerves called the “corpus callosum”. The cerebrum can be further separated into the four lobes of the brain: frontal, parietal, occipital, and temporal.

- Frontal Lobe: used for planning, problem solving, emotional regulation.
- Parietal Lobe: used for integrating sensory information (touch, temperature, pressure, pain)
- Occipital Lobe: used for processing vision.
- Temporal Lobe: used for processing sensory information, such as hearing, recognizing language, and forming memories.

Cerebellum—portion of the brain that lies in the back. Controls balance, coordination, and movement.

Brainstem—the most “primitive” part of the brain, connects the brain to the spinal cord. Used to regulate balance, heart rate,

and breathing. Can be further separated into three components: midbrain, pons, and medulla oblongata.

Pituitary gland and Hypothalamus—structures of the brain that control hormones in the body.

Optic nerve—nerve that connects the eyes to the part of the brain processing vision.

## **Procedures**

Lumbar puncture—also known as “spinal tap”, a doctor will insert a needle into your back to sample some of the cerebral spinal fluid, the fluid that your brain and spinal cord sits in.

MRI—short for “magnetic resonance imaging”, this is a common type of scan that uses a magnetic field and computer-generated radio waves to look at structures within the brain and spinal cord. Might include “intravenous contrast”, a dye that is injected through an IV to help light up certain structures.

CT—short for “computed tomography”, a quick scan that can look at structures within the brain and spinal cord. Might include “intravenous contrast”, a dye that is injected through an IV to help light up certain structures.

EEG—short for “electroencephalogram”, looks at brain waves and activity.

Brain biopsy—a procedure where a skilled neurosurgeon removes a small part of a tumor to send for additional studies. These additional studies can tell your medical team more about your tumor and inform them on how best to treat it.

Brain surgery—a procedure where a skilled neurosurgeon removes a tumor with as little effect on the surrounding structures as possible.

- Gross total resection: removing all parts of a tumor that is visible to the human eye. There may still be microscopic disease surrounding the removed tumor.
- Subtotal resection: partial removal of the tumor.

Chemotherapy—medications that are intended to kill fast growing cells. Used to treat cancer because cancer cells tend to grow faster than normal healthy cells.

Radiation—specialized, targeted beams that damage and kill tumor cells.

Central Venous Access Device (CVAD)—also known as a “central line”, a long tube (catheter) that is used to give medicine, fluids, nutrients, or blood products. Some examples include PICC line or Port-A-Cath.

Drain or Shunt Placement—when there is increased pressure in the brain, sometimes neurosurgeons will place a drain or “shunt” to divert the fluid away from the brain. Some examples include VP (ventriculoperitoneal) shunt or EVD (external ventricular drain).

## **Pathology**

Intracranial Pressure (ICP)—pressure in the brain. Since the brain and spinal cord are enclosed in a closed space (skull and spine), there is not a lot of “wobble room”. A mass growing in the brain can lead to increased ICP, which can quickly lead to symptoms. Treatment of increased pressure could include steroids to decrease inflammation and or placement of a device called a “shunt” to divert fluid away from the brain.

Intracranial Mass—mass in the brain. A mass growing in the brain can obstruct flow of blood, CSF, or affect vital structures due to “mass effect”, the effect seen when healthy tissue is pushed upon or displaced.

Hydrocephalus—when too much fluid builds up in the brain and intracranial pressure is too high. Oftentimes will require a device called a “shunt” being put in to divert the fluid away from the brain.

Tumor—abnormal cells growing and multiplying in an uncontrolled way.

- Benign tumor: slow growing cells that can be life-threatening due to “mass effect” or “increased ICP”.
- Malignant tumor: fast growing cells that can invade surrounding tissues.

Seizures—sometimes a mass in the brain can lead to sudden uncontrolled bursts of electrical activity between brain cells. Seizures look different for each patient, but a patient with generalized tonic-clonic seizure (also known as a grand mal seizure) might cry out, fall, shake/jerk, and briefly lose consciousness.

Endocrine issues—patients with brain tumors near the pituitary gland or hypothalamus (structures of the brain that control hormones in the body) may have endocrine issues such as growth hormone or thyroid hormone deficiencies. Hormones controlled by the brain include male/female hormones, hormones that help your body respond to stress (ACTH), thyroid hormones, growth hormone, and hormones that help you regulate water and salt balance in your body (antidiuretic hormone). These are managed by neuroendocrine specialists, who may prescribe different hormone replacement therapies.

Neuropathy—weakness or pain often described as numbness and tingling, results from damage to the nerves of the PNS.

Nerve impingement—occurs when a nerve is compressed, leading to malfunction of said nerve or pain and weakness in the area that the nerve originally was supposed to supply.

### **Common Types of Brain Tumors**

Central nervous system tumors are the second most common childhood cancers after leukemias/lymphomas and are the most common pediatric solid organ tumors. Many different types of tumors can occur in the brain and spinal cord. Your team will consider the type, grade, and location of the tumor when coming up with a treatment plan.

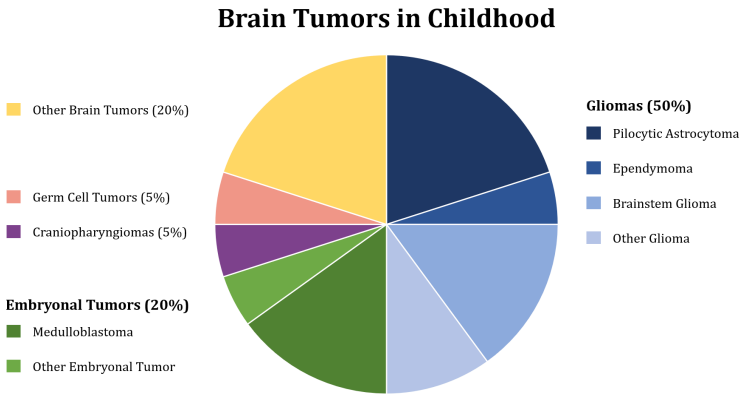
Type of tumor—determined by what type of cell the tumor starts or came from; some tumors can have a mix of cell types.

Grade of tumor—determined by looking at the tumor cells under a microscope. CNS tumors are divided into 4 grades (I – IV). Grades I and II are typically classified as low grade, while grades III and IV are typically classified as high grade. Lower grade tumors tend to grow comparatively more slowly and are less likely to spread or grow into nearby tissues.

Location of the tumor—many childhood brain tumors occur in the cerebellum or brain stem (lower parts of the brain), and others can occur in the upper parts of the brain or spinal cord.



Here is a brief list of common brain tumors that children can have:



1. **GLIOMAS**—tumors that start or come from glial cells, cells that support nerves in the brain. Some gliomas that children can have include:
  - a. **Astrocytomas:** start from astrocytes (a type of glial cell), can range from low grade to high grade.
    - i. Some low grade astrocytomas include: pilocytic astrocytoma, optic gliomas (start in the nerves that connect the eyes to the brain).
    - ii. Some high grade astrocytomas include: anaplastic astrocytomas (grade III), glioblastoma (grade IV).
  - b. **Oligodendrogliomas:** start from oligodendrocytes (a type of glial cell).
  - c. **Ependymomas:** start from ependymal cells (cells that line the ventricles and secrete cerebral spinal fluid).
  - d. **Brainstem Gliomas:** grow in the brainstem, referred to as diffuse midline gliomas or diffuse intrinsic

- pontine gliomas (DIPG) if they start in the pons (a specific part of the brainstem).
2. EMBRYONAL TUMORS—also known as primitive neuroectodermal tumors (PNETs), tumors that start from primitive or early forms of nerve cells. Tends to occur in younger children.
    - a. Medulloblastoma: most common type of embryonal tumor. Classified into types based on how the tumor cells look under a microscope and specific genetic mutations of the tumor.
    - b. Atypical teratoid/ rhabdoid tumor (ATRT): rare type of embryonal tumor that typically occurs in the cerebellum or brainstem.
  3. CRANIOPHARYNGIOMA—tumors that form near the pituitary gland and hypothalamus, which can lead to vision or endocrine/hormone issues.
  4. GERM CELL TUMORS—tumors that develop from cells that normally form egg or sperm cells. During normal development before being born, germ cells typically travel to the ovaries and testicles to form egg or sperm cells. Sometimes these germ cells could migrate to an abnormal location, and then develop into germ cell tumors in the brain. These tumors usually happen in the pineal gland or pituitary gland. Pituitary tumors can lead to vision or endocrine/hormone issues.

## Care Team

Brain tumors often require many people from different specialties working together to treat your child. Your “interdisciplinary care team” may include the following people:

**Neurologist**—a doctor that diagnoses, treats and manages disorders of the brain and nervous system.

Neuro-oncologist—a cancer doctor that specializes in brain tumors.

Neurosurgeon—a surgeon that is highly skilled in brain surgeries.

Neuro-pathologist—a doctor that is trained to look at tumors under the microscope.

Neuroendocrinologist—a specialist that focuses on how brain tumors or subsequent treatments affect your pituitary gland, a structure in your brain that controls your body's hormones.

Neuro-ophthalmologist—a special eye doctor that focuses on how brain tumors or subsequent treatments affect the way you see.

Radiation Oncologist—a doctor that plans the dosages and path of beams used for radiation treatment.

Neuro-psychologist or Neuro-psychiatrist—providers that specialize in assessing the side effects treatment has on the brain and mental health.

Audiologist—specialist that monitors your hearing before and after treatment.

Social Worker—specialist that connects patients and families to resources (financial, emotional/support system, psychosocial).

Physical and Occupational Therapist—specialists that help mobilize and strengthen your muscles so you can perform daily activities.

Speech Therapist—specialist that helps with language processing difficulties and cognitive deficits caused by the surgery.

Child Life Specialist—someone that helps navigate the process of illness through imaginative play. For example, they can explain to your child what a feeding tube looks like on a doll, making the process of getting a feeding tube put in less scary.

## Chapter 3      Diagnosis, Treatment and Clinical Trials

### How Are Brain Tumors Diagnosed?

Brain tumors are often difficult to diagnose because they are rare and, therefore, not the first thing that comes to mind for a doctor. 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. Therefore, it is not unusual for a child with vomiting to be seen several times and maybe by specialists before receiving the proper diagnosis.

Many symptoms are due to raised intracranial pressure (ICP), brought on by the tumor's size or location, blocking cerebrospinal fluid (CSF) flow from the brain. If the tumor has blocked the flow of CSF, the excess fluid builds up and causes hydrocephalus. Symptoms may include headaches (particularly in the morning), nausea, vomiting, poor coordination, seizures, drowsiness, and, in infants, an increase in head size. Other brain tumor symptoms 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 that 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). In addition, tingling or weakness in the arms or legs and loss of bladder or bowel control may occur. A child's symptoms are related to the pressure of the tumor on a particular area of the spinal cord. Once other diagnoses have been ruled out, the doctor will take your child's health history

and do several measures of neurological function. Often a neurologist is involved; they may order tests such as an electroencephalogram (EEG), a computed tomography (CT) scan, 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 cannot lie still for the scanning procedures, they 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. However, sometimes an exact diagnosis can only be made once a tumor sample is 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 gliomas are diagnosed by imaging and do not require biopsy in most cases.

## **Obtaining a Second Opinion**

For many, asking for a second opinion is difficult and something parents may not feel comfortable asking about. A second opinion does not mean you are questioning the information the doctor gave you, but rather, it ensures the medical advice on diagnosis and treatment options is accurate and appropriate. Most medical teams consult with other teams to ensure agreement on the diagnosis and recommended treatment. By asking for a second opinion, you are not asking for anything unusual from the medical team. Getting a second opinion makes sense and allows you to explore treatment options. It can clear up any doubts or provide the confirmation

you need to proceed with treatment. The best time to get a second opinion is before your child starts cancer treatment or during the first few weeks of therapy.

There may be other reasons you are asking for a second opinion, such as your doctor not having treated many patients with the diagnosis you received, being uncomfortable with their recommendations, or wanting to look into a clinical trial. Every medical team is accustomed to second opinion referrals, so do not feel you will be treated differently or that the team will be angry if you ask for a second opinion. Because a brain tumor diagnosis often happens in emergencies, do not feel guilty if initially there is not time to seek a second opinion.

The first step in seeking a second opinion is to ask your medical team for a referral. You do not have to offer a reason but feel free to discuss your questions and concerns with the team. If the conversation is difficult or adversarial, ask the hospital social worker for a team meeting.

Before asking for a second opinion, you should research different surgeries, hospitals, and their statistics to help you decide where to go for a second opinion. However, you do not have to know where to go and can directly ask the team where you should go for a second opinion. Here are some questions you may want to ask the team.

- Can I get a second opinion?
- How do I get a second opinion?
- How long will it take to get a second opinion (with my chosen doctor)?
- Will getting a second opinion delay treatment or diagnosis?
- How long can I wait before starting treatment? How long is too long?

In preparing for a second opinion consultation, it can help to have access to or copies of your medical records. Talk to your current medical team about accessing these as soon as possible to avoid delays. Think about what questions you want to ask. It is best to take someone with you to get the most out of the appointment. They could write down the answers to your questions so you don't have to remember them.

## **How Are Brain Tumors Usually Treated?**

### **Surgery**

Treatment of brain or spinal cord tumors usually begins with surgery—also called "resection"—to remove all or part of the tumor. Although complete removal of the tumor (gross total resection) is often the treatment of choice, partial removal of the tumor is sometimes necessary and will occasionally relieve a child's symptoms.

A surgery to remove only a small part of the tumor for diagnostic purposes is called a biopsy. A biopsy can also be helpful in determining what options are available for treatment. Some tumors can be diagnosed with MRI alone. However, a biopsy might still be helpful for a molecular analysis that guides decisions about participation in clinical trials or new "targeted" therapies that treat problems that might arise from specific gene mutations.

Modern surgical equipment and experience allow neurosurgeons to locate and remove previously inaccessible tumors. Advanced equipment also helps identify (and therefore avoid damage to) critical areas like cranial nerves or parts of the brain that control speech. In the past, tumors of the brainstem and other deep structures were considered too dangerous to even biopsy, but with modern techniques, this is now available and routinely performed.



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) during 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 usually has a follow-up MRI scan within the first two 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 the 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 a 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 immune system cells. 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, 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 radiation dose 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 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. A single radiation dose 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 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. Unfortunately, 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 with improved effectiveness and reduced 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, two devices are 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 them 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 these therapies' short- and long-term effects from your treatment center. 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 bloodstream. 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. 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, wonderful 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 decreases. Children taking Decadron may have an enormous appetite! Taking these medications with food is very important 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 production of steroids, so it's important that patients not discontinue this medicine abruptly. The dosage will be gradually tapered off when the doctor wants the drug stopped. 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. Different medications are available, so you can

work with your child's doctors to find the best anti-nausea treatment for your child.

### **What to expect in the future?**

Many children's tumor specialists are excited about treatments currently being researched and developed. They expect to see advances in several areas: fewer 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 immune system to kill tumor cells, and gene therapy. Research must continue in specialized medical centers and children's hospitals, where healthcare professionals are experienced in caring for 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 and a doctor or team 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 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 can 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. Researchers can more quickly and efficiently gather information about effective therapies by evaluating new therapies for large numbers of children through COG.

**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 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 the new treatment very promising, a phase III trial may be done. Patients are randomly given one of two treatments in a phase III trial. Randomly means that a computer (not the doctor or parent) decides which treatments a patient will receive. A phase III trial is usually done to determine whether a new treatment is better, worse, or the same as the established treatment for a certain disease.

#### How to Find Clinical Trials:

More information on clinical trials can be obtained through NCI's direct search for clinical trials, available at [www.clinicaltrials.gov](http://www.clinicaltrials.gov) and Virtual Trials at [www.virtualtrials.com](http://www.virtualtrials.com)

## **Tissue Collection**

The most important developments in tumor research over the past decade have come from sharing human tissues between researchers. This has led to an exponential increase in knowledge about brain tumor molecular and genetic causes. As a result, many organizations are dedicated to making tissue donations free and opening access to any scientist searching for a cure so that we have the best chance of making progress.

The great part is that you can donate tissues already removed as part of the standard surgery that would otherwise be discarded. It does not cost anything, and it does not change the surgery or treatments in any way.

Your treatment team usually offers tissue collection, especially if they are involved in a clinical trial that uses molecular or genetic analysis as part of the study. However, if they do not have a routine protocol for doing this at their institution, there are other facilities that can help make this happen for you for free.

For children who have lost their battle, many families have found that donating tumor tissue to research is a way to bring meaning to what otherwise feels like a senseless tragedy. It is very rewarding to help other families—future families—that will be faced with the same situation by moving the field of research forward. This process does not interfere with funerals or celebrations of life and can be done for free with a simple call to the Gift from a Child (<https://giffromachild.org/>) program.



## **Tips for Hospital Stays/Life During Treatment**

This may be your family's first experience with hospital stays and ongoing visits. CBTF is here for you throughout the journey. Here are tips for hospital stays that other families have provided for us.

- Take it one day at a time. Easy to say, but difficult to do.
- As parents, you will often feel as if you are forced to make difficult medical decisions and may feel as if you are a lone advocate for your child. Do not hesitate to ask for advice from your medical team.
- Children, especially teens, often feel a loss of control while in the hospital, as their independence and freedom are significantly diminished. Look for ways you can give them control. For example, ask them if there are times when they want privacy and would like the room to be visitor free.
- 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.
- Tell someone if you see something that doesn't feel right or if your child is acting out of character.
- Try to keep your parenting as "normal" as possible.
- Ask what accommodations the hospital provides for parents staying overnight, such as recliner chair-beds, toiletries and bathing facilities for caregivers, laundry

facilities, meals for parents, and available refrigerator space.

- Make yourself as comfortable as possible. Bring comfortable clothes and shoes and something to entertain yourself.
- Try caring for your other relationships, even when it feels impossible.
- For repeated stays, look for a familiar face for your child. This usually is not difficult, but if your child has a favorite person, ask when they will be in and share the news with your child.
- 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. Children may sense there is more going on and make up explanations. Young children will demonstrate a different intellectual awareness or emotional reaction to events than adolescents or adults.
- When possible, prepare your child for extended hospital stays, including letting them plan what they want to wear or bring to the hospital, including electronics.
- 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 cozier.
- Connect with the hospital social worker, who is skilled at helping parents sort out their feelings and find appropriate ways to communicate with children.

- "Medical play" with stuffed animals or dolls can help children learn about their procedures and surgeries and provide a healthy outlet for frustration, anger, and anxiety. Ask the hospital child life specialist to guide you in selecting helpful tools and provide ideas for how to use these tools.
- Ask for flexible visiting hours for parents.
- When possible, take a proactive role in your child's care by assisting with toileting, bathing, and eating.
- 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 the playroom.
- Try to arrange for treatments and procedures to be scheduled, so your child has time to rest and be refreshed before visitors are expected.
- Take advantage of when you can take a break because your mental and physical health are essential to your child's care.
- Maintain a connection to your child's school and peer group. Use programs like Monkey in My Chair (<http://www.monkeyinmychair.org/>) to help with school connections.
- Most hospitals have hospital-based teachers to help your child with schoolwork during extended hospital stays.
- Many hospitals now provide complementary medicine services such as yoga, massage therapy, meditation/guided imagery, music therapy, and Reiki, which promote wellness and relaxation.
- 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 their meals.
- Try to arrange for your child to wear their clothes as much as possible. Clearly label belongings with your child's last name using permanent ink. Ask staff members if a washer and dryer are available for your use.
- Try to keep your child's daily routine as consistent as possible during the hospital stay. This is reassuring to everyone and is particularly important for the youngest patients.
- Consider arranging for your child to talk with a hospital social worker or psychologist without your presence. Even young children try to protect their parents from their fears.
- Young children tend to be primarily concerned about separation from their parents. Reassure them every time you leave that you love them and will return as soon as possible. If you know what time that will be back, say so.
- Encourage your child to keep in touch with friends and classmates while absent from school.
- Identify a contact person that can help you inform others of the information you want to share. You can also use apps like CaringBridge (<https://www.caringbridge.org/>) to keep others informed.

- Use apps like Lotsa Helping Hands (<https://lotsahelpinghands.com/>) to help arrange meals, transportation, and other needs your family may have.
- Ask for a takeout menu. Hospital food is good for a couple of days, but it can be rough after that.
- During this time, parents often dismiss their own health needs, both physical and mental. 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, provide you with support, and offer community referrals for outside support.

*“Despite the illness, I’m still a normal child with outside friends, interests, and responsibilities.”*

*“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.”*

## **The Parent 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.

Keep a notebook, journal or electronic record of your child's medical history including the following items listed below.

- The exact diagnosis (“pathology”) and location of the tumor
- The date of diagnosis
- Hospital or clinic and doctors' names
- Names and doses of chemotherapy
- Doses and sites of radiation
- Dates and names of surgeries

Keep track of your child's health from day to day, including 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 the medical team. Note the date, time, and duration of these symptoms. These may be a mild reaction to a medication; however, a symptom does not have to be externally obvious to be serious. Write down any and everything you feel 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.

Parents often think of the questions they want to ask the medical team when they are offsite or the team is not available. Keep a list of your questions for your next meeting and bring it with you. Here are some questions you might want to ask:

- What medication side effects are possible?
- What symptoms or side effects should I report to the medical team?
- What constitutes an emergency?
- Is there anything I can do to minimize side effects?
- What specific activities are allowed or restricted?
- How long will my child have to be on this medication?

Make a habit of bringing your record keeping journal or device to all of your appointments. Listen carefully to the answers provided by your child's medical team and take notes. You may want to have a family member or friend go with you to discussions or meetings with the medical team—it's surprising how much information you can miss. Additionally, you may want to ask permission to record a meeting if no family member or friend can attend with you.

Keeping records of clinical visits and treatments can also be helpful. Note things such as:

- Blood count levels
- Treatments administered
- Medications prescribed or given and 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. Also keep a separate list of the professionals involved with your child, what their role is and how to contact them (by phone and email).

## **Chapter 4     Preparing for Life After Treatment**

### **Medical History and Disclosure**

As treatment ends, people may ask questions about your child's medical history that you may or may not want to answer. It is up to you and your child as to how much information you want to share. Thinking about this in advance makes it easier to answer questions when they come up. Depending upon their age, your child may have feelings about how much information they want to disclose about their medical history. Talk with them in advance so that you know what information they are comfortable with you sharing and that they know they are a part of the decision-making process.

### **Emotional and Social Impact**

Navigating the brain tumor experience is difficult and impacts the patient and every member of the family socially and emotionally. Reaching the end of treatment is a significant milestone; however, it is often met with mixed emotions of relief from treatment being over and anxiety about what the future holds. Pediatric brain tumor patients are at a higher risk for depression, anxiety and social withdrawal than other pediatric cancer survivors. This can have long-lasting effects extending into young adult and adulthood, affecting familial and peer relationships, academic and employment success and emotional well-being. Early detection of symptoms is crucial. Developing a follow-up plan with your medical team can identify issues early and get your child the help they need. Assisting survivors with re-entry in the school environment and during key transitions may also help improve psychological outcomes, in addition to helping them build and strengthen social skills.

Brain tumor survivors often feel different or isolated from their peers. Most will experience physical, cognitive and/or



emotional changes as a result of their diagnosis and treatment. They may have to relearn basic skills or give up aspects of themselves that were key to their pre-diagnosis identity. Successes and milestones begin to look different from those of their peers. Even friends who stick by them during and after treatment and do their best to understand are unable to fully relate to their experience.

Community-based organizations like CBTF exist to help survivors and their families feel less alone. Online social programming and group discussions can help survivors and family members, regardless of where they live, build a support system and discuss challenges with others who understand. Ongoing support from family, friends and community will help survivors and their families navigate the brain and spinal cord tumor experience more successfully.

### **Changes in Physical Appearance**

Treatment for a brain or spinal cord tumor can bring about changes in physical appearance. Some of these changes are temporary; others may be long-term. For children and especially teens, self-esteem and self-confidence are often closely related to physical appearance. It can take time and creativity to help your child manage these physical changes. A common side effect of chemotherapy and radiation is hair thinning or loss which can happen all over the body or just on the head depending on the type of treatment. For the minority of children who receive whole-brain radiation, hair loss can be permanent; however, in most cases the hair will grow back. Small patches of hair loss may remain and the hair that does grow back may be a different color or texture. When their hair starts to fall out, some children may choose to wear a hat, wig or bandana; others may opt to shave their heads or do nothing. Empower your child to make decisions about managing these physical changes. If your child chooses to go bald, the sensitive skin should be covered with a hat or

sunscreen when they go outdoors. Scars on the head resulting from surgery are more permanent; however, they may in time come to symbolize healing and strength.

If your child decides on wearing a wig, consider buying one 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. Insurance plans often reimburse for wigs if a prescription is submitted. The prescription should read: Cranial prosthesis.

As these changes occur, allow your child to express concerns, anxieties, fears, and frustrations. Explain that you accept any and all physical changes because they are part of a necessary treatment to help them get better. Remind your child they are the same person inside. Surround them with family, friends and peers who can provide support, acceptance and encouragement. It may also help for your child to meet and talk with other children who have experienced similar challenges.

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

### **Sharing with Your Child's Peers**

Fortunately, most school-aged children don't know many people with brain or spinal cord tumors. As a result, they know little about the topic and misconceptions can be easily formed. Children may not know how to cope or react to their friend's illness and, as a result, may withdraw. Communicating with the parents of your child's friends can help keep them connected to their peers. Provide age-appropriate information for parents to share with their child about what is happening to their friend.

Give examples of ways they can support their friend (cards, notes, texts, gifts) while they undergo treatment. Maintaining peer relationships can help reduce the social isolation experienced by brain and spinal cord tumor patients post treatment.

When your child is ready, physically and emotionally, set up times for them to connect with peers online or in person. Talk with the parents of your child's friend about the changes they will see as a result of the treatment that is helping them to get better. Ask your child how they would like to interact. Start small, maybe a short video call or half hour visit to start. Keep the lines of communication open and remind parents and friends how much their support means to you and your child.

## **Parents, Marriage, and Family**

The logistical and emotional challenges related to having a child with serious illness can strain even a strong marriage and family. Divorced or separated parents may need to put their differences aside, and single parents may need to seek additional support from the community to help their family navigate the brain or spinal cord tumor journey.

Since the start of your journey, you may have already seen some changes in your family relationships. Anticipate, expect, and accept that shifts in roles will occur. Who does what in the family may change, and these new jobs may have to be negotiated. For example, the roles of primary caregiver and primary breadwinner may shift, especially when health insurance is tied to employment status. Each job is needed for the family to function as a whole, and no single role is more important than the other. Respect and accept your partner for what they do and try to include each other and other family members in the everyday care of your child.

## **Chapter 5     Caring for Siblings**

A brain or spinal cord tumor diagnosis affects the entire family forever. It can lead to changes in roles and responsibilities within the family, shifts in attention and focus, and disruptions in daily routines and schedules. This can have a deep impact on the lives and emotions of siblings. This chapter includes information on some of the feelings siblings may experience at different times. It includes tips for siblings on how to manage these feelings and a checklist that can help them organize their thoughts. It also includes suggestions for parents on how to support siblings throughout your family's journey. Parents can help by accepting and acknowledging the feelings of siblings as normal and understandable. Share your feelings with all your children and keep the lines of communication open. Listen, let them ask questions, and keep them updated on what is happening with their sibling. Letting them know that you, too, are concerned, sad or worried will make it easier for siblings to express their emotions and share what they are going through so that you can navigate this journey together, as a family.

### **Common Feelings of Siblings**

#### **Fear and Anxiety**

Upon diagnosis, siblings may experience feelings of fear and anxiety. They may wonder what is going to happen to their brother or sister, what caused the tumor, will they get a brain tumor too, and will their sibling survive. They may be afraid to express their feelings to protect you, their parents, who are already stressed and may not know what to say to their sibling who was diagnosed. In addition, families sometimes need to be separated during treatment, and school and activity routines are often disrupted, causing additional anxiety and stress among siblings.

## **Anger and Resentment**

Anger is another feeling siblings may experience. Anger can be over their sibling's diagnosis, that so much attention is given to them, and that they don't have to go to school. Siblings may feel anger over having their schedules disrupted and at having to spend time with other relatives and adults who have been charged with their care. When treatment ends, siblings may become resentful, thinking that their brother or sister is given special treatment and gets away with things, like not doing chores.

## **Guilt**

Some siblings feel guilt that they did not get sick or from their reaction to their sibling's illness. Others feel guilty because they are healthy and able to continue their typical activities or because they picture life without their sibling.

## **Feeling Neglected**

When a child is diagnosed with a brain or spinal cord tumor, their health, understandably, becomes the primary focus of the family. Getting them to their appointments and treatments may mean that siblings miss out on certain activities. Parents are stretched thin, and even when they do their best to make sure their other children maintain their normal activities, this sometimes just is not possible. During these times, siblings may feel neglected and that no one is paying attention to their needs.

## **Embarrassment**

After a child completes treatment, there may be some differences in the way they look, behave, or react to certain situations. Sometimes these changes may cause siblings to feel embarrassed. Embarrassment can sometimes lead to other negative feelings like guilt, shame, or annoyance.

## Tips for Siblings

- Ask for information. Oftentimes, parents feel they are protecting you by not telling you what is going on. Parents may worry they will scare you by giving too much information. One thing you can do to gather information you would find helpful is to write down your questions and take them to your parents. Show your interest by asking if you can attend appointments or speak with the medical team about your specific questions and concerns.
- Ask your parents if there is anything you can do to help. Ask your sibling if they want to do something with you. They may be feeling lonely too.
- Identify someone you can talk to. Sometimes it is difficult to talk with your parents about what you are going through. Find someone you trust, who you feel you can talk to about your feelings. This person may be an aunt or uncle, grandparent, coach, teacher, or other important figure in your life. If you are struggling, see if they are available to chat. It is also important to tell your parents who the person is so that they know you have someone to talk to.
- Take care of yourself. Getting a good night's sleep, exercising, and eating well keep us healthy and help us to better cope with stressful situations.
- Talk with your parents. You may feel your parents are the last people you want to reach out to at this time. They are busy spending time at the hospital, running your sibling to appointments and treatments, or on the phone with relatives updating them on what is going on. You may feel your worries are not as big as everything else that is happening; however, your parents are concerned about you. They are being

pulled in many directions and may need you to reach out. Asking for help, lets them know what you need.

- Continue to participate in activities you enjoy. When stressful or scary things happen, people sometimes stop doing the things they like to do. While it may feel awkward to go out and have fun when your sibling isn't well, it is an important part of taking care of yourself and will help you be a better support person. If something is important to you, share with your family that you hope you can attend or that they can attend with you. It may not always be possible, but it is important to communicate your feelings.
- Write down your thoughts. While talking with someone is helpful, sometimes what you are feeling is hard to communicate; this is when writing down your thoughts and feelings can help. Giving voice to your thoughts helps to reduce stress and process what we are thinking.

## **Ways of Offering Support to Your Sibling**

Below are some ideas of ways you can support your sibling after their diagnosis. Most importantly, talk to them and find out what would be most helpful for them.

- Bring their favorite items to the hospital (stuffed animal, game, blanket, etc.).
- Hang out with them (listen to music, watch a movie, play a game, etc.).
- Include them when hanging out with your friends; alter activities so they can participate.
- If they need to miss school, drop off their homework at school or bring their homework to them.

- If your sibling has to stay in the hospital for an extended period, call or text them when you are thinking about them; gather and deliver notes or cards from their friends.

## **Remember**

- You did nothing to cause your sibling's diagnosis.
- Your sibling's diagnosis is not contagious.
- You can help care for your sibling; they need and want your support.
- It is okay to ask for help.
- Don't feel guilty for having fun and doing things you enjoy.
- Ask your parents questions.
- Even when you feel neglected, your parents love and care about you.
- Take care of yourself.

## **Tips for Parents**

- Tell your other children, as soon as possible, about their sibling's diagnosis. Explain the illness in ways that are age-appropriate, providing as much information as they can understand about their sibling's condition.
- 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 helps to reduce fear and anxiety.
- Using the correct terms—brain tumor or cancer—is helpful, because avoiding the terms can make the subject taboo.
- Encourage questions and provide frequent updates about their sibling's condition.



- Assure siblings that they are in no way responsible for their sibling's condition—and that cancer isn't contagious.
- Explain that the doctors don't know all the answers, but everyone is doing whatever they can to help their sibling.
- Help them to keep in touch with their sibling by sending text messages, emails or notes. Take them to the hospital to visit or to the clinic during treatment, if possible. This helps to relieve anxiety about what goes on in these settings.
- Involving them in the care of their sibling can help them to feel useful. 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.
- Make a point of recognizing their efforts and accomplishments, rewarding them with praise, plenty of extra hugs, and thank yous.
- When possible, spend some time alone with each of your healthy children. Quality time doesn't need to be a big event; it can be preparing a meal together or watching a show. When you can't be together physically, talk on the phone or do a video call. Let them know that you miss them when you can't be there.
- Be consistent with schedules so that children can feel safe in their routines.
- Encourage them to become involved in outside activities and do things they enjoy. Tell them it is okay to have fun.
- Acknowledge siblings' feelings and worries. Reassure them that they are equally important and loved.

- Enlist the help of friends or relatives to transport siblings to their usual activities or just get them out of the house for some fun.
- Alert your child’s school, their teachers, coaches, counselors, etc., to what is going on at home—the family health crisis may cause siblings to express themselves in different ways. Behavior changes in the siblings of children with serious illness are common. Let your child’s school know of any changes they should be aware of and ask them to communicate any concerns with you.

*“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 go away.”*

*“Close friends watching my brother offered my parents opportunities to stay with me in the hospital night and day as well as during chemotherapy appointments.”*

### **Checklist for Siblings**

Below is a checklist that can help you understand a little more about your siblings’ health situation, as well as some questions to help you and your family communicate more easily about what you are going through.

- Your sibling’s diagnosis
- Types of treatment your sibling received
- Name of person or people you feel comfortable talking to
- Names of family/friends you would like to stay with should you need to spend the night with someone (1st, 2nd and 3rd choice)
- Things you are worried about

- Activities that help you feel less stressed/worried
- Questions you would like to ask about your sibling's health or treatment
- Ways you want to help your sibling

## **Chapter 6      Transitioning from the Medical Setting**

Advancements in the treatment of childhood cancer have led to improved survival rates. There are more than 500,000 childhood cancer survivors in the United States, and many of them have a history of a brain or spinal cord tumor. According to the American Cancer Society, about 3 out of 4 children with brain tumors (all types combined) survive at least 5 years after being diagnosed. The outlook can vary a great deal based on the type of tumor, where it is and other factors.

After treatment ends, the frequency of visits with the primary oncology team lessens, and eventually these survivors are seen in community by primary care providers for the majority of their health care needs. Close monitoring of survivors is vital because they are at risk for late complications of their treatment such as organ system problems and secondary cancers. Survivors need lifelong medical care.

Ideally, medical care for survivors can be achieved by participation in a survivorship clinic that specializes in late effects of cancer survivors. But not everyone has access to such a clinic. That is why education of survivors and their families of the potential late effects of treatment is critical.

A person can develop their own treatment summary and survivorship care plan and be better informed. Remember, knowledge is power!

### **Survivorship Care Plan and Treatment Summary**

#### **What is a treatment summary and survivorship care plan? And why is it important?**

A treatment summary and survivorship care plan is a comprehensive and clear summary of the treatment a patient

has received and includes an outlined plan of how the patient should be monitored.

See an example of a treatment summary and survivorship care plan at the end of this chapter.

### **Where can a person get a template for a treatment summary and survivorship care plan?**

The Children's Oncology Group (COG) has developed evidence-based guidelines for screening and management of late effects resulting from treatment of childhood cancers. COG also offers templates of plans on their website. (<http://www.survivorshipguidelines.org/>)

Ideally, the plan should be completed by principal providers of oncology treatment (doctors, nurse practitioners who administered care).

The diagnosis, date and type of treatment received (surgery, radiation, chemotherapy and/or immunotherapy) are important parts of the plan as well as the outline of **potential** late effects related to treatment. Potential is bolded and underlined because not all side effects listed in the plan could occur, but survivors and families should be aware of what **could** happen.

Recommendations might include earlier colonoscopy, which is currently recommended for the average American at age 45, or testing for physical effects of treatment, like balance issues. These are just two examples.

### **Tips on utilizing your treatment summary and survivorship care plan:**

- Educate and re-educate yourself with your/your child's history.

- Use the treatment summary as your/your child's "medical resume."
- Share the treatment summary and survivorship care plan with health care providers.

## SUMMARY OF CANCER TREATMENT AND SURVIVORSHIP CARE PLAN

Date of preparation:

<b>Name:</b>		<b>Date of Birth:</b>	
<b>Cancer Diagnosis or Tumor Type:</b>			
Treatment center:			
Date of diagnosis:			
Age at diagnosis:			
Date of completion of therapy:			
<b>Surgery</b>			
<b>Date</b>	<b>Procedure</b>		
<b>Radiation Therapy</b>			
<b>Date Start</b>	<b>Date Stop</b>	<b>Field</b>	<b>Dose (cGy)</b>
<b>Chemotherapy</b>			
<b>Drug Name</b>		<b>Dose (units or mg/m<sup>2</sup>)</b>	
<b>Potential Late Effects</b>		<b>Screening Recommendations**</b>	
<ul style="list-style-type: none"> <li>● Hypothalamic pituitary dysfunction: adrenocorticotropic hormone (ACTH) deficiency, growth hormone (GH) deficiency, thyroid stimulating hormone (TSH) deficiency, gonadotropins (LH/FSH) deficiencies</li> <li>● Cardiovascular disease</li> <li>● Lung problems</li> <li>● Hearing problems</li> <li>● Cataracts</li> <li>● Thyroid problems</li> <li>● Fertility problems</li> <li>● Altered bone health</li> <li>● Kidney problems</li> <li>● Bladder problems</li> <li>● Diabetes</li> <li>● Peripheral neuropathy</li> <li>● Cognitive changes</li> <li>● Gait disturbances</li> <li>● Distress (including anxiety, depression, fatigue and/or sleep disturbance)</li> <li>● Second cancers (infrequent)</li> </ul>		<ul style="list-style-type: none"> <li>● Complete physical exam every year</li> <li>● Annual labs: CBC, comprehensive profile, Mg TSH, free T4, am cortisol, testosterone, HgbA1C, lipid profile</li> <li>● Echocardiogram; initial to assess valve function and then as clinically indicated (for pts who received spinal RT)</li> <li>● EKG baseline and as clinically indicated</li> <li>● Pulmonary Function Test baseline and as clinically indicated</li> <li>● Baseline Bone Density Study (DXA)</li> <li>● Ophthalmology exam every year</li> <li>● Audiogram at baseline and as clinically indicated</li> <li>● Neurocognitive testing</li> <li>● Semen analysis as requested</li> <li>● Counseling as needed</li> </ul>	

\*\*Screening recommendations adapted from the 2018 Children's Oncology Group Long-Term Follow-Up Guidelines: <http://www.survivorshipguidelines.org>.

## Chapter 7     Getting Ready for Adulthood

Parenting is the toughest job—especially when it includes an extremely stressful event like a brain tumor diagnosis. It involves a lot of worry and doctors' appointments, but also nagging and saying the same thing repeatedly (especially if your child has memory problems). But is the battle of making your kid do their laundry, struggle to connect with others their age, make their peanut butter sandwich, or put down their video game controls to move their body every day really worth it?

Many of us don't start planning for life after high school until our kids are in their late teens, but that's too late. Sometimes, you are just thankful that treatment is over and are not ready to think about the future, but the sooner you do, the better your child's and your quality of life will be. It would help if you were thinking about their life as an adult from the minute your child is discharged from the hospital and you begin the journey of survivorship.

Many childhood brain tumor survivors indeed experience common neurocognitive issues such as poor working memory, slow processing speed, low attention, challenges with social issues, memory problems, and others. However, children may also benefit from *neuroplasticity*, which is the ability of the brain and nervous system to reorganize neural pathways, connections, and functions throughout development. In other words, if surgery or other treatments have blocked one path of function, a young person's brain (and, to some degree, older brains) can look for detours or alternate routes.

Repeated experiences can weaken or strengthen neuronal bonds (or the "brain connections") based on your child's activities. This is one reason we often recommend less video gaming and more reading. It's not enough to rely on reading to be left to your child's teachers. Many of our survivors leave



high school with reading (and math) skills well below the 6th grade level—the grade level many consider necessary to be functionally literate as an adult and to be able to read a doctor's instructions or a job application. More practice opportunities at home and during the summer months may provide essential opportunities for new learning and improving reading skills, particularly when your child struggles with memory.

## **Fostering Independence at Home**

**What other ways can you begin laying the groundwork for your child to develop more independence skills—at any age?**

- **Establish behavioral expectations.** Because your child has experienced a significant medical event, they may sometimes feel powerless to control even the smallest things. Your child may try to take control over situations by behaving inappropriately (throwing temper tantrums, refusing to take medication, or staying out past curfew). You can help your child feel more in control by offering choices whenever possible and seeking their input when making decisions. Looking the other way and giving your child "a pass" on their behavior because they've had a brain tumor is not going to help them in the long run.

A big part of our job as parents is to help our children be someone other people want to spend time with. That will be more of a challenge if their behavior is allowed to go unchecked and they grow up to be someone unpleasant to be with. Children with behavioral challenges grow up to be adults with behavioral challenges, which may significantly limit options for support programs, education, housing and employment. Some suggestions include the following:

- **Use appropriate and consistent discipline strategies** that encourage your child to behave appropriately.
- **Establish limits and behavioral expectations** ("I expect you to be in bed with lights out by 9:30 PM. Do you want to set a reminder on your phone or should I? How much advance time do you think you will need to get ready?") All of these questions are helping your child develop some executive skills of planning, problem-solving and time management.
- **Establish clear expectations** ("You need to clean your room before you can play on your Xbox") and set firm limits ("You may not play with your Xbox because you did not finish cleaning your room yet").
- **Provide frequent praise** ("You did a great job remembering to take your medicine this morning") and encouragement ("I really like how you kept working on those math problems even though they were hard for you").
- **When your child engages in inappropriate behaviors**, timeouts for younger children and loss of privileges for older children can decrease unwanted behaviors.

If some or all of these suggestions are challenging for your family, ask for a referral to a child or pediatric psychologist to help you move your child's behavior to a better place.

- **Maintain a schedule.** By setting up and maintaining a schedule for your family, you are also teaching your children how to manage their time and how to organize their days. Your child and family will function best when their daily schedule is predictable and consistent (same bedtime and wake-up time every day of the week).
- Make sure your child goes to bed, wakes up, and eats healthy meals at regular and predictable

times--especially teens. Have limits on video gaming or phone use and have everyone in the family "check" their phones/controls into a box before bedtime.

- Give your child choices and encourage them to take over more aspects of planning as they get older ("Let's work together to plan a family outing this weekend. How can we find out what the weather will be like? Where can we get ideas of what to do? How can we figure out how much this will cost for our family?")
- **Help your child follow their health plan.** When your child does not follow the treatment plan, there are increased risks to your child's immediate and long-term health. Poor health in adulthood can not only limit your child's options for employment, social relationships, and other life goals, but it can also directly affect cognitive functioning and quality of life.

If your child has good language skills, help them develop their verbal problem-solving skills: "What do you think we should do? What do you think will help at school? What's not working?"

- Support your child in following the treatment plan (including diet, exercise, OT/PT/speech goals, endocrine recommendations, and medications) with clear and straightforward explanations, praise and encouragement, appropriate limits, and consistent consequences.
- Dietary goals are easier when everyone in the family commits to eating healthier. When kids eat junk, it's mostly because their parents purchase it for them.
- Commit to moving together as a family. If I told you I could give you a pill to help you be smarter, feel better, and have better physical and mental health, people would be lining up around the block to get some. But being told to move more makes most of us groan. Look

for activities that will move your child up the scale 1-2 METS from what you are doing now; for example, if your child does no physical activity, start with activities in the "light" category like easy walking or chair yoga. (<https://media.hypersites.com/clients/1235/filemanager/MHC/METs.pdf>)

## Communication in the School Setting

- **Help your child understand and learn how to explain their strengths and weaknesses.** Because the effects of cancer treatment emerge and change over time, a single neuropsychological evaluation will usually not be adequate to address the child's needs as they develop. Similarly, your child is changing and growing, and testing must be updated to ensure the goals are appropriate. Follow-up testing can also help change interventions at school if your child is not making expected progress.
- Obtaining an evaluation during the first year after diagnosis will help address immediate difficulties that may occur because of medication side effects or school absences and will also provide a "baseline" for determining whether there are "late effects" of your child's tumor and treatment.
- Unlike a school educational evaluation for an Individualized Education Plan (IEP), which typically does not evaluate common problems in brain tumor survivors like memory, attention, executive functions and other issues, a neuropsychological evaluation will take into account your child's specific medical history and developmental context and follow changes over time.

Make sure you understand the results, and don't be afraid to ask questions or to ask the evaluator to explain things to you

in a different way. Read the report and follow up with the evaluator if you have questions or need help understanding or agreeing with the information. Then, share it with your child's school and ask them to schedule a meeting to discuss the results and recommendations.

- Re-evaluations every 18 months to 3 years (shorter intervals during the elementary years, with longer intervals in adolescence and young adulthood) are usually recommended to assess changes due to treatment and other factors and revise recommendations for intervention.
- **Commit to reading AND understanding your child's IEP.** Just having an IEP in place is no guarantee of educational success. You need to make sure the school's IEP plans for your child align with your own goals for your child.

You also can't put your child's education on autopilot and expect the school to make sure your child is getting what they need. Parents must ask hard questions when they do not see progress over time.

- Make a list of your top 3 concerns or questions and share them with your IEP team before your next meeting.
- Ask your school district's assistive technology specialist to participate in every IEP meeting and use technology to support your child in the classroom.
- Bring a support person to EVERY meeting with the school.
- Please do not sign an IEP without reading it first.
- Ask for help from your child's neuropsychologist or psychologist if you need help understanding the IEP.
- Are the goals what you want for your child? Don't rely on your IEP team to do this.

- Is your child making progress on their goals, or is this the 5th year in a row he is supposed to be mastering times tables? Move to using a calculator.
- Learn more about IEPs and how to advocate from a wonderful book called *From Emotions to Advocacy* by Pam Wright and Pete Wright, Esq. Pete was a struggling student on an IEP throughout school and grew up to become a special education lawyer.

## **Fostering Independence Outside of the Home**

- **Limit technology, phone use, and video gaming.**
- Kids spend more than seven hours a day using technology, which might increase stress and reduce the time available for other activities such as reading a book, socializing, or going outside. Limit your kid's tech time and spend more time being active as a family. Consider having a "phone break" for a full or half day on the weekend.
- **Helping others helps us feel better about ourselves.** Volunteering can build confidence, empathy and help your child practice social skills. For older children, this can be an important first step for working towards a job (so look for opportunities to build skills in areas of interest) – following a schedule, timeliness, direction, and a sense of accomplishment.
- Donate food to a food pantry. Have your child pick out one item each time you go to the store. When you get a bagful, take it to a local food pantry.
- Visit a nursing home. Your family can be matched with one person to call on regularly.
- Clean up. Pick up litter at a local park or while walking in the neighborhood. (Wear gloves and supervise your children closely.)
- Be kind to animals. Volunteer to care for abandoned dogs or cats or foster an animal.

There are lots of ideas here. First, talk to your child about what they want to work on. Pick one goal, tell someone else about it so you have some accountability, and focus on it for the next month or two. Then, as that becomes more of a habit, pick a new thing you want to work on and focus on that until you are ready to add a third thing. Keep moving forward with baby steps. If you mess up, tomorrow is a fresh start.

Your child may need a lot of reminders or support, but look for ways to help them be independent of you. For example, there are medication reminder apps that your child can use to help them remember to take their medication (see a review here: [A Comprehensive Review of Medication Manager Apps](https://blog.cincinnatichildrens.org/healthy-living/review-of-medication-manager-apps/) (<https://blog.cincinnatichildrens.org/healthy-living/review-of-medication-manager-apps/>)).

Encourage your child to count the change at the grocery checkout or use the credit card reader. Have them look for the lowest priced shampoo or the cereal brand the family enjoys. Ask them to take the lead in finding their way someplace (have them give you directions in the car or take the lead on a walk around the neighborhood).

With teens, you might start by going to the Casey Family Foundation resource at Casey Life Skills Toolkit - Casey Family Programs (<https://www.casey.org/casey-life-skills/>) to identify your older child's needs and get ideas (CLS Resources to Inspire) for how to fill in the gaps. You could also share these ideas with your child's IEP team and ask them to be included in their transition plan.

Finally, look for opportunities to build your child's independence skills away from parents. Think about camps online and in-person groups like those offered at CBTF,

including the mentor and Teen Leader programs. In addition, they may want to start volunteering on their own. If your child is likely to need considerable support and guidance as an adult, you should begin thinking well in advance of your child's 18th birthday about guardianship/conservatorship options and talk to an attorney who specializes in such matters. Know that students who are on an IEP can continue to receive transition support until they turn 21 years of age. Parents must work closely with their students and the educational team to ensure that transition goals are meaningful and appropriate. The PACER Center has a wealth of information online: National Parent Center on Transition and Employment ([https://www.pacer.org/transition/?gclid=EAlaIQobChMI8sS5slz6\\_AIVQsmUCR39cwz-EAAYASAAEgLm0fD\\_BwE](https://www.pacer.org/transition/?gclid=EAlaIQobChMI8sS5slz6_AIVQsmUCR39cwz-EAAYASAAEgLm0fD_BwE)).

## **Healthcare Transition Resources**

- Teen Care Notebook:  
<http://cshcn.org/planning-record-keeping/teen-care-not-ebook>
- The Youthhood: <http://www.youthhood.org/>
- Got Transition?:  
<http://www.gottransition.org/youth-information>
- Healthy Transitions:  
[http://healthytransitionsny.org/skills\\_media/tool\\_show](http://healthytransitionsny.org/skills_media/tool_show)
- My Med Schedule: <http://www.mymedschedule.com>



## Chapter 8      Education

### Cognitive and Emotional Changes

A brain or spinal cord tumor diagnosis and treatment can lead to cognitive, physical and emotional changes, which create new academic and social challenges. You may have to educate the school system about the visible and invisible changes in your child. You will also want to work with your child to determine the best learning methods for your child. All of this may be new to you.

This chapter provides information on neurocognitive and social skill effects, educational rights, accommodations, and communication tips to help families become educational advocates so their child can reach their full academic potential.

The location of your child's tumor, your child's age, and their treatment (surgery, radiation and/or chemotherapy) can affect cognitive and sensory functions, which may result in difficulties with thinking, learning, and remembering. These changes are called **neurocognitive impairments**. Such impairments can be temporary or permanent.

During treatment, certain medications and chemotherapy agents may cause acute changes that come and go with no real pattern, such as agitation, hallucinations, and memory issues, and may be reversible. Neurocognitive difficulties that develop or persist after therapy is completed are called **neurocognitive late effects**. These emerge after treatment is completed, and in younger children, they may only be noticed once more complex thinking is needed in about second or third grade. This includes long-term learning and functional problems, including persistent memory loss, slowed processing speed, reduced attention, and academic skill

deficits (Palmer et al., 2013, Ellenberg et al., 2009, Conklin et al., 2008, Ris et al., 2008).

Approximately two-thirds of survivors will have cognitive changes related to their tumor and its treatment and are more likely to need special education services than their siblings. When survivors receive these services, they have comparable high school graduation rates to siblings (Gurney et al., 2009). But without the appropriate accommodations, the ability of survivors to meet their academic potential is much lower. In addition, they may face emotional, behavioral, and physical changes in both ability and appearance, making building and maintaining peer relationships difficult and impacting overall social skills.

## **Your Child's Educational Rights**

Your child is protected by federal laws, which assure they receive the necessary accommodations in the least restrictive setting. Your child should remain in a classroom environment with non-impaired children whenever possible. Below are the primary federal laws requiring all public and some private schools to provide appropriate educational services to children with special needs.

### **The Americans with Disabilities Act (ADA**

<https://www.ada.gov/>) guarantees equal opportunity for people with disabilities. The ADA, the most general of the three laws, may help get your child the support services needed.

### **The Individual Disabilities Education Act (IDEA**

<http://idea.ed.gov/>) applies to all public schools and covers children with one of 13 classifications of specified disabilities or special needs. A child with a tumor may be classified as hearing or visually impaired or under traumatic brain injury or a specific learning disability. In some states, brain tumors are not

considered a traumatic brain injury and services may be provided under the “other health impaired (OHI)” classification.

Under the IDEA, your child is entitled to an evaluation to determine service eligibility. Then, depending on your child’s needs, a recommendation may be made to create an individualized education plan (IEP). The IEP is written by the educational team, parents, the child (if over 14), and any advocates involved. The IEP will establish your child’s unique and individualized education needs and document appropriate accommodations, services, and academic goals. The federal government gives money directly to school districts to cover services for eligible students, including occupational therapy, speech therapy, or counseling. A formal meeting process can change the IEP during the school year. 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 of the Rehabilitation Act of 1973**, commonly referred to as Section 504

(<http://www2.ed.gov/about/offices/list/ocr/docs/edlite-FAPE504.htm>), applies to any school that receives federal funding. As a result, many private schools are subject to the requirements of Section 504, which prohibits discrimination against a child or individual with disabilities. As a result, a child with special needs is entitled to appropriate educational accommodations to ensure their education is comparable to that provided to non-disabled students.

To head off developmental delays, infants and toddlers (birth through age three 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. These services do not

depend on a family's ability to pay. The child may receive physical and occupational therapy, speech therapy, and special instruction according to their needs. In addition, 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 ages **3-21** years, and a state's health department is for children from birth to age three. The state's health department refers parents or healthcare team members to early intervention services. After assessing a child younger than four, the early-intervention team will develop an individualized family service plan (IFSP), which must include the parent or guardian.

As a general rule, every school is required to have guidelines for accessing special education services. Public schools have guidelines explaining how the IDEA works in their 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 its ability to comply with IDEA or contact your state's Office of Special Education and Rehabilitative Services to clarify the rights of private school students.

Both IDEA and Section 504 give schools **30 days** to evaluate after receipt of a written request for testing 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.

## **School Communication**

Upon diagnosis, it is best to establish a chain of communication with your child's school. Make sure the principal and other school personnel involved with your child's

education know your child's diagnosis, treatment, and the potential effects of each. Ask the school for a primary contact person for you to share medical information with and discuss educational support and services when your child is ready to return. The contact person can provide medical updates to other school personnel. The more knowledgeable the school is with all aspects of your child's treatment and its impact, the more the school environment can be adapted to meet your child's unique educational needs. Open communication can make the child's transition back to school smoother and less isolating. Classmates, parents, and school personnel should be viewed as advocates and allies throughout the entire process to help your child re-acclimate and assimilate back into the academic world.

## **Returning to School**

When your child returns to school, you want the transition to be as smooth as possible. To do this, you will need the cooperation of both the school and your healthcare team. It is not uncommon for survivors to feel hesitant to return to school. Changes in appearance, learning, and physical abilities can make your child look and feel "different". Finding acceptance and understanding may be difficult; therefore, it is important to consistently monitor changes in behavior, school performance, and peer relationships.

Before your child returns to school, set up a meeting with your child's educational team. This may include your child's teacher(s), school nurse, counselor, and principal. This meeting will give you an opportunity to discuss any special requests or concerns you might have. When possible, include a healthcare professional or social worker familiar with brain or spinal cord 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 and who to contact first.
- During treatment or at times when your child's immune system may be compromised, your child's teacher and/or school nurse must inform you of any communicable diseases that any class member has contracted, such as Covid or the flu.

Keep an open line of communication with your child's school. It is likely they have had limited or no experience with brain or spinal cord tumor patients. Determine a regular meeting or check-in schedule to help facilitate your child's transition. As much as possible, directly communicate with your child's teacher(s) as they play a significant role in your child's developmental adjustment and re-entry into school.

To help prevent your child from falling behind academically, they should try to keep up with school work during treatment as much as possible. States differ in their laws related to the provision of homeschooling during hospitalizations, but all states have provisions to make sure your child's education continues. During treatment, ask the healthcare team about an estimated date your child can return to school, even if it is only

for partial days. Fatigue and medical needs may warrant a slow, transitional phase. 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 help some children with the re-entry process.

### **School Re-entry Program**

Some hospitals have a school re-entry program during which a representative meets with your family and the school, determines what is needed to return to school, helps educate the school about your child's needs, and provides any necessary documentation. If your hospital does not have a re-entry program, talk to your social worker or child life specialist about helping with the transition.

Pediatric brain and spinal cord tumor diagnoses are rare; therefore, educators and students may have limited knowledge and some misconceptions. You may want to talk to the school about preparing classmates by offering a presentation about your child's diagnosis and treatment and giving students an opportunity to ask questions. This can help to eliminate fears and allows you to share what has and has not changed about your child. It is important to talk with your child about how much they want to be involved in a presentation to their class. Treating them as the expert in front of their classmates can help support the child's transition back to the classroom, although by high school, some survivors may prefer that limited information is shared.

Additional support may be found through community-based programs such as CBTF who have advocates with expertise in the educational needs of survivors.

## Classroom Presentation Tips

- Ask your child how much they wish to be involved in the presentation and how much information they would like disclosed to their classmates.
- Keep all information clear, simple, and age-appropriate.

## Presentation Key Talking Points

- Types of symptoms your child experienced that led to their diagnosis.
- Treatment your child is undergoing to treat the brain tumor.
- Emphasize that your child's condition is not communicable, that they are still the person their friends have known, and that they need support.
- Explain the differences in your child's appearance: hair loss, weight loss, etc.
- Explain the differences in your child's abilities (cognitive and physical abilities, balance, stamina, etc.) and why they need help to do certain things (accommodations).
- Empower classmates to continue to be involved in your child's life, to visit, call, send email or letters, Facetime, Zoom, invite them to parties, sleepovers, etc.
- Answer and encourage questions to ensure classmates understand the main points.
- Keep classmates informed of your child's progress, and encourage activities to help them stay involved.

## Social Emotional Supports

In addition to education, school helps children and adolescents develop a sense of identity and build peer relationships and support. The return to school helps to create a sense of “back to normal”. Therefore, despite concerns which may include



exposure to communicable disease or fear of not being accepted, returning to school as soon as medically possible is very important for your child.

Many children can continue to attend school while they are undergoing treatment. Others may need to wait until treatment is over. Your healthcare team will help you determine what is best for your child. Long absences and changes in appearance, physical abilities, or educational abilities can affect self-esteem. This can lead to feelings of depression, anxiety, and frustration and make returning to school difficult for your child. They may be self-conscious about their differences and the way others are treating them.

Providing open communication with your child's school will help them gain an understanding of your child's changing needs. If informed, teachers can manage problems with self-image and peer relationships and help your child feel more comfortable and included.

It is important during this transition time to check in regularly with your child not only about academic concerns, but about their relationships with classmates. There can often be a communication gap between families and the education team working with your child. To ensure that each staff member is alerted to either your child's special needs or those of their siblings, a communication form can be developed between you and school personnel. ***See an example of a communication form at the end of this chapter.***

## **Dealing with Physical Changes**

Accommodations may be required to meet your child's current and future physical needs. The hospital can assist with providing the necessary documentation to outline your child's needs. 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, they may need playground or gym exemptions, time to rest, a locker closer to the classroom or an extra set of books at home to eliminate the need to carry them to and from school. You may want to discuss modifying homework assignments with the classroom teacher. Medications, a need for extra drinks throughout the day, and additional restroom breaks should all be addressed with the school. While these changes may be necessary, the way in which they are implemented can assist in making your child feel more at ease, highlighting the importance of good communication with the school.

## **Dealing with Cognitive Changes**

Cognitive changes may become more apparent as your child requires more advanced thinking. While cranial radiation may have an impact on global IQ, this is not the primary academic challenge your child will face.

Some of the common cognitive challenges faced by 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
- Reduced ability to remember new or old information

Other observable changes may be:

- Increased time needed to complete homework
- Going from an A student to a C student
- Increased frustration with school work and feelings of not understanding

Some examples of accommodations that can be helpful:

- Use of a computer or audio books
- Provision of written class notes
- Weekly assignments given ahead of time (assist with organization)
- Use of a calculator
- Extended testing time
- Shortened homework assignments

New cognitive changes may result in the need for additional academic accommodations and support and may require the involvement of the special education department. The first step is to identify whether your child has special educational needs and what those needs are. If you are unsure where to start, communicate your concerns with the school and your healthcare team. CBTF staff is also available to guide you in this journey.

## **Neuropsychological and School-Based Testing**

If you are interested in having your child tested to determine what services they may qualify for in school, you must make a request in writing. Despite Federal laws, each state has its own requirements and timelines for testing and evaluation. CBTF can help create this letter and guide you through the process.

An alternative to school-based testing is a neuropsychological evaluation. This is often preferred by many parents; however,

some states will not use test results from outside the school system to inform IEP or 504 plans. A parent, healthcare professional, or school personnel may request a neuropsychological evaluation. This testing is typically done in a medical setting, and the cost may be covered by health insurance. Importantly, this testing is slightly different from the testing typically provided by the school system. A neuropsychological evaluation will examine cognitive areas normally impacted by a brain or spinal cord tumor as opposed to just evaluating IQ and academic achievement. The testing will help determine your child's strengths and weaknesses and will likely assess areas such as attention and concentration, processing speed, memory, visual-motor integration, motor speed and dexterity, and executive functioning. It is important to provide the school with any neuropsychological testing results from the beginning of the special education evaluation process. Because the recommendations may be difficult to interpret for both you and the school, you may want to work with an advocate (like CBTF) who can help you and the school understand the recommendations.

Getting your child the help they need can be a complicated and frustrating experience. Remember that you are not alone and that there are other families in the community who have gone through this before and can help. CBTF social workers can connect you through their Family 2 Family peer mentor program and are available for support at any time along this educational journey. Additional educational resources can be found on the CBTF website.

**Sample School Communication Form**

*This form can 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, they 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 that they will be alert to and able to respond to any medical problems, educational changes, or emotional concerns this student may encounter.

Student

Photo:

Name: \_\_\_\_\_

Grade: \_\_\_\_\_

Homeroom

Teacher: \_\_\_\_\_

Diagnosis: \_\_\_\_\_

Undergoing Treatment? Yes No

Parent Name: \_\_\_\_\_

Phone Number: \_\_\_\_\_

Limitations:

Medical Concerns:

Emotional and Educational Concerns:

For further information, please contact:

## **Chapter 9      Palliative Care**

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.

## Chapter 10 Nutrition

Nourishment is an important part of your child's treatment and journey living with a brain tumor. After all, your child's body needs to heal and gain strength to resume normal activities and undergo necessary treatments. That said, it's normal to expect changes or difficulties with food and nutrition. As best as possible, try not to deviate from your child's normal diet and know that needs and acceptance of food fluctuate during treatment. It may also feel like food is something your child can control at a time when things feel out of control. Frequently, parental battles over eating do not lead to change but leave all parties frustrated. After ruling out a medical problem, there are times when families should consider counseling or psychological support to determine the cause of the problem.

Treatment, whether it's surgery, chemotherapy, or radiation, may have temporary side effects. Cancer can place extra nutritional demands on the body and change how nutrients are used. A way that you can improve nutritional intake is by tailoring the foods you provide to the side effects as well as setting realistic expectations.

**Diet does not cause brain tumors.** In most cases, the cause of pediatric brain tumors is unknown. There is a huge misconception and caretaker guilt around diet causing brain tumors. The best thing we can do for our kids during and after treatment is to meet them where they are and try to guide them to various foods and a healthy relationship with their bodies.

## Nutrition During Treatment

**Appetite** may fluctuate through treatment. Try not to overreact if your child is having an “off eating day,” but on the flip side, try to increase the nutritional or caloric value of foods when they are having an “on day.” On off days, focus on proper hydration and overall symptom management. On the flip side, medications like steroids may cause an increase in overall appetite. During appetite spikes, provide foods with more volume but not excessive calories, such as popcorn, pretzels, crunchy fruit or veggies, or lower fat alternatives. If any of these changes cause your child *continuous* appetite problems and *significant* weight changes, call your child’s doctor or nurse. They may prescribe a specific medication or arrange an appointment with a dietitian, who can provide more individualized strategies.

After surgery or treatment, children may experience **nausea and/or vomiting**. Providing smaller, more frequent meals rather than large portions can be helpful. Providing simple carbohydrates such as crackers, pretzels, or bread can easily bypass the stomach without feeling “heavy.” Focusing on smoother, easier to digest textures like smoothies, soups, yogurt, or apple sauce can be more effective for keeping things down. Other therapies include acupuncture on the wrists, smelling therapeutic oils like peppermint or tangerine, deep belly breathing, ginger chews, and oral rehydration solutions.

Your child may experience changes in their **digestion**. **Diarrhea** can be improved by increasing electrolytes through oral rehydration solutions, increasing soluble fiber (through food or supplement), reducing skins/seeds in food, and focusing on smaller, more frequent meals. Another suggestion is to consider lactose-free dairy since high lactose intake may trigger looser stools. **Constipation** can be supported by



adequate hydration *with* meals, increasing plant-based foods, especially fruits, vegetables, legumes, and seeds, moving the body every day, and creating a consistent bathroom routine.

**Taste changes**, such as complaining that food tastes metallic, are another common side effect. Sour/tart ingredients like lemon, oranges, vinegar, pickles; spices and herbs; and sugar-free sour candy can help overpower that metallic flavor. Focus on cold or frozen foods and opt for wood, plastic, or silicone utensils rather than metal.

**Dry or sore throat or mouth** are common as well. Make sure to drink water with meals or use ice chips to keep the mouth wet. Texture consistencies that are helpful are soft, moist, bland, and not too dry or salty. Add lubricating foods such as soups, smoothies, salad dressings, sauces, and yogurt, and make sure to chew the food well to help stimulate saliva. Making a conscious effort to breathe through the nose rather than mouth and using a humidifier at home can help too.

Some **alternative treatments** may include strict diets and supplement regimens with healing claims that may not be true. In addition, children may especially need the calories that are forbidden by alternative treatments. Certain compounds can also interfere with cancer treatment and can cause harm. Check with your child's doctor, nurse, or dietitian before giving vitamins, herbs, alternative supplements, or starting a new diet regimen. Remember that eating favorite foods may be the only way to provide nutrition, energy, and pleasure during this time.

## **Hypothalamic Obesity**

One of the most common causes of hypothalamic obesity is injury to the hypothalamus during brain tumor treatment. Two general things occur: 1) a child can show abnormal signs of hunger and food-seeking behavior, i.e., sneaking food leading

to higher consumption of energy, and/or 2) slow metabolism affecting energy balance, which can be seen by disrupted sleep/wake cycles, fatigue, and decreased physical activity. A multidisciplinary approach is highly recommended to find the proper treatment for your child. Please refer to your clinician for medication or surgical options. A few strategies are:

- Improve blood sugar management by including more whole, plant-based foods such as whole fruits, vegetables, legumes, whole grains, nuts, and seeds in most meals. Trying to pair protein, fat, and fiber along with starch improves our blood sugar and insulin response more than eating starch or sugar on its own. It does not have to be about restriction.
- Improve the circadian rhythm and sleep/wake cycle by focusing on meal timing, sleep routine, and getting outside in the fresh air/light for at least a few minutes daily.
- Move the body. Find something your child enjoys doing, whether it's dance, shooting hoops, or taking nature walks, and do it consistently.

## **Nutrition After Treatment**

The following are dietary and lifestyle strategies associated with reducing cancer risk and improving quality of life, including reducing the risk of comorbidities such as diabetes or cardiovascular disease. Remember to start with small, tangible strategies that are easy to do consistently and build on.

- Highlight more plant-based foods filled with phytochemicals and fiber associated with a reduction in tumor growth and anti-inflammatory properties. Choose various colors and textures such as, but not limited to, berries, leafy greens, oats, bran, lentils, beans, flax, pumpkin seeds, dark chocolate, and spices.

- Reduce added sugars in the diet. Avoid/reduce juice, soft drinks, sweetened beverages, energy drinks, candy, pastries, or sugars in sauces/ yogurt/ condiments. If eating a sugary food/treat, avoid it on an empty stomach, which helps mitigate a blood sugar and insulin spike and reduce overall cravings.
- Be intentional about meal timing and snacks. Eating consistently every ~2-5 hours is important to stay nourished, improve blood sugar management, and avoid getting overly hungry. Snacks can include: peanut butter and apple, banana with nuts, cheese sticks and whole grain crackers, carrots and hummus, protein bars, or Greek yogurt with a handful of granola.
- Move your body every day. Movement aids in hormone balance and weight management, improves energy, reduces fatigue, and boosts mood. Choose a movement that you can fit into your schedule and budget. Aim for 30 minutes per day. Note: it does not have to be consecutive.

## Chapter 11 Complementary Therapies

As a parent there may be times when 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 complement, to conventional treatment and surgery, complementary therapies and nutrition counseling may improve your child's ability to cope with and tolerate treatments as well as improve their physical, mental, and emotional well-being.

**Complementary Integrative Medicine (CIM)** focuses on the whole patient, not just the disease, and can enhance quality of life while setting patients up for the potential of better outcomes. Many may be skeptical of or confused by which CIM therapies are well vetted. Remember, you are the CEO or chairman of the board and engage advisors to help support you and your "company"— in this case, your precious family member. Here we encourage the use of CIM, and the concept of evidence-informed, not just evidence-based practice, in understanding the circumstances in which CIM can be elegantly combined with conventional treatments.

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. 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, and they can be a large out-of-pocket expense. Some insurance companies will offer discounts if you use a provider approved by them. We recommend speaking with your team about how to include your child's individual complementary treatment plan within their protocol in hopes to standardize

fees, maintain transparency, and ensure safe and effective care.

## **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 acupuncture points, areas along the body that when manipulated help correct and rebalance the natural flow of energy in the body. Acupuncture can be 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 and stimulate vitality. Some children have a fear of needles, but if your child is willing to try this technique, they may find an acupuncture needle does not hurt. An alternative to the needles is tui na, gua sha, cupping and other Asian massage techniques such as Shiatsu that massage and manipulate these points, offering similar benefit to the needles in those who are needle-averse. 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.

## **Aromatherapy**

Aromatherapy means "treatment using scents." It is a holistic treatment of caring for the body with pleasant smelling essential oils such as rose, lemon, lavender, and peppermint. Essential oils are added into a bath, massaged into the skin, inhaled directly, or diffused to scent an entire room. Essential oils can relieve pain and nausea, affect 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, so this tool can offer some much-needed support. Some bone marrow transplant units use aromatherapy during bone marrow infusions to alleviate anxiety.

This may be an easy way to help your child at the hospital; however, experts suggest your child may not like the smell used while at the hospital in the future. It is important to keep this in mind when picking an aroma. It is important to work with a qualified aromatherapist as this seemingly innocuous treatment is not without potential side effects. Keep in mind that a single drop of aromatherapy is equivalent to 20 cups of tea. Would you give your kiddo 20 cups of tea? Probably not. The same holds true for topical and inhaled forms. Diluting just a few drops in an oil carrier to apply over large areas of the body, or vaporizing away from where the child will be sleeping, or sitting, helps prevent overdosing and creation of toxicity. Expert Panel Confirms that Fragrance Ingredient Can Cause Cancer

(<https://www.ewg.org/news-insights/news/expert-panel-confirms-fragrance-ingredient-can-cause-cancer>)

Quality is key here as well, and this interview with an integrative oncology expert in aromatherapy can offer some more insight: Using Essential Oils with Great Respect (<https://www.drnasha.com/2016/05/19/dr-judith-boice-nd-lac-fabno/>)

## **Cannabis**

The use of cannabis to help alleviate symptoms associated with cancer and tumor treatment is said to aid with side effects of chemotherapy and radiation such as pain, stress, anxiety, and nausea. Cannabis can also be used as an appetite stimulant. It can be used in various forms such as in edible form and as oils. Laws regarding the use of cannabis for medical treatments vary state by state. A list of states which

have passed the use of cannabis for medicinal purposes can be found here:  
<http://healthcare.findlaw.com/patient-rights/medical-marijuana-laws-by-state.html>.

It is very important to discuss potential use of cannabis with your child's doctor as there may be drug interactions and other effects that should be taken into consideration before use. Quality of the cannabis product is key, as regulation varies widely, along with knowing your child's constitution, Single Nucleotide Polymorphisms to understand pharmacogenomics (how they will respond to the medicine), and ensuring you are not adding more toxicity to the system.

### **Guided-Imagery and Visualization**

Guided imagery uses the power of a soothing voice and your child's imagination to help your child cope 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, 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 overtaking any brain tumor cells or the chemotherapy gobbling up the "bad cells" like in the Pac-Man video game. There are many free apps available for smartphones that offer a wide range of coping mechanisms for dealing with cancer and its treatments—from "cancer fighting" games where the player can use super-powers and action techniques to destroy their cancer cells, to meditation apps that can help your child through guided imagery and some of the calming techniques previously discussed.

Other effective therapies in this realm to consider are Vagal Work and EFT (emotional freedom technique) tapping. What is The Vagus Nerve (<https://www.ncbi.nlm.nih.gov/books/NBK537171/>)? You have two vagus nerves—one on the left and one on the right side of your body. They are the longest nerves in your body, from the base of your brain down your body and into your abdomen; they attach to almost every major organ, including the heart. The vagus nerve contains both motor and sensory functions, is quite complex, and plays a large role in overall health and wellness. The vagus nerve has a major influence on the parasympathetic nervous system, which works to bring your body back into balance after periods of stress and is also activated when the body is resting or digesting food.

Stimulating the vagus nerve can help with stress, digestion, blood pressure, mental health, and relaxation. Some ways to stimulate the vagus nerve include exercise, singing, chanting, gargling, deep breathing, exposure to cold temperatures, and EFT tapping. What is EFT tapping (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6381429/>)? EFT tapping focuses on tapping the 12 meridian points of the body to relieve symptoms of a negative experience or emotion. EFT tapping is an evidence-based alternative acupuncture therapy treatment used to restore balance to your disrupted energy. It's been an authorized treatment for PTSD; it has demonstrated benefits as a treatment for anxiety, trauma, depression, physical pain, and insomnia; and it has been shown to improve physiological markers and help with chronic disease.

*“Our nervous system is always trying to figure out a way for us to survive, to be safe.”*

— Dr. Stephen Porges, The Polyvagal Theory



Interested in more information on the vagus nerve, EFT tapping, and The Polyvagal Theory? You'll find a wealth of content for your reference in the links below.

- Clinical EFT (Emotional Freedom Techniques) Improves Multiple Physiological Markers of Health: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6381429>
- EFT Tapping: <https://www.healthline.com/health/eft-tapping>
- The Polyvagal Theory: New Insights into Adaptive Reactions of the Autonomic Nervous System: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3108032/>
- Polyvagal Theory: Start with Safety: <https://integratedlistening.com/polyvagal-theory/>
- The Polyvagal Theory: Neurophysiological Foundations of Emotions, Attachment, Communication, Self-Regulation: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3490536/>
- Polyvagal Theory in Practice: <https://ct.counseling.org/2016/06/polyvagal-theory-practice/>
- Polyvagal Theory: A Science of Safety: <https://www.frontiersin.org/articles/10.3389/fnint.2022.871227/full>

## **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. It 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. Music 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, downloading favorite songs, or playing in a band with other children receiving treatment are all possibilities in the realm of music therapy. Many children and their families like to come up with a "fight song," which can be a favorite song that helps them to keep positive through diagnosis and treatment. Most hospitals can also provide music to be played during MRI's, which can help distract your child from the sound of the machine. Here are some great resources for learning more about music therapy and its healing powers:

- Anthroposophic Music Therapy: <https://anthroposophichealth.org/Anthroposophic-Music-Therapy>
- Discover the Healing and Transformative Power of Music: <https://www.thesoundoftransformation.com/home1>
- Barry Goldstein: <https://www.barrygoldsteinmusic.com/>

- The Healing Power of Sound as Meditation:  
<https://www.psychologytoday.com/us/blog/urban-survival/201907/the-healing-power-sound-meditation>

## **Play Therapy**

Many children's hospitals have Clinical Child Life Specialists (CCLS) who offer support to families and children diagnosed with a serious illness through therapies such as play therapy. A CCLS may use things such as toys, games, and art as a way for children to work through emotional difficulties such as fear, anger, and confusion, which may accompany a brain tumor diagnosis. Alternately, play therapy could serve as a distraction from many unsettling parts of treatment.

Another form of play therapy to consider is Therapeutic Eurythmy. Therapeutic Eurythmy is an active therapy that allows one to take part consciously in the process of becoming healthier and more balanced, achieving true healing and not just a cessation of symptoms. Eurythmy was first created in 1912 as a form of artistic expression and, soon after, as a means to support healthy development in children. The whole human being is taken into consideration—not only the bodily condition but also emotional and spiritual aspects. This is a play therapy that you can do with your children, or as a family. Learn more about Therapeutic Eurythmy for children (and adults!):

- Therapeutic Eurythmy for Children & Adults:  
<https://iws.edu.hk/therapeutic-eurythmy/>
- Therapeutic Eurythmy:  
<https://anthroposophichealth.org/Eurythmy-Therapy>
- Eurythmy therapy in clinical studies: a systematic literature review:  
<https://www.ncbi.nlm.nih.gov/books/NBK75359/>

## **Reiki**

Reiki, 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 Sanskrit 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 gentle and non-competitive, and it works not only on the entire body but also on 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, eliminate toxins, and keep children healthy and happy.

Each of these techniques is unique, and what may work for one child may not work for another. You will quickly learn what the best is for your child.

## **Diet**

Quote from Hippocrates: "Let food be thy medicine."

Many clinicians still feel that diet has little to do with cancer care and recovery, but clinical results suggest otherwise. Diet is another opportunity to overcome your sense of powerlessness.

Many researchers in the field of oncology, and metabolic oncology specifically, and even more in relation to primary brain tumors, suggest that a carbohydrate restricted diet offers

improved outcomes. There are resources put forth by organizations such as Charlie's Foundation (<https://charliefoundation.org/>), MaxLove Project (<https://www.maxloveproject.org/>), and papers such as this: Is the restricted ketogenic diet a viable alternative to the standard of care for managing malignant brain cancer? (<https://pubmed.ncbi.nlm.nih.gov/21885251/>) You may want to explore weaving this into your foundation to improve response and lower toxicity of standard of care.

Here are some other inspirational and simple resources (all authored by Maria Emmerich) for your family to explore.

- Sugar-Free Kids: Over 150 Fun & Easy Recipes to Keto the Whole Family Happy & Healthy
- Keto Comfort Foods: Family Favorite Recipes Made Low-Carb and Healthy
- The Art of Healthy Eating–Savory, Sweets and Kids
- Keto Instant Pot: 130+ Healthy Low-Carb Recipes for Your Electric Pressure Cooker or Slow Cooker
- Art of Healthy Eating–Slow Cooker Grain Free Low Carb Reinvented

## **Chapter 12 End-of-Life and Bereavement**

### **End-of-Life Care**

When a child is first diagnosed with a brain tumor, death is the furthest thing from a parent's mind. 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 goodbye to your child.

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 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.

### **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. For more information about hospice, you may contact:

Children's Hospice International  
703-684-0330  
<https://www.chionline.org/>

## **Bereavement**

The loss of a child is a devastatingly unnatural experience. 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. Throughout this process you may find it helpful to seek information and learn more about grief. You will see that your thoughts, feelings, and experiences are shared by others. Finding the type of support that meets your own unique needs can also be helpful. In addition, families often find it incredibly helpful to connect with a supportive community of bereaved families. Grief is a unique and personal experience shaped by many factors. People can have very different coping styles. Some need to talk, express emotion, and share their feelings. Others prefer to think about grief (as opposed to talking about it), and choose different outlets to process their grief. They may find comfort from getting involved in the cancer community to raise money to promote awareness and fund research. They may choose creative expression outlets such as painting and music, or prefer to keep busy and active. Many people use a combination of styles to grieve. There is no right or wrong way to grieve, although it is helpful to understand your own personal style of grieving and what type of supportive outlets you need. It is very common for family members to have different coping styles. For example, a bereaved mother may grieve very differently from her spouse

and have different needs. Having an understanding of such differences helps couples and families to move forward and support each other throughout their grief journeys.

There is no set amount of time it takes for a bereaved parent to feel “better,” or for the intensity of grief symptoms to subside. At some point it may feel as if grief comes in waves. You may have good days followed by very difficult days. Grief does not have an ending point, and bereaved parents often fear they will never experience joy again. However, many report that they do in fact feel joy and happiness again. Parents explain they adjust to living with their grief. They can be happy while also living with the pain of loss.

Although it is common for bereaved parents to feel very intense pain and sorrow, there are certain situations that require professional help and guidance: for example, when a person feels as if they cannot function (attend work, care for children and family, care for self, etc.) or if a person feels as if they are “stuck” in grief for a very long time. And, if other stressors in life are impacting your ability to cope with grief, it can help to talk with a professional. A professional counselor or therapist can help determine what type of additional support might be needed.

It is common for grieving parents to experience certain challenges. They often feel isolated as they watch the world go on around them. Sometimes relationships end or change. Many find it difficult to support their spouses, partners, and children while grieving. Coping with milestones and holidays can also be very difficult. A person’s faith and spirituality can be challenged, causing a grieving person to reshape their beliefs. Bereaved parents can find support and guidance around all these challenges from each other and through professional help offered by counselors and support groups.



Parents often want guidance on how to support grieving children and adolescents. Children and teens do not grieve like adults grieve. Depending on age or developmental stage, children have varying levels of understanding toward death. Many will express grief through play or emotion/behavior. Some may not appear to be grieving because they may not talk about it or acknowledge it in an obvious way. When they do express emotion, they may do so for a short period of time and then return to playing or other activities. It is important to remember that they are always grieving. Parents can help by telling their children that they are there to listen and talk. Children need to know they can safely ask questions, talk, and express emotion. Parents can give age-appropriate explanations when questions are asked and can assess how much information children are able to handle.

Teens are faced with the challenge of coping with loss while also going through many developmental milestones. Developmentally, they may desire independence but may also need support and comfort because of their loss. Again, parents can help by letting teens know they are there to listen and talk. Sometimes they won't want to talk, but knowing they have a safe and supportive place to go to is helpful. With both teens and children, it helps when parents model healthy expressions of grief such as talking about their feelings, talking about the deceased child, and showing that it's OK to express emotion. Many children and teens benefit from attending grief groups and grief camps when they feel ready to attend. Private counseling can be very helpful too. CBTF can help you locate in-person resources in your area.

Regardless of how one grieves, bereaved parents often share similar thoughts, feelings, and experiences. Parents provide each other with support, hope, and inspiration. Making connections with other bereaved parents enables parents to feel understood, validated, cared for, and connected. There

are many ways to get involved in bereavement communities. Parents can attend support groups, grief camps, and retreats, and connect with others through numerous online communities.

We grieve intensely because of the love we have for the person we lost. Many parents find comfort from realizing that love never dies, and our relationships with the deceased can continue. There are many ways family members stay connected to their loved ones. CBTF's website contains additional information on loss, grief, and bereavement. The goal of our national program is to connect bereaved families to a supportive community, provide support programs for families, and offer educational information and resources. CBTF offers support for families receiving end-of-life care and for grieving families. Visit <https://cbtf.org/bereavement/> for more information.

*“Hope has been my one and only link through the entire experience, from the time of my son’s diagnosis, through all the 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’ll 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.”*





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