



# Brain Tumor Guide *for the* Newly Diagnosed

Version 7

*If you will be having a brain  
tumor surgery soon, there are a  
few things to consider  
which can keep  
your options open.*

*See Chapter 4  
for new treatment options!*

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# Chapter 1: Introduction

## Where, When, How and Why Me?

Whether or not it was a loss of physical balance that led you to be diagnosed with a brain tumor, surely a loss of emotional balance quickly followed.

Every day over 100 adults will be diagnosed with a primary brain tumor and many more will be diagnosed with a cancer that has spread to the brain from someplace else in the body, such as the lung or breast. Additionally, thousands of parents each year will hear those two devastating words – brain tumor – in regards to their child.

There is no known cause of most brain tumors starting in the brain. There are indications that genetic factors or exposure to toxic chemicals or ionizing radiation may contribute to the formation of brain tumors. However, it is important to remember that you and your loved one did not do anything to cause the brain tumor and that each person and brain is different.

There are over 100 kinds of primary brain tumors, some very rare. However, not all brain tumors, or even all malignant brain tumors, are invariably fatal. With surgery, radiation therapy, and chemotherapy, some types of tumors respond very well to therapy and may even be cured. While many of the more common tumors, such as gliomas, are not typically cured by surgical resection, there are more long term survivors now than ever before, as new treatments have been introduced. (For **survivor stories**, see <http://www.virtualtrials.com/survive.cfm>) Unlike most other medical conditions, you will have a lot of important decisions to make. You can make them yourself, or you can select a loved one or team of loved ones to advocate for your care and treatment and to help you make important decisions. Not only will you have to make choices between treatment options presented to you, but you and your advocate may have to actively seek out options that your medical team might not have access to. We are here to help you sort through various treatment options and be a resource for you so that you can further understand your disease.

You must learn to question what you're told initially and, as treatment plans are put into place, to ask what qualifying factors your diagnosis and treatment plan are based upon. You must also seek out the foremost expert advice.

Typically your physician will have a plan to discuss with you following your initial diagnosis. This plan may include a referral to a neuro-oncologist or neurosurgeon for a consultation regarding treatment options, such as surgery, radiation, chemotherapy, or a clinical trial (more on clinical trials later). While in some cases circumstances are such that emergency surgery is the only immediate option due to brain swelling or risk of acute brain injury, typically

there is ample time to seek a second opinion and gather more information that can assist in your decision making process.

The initial diagnosis is often stated as a brain lesion. A lesion is an abnormal tissue from disease or trauma; basically there is something different about your brain and a part of it does not look like normal tissue. Further testing is usually ordered to get a better idea of the size, location and impact of the tumor, as well as locating any cancers in other parts of the body. It takes experience to be able to see some of the subtle differences in MRIs. A second opinion from an experienced doctor or team that frequently deals with brain tumors may change the initial diagnosis, in either tumor type or grade and, thus, change in your treatments. An MRI alone can be inconclusive (it may not be a tumor at all), making a thorough examination of all of your symptoms, and when possible, a biopsy, vital to your diagnosis.

The most important factor in your care will be the experience of the team treating you. If possible, ask for a second opinion from an expert source, preferably a major brain tumor center that is familiar with advanced forms of diagnosis and treatment of brain tumors. Also, ask for a neuropathologist experienced in brain tumors to review your biopsy. In many cases, brain tumor centers can coordinate your treatment (radiation and chemotherapy) with doctors more local to you, so that extended stays near the brain tumor center may not be necessary.

Your primary physician or oncology (cancer) specialist may not be familiar with the advances being made in the treatment of brain tumors. If your medical care team cannot answer your most pressing questions or is unwilling to consult on your behalf with available brain tumor experts, you must seek out further information and reliable sources for care, such as those found within major brain tumor centers. Many of these specialized centers will allow you to submit your MRI and CT scans, as well as biopsy specimens, for further examination directly without a referring physician (see Chapters 2 & 3).

The brain tumor neurosurgeons and team members found at these brain tumor centers perform over fifty brain surgeries annually (some as many as five or more per week) and may offer the most technologically advanced procedures with higher rates of survival. Your choice of surgeon and treatment team can profoundly affect the outcome of your care. Included in this guide are links to the major tumor centers nationally, as well as the expert physicians available to assist you locally.

If knowing your enemy (type and grade of tumor) is indeed half the battle, then having the tools to employ a strategy – a strategy for life – is equally important. Brain tumors can change, grow and recur, so it is important to be organized and knowledgeable about your tumor's makeup and location, and your medications and their side effects, symptoms you might expect throughout your treatment and to maintain an ongoing, open dialogue with your medical care team. Physicians rarely engage one another in the type of dialogue patients often assume is transpiring on their behalf. Being organized can assist you by ensuring all of your team members are up-to-date with current information at the time of your appointments and consultations. You and your advocate team must become your own primary care manager!

This guide is made available to help you understand some of the common decisions you'll be facing. It will answer some of the questions frequently asked by patients and caregivers and connect you with a support community. Additionally, it will help you get organized so that you can best advocate for the quality of care you both need and deserve. Wherever possible, resource links to further online information have been provided for your convenience and are directly linked on the electronic copy- just click the URL. But, most importantly, it provides you with information on tumor types, the most current treatment options, and how to find major brain tumor treatment centers.

If you ever have questions or comments, feel free to call us at 888-295-4740 from 10 AM to 9 PM, Eastern Time, 7 days a week and visit our website at: <http://virtualtrials.com/>



# Chapter 2: From Day One, A Place for Everything

## Tools to Help You Get Organized

The diagnosis of a brain tumor can leave patients and their loved ones in a mental fog; a fog so thick with questions that where to begin, in and of itself, can be debilitating. There are ways in which you can regain control, stepping out from the fog and into the light of day. Organization is your key to obtaining the information you'll need to find the proper treatment necessary for your specific type of tumor. The following is a list of tools that has helped other brain tumor patients.

A three-ring binder can become your best friend and treatment partner, easily safeguarding all the necessary information about your tumor-type and treatment plan at your fingertips. Referrals to specialists or for a second (or third) opinion are often delayed by the need to obtain records and, sometimes, by records that have been lost along the way. Maintaining your own copies of the following will ensure your consulting physicians have access to all of your important documents at the time of your appointment. Many people maintain these records on their computer or flash drive and occasionally print them out and store them in the binder as needed – since it is easier to carry a binder around! Also print out a copy of your current medications and allergies to store in your wallet or pocketbook in case of emergency! Items to include in your treatment binder include:

- **Medical History** – Start with a copy of the first medical history form you are asked to fill out. This will list past medical problems, such as diabetes or heart problems, which may impact the treatment choice, as well as any allergies you have. An important allergy to note is one to either iodine or shellfish, as the dyes (contrast agents) used in some brain scans contain iodine. This will be helpful when you have to keep filling out similar forms. Keep it updated as things change. You can also ask your doctor for a copy of the history and physical they perform on you.
- **Copies of MRI Films and Reports** – Most radiological centers today can provide you with a copy of your MRI or CT (CAT scan) on a CD that can be viewed on any computer. When you check in at the MRI Radiology facility, it's very important to request a copy of the film or a CD along with the written report of the radiologist's findings. Ask BEFORE you go into the scanner, as it is easier for the staff than if you tell them afterward. Most office supply stores carry special three-hole vinyl pages that hold multiple CDs safely within a binder.

- **All Routine Lab and Pathology (biopsy) Reports** – Different members of your medical team will benefit from recent lab results that may have been initially ordered by another physician. Having your personal copies of these items available for review on demand will save time, increase your understanding, and in some cases, eliminate the need for unnecessary blood work. As a bonus, if you are computer literate, keep track of lab results in an Excel spreadsheet so you can graph results over time and see how you are doing.
- **Medication At-A-Glance** - It's important to disclose **all the medications** you take to your physician and care team members. Keeping an up-to-date medication record in your treatment binder (including herbal supplements and over-the-counter items) can provide a quick and clear snapshot of your daily meds at-a-glance, *reducing the chance of error when more than one physician is involved with your care.*

You may experience symptoms that are medication related; side effects to a medication that one member of your medical team may not realize you're taking and thus may be incorrectly diagnosed or treated.

Take your treatment binder to **every** appointment with **every** doctor and request that they review this list before prescribing any new medication. You should also request a copy of the drug formulary – a list of covered medications – from your insurance company and keep it in your treatment binder. It may be necessary for your physician to request prior authorization for some medications. Knowing this in advance can save you time and expense.

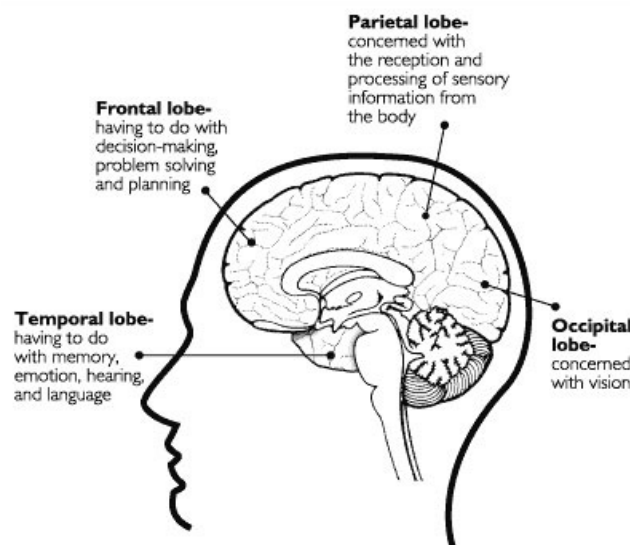
- **Location, Location, Location** – Knowing the exact location of your tumor will assist you in many ways. By researching the functions of that part of the brain, you can more clearly understand (and be prepared for) many of the symptoms you are experiencing, or might expect to experience. Ask your physician to be specific about the location, perhaps even provide you with a diagram of the brain with a penciled-in tumor site. To understand your tumor, and thus certain therapies available to you, you must understand your tumor's location. Ask what symptoms to expect if the tumor expands. A good overview of the brain and its functions can be found at: <http://www.waiting.com/brainanatomy.html>

The brain is divided into six primary regions, each controlling specific functions. The following is a brief overview of each region and their correlating functions:

- **Brain Stem:** Where the brain connects to the spinal cord is called the brainstem and is considered the pathway to the face, also controlling vital heart and lung functions such as breathing, digestion, heart rate and blood pressure, as well as being awake and alert. It is the pathway for all nerve function through the spinal cord to the highest part of the brain. Problems in the brainstem often cause things like double vision, problems with facial muscles, nausea, sleepiness, or weakness on one side of the body. However, because so many nerves go through the brainstem, problems here can cause almost anything.



- **Cerebellum:** Located at the back of the brain above the brain stem, the cerebellum coordinates balance, posture, and coordination, and affects activities such as eating, walking, talking, and moving your eyes.
- **Frontal Lobe:** As the name suggests, the front part of the brain is responsible for organizing thoughts, planning, problem solving and selective attention. The frontal lobe is also the “personality center” of behavior and emotions, judgment and sexual urges. The posterior (back side) of the frontal lobe also houses nerve cells that produce movement.
- **Occipital Lobe:** Located in the mid-back of brain, the occipital lobe is in charge of vision. It takes input from your eyes and turns it into the pictures that you see. Problems in this lobe can cause partial blindness or the inability to recognize things like shapes, colors, or faces.
- **Parietal Lobe:** Located behind the frontal lobe at the top of the brain, the parietal lobe is comprised of a right and left lobe, which together, control our sense of touch, feel and understanding of weight, size and texture, as well as comprehension. Problems in the parietal lobe can cause numbness, tingling, or other problems with sensation. Problems with the right parietal lobe can cause difficulty with figuring out where you are or how to get from one place to another as well as difficulty recognizing your arm when you see it. Problems with the left parietal lobe can cause difficulty speaking or difficulty understanding what other people are saying.
- **Temporal Lobe:** Located on the right and left side of the brain (near ear level), the two temporal lobes help us to distinguish smells and sounds, experience fear and may impact short-term memory. The right lobe is primarily responsible for visual memory while the left controls verbal memory.



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[http://www.wpclipart.com/medical/anatomy/brain/brain\\_lobes\\_color\\_coded\\_and\\_labeled.png.html](http://www.wpclipart.com/medical/anatomy/brain/brain_lobes_color_coded_and_labeled.png.html)

**A Personal Diary** – Keeping a diary is very important as you travel through various treatments options with specialists, beginning on day one! Recording your specific questions and concerns will help ensure that your medical team addresses the answers you and your loved ones or caregivers need. You may want to create a separate section for each team member, writing down which doctor is responsible for the various aspects of your care; medication refills, routine lab work, referrals, as well as, what was discussed at appointments. Questions often arise after leaving an appointment and referencing these pages later may be helpful. It’s also recommended that you maintain monthly calendar pages to record the start of new medications or therapies, and any bad reactions to them. The starting times of symptoms and side effects may be difficult to recall at a later date, but are important to distinguish their origin.

- **Legal papers** – HIPAA: Every doctor you see will ask you to sign a privacy form (called a HIPAA form). When you fill it out, write in that you want to specifically allow the following people to discuss details of your case with the doctor (or facility); then list by name your spouse / parents / children and maybe a friend. Then ask for a copy of the form, as they keep the original. This will help save time when you need to send someone to pick up reports or films, or to ask questions for you. When they tell you they can’t give your children something or talk about something to anyone other than the patient, just show them your copy of the form and they have to allow it!
- **Advance Directives and Durable Power Of Attorney** – We all hate to think about these things, but it can save a lot of trouble later if you handle this now. An advance directive tells your doctor what kind of care you would like to have if you become unable to make medical decisions. A Durable Power Of Attorney lets you designate who will make medical decisions for you if you are unable to. The first time you are admitted to a hospital, they will ask if you want to fill out the forms for these directives, if you do not already have them in place. Do it, and ask for a copy and keep it in your binder. Or search google.com for “Advanced Directives in [your state]” (each state has different laws and forms). If you do already have these forms in place, bring them with you and staff will make a copy for your files and return the original to you.

It is very important to tell your family who your medical power of attorney will be and to tell them what your values are and what kinds of medical treatment you would want or not want, including breathing machines and feeding tubes, if your condition were to worsen and you were unable to communicate or were in a coma.

You may also want to consider drafting a Financial Durable Power of Attorney. A financial durable power of attorney designates a person of your choice to manage your finances if you become incapacitated and are unable to make financial decisions for yourself. Your financial power of attorney document should not contain medical directives, as this is covered in your medical power of attorney document. Standard power of attorney forms are available online or through an attorney. They are straightforward and easy to complete. If you have special circumstances, you may wish to consult with an attorney.

- **Phone numbers** – Record the name, address, phone number, email address, and a short description of all of your important contacts. Be sure to include your family members who should be contacted in an emergency, all of your doctors, your lawyer and financial advisor and/or insurance agent and clergy.

## ***Second “Expert” Opinions***

Diagnosing a specific type of brain tumor can be a complicated affair, making confirmation of your diagnosis essential. Second, third or fourth opinions should come from experts within a specific area, such as those who are experts in the removal of brain tumors—neurosurgeons performing at least ***twenty-five brain surgeries per year, or an expert in Neuropathology who can qualify the diagnosis*** of your tumor biopsy. It’s estimated that as many as twenty-five percent of brain tumor patients will have their diagnosis changed upon further examination by a second, expert opinion, which can drastically change not only the prognosis, but also the recommended treatment plan.

If your primary physician is not familiar with the most current treatments or clinical trials available for patients with brain tumors, request that he/she consult with one of the many major brain tumor centers and arrange for you to obtain a second, expert opinion. Even if you are diagnosed by a major brain tumor center, you may still wish to get a second opinion from another major brain tumor center as a confirming diagnosis, to confirm a treatment plan and/or to locate a clinical trial. It is your right to have a second opinion.

A review of your MRI or CT scans, tests, and pathology reports, along with an overview of new resources and treatment programs can be obtained through many of the leading major brain tumor centers.

For a list of **major brain tumor treatment centers**, some of which offer free scan reviews, visit: [\*\*http://www.virtualtrials.com/btcenters.cfm\*\*](http://www.virtualtrials.com/btcenters.cfm)

Your physician can also consult with **The National Cancer Institute**. They will also review your case for free. They have excellent adult and pediatric brain tumor specialists available to help you.

For more information, visit:

[\*\*http://home.ccr.cancer.gov/nob/\*\*](http://home.ccr.cancer.gov/nob/) and select Patient Referrals

Most pathologists do not see enough brain tumors to make the subtle distinctions that may be necessary for diagnosis. You can also ask for a second opinion on the reading of the biopsy slides from a major center, such as **Johns Hopkins Neuropathology**. There is a cost, but the process is easy – your hospital just mails the slides.

For details, go to:

[\*\*http://pathology.jhu.edu/consultations/neuropath.cfm\*\*](http://pathology.jhu.edu/consultations/neuropath.cfm)

**If you do need to travel for a second or third opinion, there are many organizations that provide financial assistance specifically for brain tumor patients.**

For a listing, see

**<http://virtualtrials.com/braintumororganizations.cfm>**

**Mission4Maureen** funds go directly to patient needs, which may include travel for treatment, maintaining a place to live, and paying medical bills not covered by insurance.

More info is available at **<http://www.mission4maureen.com>**

**Angel Flight**, created by a group of volunteer pilots, will arrange for free air transportation for a medically related need for those where time is of the essence, but non-emergency, to those who are financially in need.

More info is available at **<http://www.angelflight.com>**

**Miles for Hope** provides flight assistance to those participating in clinical trial treatment programs.

For **travel applications** go to: **<http://www.milesforhope.org/download/TravelAp.pdf>**

## **The Role of Caregivers and Loved Ones**

It's all too common; you enter your doctor's office with a list of questions and as your physician begins to satisfy his/her query of information, you forget your questions, or worse, forget or misunderstand their answers. Emotions, not your brain tumor, are typically responsible. Emotional support and a second pair of ears can be of tremendous help while you navigate through a new world of tumor terminology.

Even for seemingly routine appointments, whenever possible, take a friend, loved one or caregiver with you. Aside from taking notes of your session, should an overwhelming moment arrive during your physician's explanation of a particular treatment, necessary tests, or expected results, another person will often hear (or interpret) details differently and be able to ask questions that you might not think of at that moment. Encourage them to make frequent notations or observations in your personal treatment binder and take an active role in your care options. If your physician will allow recorded sessions, have your companion manage a small, hand-held recording device and review the discussion afterwards with you.

## Support Groups

The Internet offers an unlimited resource for brain tumor patients, including online support groups, sometimes called “mailing lists” or “list serves”, chat groups and message boards for sharing experiences and treatment options with others who understand what you’re going through. Support groups, either found on the Internet or a local group sponsored by your hospital/regional cancer organization, can often assist with non-medical issues as well, such as nutrition, relationships, and/or financial concerns.

For a list of **online support groups**, go to: <http://virtualtrials.com/lists.cfm>

There are many different groups with different focuses. The best group for medical discussions about brain tumors is **Brain Tumor Treatments**, formerly known as Brain-Temozolomide Group. It is now dedicated to all treatments for brain tumors, but it was originally started for only the drug Temodar.

For a list of **“real world” support groups**, go to: <http://virtualtrials.com/support.cfm>

Most people are shy about joining a support group, but don’t be. You will be amazed at how quickly you feel at ease because the members know and understand what you are going through, something (hopefully) nobody else in your circle of friends knows about.

A word of caution: support groups (both online and “real world”) play an important and in many cases, vital role in maintaining a positive outlook during treatment, as well as staying up-to-date on the latest brain tumor issues. However, you have to be cautious and evaluate how much you can trust anything you find. There are bad people out there looking to make money off of your misfortune, and even people who are trying to help might inadvertently supply you with misleading information. **NOTHING** on the Internet or a support group meeting should be taken as medical advice. You have to research anything you find and discuss it with your doctors. The chat rooms are most susceptible to problems because there may not be other people with which to discuss the pros and cons of the treatment. On the other hand, in an online support group like the Brain Tumor Treatments group, you can ask for many people’s experiences with a treatment and get a broader view of it.

When using the Internet use common sense and discuss information with your doctor to help you make the best possible decision for your care. To evaluate the information you find on a web site, consider the credentials of the person posting the information, how up-to-date the site is, if there is contact information posted on the site, and if the claims on the site are too good to be true or it is selling something.

### The Brain Tumor Virtual Trial

This is a study being run by the Musella Foundation. It is a database of brain tumor patients, the treatments they are using and the outcomes. Participants record the treatments that

they and their doctors decide to pursue (we do not tell you what treatments to do, we just record the outcome). There is no cost to participate. The patient or caregiver records information in simple forms on our website and posts an update every month. We send email reminders on the first of every month. You also send in a copy of each of your MRI reports (not the films) and pathology reports so that we can verify the information. Participants get to view the ongoing results of the project. The idea is to try to identify which treatments, or combination of treatments, are working the best. In addition to providing greater insight to beneficial therapies for researchers, participants become expert managers of their condition, and can generate reports on the information they entered, such as a graph of their status over time.

To join, or for more information, go to: <http://virtualtrials.com/brain>

## **Mind, Body & Soul; Faith in Healing and Emotional Wellness**

While your primary physician may appear anything but spiritual in his/her approach to your brain tumor, some within the medical community are aware, and in support of, the power of prayer. Prayer, while very personal, may be empowering and pro-active at times when “control” seems out of reach.

To add your name to the **Musella Foundation** prayer list, visit:

<http://www.virtualtrials.com/prayer.cfm>

Also do not neglect the rest of your body. When facing a major problem like a brain tumor, the smaller problems sometimes get overlooked. You have enough problems to handle without having a “minor” problem blossom into a “major” problem. Be especially mindful of swelling and/or pain in the legs, (which may indicate blood clots, which unfortunately are common with brain tumors), dental problems (since some treatments may hurt the gums and teeth), and rashes (which can indicate allergic reactions to treatments).

**Emotional Wellness-** Your life, as you once knew it, may change throughout the journey. Things may not seem “normal”, but there will be a new “normal” for you and your family. The new normal will be what you and your family make it. It will take time, but you will settle into a routine that is comfortable for you. Like anything that is lost, you will go through a grieving process. Although, everyone experiences grief and loss differently, you will probably experience some of the universal steps in this process, which may include:

- Shock
- Denial
- Anger
- Depression
- Acceptance

How you work through this process will be highly personal and individual. As you work through each step, you will probably have some additional feelings which may at times present conflicts for you. These emotions are many and can be unpredictable. Neither right nor

wrong, they just are and you are entitled to feel the way you do. They may include a feeling of loneliness, sorrow, anger, sadness, blame, and shame that may lead to anxiety and stress. Sometimes you will feel helpless.

To combat this, concentrate on wellness and try to work through each of the feelings rather than denying them. Have a set of coping strategies that will guide you through each step. These strategies may include: (1) accept and understand your limitations, if you have any, and set realistic goals (2) get as much up-to-date expert information about your condition as you possibly can so you don't fear the unknown and be pro-active in your treatment plan (3) take good care of yourself by eating well, getting exercise and rest, and not self-medicating with alcohol (4) see a mental health provider if you feel it necessary, as they can help you handle your emotions and stress (5) record your feelings in a journal and/or (6) try exercise, yoga, massage therapy or mediation.

Palliative care can be a support mechanism for you, your caregiver and family. It is not new, having come on the scene to patients around the 1970's. However, today it has evolved into so much more and is provided to patients for any diagnosis, at any stage of the condition and/or treatment plan. If you receive palliative care you, your caregiver and family receive emotional support, knowledge and resources associated with your illness to ensure that your concerns about treatment, medications, side effects, and symptoms are addressed and to enable you to make the most knowledgeable decisions about your care. The first step in seeking palliative care is to ask your doctor or cancer center. Additional resources are listed in Appendice III of this book. Your goal will be to reestablish the quality of your life, ease stress, and be more in control. It will take time and patience, but you will find your comfort zone.

**The Center to Advance Palliative Care** maintains a directory of providers and resources, which can be found at:

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

At some point, you may need to transition to hospice care which can be given at home, in hospitals, nursing homes, or inpatient hospice facilities. This highly specialized concept of care given by a partnership of family members or caregivers and medical professionals focuses on providing on-going comfort, emotional support, and pain management 24 hours a day. It may also include spiritual counseling for the patient and family members. Hospice will provide medications, equipment and any medical supplies needed, as well a physical, speech and occupational therapies to make you feel as comfortable as possible. You will work with an interdisciplinary team including medical professionals, social workers, home health aides, clergy members, and trained volunteers. Because most people see hospice as end of life, most times it is not started soon enough to provide the comfort, care and support needed by patient, caregiver and family members. You can always opt out of hospice care if you wish to re-enter appropriate treatment or experience remission. You can enter hospice at a later time if treatments are no longer effective or you do not wish to continue with them. Like palliative care, the main focus of hospice is to bring quality of life and support services to the patient, caregiver and family members. While palliative care may be given at any time and even through treatment, hospice is appropriate when life expectancy is six months or less and treatments are no longer an option.

For more information on **hospice**, visit:

<http://www.hospicefoundation.org/>

<http://www.hospicenet.org/>

<http://www.brainhospice.com/>

## **Impairments & Strategies for Coping**

Now that you have been diagnosed with a brain tumor, you may start to experience a variety of impaired functional abilities depending on the size and location of your brain tumor and your treatment plan. You may experience depression, memory and concentration lapses, personality and mood shifts, anxiety, insomnia, self-care, physical and balance difficulties, bowel and bladder incontinence and conversational speech and word finding problems. Healing and recovery from post-surgery and treatment are very important. When you are discharged from the hospital, make sure you are given clear instructions for caring for the surgical site, what activities you can and can't do for a period of time, medication and dosage, and what to do if a problem develops. Arrange your ride home from the hospital and have someone at home to help you until you feel well enough to manage on your own.

Each brain reacts differently to treatment, but you can find a way to adjust and compensate. There are strategies you can use that will help you to function and feel better and in some cases regain lost functional ability.

First and foremost, speak with your doctor(s) about your difficulties before they become more complicated. He/she may prescribe some medications to ease your symptoms or refer you for physical, speech, occupational or hyperbaric therapy sessions. Physical therapists will provide exercises that strengthen your muscles, increase flexibility and mobility, and help to regain balance. Occupational therapists will work to strengthen small muscle control and gain functionality with self-help daily activities. Speech therapists will help in developing communication skills, vocabulary and swallowing. Neuro- psychologists will help you cope with and assess cognitive and emotional changes, as well as memory, thinking skills, problem-solving and reasoning, and perception. Hyperbaric therapy sessions may be recommended to aid in healing damaged tissue. Each of the therapists may also recommend adaptive devices which will help you regain some degree of functional independence.

Second, speak with your partner or family members and explain how and what you are feeling. It is important to bring people on as part of your team to support you and help make things a little easier for you. But first, they need to understand what you are experiencing before they can help. The more informed they are, the better they will be able to cope, understand you and help you set goals.

The following coping strategies have been used successfully by people in our online support group to regain quality of life. But first you must understand your strengths and weaknesses, identify or know the problems, and be willing to try a solution. At this point you



may be feeling overwhelmed and confused about the changes you are experiencing. You may also feel some grief or denial for the loss of functioning. Hopefully these strategies will provide the tools you and your loved ones need to help you rebuild your life.

Sometimes, the simplest solutions for what you are experiencing are organization and altering the environment. For cognitive difficulties making notations on a legal pad, calendar or day planner will aid memory. Include a “check off” sheet or page as needed for each task completed. It will be helpful to use an alarm watch or kitchen timer to alert you of time sensitive activities. You may wish to use a weekly medicine dispenser with slots for A.M. and P.M. medications. For better concentration, you may need to minimize or avoid distractions such as loud noises; stay focused on one task at a time or alter a task by breaking it down into smaller parts. Sometimes a daily activity or time management chart may help organize your day. Set limits and don’t schedule too many activities in one day. Rest when you need to. You may find it helpful to follow a routine by keeping a consistent schedule. Keeping daily items in predetermined designated places will make them easy to find and save time locating them.

For physical safety and comfort be aware of potential dangers in and outside of the home such as clutter, fire hazards, sharp objects, hazardous household products, scatter rugs, inadequate lighting, water heater temperature, and outside hoses, etc. Don’t forget to declutter drawers and closets. Switch to plastic cups and plates when needed. You may need to install additional handrails or place brightly colored tape across steps. You may need to conserve your energy or find it safer to use assistive aids such as canes, walkers, wheelchairs. You may also need to install grab bars in bathroom/shower areas, use a shower seat while bathing or purchase disposable underwear. Daily movement, which may be as simple as stretching, no matter how limited your ability, will help with improving your night’s sleep, negative emotions, reducing stress, and help you focus.

You and your family may find it helpful to communicate with the use of word cues, picture flash cards, use of simple language and sentence structure, asking only one question at a time and repeating back information to ensure understanding. But first, make sure you are looking at the person speaking to you so you can focus and pick up visual cues. You may also find it helpful to play word games and puzzles.

It is important to recognize there is no one way of doing things. You will learn to compensate for your deficits by learning new ways. Sometimes, you may feel that you have reached a plateau, but that doesn’t mean that you will not progress again. You may continue to experience progress and setbacks in functioning. However, it is important to realize that when the way of doing things may no longer work for you, the strategy needs to be changed. Having patience and flexibility will be essential to your recovery. Your life will feel more normal and on track by using coping strategies that work for you.

## Chapter 3: Brain Tumor Guide: FAQ

### What Are The Different Types Of Brain Tumors?

Brain tumors are described by where they are located in the brain and what kind of cell they started from. **Primary** tumors begin in the brain, while **Secondary** tumors are caused by tumor (cancer) cells that spread to the brain from another “primary” source in the body, such as breast or lung cancer.

Primary brain tumors are classified (diagnosed), in part, by the type of cell it originates from. For example, astrocytomas come from astrocytes, oligodendrogliomas from oligodendrocytes, meningiomas from meningeal cells and medulloblastomas from medulloblasts, just to name a few.

### What is a Glioma?

The most common type of primary brain tumor is a **glioma**, originating in the brain from glial cells. Glial cells are the “support cells” of the central nervous system, helping neurons and nerve cells do their jobs by communicating information through electrical energy.

While glial cells can belong to several families of cells, most gliomas are made up of either astrocytes or oligodendrocytes, thus, these tumors are also frequently called Astrocytomas or Oligodendrogliomas (oligos). The terms glioma and astrocytoma are sometimes used interchangeably, although this isn’t technically correct.

**High-grade** (malignant) forms of these gliomas are called Glioblastoma Multiforme (GBM), Anaplastic Astrocytoma, and Anaplastic Oligodendroglioma. They are considered fast growing, rapidly invading nearby tissue. GBMs are the most common malignant brain tumor in adults.

Cellular makeup, speed of growth, location of the glioma, and even the age of the patient can all affect tumor behavior, resulting in a variety of symptoms and different experiences among patients. For this reason, you must guard against assuming that one person’s outcome of treatment will be yours.

For more information on specific types of tumors and treatments read  
**“What You Need To Know About Brain Tumors”**  
by the National Cancer Institute located at:  
**<http://www.cancer.gov/cancertopics/wyntk/brain>**

## What does “Tumor Grade” mean?

All tumors are given a “**grade**”, meaning a specific classification that relates to the current speed of growth and the potential to interfere with brain function. Grading is a determination of what stage, or how advanced (bad) a tumor is in its development.

Diagnosing and “grading” a specific tumor type has been described as something that is as much an “art form” as it is a science; typically a determination made by a pathologist after a biopsy. But grading can be somewhat controversial depending on the size of biopsy specimen obtained. One part of the tumor may have smaller, lower grade cells, while larger, more aggressive cells are present in a different location of the tumor. Furthermore, tumors initially assigned a low grade can become aggressive in growth, changing the status of the grade as well during the course of treatment. It is important to have your biopsy examined by a neuropathologist who sees a large number of brain tumors, requesting always, a copy of their report for your records and comparison.

**Both type and grade of a tumor is critical to your diagnosis and treatment, which is why a second opinion regarding biopsy specimens is so important.**

The most common grading system is called the WHO system based on its approval by the World Health Organization. The WHO system classifies all cancers on a grade of I – IV (1 – 4), a grade of 1 or 2 being slow-growing, “benign” tumors, while grades 3 and 4 are faster growing and are considered malignant. A grade 3 is called an “anaplastic astrocytoma” and a grade 4 is called “glioblastoma multiforme”.

When dealing with brain tumors, the word “**benign**” is a little misleading. It implies that the tumor is not dangerous. Unfortunately, the brain is enclosed in a rigid container (the skull) that allows no space for a tumor mass to grow. As a tumor (even a “benign” tumor) grows, it builds up the intracranial pressure and compresses everything around it, which can lead to neurological problems and even death. Luckily, there has been a lot of progress in the treatment of “benign” brain tumors. One type, the acoustic neuroma, used to be incurable and usually fatal. Now, it can be cured in over 95% of the patients, sometimes with a relatively simple radiation procedure. There is controversy over which way to treat it, either by radiation or surgery, but both options are so good that the decision is now made by trying to determine which treatment will have fewer side effects, as both may be curative.

Just be aware that a few hospitals use a different grading system for brain tumors, using a scale of 1 to 3, where WHO grades 1 and 2 are combined into “grade 1” and the rest are moved down 1: an Anaplastic Astrocytoma is then a grade 2, a GBM is then a grade 3. The terms Anaplastic Astrocytoma and GBM are more precise.

## How long has the tumor been there?

It’s not an easy question to answer, but slow growing tumors can be present for years

without causing any symptoms. Fast-growing tumor types can occur and cause symptoms within a span of six months or less. Nobody really knows how long you had your particular tumor.

## **Are brain tumors the same as brain cancer?**

This is controversial. There are arguments for both sides: some argue that a brain tumor rarely spreads outside of the brain, so it isn't "cancer". Others argue that it has the potential to grow and be deadly, so it is. I feel that brain tumors should be considered "Brain Cancer".

## **Can brain tumors be removed surgically?**

In many cases, yes, they can be removed with surgery. Surgery may actually "cure" some low-grade tumors, such as an Acoustic Neuroma. However, for high-grade tumors, surgery is not a cure, but it does buy time for other treatments to work, offers an opportunity to get material for a biopsy, drug resistance assay, special testing and an opportunity to use treatments that require surgery, such as Gliadel wafer, Gliasite Radiation Therapy System, creation of vaccines and many clinical trials. Any tumor can theoretically be removed, but the neurosurgeon uses his experience to make a judgment on the risks versus the benefits. Each tumor is different, but the neurosurgeon can usually predict if – and how much – neurological damage will be done if the tumor is removed. Since surgery for the high-grade tumors isn't a cure, sometimes they are considered inoperable if the expected neurological problems would create unacceptable problems for the patient.

**In brain surgery, experience matters A LOT.** Doctors who operate on a lot of tumors can usually remove more of the tumor, with fewer side effects than doctors who only operate on a few. They are also much more likely to have the latest high-tech surgical tools available. In general, the more of the tumor removed, the better the outcome. This is why the single most important decision you have to make is WHERE and by WHOM to have treatment. A more experienced doctor may consider what one doctor might consider inoperable, relatively easy. However – keep in mind that some doctors may be overly aggressive. Discuss the expected risks of the surgery to make sure your doctor understands your views on how aggressive you want them to be.

Furthermore, while **there are over forty-five hundred neurosurgeons in the United States, only one-hundred and twenty five (approximately) are considered experts in the removal of brain tumors, performing these delicate surgeries at least twenty-five times per-year or more.** Again, an experienced neurosurgeon can impact the outcome of tumor removal and recovery, making a second opinion with such an expert vital.

To find a **brain tumor center** near you, go to  
**<http://virtualtrials.com/btcenters.cfm>**

## What are the survival statistics for patients with brain tumors?

Nobody knows how long you are going to live with your tumor. Statistics are a tool used to compare treatments and describe what has happened in the past to groups of people with your tumor type. *They cannot predict how long any individual person will live.*

There are 2 important terms that you will see mentioned as you read about brain tumors: **Overall Survival (OS) and Progression Free Survival (PFS)**. Overall Survival is the % of people in the group that is being reported on, who live past a point in time – such as 1, 2 or 5 year survival. Just because a “1 year” or “2 year” survival statistic is reported does not mean you will live 1 or 2 years – it means the research that is being reported only observed people for that length of time. Progression Free Survival is reported either as the % of people who reach a milestone without having tumor progression – such as 6 month or 12 month PFS, or the average number of months before progression for the group. You can compare treatments by looking at either number. I feel PFS is the better number to use because after people have progression, they usually move on to another treatment which may confuse the impact of the treatment you are considering. As you read about statistics, keep in mind they fail to factor many items that must be accounted for on a case-by-case basis such as age, general health, the tumor’s involvement and location within the brain, how much was removed with surgery, and much more, including but not limited to, access to advanced brain tumor experts.

Surgical technologies and the ability to accurately diagnose a brain tumor have improved dramatically, and on-going, progressive clinical trials are leading the way to new and better treatments. Your ability to challenge “statistics” will greatly depend on surrounding yourself with a medical team that does not fall prey to such “statistics”. Try to avoid those within the medical community who have an unfortunate and bleak outlook and may not be current in their understanding of progressive new treatments. Physicians associated with, and in consultation with, leading brain tumor medical centers are your best defense against negative mortality statistics and will enhance your ability to remain positively engaged during your journey through treatment.

**Harvard University professor, Stephen J. Gould,**  
wrote about the nature of statistics  
during his battle against a rare tumor, called “mesothelioma”. His essay,  
“**The Median Isn’t the Message**” can be found at **Steve Dunn’s cancer guide** at  
**[http://cancerguide.org/median\\_not\\_msg.html](http://cancerguide.org/median_not_msg.html)**

Look at the **survivor’s stories** at **[www.virtualtrials.com/survive.cfm](http://www.virtualtrials.com/survive.cfm)**

Look for people with your tumor type who are leading normal lives. These people prove that no tumor type is completely hopeless. Participate in online and real world support groups to meet others who are going through the same thing as you, but who are many years out and doing well. It is important to see that there are people who do well.

If you want to see the **survival statistics**, look at:  
**<http://www.cbtrus.org/factsheet/factsheet.html>**  
for the average survivals for the entire USA.

## **What type of physician-specialist should I see?**

Your medical team will likely include several experts who are experienced in various specialties including, but not limited to, neuro-oncology (the medical treatment of brain tumors), neurology (conditions of the brain and spinal cord – the nervous system), surgery, radiology (MRI/CT), radiation therapy, and pathology (the study of tissue). The make-up of your team will vary depending on the type and location of your tumor, and may include those with a variation of names and cross-specialties, but should always comprise a team experienced **specifically in the treatment of brain tumors.**

A medical (board-certified) **oncologist** treats many forms of cancer; however, not all oncologists are experts in treating brain tumors. As part of your medical team, your general oncologist can assist you with obtaining second opinions and researching available treatment options, but should refer you to a neuro-oncologist, experienced specifically in the treatment of brain tumors. Most **neuro-oncologists** are also neurologists, treating disorders of the nervous system (some also started as general oncologists), and treating general cancer. Whether your physician-expert is called a neurologist or a neuro-oncologist is not as important as whether or not he/she has experience with your type of tumor. It is important that you establish his/her experience in treating your type of tumor and if he/she is up-to-date on advances in both surgery and alternative treatments. If a neuro-oncologist is not available in an area, an experienced oncologist is the next best thing.

A **neurosurgeon** is someone who performs surgery involving the nervous system, typically specializing in one particular area or system, such as the spine. Not all neurosurgeons are experienced experts in systems relating to the brain and/or the removal of brain tumors. An expert commonly performs twenty-five or more brain surgeries per year to remove tumors. Of the current estimated forty-five hundred neurosurgeons, only about one hundred twenty five are considered experts in the removal of brain tumors to date. Before considering any surgical procedure, it is important to know the experience level of your neurosurgeon, opting for a second opinion (preferably) from a neurosurgeon associated with a major brain tumor center. While some neurosurgeons also practice neuro-oncology and oversee the administration of chemotherapy treatments, most confine care to surgical therapy and follow-up care.

A **neuro-radiologist** is a specialist in the area of reading MRI and CT scans involving the nervous system. Your MRI or CT scans should always be reviewed by a neuro-radiologist experienced with tumors within the brain.

A **radiation oncologist** specializes in the administration of radiation therapy (solely and specifically) and should work in cooperation with your neuro-oncologist/surgeon to develop an appropriate course of therapy (duration and intensity).

You should consider other specialists for complementary care throughout your treatment and recovery, such as:

- Rehabilitation Specialists (physical/speech therapist, occupational therapist)
- Neuropsychologist/Psychiatrist
- Endocrinologist (Internal medicine specialist to monitor blood sugar levels, liver, kidney, and other organ functions and chemistries adversely affected by medication and treatments)
- Ophthalmologist (eye doctor)
- Dentist (especially important prior to chemotherapy)
- Pharmacist
- Tumor board at your hospital of care

### **What questions should I ask my doctor(s)?**

What type of brain cancer do I have? What is the grade?

Do any additional tests need to be done?

How many tumor types like this do you treat each year?

Will the brain tumor board review my case? How often?

Where would you recommend I get a confirming/another opinion?

Do you have any written information about my type of cancer?

How will the tumor affect my functioning?

What are my treatment options? Which treatment do you recommend? Why?

What are the benefits of this treatment?

Can you recommend an oncologist who specializes in this type of cancer?

What other specialists will be part of my care?

What is the timeline for treatment(s)?

Where will I get the treatment? Will I be able to drive myself to and from?

Does my medical insurance cover this type of treatment? At this facility?

How will this affect my work schedule?

Will I need to apply for disability? Social security disability?

Will I need to take medications? If so, what kinds and how often?

Are there any side effects? What kind?

Are there short-term and long-term side effects?

How can the side effects be managed? Medicines? Physical therapy?

Will my quality of life change? Will I function differently?

Will I see a change in my personality? Appetite? Sleep habits? Memory?

What can I expect before, during and after treatment?

What is the follow-up plan if this treatment doesn't work?

How often would I need scans? What kinds?

Do you think I should attend a support group now? Are there any nearby?

## **What are brain scans?**

Brain scans allow the doctors to get an idea of what is going on inside the head. No scan is 100% accurate, and they are open to interpretation. The more experienced the doctor reading the scans, the more confident you can be in the results. As mentioned elsewhere, it is a good idea to get a copy of the films (or a cd of them) and the report. You can show this to your doctors and make sure they agree on the reading of the scan. If not, get multiple opinions. The copies are also useful to have in case you need a quick second opinion from other brain tumor centers, and in case the originals are lost, which happens more than you would think!

A **CT scan** (or CAT scan, a computerized axial tomogram) uses x-rays to generate a computer simulation of a picture of the cross section of your head. Usually they inject a contrast agent (a dye) into your arm halfway through the test, to enable the tumor to show up better. A CT scan is readily available and much cheaper than an MRI. A CT scan shows some things



very well, such as bleeding into the brain, signs of swelling and is sometimes used for planning surgery and radiation. Since CT scans use x-rays, there is a tiny risk with their use, so they are usually limited to only when absolutely needed, especially in children. If having a CT scan on a child, ask the tech if they reduce the exposure dosage for children. Some older machines do not. If they do not, select a different facility.

**MRI** (Magnetic Resonance Imaging) uses magnetism and radio waves to create a “picture” of the inside of your head. It is more detailed than a CT scan and usually preferred when trying to diagnose a brain tumor. An MRI will find smaller tumors than a CT scan. A different contrast agent is used for MRIs than for CT scans, so if you had an allergic reaction to the dye used for a CT scan, you can still usually use the contrast agent for an MRI (and vice versa). Sometimes you cannot have a MRI if there is any metal in your body. If there is any metal in your body, tell them when you make the appointment so they can determine if it is safe. Other than the problem with metal, and a small risk with the contrast agent, MRIs are thought to be safe.

There are many variations of MRI available. Here is a listing of some of the important ones:

- **MRA** (Magnetic Resonance Angiography) shows details of the blood vessels.
- **MRS** (Magnetic Resonance Spectroscopy) shows the chemical makeup of the brain, which can sometimes be used to tell the difference between radiation necrosis, normal brain, swelling and tumor. Sometimes, it can tell the difference between low-grade and high-grade tumors, and pick the best area for a biopsy. It is now also being used to tell if treatments are working much faster than regular MRIs can tell. They are most useful when repeated to compare with the previous scan to see if you are getting better or worse. This is available at most brain tumor centers and is starting to become available everywhere.
- **fMRI** (Functional MRI) – this scan measures blood flow in the brain, and is used to try to map which areas of your brain control which functions. For example, if the tumor is near your speech area, they will ask you to talk while doing the scan, to highlight the areas you use while talking, and to see if the tumor invades that area.
- **Diffusion MRI** – a new variation that measures water movement in the brain. It can be used to determine how well the treatment is working.

See: <http://virtualtrials.com/news3.cfm?item=3061>

- **PET Scan:** (Positron Emission Tomography) – Uses a tiny amount of a radioactive substance injected into your arm, and it shows how metabolically active (how much glucose is being used) each area of the brain is. This can be used to help determine (it isn't perfect) the difference between tumor, swelling, radiation necrosis and normal brain. It isn't available everywhere, and is expensive.

# Chapter 4: Treatments of Brain Tumors

## Treatment Options

For definitions of **treatment terms**, visit our dictionary at  
<http://virtualtrials.com/dictionary.cfm>

**Official government information on treatments** can also be accessed at:  
<http://clinicaltrials.gov>

For additional information on **specific treatments**, as well as, general information on chemotherapy, radiation, immunotherapy, and surgery, visit: “Noteworthy Treatments” section of our website at:

<http://Virtualtrials.com/noteworth.cfm>

and **our video library** at  
<http://virtualtrials.com/video.cfm>

**Surgery** is usually the first treatment. In some low-grade tumors, it is curative and no further treatment is needed. Unfortunately, for the majority of brain tumors, additional treatments are needed.

If you were just diagnosed and about to have a surgery, there are a few choices to consider. Ask your surgeon about the **personalized vaccine therapies** that require a tumor sample (or you can plan for future vaccines by having the tumor sample frozen in a special way). You can ask about special tests that can test the genetic makeup of your tumor. Ask if there are any **clinical trials** that require a surgery and ask about the possibility of doing a Drug Resistance Assay. You can read about them in later chapters, but for now, just know that you need to ask about these things before surgery!

Surgery (for a high-grade brain tumor) should be looked at as an opportunity to use a treatment or do a test that requires surgery, since you don’t want to have an additional surgery just to implant something or get a tumor sample for subsequent treatments.

Be aware that most long-term high-grade brain tumor survivors have had multiple surgeries. Usually, the surgery won’t be as bad as you expect. The worst part may just be

worrying about it the night before. There are risks to surgery anywhere in the body, but surgery today is so much safer and easier than it was even 10 years ago. Serious side effects are much less common than they used to be, so don't let horror stories from the past bother you. Problems still do occur but not as frequently as in the past.

Following surgery, **radiation and chemotherapy** at the same time is currently the standard of care (for high grade gliomas only). Radiation is given 5 days a week for 6 weeks, and the oral chemotherapy drug, Temodar, is usually used at the same time. If it is not offered to you, ask why not. If **cost** is the barrier, contact us. The Musella Foundation has a new **co-payment assistance program** that may be able to help in some circumstances with your out of pocket expenses.

For details, go to:

**<https://braintumorcopays.org>**

After radiation is completed, **Temodar** is usually continued. For GBMs, it is approved for only 6 months following radiation, but in practice, it is used until it either stops working or until it is no longer needed which is determined by no tumor growth on the scans (MRI and MRS/ MR perfusion or PET) for a few months. Some doctors use it for 12, 18 or 24 months or more.

For an overview of Temodar, go to:

**<http://Virtualtrials.com/temodar>**

Some brain tumor centers add a second (and sometimes a third) treatment to Temodar to try to make it work better. Third treatment options added to Temodar may include **Avastin**, the **Novocure Novo TTF-100A device**, **Celebrex** or **any of the targeted agents**.

In some cases, if there is still tumor on the scan after the "standard" radiation, an additional dose of a much-focused form of radiation, called **stereotactic radiotherapy**, may be tried. If these treatments do not work, (or they may be considered instead of the standard therapy), then other therapies are considered.

**There are 2 general classes of treatment: "FDA Approved" or "Experimental".**

- **"FDA approved"** treatments have been deemed "safe and effective" for at least one disease; not necessarily for brain tumors. If they were not approved for brain tumors, your doctor may still prescribe them for your brain tumor. This is called "Off Label Use". Many drugs used commonly for brain tumors are used off label. Although legal, and easily available, you sometimes have trouble getting your insurance company to pay for off label usage because they argue it is experimental. In such cases, know that you can fight the insurance company's denial. You should enlist your neuro-oncologist to help get it approved by your insurance company.

- **“Experimental”** – The treatment has not been approved yet, and may be hard to obtain. A clinical trial (defined below) is the best way of trying experimental therapies, as the doctors will watch you very carefully for signs of side effects. Be aware that there is a mechanism for using an experimental drug outside of clinical trials, but it is only for those who do not qualify for the usually rigid entrance criteria of clinical trials. This is called “Compassionate Usage”. People in clinical trials seem to do better than people who choose not to participate. This may be due to the fact that you are watched much more closely while in a trial than when not in a trial. Also, once the cure is actually found, the first people to get it will be those in the clinical trial for it. This has happened with other types of cancer, and it will happen for brain tumors, hopefully someday soon.

## Clinical Trials

Clinical trials are experimental treatments which are providing new inroads to extended life expectancy and an improved quality of life for many patients. Understanding current availability of clinical trials requires time and due-diligence. I hate to say this, but some doctors are reluctant to refer you to other treatment centers. You must search out the appropriate trials available for your specific tumor-type, always advocating in your own best interest towards a cure.

For a complete introduction to clinical trials see **“Clinical Trials for Brain Tumors”** by

Terry Armstrong at:

**<http://www.virtualtrials.com/What.cfm>**

## Understanding Clinical Trials

Most clinical trials are designated as phase I, II, or III, and are based upon specific questions that a particular study is seeking to answer. These phases are defined by the Food and Drug Administration in the Code of Federal Regulations.

- **Phase I** – examination of a new drug or treatment in a small group of people (20-80) for the first time to evaluate its safety, determine a safe dosage range and identify potential side effects.
- **Phase II** – the study drug or treatment is given to a larger group of people (100-300) and further measured for effectiveness and safety. Dosage of medication may be increased to determine toxicity levels.
- **Phase III** – the study drug or treatment is given to large groups of people (300-3,000) to confirm its effectiveness within a sizable population, monitor side effects and toxicity levels, compare it to the standard treatments, and further determine safety.

## **Why should I consider participating in a clinical trial?**

For most types of malignant brain tumors, there is no cure. Clinical trials provide access to some of the newest and most promising treatments that are still being investigated in areas for which there are no curative measures otherwise available, or for which a better delivery of therapy with fewer damaging side effects may be possible. In many cases, these trials, guided by experts in their field, may represent your best possible chance for survival, or perhaps an opportunity for a better quality of life. By participating in a clinical trial you help researchers take one small step, or perhaps even a giant leap, closer to a cure. Aside from helping yourself, your experiences help advance the state of the art in the field, which may lead to better treatments in the future.

Another advantage to clinical trials is the cost: ALL brain tumor treatments are very expensive. In general, the experimental treatment inside a clinical trial is free to you. There may be charges for the associated costs – such as surgery, doctor’s consultations and visits, MRIs, blood tests and others – so ask about the costs and ask what your insurance should pay and what your out of pocket expenses should be. IF you have no insurance, there may be trials available that cover all of costs.

## **When should I consider a clinical trial?**

The decision of when to participate in a clinical trial varies among patients and should be discussed with your doctor. Some patients and physicians feel more comfortable exhausting traditional treatment avenues first. Others choose to participate in trials from the onset of diagnosis. You may wish to discuss certain points of progress (or lack of) with your doctor as a guideline to help you with your decision. Obviously, if you have a low-grade tumor that has good treatments available, you would be less likely to try something experimental. If you have a high-grade tumor where the expected outcome of the standard treatments is not acceptable to you, it is easier to make the decision to try something experimental.

Clinical trials each have their own set of requirements that might include the age-range of participants, location of the tumor, grade and/or type of tumor, or a specific degree of stabilization before a patient is admitted to the trial. Some clinical trials are specific to patients experiencing a recurring tumor, rather than a first-time diagnosis. Whether or not you decide to wait or move forward, it is important to research available trials early for your specific type of tumor and know in advance if, or when, you might qualify. Be especially careful not to miss deadlines. Some trials require that you sign up for them BEFORE surgery. Others require that you sign up half way through radiation or before radiation ends.

One thing to keep in mind is to plan ahead and think through a large range of contingencies. Some treatments will disqualify you from trying some experimental treatments.

In such a case, you will usually not have enough real data to make an informed decision. In the old days (over 5 years ago), it was an easy decision – the standard treatments had so little hope that you had nothing to lose. The standard has progressed to the point where you now have a difficult decision to make – as the standard treatment does help some people for a long time.

### **How do I assess a clinical trial?**

The best way to evaluate if a clinical trial is right for you is to speak with your primary physician, your neuro-oncologist or surgeon, and other members of your health team including those from whom you have turned to for second opinions. You might also contact one of the major brain tumor centers for additional insight to a specific clinical trial. You should also consult with the physician in charge of the trial. It is always helpful to know how earlier trials of the proposed treatment came out. Lastly, it is important to ask any physician not in favor of your participation, why not? What would they recommend instead, and why?

Although individual cases are meaningless statistically, the experiences of others may help give you enough information to choose between two treatments that are otherwise a toss-up. You can find these individual experiences in the online support groups, real world support groups and the brain tumor virtual trial results.

### **How do I find clinical trials?**

Our website, <http://Virtualtrials.com>, offers some of the most current information available regarding clinical trials. We offer many ways to find a trial; see the Appendix for a listing of the ways to search. Also check <http://clinicaltrials.gov>, as they have some trials that we do not have listed yet, and we have some that they don't have. Together, most of the important trials are listed!

### **Medications**

In the treatment of brain tumors, not unlike any other acute or chronic illness, a variety of medications are used to combat symptoms, such as pain, fatigue, swelling and seizures. They may include antibiotics, steroids, analgesics or narcotics and anti-convulsants. It is necessary to take responsibility for your medications to ensure your safety.

As your medical team will be made up of physicians from various specialties, all of whom may prescribe different medications or alter dosages in the context of your care, it's vital that you keep ongoing and accurate (up-to-date) records in your treatment binder regarding your medications, including:

- Medications you're currently taking (including dosages) and who is responsible for monitoring you (prescribing physician) or providing refills. This information can be very helpful to a caregiver seeking information or assistance on your behalf.
- Medications you have taken in the past, noting their value (i.e., was most helpful for sleep, etc.)
- Medications discontinued due to negative side effects.
- Any allergic or adverse reactions, mild or otherwise, noted in RED.

**Always:**

- Ask your doctors to review your list of current medications prior to prescribing something new.
- Check to ensure that the recommended drug is covered on your insurance plans drug formulary, or if you'll need a prior authorization.
- To avoid receiving the wrong medication at the pharmacy (a growing concern), write down the specific medication and dosage as stated on your prescription **before** submitting it to a pharmacist and compare this information to the label on the bottle to ensure it is the same drug as stated on the prescription.
- Your prescription might be filled with a generic substitution if your doctor did not prescribe it "as written". If the medication you receive is different than what was written on the original prescription by your physician, ask the pharmacist. Also ask the pharmacist for his thoughts on the generic. Most generic drugs are okay to use, but for some drugs that have a very narrow effectiveness range it may be worthwhile to pay the extra for the brand name or insist on the same brand of generic each time.

Whenever possible, having all your prescriptions filled through a single pharmacy source can be a safeguard against medical errors, preventing adverse drug interactions, as most pharmacies now utilize computer systems that automatically flag dangerous interactions based upon your previous medications. Should your physician fail to recall a particular medication that might present a problem, chances are your pharmacist will catch it. Still, asking your physician(s) to review your medication sheet in your treatment binder – each and every time a new drug is prescribed - is an important, life-saving step.

It's important that you understand the side effects and drug interactions of all the medications you are prescribed. Additional information regarding your medications can be found in the Physician's Desk Reference (PDR) found at your local library, or through online sources, such as

*RXMED* <http://www.rxmed.com/> and *Drugstore.com* <http://www.drugstore.com/>

However, most of the drugs we use have very scary package inserts and list every side effect ever reported to happen in people who were taking the drugs – whether the drug caused it or not. Our point is to be aware of the most common side effects and watch for them, not to be scared away from using the drugs.

## Common Medications

The following is a general list of medications commonly used to treat symptoms and/or conditions caused by a brain tumor itself, or resulting from surgery and/or other standardized treatments of brain tumors. Many of the significant/common side effects regarding a particular medication are noted, but may be incomplete. Your physician may recommend medications not covered within this general guide. You are advised to thoroughly discuss and understand all the benefits and side effects with your physician before a prescription is issued. Physicians are often creatures of habit – ask about alternative medications and why he/she would choose the recommended medication over another. This is a general overview. Always ask your doctor before taking anything, even over the counter pain medications.

### Pain Relief

Because the brain itself does not feel pain, studies show that physicians treating patients for brain tumors often overlook pain. However, pain, as a by-product of disease or due to complications from surgery or other forms of treatment, is very real and deserves real attention. Headaches from brain inflammation or tension, scalp sutures, muscular pain and hairline fractures due to steroid therapy, and pressure points on arms and hips from extended bed rest can all attribute to pain and require medication. Pain left untreated can slow healing, deplete emotional reserves, exacerbate depression and sleep deprivation, and detract from your quality of life.

**Mild Pain** - can usually be managed with Tylenol or Advil (Note that aspirin can affect how fast your blood clots, which may be bad if you need surgery, or good as it prevents blood clots. Always ask your doctor about it first!).

**Moderate Pain** - More powerful prescription medication, such as Percocet and Percodan (which contains aspirin), can be taken as directed by a physician.

**Severe Pain** - Codeine, Vicodin, Oxycodone and stronger, morphine-type medications are typically long acting and taken less frequently. Many also come in “patch” form for slow absorption and continuous relief. Ritalin (used to treat attention-deficit disorders), taken in small doses with pain medication, can increase the narcotic effect (enhancing pain relief) while reducing the drowsiness commonly associated with these drugs. Ritalin has also been shown to benefit patients who suffer from fatigue.

According to the pharmaceutical disclosure (package insert) for drugs that contain morphine, this drug should not be used in patients with brain tumors, however, it is still commonly used and the benefits may outweigh the risks when you are in severe pain. Discuss any concerns you might have with your physician.



## Steroids

**Steroids are powerful anti-inflammatory drugs** typically prescribed to reduce swelling in the brain (cerebral edema) before and/or after surgery, during radiation treatments, or to relieve symptoms such as memory loss and limb (arm/leg) weakness caused by brain swelling. While common, swelling can be harmful if excessive and must be controlled.

Synthetic steroids such as **Decadron and Hexadrol** (common brand names for dexamethasone) are man-made hormones similar to cortisol, which is produced naturally by your body. Taken orally, these steroids create higher levels in the body than what is normally secreted, reducing inflammation, but also causing the body to temporarily stop natural production on its own. For this reason, it is very important to “wean” yourself (cut back slowly) when stopping oral steroid therapy. Always follow your physician’s recommended schedule for reducing dosages. During this reduction period, your body will slowly come back “on line” and begin to produce normal cortisol levels again. You should never abruptly stop taking steroid medication, as in extreme cases, going cold turkey can cause sudden death, as the body is not yet ready to resume full production of cortisol on its own, a necessary and vital hormone.

While the benefits of steroids are undeniable, often unmatched by any other medication, they are not without short and long-term side effects.

**Long-term side effects** can include (but are not limited to):

- Diabetes
- Muscle pain/weakness
- Osteoporosis (bone loss) leading to fractures
- Susceptibility to infections.

**Short-term effects** include:

- Increased appetite, weight gain and indigestion
- Swollen or “moon-faced” appearance
- Stretch marks, rash/flushing of skin and acne
- Increase in blood sugar
- Brittle bones
- Depression, behavioral changes
- Anxiousness/paranoia
- Suppressed immune system

Other oral steroidal therapies include prednisone or prednisolone. While not as strong as dexamethasone (Decadron), side effects are generally the same, although perhaps not as severe in most cases.

**Xerecept** is an experimental medication currently being tested in comparison to dexamethasone (Decadron) for the treatment of brain swelling (edema), thus reducing pain and

adverse neurological symptoms, most commonly, seizures. For those patients who require high doses of steroidal therapy to reduce swelling, Xerecept might prove equally (or more) effective without the side effects of current steroid therapies.

## **Anticonvulsants**

Roughly 30-40 percent of patients will experience some level of seizure activity and require medication to reduce electrical responses in the brain. Due to the location or size of some tumors, many neurosurgeons will prescribe anti-seizure medication as a matter of routine before, during and/or after surgery when the risk of seizure is considered high. In the past, all brain tumor patients were put on anti-seizure medications routinely for life, but since they can have a lot of side effects, *many doctors now try to do without these drugs until seizures occur.*

In some cases, a seizure will appear as something slight and quick – muscle or eye twitching, or a sense of being “out of the moment” mentally and/or physically for a brief time; a blank stare or sudden pause without response. These are called **Focal Seizures**. For others, seizures will involve full body activity, often categorized as **Grand Mal seizures**.

Most anticonvulsants share common side effects, such as fatigue and dizziness, so for obvious reasons you may be restricted from driving a car or operating dangerous equipment while taking anti-seizure medications, even when seizures have not been documented or have subsided. Other medications and certain foods can prevent proper absorption, so frequent blood draws for proper dosage and serum levels are necessary.

**Phenytoin**, commonly prescribed under the trade name, **Dilantin**, is a commonly used medication to prevent full-body seizures in high-risk patients. Individuals metabolize Dilantin differently; so periodic blood levels are taken to ensure dosages are adequate and stable. Side effects of Dilantin include muscle fatigue, dizziness and loss of coordination, as well as tooth decay and gum problems. Regular dental checkups and extra attention to oral hygiene are advised. Long-term use of Dilantin can cause a decrease in certain nutrients, such as folic acid and calcium. Ask your physician about supplements if necessary. Dilantin can also interact with other medications, including over-the-counter drugs, birth control pills and herbal supplements. It’s important to disclose **all the medications** you take to your physician and pharmacist. Dilantin can also make some chemotherapy drugs less effective.

**Neurontin** (trade name for gabapentin) carries similar side effects as Dilantin, as well as, double vision, tremors and involuntary eye movements. While Neurontin has fewer drug interactions than Dilantin, it does interact with certain antacids, such as Maalox.

**Tegretol** (carbamazepine) is an anticonvulsant that is also prescribed in the treatment of manic depression and other psychiatric disorders. Effective in its ability to control Grand Mal seizures, Tegretol must be monitored closely with frequent blood levels, as in rare cases, it may suppress bone marrow production. You should report any onset of a rash to your physician immediately. Tegretol also reduces or increases the effects of many medications. Double vision, pounding or slow heart rate, and nausea are noted side effects with this drug.

**Depakote and Depakene** (trade names for valproic acid or valproate) are commonly prescribed for focal seizures and require periodic blood levels to ensure adequate dosage and guard against liver damage. As Depakote interacts with many medications, make sure your physician reviews your current medication list (including over-the-counter and herbal supplements) at the time of recommendation.

**Phenobarbital** (a barbiturate and strong depressant), or Primidone are less frequently prescribed, as the effectiveness of other anticonvulsants can be more easily achieved without the potentially addictive qualities.

**Keppra** (levetiracetam) is a newer anticonvulsant drug. Sometimes it is used alone and sometimes for difficult cases it is combined with other drugs. Keppra does NOT interfere with chemotherapy drugs.

## **Anti-Nausea**

Nausea is common with brain tumors, as both a part of the disease process itself and as a by-product of radiation and chemotherapy treatment. **Zofran** (trade name for Ondansetron) is used to control nausea caused by chemotherapy or radiation specifically, usually administered by IV prior to treatment and can be taken orally after treatment, if necessary. Effective for only a few hours, Zofran is limited to nausea caused by chemotherapy and radiation only, and is not to be taken for motion sickness or other generalized conditions related to nausea. While mild in nature, side effects include headache, fatigue, diarrhea or constipation and may exacerbate pre-existing liver disease.

**Kytril** is similar to Zofran in both treatment administration and side effects, although it may also cause abdominal pain. It lasts up to 12 hours.

**Compazine** (trade name for Prochlorperazine) is a commonly prescribed medication for the treatment of generalized nausea, given either orally, via IV, or as a suppository. Compazine belongs to a family of antipsychotic agents called “phenothiazines”, and may cause drowsiness, low blood pressure, dizziness, constipation, dry mouth, blurred vision and sensitivity to light. While effective in the management of nausea, Compazine should not be used in conjunction with alcohol, may interact with other medications, and could potentially cause an irreversible condition called Tardive Dyskinesia; involuntary movements or twitches of the face, tongue or arm muscles. It is important to discuss possible interactions and side effects with your physician.

**Anzemet** is a new anti-nausea drug currently being used with success, given prior to chemotherapy. In some patients, a combination of Anzemet and Decadron prior to chemo works in cases when the older drugs don’t provide enough relief.

**Haldol** is another antipsychotic medication used to control nausea with similar risks and side effects to those of Compazine. Both Haldol and Compazine should not be taken without a detailed discussion with your physician.

**Transderm Scop** is a seasick drug, which can sometimes be used for nausea. It is a patch that is applied to the skin and works for 3 days per patch. A main side effect is dry mouth, which can be a benefit when the patient has trouble swallowing and produces too much saliva.

There are also many alternative treatments. Some patients report that acupuncture, biofeedback and hypnosis provide nausea relief with no side effects and are much cheaper than most commonly used drugs.

## **Anti-Depressants**

Being diagnosed with a brain tumor alone is enough to create overwhelming anxiety and stress. It's important to understand that during the course of treatment, intense and seemingly "over-emotional" reactions, such as acute depression, sexual dysfunction, sudden outbursts, and visual or audio hallucination may be the result of medication or a condition stemming from the tumor itself, not necessarily an emotional response. It's important to communicate these emotional changes with your physician and seek out proper assistance and guidance to help you distinguish the many moods of treatment and recovery, and to help you cope.

A psychiatrist is a medical doctor who can assist with those conditions that are tumor-related (impairments directly caused by the presence or treatment of the tumor itself) that may require drug therapy. Psychologists can provide help with coping difficulties and mild depression due to issues of long term care, financial strain or the stress placed upon family and other important relationships. Make sure that the psychiatrist is experienced in treating brain tumor patients. Ask your neurosurgeon to refer you to one.

Common anti-depressants include Zoloft, Paxil and Prozac, all of which are from a class of drugs called "selective serotonin reuptake inhibitors", or SSRI's. Side effects may include sleepiness, tremors, diarrhea, nausea, insomnia, increased sweating, weight loss and decreased sexual ability. Side effects may be reduced when taken with meals; however, Zoloft in particular, should always be taken with food. In some rare cases, anxiety and depression may worsen while taking SSRI's and should be reported to your physician immediately. Don't let the risk of side effects stop you from trying these drugs. People report a remarkable increase in quality of life when these drugs work.

Herbal remedies may be of some benefit; however, herbal mixtures can adversely interact with other prescription medications and should always be discussed with your physician for safety and adequate dosing information. If you are thinking of taking Hypericin, make sure to ask your doctor first, as it can interfere with other drugs.

## **Anti-Coagulants**

Brain tumor patients are at a higher than normal risk for developing dangerous blood clots. Blood clots commonly start in the legs as Deep Vein Thrombosis (DVT). Symptoms of

DVT may include pain, tenderness, swelling or discoloration of the affected leg, and skin that is warm to the touch. If you develop these symptoms, you must call your doctor and get it checked quickly. Left untreated, the blood clots can break away and travel to the lungs where they cause a pulmonary embolism, which may be rapidly fatal. Symptoms of a pulmonary embolism include sudden shortness of breath, chest pain (worse with breathing), and rapid heart and respiratory rates. If you develop any of these symptoms, you must go to the emergency room immediately.

Medications called anti-coagulants help to thin the blood and reduce clotting, the body's normal response to help stop bleeding. Heparin (lovelox) is an anti-coagulant that is given by injection, usually for a short period of time to prevent or treat blood clots. Warfarin (commonly referred to as Coumadin) is an oral medication that can be taken over a long period of time to prevent blood clots. Aspirin is a milder blood thinner, which some doctors recommend to prevent blood clots.

While taking anti-coagulants, normal cuts and scrapes may take longer to stop bleeding or heal, and there is an increased risk of the tumor bleeding into the brain – so these drugs are a double edged sword – and should be taken exactly as prescribed. Warfarin interacts with many medications and should be discussed thoroughly with your physician before treatment. You doctor will also order periodic blood tests to ensure appropriate medication levels are maintained. Plavix is another commonly used drug that prevents clotting.

It's important to note that changes to your diet can have a negative effect on the blood thinning measures of anti-coagulant medication. Suddenly increasing foods such as spinach in your diet can adversely affect bleeding times. The sudden introduction of fish oil capsules (Omega 3's) as a dietary supplement can also alter bleeding times. While there is no need to eliminate spinach and other healthy items (including supplements) from your daily routine, you are advised to maintain your normal diet and not increase (or decrease) items significantly, or add new supplements without discussing them with your physician. This is **not** the time to begin a new diet for weight loss without consulting your physician.

It is always a good idea to wear a **medical alert bracelet** informing medical personnel that you are taking anti-coagulants in the case of an emergency. They are widely available in most retail pharmacies and on the Internet, inexpensive, and an important safeguard for your health.

## Neurosurgery

Surgery is performed to improve neurological function, confirm your diagnosis by means of a **biopsy** (“open biopsy” or “Stereotactic biopsy”), or to completely (“**total resection**”) or partially (“**sub-total resection**” or “**debulking**”) remove the tumor. With a resection, you also get a biopsy of the sample removed. You should ask your surgeon for a copy of the pathology report. You can easily (but it may be expensive – check first) get a second opinion on the reading

of the pathology slides. There is a lot of interpretation put into the reading of the slides, and this is the single most important test you will ever have in your life, so it may be worth the money to double check it. Best of all, getting a second opinion doesn't involve any pain – and can be done by mail – no need for traveling.

For some benign tumors, surgery may be curative. For the malignant tumors, surgery may relieve symptoms of too much pressure in the brain and allow time for other treatments to work. Malignant tumors can grow so fast that without surgery, other treatments might not have the time to work. Surgery is also an opportunity to try a treatment that requires direct access to the brain.

Surgery is performed by a neurosurgeon; however, a general neurosurgeon may not have adequate experience in the removal of brain tumors, and may be less informed regarding current treatment therapies. Most neurosurgeons do not see many brain tumors. You need to find one that specializes in brain tumors. Check out their website and make sure that “brain tumors” is listed as one of the main areas of expertise.

**An “expert” is defined as one who performs a minimum of twenty-five surgeries per year; typically these neurosurgeons are associated at some level with major brain tumor centers.** Studies indicate that major brain tumor centers and/or surgical teams that perform fifty or more surgeries a year exhibit better survival rates and fewer complications.

“Brain surgery” sounds like a very scary thing. It is. But as previously mentioned, it is now much safer and easier than ever. Advances in 3-d computer guided imaging, intraoperative imaging with ultrasound or MRI, brain mapping, and small endoscopes allow surgeons to remove many tumors that used to be considered inoperable. There are still some tumors that because of the size or location are too dangerous to remove, but the limits are shrinking every year. If you are told that your tumor is inoperable, get another opinion.

## **Radiation Therapy**

Radiation therapy is performed under the care of a **radiation oncologist** or neurosurgeon typically after surgery or in cases where surgery is not an option due to the location or size of the brain tumor. The tumor and a small margin are usually targeted by a powerful beam of radiation. The radiation disrupts the DNA of the cells that are reproducing.

Tumor cells reproduce much more often than normal brain cells, so they are affected more than normal cells. Normal cells are also better able to repair the damage from the radiation than tumor cells. We take advantage of this by breaking up the course of radiation into a number of smaller treatments instead of one big treatment (except for a special form of radiation called “**stereotactic radiosurgery**”, see below). This is called “**fractionation**”, and gives the normal cells time to repair themselves, but not enough time for the tumor cells to repair themselves between treatments. A typical course of radiation involves a few minutes of treatment 5 times

a week for 6 weeks. It has been shown that adding the oral chemotherapy drug, Temodar, to radiation makes the radiation work much better. Ask your doctor about it. Side effects of radiation can range from mild to severe and include skin burning and peeling, swelling (edema), diarrhea and nerve damage. There are many types of radiation:

**Whole Brain Radiation:** Radiation is applied to the entire brain. This is usually only used when there are multiple tumors, especially with metastatic brain tumors. In the past, it was used for all brain tumors, but more focused forms of radiation are now usually used.

**Conformal 3-D radiation** – targets the tumor and a small margin with “conventional” external beam radiation. This spares more of the normal brain from radiation damage, and is the standard of care now for most brain tumors.

**Interstitial radiation therapy** (also known as brachytherapy) - this is delivered directly to the tumor bed by the implantation of radioactive material. It may be in the form of radioactive seeds, which are implanted permanently or temporarily; via the Gliasite Radiation Therapy System, which is a balloon implanted into the tumor cavity which is later filled with a radioactive liquid for a few days then removed. The advantages are a much higher dose of radiation exactly where it is needed. The disadvantage is that surgery is needed to implant these devices. A variation on brachytherapy is targeted administration of a radioactive substance combined with a monoclonal antibody. The antibody seeks out the tumor cells and drags the radiation to where it is needed. This is experimental, but shows a lot of promise.

**Stereotactic Radiosurgery (SRS)** - While there is no “knife” or incision to expose the brain involved with radiosurgery, rather a precise, high-dose beam of radiation, it is considered “surgical” because of the degree of change that transpires following any radiosurgical procedure.

Radiosurgery can involve one treatment session, or several (fractionated) sessions over a period of several days or weeks, assisted by computer-aided planning. Radiosurgery delivers a much higher dose of radiation to the target than conventional radiation. In some low-grade tumors it can be curative. For metastatic tumors, there is a good chance that stereotactic radiosurgery can permanently control individual tumors. SRS is also sometimes used as a boost at the end of conventional radiation or for small recurrences.

**There are many different machines that can be used for stereotactic radiosurgery: Gamma Knife, Novalis System, Linac, Cyberknife and many more.** Each has advantages and disadvantages, which is beyond the scope of this article. Just know that if you are told your tumor is too large or the wrong shape for SRS, get another opinion from a doctor who uses a different machine. For example, the Gamma Knife has a size limit of 3 or 4 cm, which the other tools do not have.

**Proton Radiation** – this is another form of radiation, using Hydrogen proton particles instead of X-ray or Gamma Rays. Its main advantage is that it delivers its energy to a better defined area. This is useful when the tumor is up against an important structure such as the optic

nerve, or in children where you want to limit exposure to the normal brain as much as possible. There are only a few centers in the USA that use this and the cost is significantly higher than standard therapies.

**Carbon Ion** – This is another form of radiation, using carbon ion particles. The advantage over Proton radiation is that it has a higher biological efficiency – it kills cancer cells better, but the disadvantage is that it is not as precise as proton beam in limiting damage behind the target. It is in use in Germany, Japan and other countries but not yet available in the USA.

**Boron Neutron Capture Therapy** – This is a more targeted form of radiation: a Boron compound which has a higher affinity to tumor than nontumor is injected into the patient, then a Neutron beam is directed at the tumor area. The neutron beam reacts with the boron to kill the cells that attracted the Boron. There has been some limited success with this in the past, but now with the development of better ways to target the Boron to the tumor, it is showing promise. It is available in Europe and Asia but considered experimental in the USA.

For more information on **radiation**, look at our video library at  
<http://virtualtrials.com/video.cfm>  
and look through all of the radiation lectures.

## **Chemotherapy**

Chemotherapy is the use of drugs to kill tumor cells. These drugs work in several ways, each unique to the type of treatment recommended, by either a) destroying the tumor's DNA directly, b) restricting the tumor cell's ability to divide, grow and invade healthy tissue, or c) by blocking the blood supply to the tumor itself and inhibiting the growth of new blood vessels that would otherwise, feed the tumor.

Traditionally given in the form of pills that are taken by mouth, or delivered through an intravenous tube or sometimes called an IV, new forms of delivery to the tumor site specifically are showing great promise, bypassing the blood brain barrier (getting higher concentration of drug to where it is needed) and reducing the harmful side effects to the body. The three most interesting approaches include “**Super Selective Intra Arterial Infusion**”

( see <http://virtualtrials.com/video2012.cfm> for details) as well as convection enhanced delivery or by surgically placing a drug-wafer into the tumor cavity that dissolves over time. This wafer approach is FDA approved – Gliadel Wafer – the other 2 are still experimental.

Chemotherapy can be done prior to, during and/or after radiation therapy. For high grade gliomas, the standard of care now is to have surgery first, then radiation and chemotherapy with Temodar at the same time, followed by 6 months of Temodar. However, most doctors extend the length of time on Temodar to 12, 18, 24 or more months. It is not yet known how long is best.



Common side effects to chemotherapy include nausea, weakness and fatigue, dehydration, and low white blood cell counts, which increases the risk of infection. Because a simple cavity or early gum infection (gingivitis) can quickly escalate into an acute infection for the patient undergoing chemotherapy, patients are advised to obtain a thorough dental examination **prior** to beginning chemo and **follow up** frequently with your dental care team.

**FDA Approved Chemotherapy Drugs – Note: some of these are not approved for brain tumors, but are used “off-label”.**

For a current list of **chemotherapy clinical trials** visit:  
**<http://www.virtualtrials.com/chemotherapy.cfm>**

**Temodar:** Also called temozolomide and temodol – an oral chemotherapy. This is the most popular drug for brain tumors – and is FDA approved for brain tumors.

For details, see **<http://virtualtrials.com/temodar>**

**PCV:** a combination of Procarbazine, CCNU and Vincristine. Part oral, part intravenous/IV. This was the most popular treatment before Temodar came along. It is now used as a second line treatment for when Temodar doesn't work, and sometimes as a first line treatment for a type of tumor called an oligodendroglioma. There is a test available to tell if an oligodendroglioma will be sensitive to PCV.

For details, see **<http://virtualtrials.com/pcv.cfm>** and **<http://virtualtrials.com/oligotest.cfm>**

**CPT-11:** An IV chemotherapy approved for use in colon cancer, but being tried for brain tumors. There is hope that using experimental high tech delivery methods to get a high concentration of CPT-11 to the tumor may allow it to work much better

For details on CPT-11, see **<http://virtualtrials.com/cpt11.cfm>**

**High Dose Tamoxifen** – this is approved for use to prevent recurrence of breast cancer, but is used in much higher doses for the treatment of brain tumors. Only a small percentage of brain tumor patients respond to this, but when they do, it can sometimes work miracles. It is oral with little side effects such as a small increased chance of blood clots, and puts females into menopause immediately. Some doctors add this to other treatments so no opportunity is lost. Others use this as a last resort. There is a report that inducing a hypothyroid state in the patient makes Tamoxifen work better. This was used more in the past before we had so many other choices, but is still worth a look.

For details, see **<http://virtualtrials.com/tamoxifen4.cfm>**

**VP-16** (also called Etoposide) – an oral chemotherapy with minimal side effects. It is now used as a second line treatment for high-grade gliomas.

For details, see <http://virtualtrials.com/vp16.cfm>

**BCNU and CCNU:** These are the oldest, but still useful, treatments for brain tumors. BCNU is given intravenous/IV and CCNU is usually given orally. They are basically different forms of the same drug. Some doctors use these instead of Temodar, or alternating with Temodar. The major side effect is pulmonary fibrosis – so a breathing test is required before starting and frequently after. BCNU is making a comeback in a different form – as directly placed into the tumor bed in the form of wafers such as Gliadel.

Pharmaceutical companies often have sponsored programs to help pay for any medication not covered under your insurance plan; usually those that are considered “off label”. Ask your treating physician if the pharmaceutical company making the medication has such a plan available. Plans are usually income based, but most physicians won’t know the income cut offs, as only the pharmaceutical company will have that information.

For a **list of assistance programs**, see: <http://needymeds.org>

And remember, the **Musella Foundation** has a **Co-Pay assistance program** – details at <http://braintumorcopays.org>

## **Anti-Angiogenesis Drugs**

**Avastin** (as of Aug 2012) the only FDA approved anti-angiogenesis drug for recurrent GBM brain tumors. Avastin sometimes has an immediate (within a few days) effect and remarkable impact on the MRI scans and patient’s well-being - at least for a while. Research is under way to figure out how best to use it so that this effect lasts a long time. Recent evidence points to the use of Avastin for newly diagnosed GBM patients as well – although some doctors think it is best held in reserve to be used at the time of recurrence. Trials are ongoing to see the best way to use it.

For more information visit: <http://www.virtualtrials.com/avastin.cfm>

## **Gene Therapy / Viral Therapies**

Gene therapy is the insertion of a gene into the cells (usually using a virus) to replace a defective gene or to install a new gene that causes the cell to produce a protein that fights the tumor. There have been many gene therapy trials in the past for brain tumors which did not show exciting results, however, there has been renewed interest in this method with the introduction of the Tocagen Toca 511 trial.

**Toca 511** -The basic concept is that a virus (Toca 511) is injected into the tumor. This virus was designed to infect only the brain tumor cells and leave the normal cells alone. When

it infects a cell, it adds a gene to the cell which encodes for an enzyme that can convert an antibiotic drug (Toca FC) into a toxic chemotherapy (5-FU), selectively in the tumor. This drug (Toca FC) is given orally every few weeks, and it kills the tumor cells that have enough copies of this enzyme to convert Toca FC to 5-FU. The tumor cells that are infected but don't have enough of the enzyme act as a reservoir - they start the process over again - spreading the infection for a few more weeks, and these cycles are repeated over and over again until the entire tumor is potentially gone. This is still in clinical trials.

For more information about **Tocagen**, visit: <http://www.virtualtrials.com/tocagen/>

There are a few other interesting **viral based therapies**.  
See <http://virtualtrials.com/genetherapy.cfm> for details.

## **Immunotherapy / Vaccine Therapies**

This is one of the most exciting areas of research for brain tumors. There are about 18 different immunotherapy clinical trials for brain tumors. Immunotherapy is the treatment of disease by inducing, enhancing, or suppression of an immune response. Vaccines, in this sense, are used to TREAT the brain tumor, not PREVENT like most vaccines that you think of.

There are 2 main types of vaccine approaches:

1. The **personalized vaccines** are tumor specific vaccines which require a tumor specimen which is sent to the lab to identify specific tumor antigens (proteins) on the surface of the cells. Specific tumor antigens are combined with the patients own dendritic cells to form the personal vaccine. These antigens stimulate the immune response activating the killer T cells to kill the tumor. Findings from a phase one clinical trial of the personalized cancer vaccine, DC Vax®-Brain show that patients are surviving more than twice as long as the standard approved treatments currently available for GBM. Note: If you are interested in this approach, **you need to make arrangements before you have surgery** to either have the vaccine made, or at least freeze it in such a way that you can have the vaccine made later if needed.
2. The **“stock” vaccines** use a different approach – they find the most common targets on the tumors and create a vaccine against them. One trial, called the ICT-107 trial, selected 6 of the most popular targets to make one vaccine from. The early results were very impressive– more than doubling the survival rate, but also showed that 75% of patients had all 6 targets on their tumors and 100% had at least 3 of the targets – which means they may have found the right targets.

For more details on these and other **vaccines**, visit: <http://virtualtrials.com/vaccines.cfm>

## **Tumor Treating Fields**

The **Novocure Novo TTF-100A System** was approved by the United States FDA in 2011 for use in adult patients (age 22 years and up) with recurrent glioblastoma multiforme (GBM), following initial chemotherapy. It is currently in a large multicenter phase 3 clinical trial for patients with newly diagnosed GBM. The Novocure system is a unique new form of treatment, which uses Tumor Treating Fields (TTF) to kill dividing cells. The battery operated device is a portable device for chronic administration of alternating electric fields (TTF) to the region of the malignant tumor, by means of surface, insulated electrodes placed on the head. The device is intended as a monotherapy after maximal surgery and radiation and as an alternative to additional medical therapy.

For Research results, and to find a doctor who is certified in using the device, go to <http://www.virtualtrials.com/novocure>

## **Long Term Side Effects**

In the past, we never worried about long term side effects, because people didn't live long enough to experience them. Luckily, there has been a steady rise in the number of long term survivors, and we now have to consider the long term effects when choosing a treatment, and consider ways to minimize them.

Radiation can cause vascular injury and increase the risk of stroke. Unfortunately, this is fairly common in long term survivors and may be completely asymptomatic or devastating, depending on the location. This is important because stroke risk can be reduced in some patients with diet, aspirin, etc. Another long term side effect is cognitive loss, which varies with the dose of radiation and the volume and location radiated but is nearly universal with whole brain radiation. We try to minimize these by limiting the volume of brain treated to only the area of the tumor and a small margin when possible.

Chemotherapy is often associated with long term infertility, but you can plan for this by freezing sperm or eggs before starting. This may be the last thing you are worried about now, but what happens if you want kids a few years from now and can't have them? Think about it.

Drugs such as BCNU and CCNU can cause pulmonary fibrosis. You need to monitor lung function with these. There are rare cases of myelodysplasia or "pre-leukemia" conditions related to chemotherapy, particularly with the alkylating agents such as Temodar. So although we don't know what the best length of treatment for Temodar is yet, staying on it forever might not be best either. More research needs to be done on this. Avastin can cause severe high blood pressure, problems with wound healing and rupture of the intestines. Report GI pain or rectal bleeding to your doctors immediately. You need to see your internist regularly to check the rest of your body.

Brain tumor patients have a higher chance of getting blood clots in their legs and lungs. Watch for swelling of the legs and feet and pain in the back of the leg, or pressure in the chest, or difficulty breathing. These may be blood clots and you need to see a doctor immediately. If your doctor is not available, go to an emergency room.

## **Alternative & Complementary Treatments**

This is a very hard and emotional topic – like discussing religion or politics – and there are many points of view. This guide will give you an understanding of the definitions of alternative and complementary treatments, but like anything else, the final decision will be yours.

**Alternative treatments** are treatments that have not yet been proven to work based on scientific testing, and are used **INSTEAD** of mainstream treatments.

**Complementary treatments** have also not yet been proven to work, but are used **IN ADDITION to mainstream treatments**. Once it has been shown to work, it crosses over from “alternative”/“complementary” to “mainstream”.

A GBM treatment becomes part of mainstream medicine when someone invents or discovers a treatment that they think may help with a GBM tumor. They then test it in the lab on cell cultures and/or on animals. If they still believe in it, they start human trials. We discuss clinical trials in another section, but basically, it is tested on people with GBMs and compared to either historical controls or to a control group. The early stages of a trial, where only a few people are tested, cannot really show how well the treatment really works. ALL phase 3 trials had successful phase 1 and phase 2 trials leading up to the phase 3 trial, however, most phase 3 GBM trials have failed to show significant benefit compared to standard treatment even though they looked very good in early trials. The reason for this is because the course of a GBM is variable. A small percentage of patients will do well no matter what treatment you give them, and the natural history is a roller coaster – you have wild ups and downs. If you happen by chance, to select a handful of GBM patients who happen to have the right subtype, genetics, age, resection extent, Karnofsky score, and other prognostic factors, and are on the right track of the roller coaster at the time, they may do well in a small trial even if the treatment is not as good as the standard treatment. The next step is to test it in a large group. This is where you randomize some of the patients to get the treatment and some to get standard treatments (or placebos). Then, when the two groups are compared, you get a much better feel for how the treatment works, since all the other variables are controlled. The trials need to be repeated a few times on large numbers of patients treated before you will know if the effect is treatment-related or chance-related.

Statistics are used to try to make sense of the trial results. A number is calculated called the significance level. The number chosen as the benchmark was .05, which means that there is a 95% chance that the effect seen in the trial was caused by the treatment and not by chance alone. Conversely, this means that if you run 100 trials of a worthless drug, about 5 of those trials may report success even though there is none. Or stated another way - if you run 100 trials of 100

different worthless drugs, about 5 of those trials will come out successfully as being statistically significant. This is why multiple trials are needed, and it is best if it is from different centers. The FDA will approve a drug that is better than standard treatment, or is at least as good as standard treatments, if it has fewer side effects. Once approved by the FDA, everyone can get access to it, not just those on clinical trials.

Alternative treatments are developed when someone has an idea that a certain treatment may help a GBM, or they notice that a GBM survivor has tried a certain treatment. They then try it on a few more GBM patients and see that some of them get better. (As I mentioned before, some GBM patients are on the upswing of the roller coaster and would have been doing better even without the treatment) At that point, they are convinced the treatment works and they try to promote it so more people can benefit from it. In many cases, these are the most well-meaning people with the best of motives. They saw something work in a few patients and want others to do well also. However, the difference is in the science. At this point, it would be good to follow the mainstream path and do rigorous trials of a new treatment, and if it passes the tests, the novel treatments would become mainstream and help everyone. However, that is often not the path taken. Instead, many promoters of alternative and complementary therapies skip the proof and go on to marketing. They use individual case reports or small trials to justify the treatment. Now with the Internet, we read about many of these types of treatments. This introduces a huge new problem: selection bias. This means that you hear from and see the people who do well with a treatment, but you do not see the ones who died (as they tend not to post online after they die). For example, if the standard treatment for a GBM has an average survival period of 18 months, (and some of the experimental treatments more than double that), an alternative treatment needs to reach that point to just say it is as good as standard treatment. Put another way: If you take 1,000 patients and put them on standard treatment, you would expect 500 of them to be alive in 18 months. If you take the same 1,000 patients and give them a treatment that is half as effective as standard treatment, you would expect to see 250 alive at 18 months. If you see 250 people telling you that this miracle alternative treatment worked for them, you may tend to believe them. Because you are not seeing the 750 who died – they can't tell you it didn't work for them. So, at that point what question should you ask? If they tell you they have 250 18-month GBM survivors, ask out of how many that started? If it is 250 out of 250, it is a miracle. If it is 250 out of 1000, it is only half as good as standard treatment.

Frequently, those who recommend “alternative treatments” for serious illness will say, “It doesn't hurt to try since the standard treatment does not result in a cure”. This is an erroneous statement, since, even if the treatment itself is not toxic or dangerous, the use of such treatment often works against the science-based treatment, or sometimes is even used as a sole approach (stopping the scientific treatment which, while not curative, may temporarily bring some relief to patients). Also, the high cost of alternative treatment, usually not covered by health insurance, can cause serious financial pain to families and patients who desperately cling to straws of a “cure” offered by those who sell these nonscientific treatments.

There are several “red lights” to watch out for when dealing with non-scientific-based treatment. The following are some common “landmarks” to watch out for:

- They are proprietary (available from one or a limited source) and are not available on the standard pharmaceutical market (which is subject to government supervision and regulation).
- They are expensive and patients and their families must usually “pay up” in advance before the treatment can be started or continued. Most true clinical trials are licensed and supervised by government entities and are backed with public or private grants, so that patients pay little or nothing for the treatment. Most legitimate studies are run in or by major universities or other institutions of higher learning, whereas the majority of “alternative” schemes are run by for-profit entities.
- The results of the “alternative” programs have not stood the test of review by peer-reviewed journals (in most cases, the data has not even been submitted to such journals for publication). The “alternative” programs rely on “testimonials” by patients or former patients, and these are highly unreliable, especially when the diagnosis (of cancer) has not been based on scientific diagnostic techniques, such as pathological examination of tissue.
- There is often a tendency for the providers of “alternative treatment” to speak ill of traditional scientific medicine, frequently asserting that “organized medicine” is involved in a conspiracy to force patients to get orthodox treatment for the economic gain of the medical profession.

GBM patients contact us frequently at the Musella Foundation. Many of them have tried just about every alternative treatment ever proposed for GBMs. Some of them do well. Most do not. We track them with our brain tumor virtual trial project (see the section on [virtualtrials.com](http://virtualtrials.com)). We analyzed our data and found that not one of the alternative treatments reported had any effect on the outcome of the cases. I still keep an eye on the ones who don't join the project. The ones that use mainstream treatments do better than the ones who use alternative treatments alone. I have seen many people decline and die rapidly when refusing standard treatments. They usually change their mind near the end, and start standard treatments, but of course it is too late. Unfortunately, they then blame the standard treatments for the death.

However, when it comes to complementary treatments, where you do mainstream treatments but add to it, you may see more positive results. There may be some complementary treatments that do help with treatment side effects, and possibly may make treatments more effective. However, keep in mind that if you feel a complementary treatment is powerful enough to change the course of your tumor in a positive way, it is just as likely – or more so – able to change it in a negative way. The body is very complicated. You cannot predict what would happen if you change one thing, because one small change can upset the delicate balance of the body and have unseen consequences. The only way to tell is by trying it in a well-designed trial. Proponents may say there is no money in it so no one would fund the trial. That is not true. The Musella Foundation, as well as most of the over 100 other brain tumor foundations, fund research projects like this. Conspiracy theories may be put to rest by these two simple thoughts: (1) there

is no way the medical industry is organized enough to keep a cure away from the public – that would be the biggest money maker in the world; and (2) that there are many researchers who dedicate their lives to finding the cure.

**Patients need to learn to ask the right questions:**

**WHAT** exactly is this treatment?

**WHO** has received it?

**HOW MANY** brain tumor patients have had documented responses, and how many patients have tried it?

**HOW** are responses assessed?

**WHY** is it not given in the U.S.?

**HOW** was the diagnosis of brain tumor made? (In some countries, MRIs are not routine on brain tumor patients, and even if there is an MRI, there are many diseases that look similar to a brain tumor. A biopsy is the best way to tell if the diagnosis is a brain tumor and which type it is.)

**HAVE** the treatment results been published in a peer-reviewed journal? IF NOT, WHY NOT?

In the case of malignant brain tumors, we, in the scientific arena, do not have an answer to the diagnosis and treatment of these dreaded conditions. Brain malignancies, especially the glioblastoma multiforme (GBM), one of the most common of brain tumors in adults, resists most methods of treatment, including surgery, radiation of all types, and treatment with anti-cancer drugs. One of the reasons for this is that we have not yet developed a completely reliable method of localizing the position of these tumors, and determining “where the cancer stops and the normal brain begins”. Progress, using modern imaging techniques, including high-resolution magnetic resonance imaging (MRI), MR spectroscopy and perfusion studies, functional MRI (fMRI) studies, positron-emission (PET) scanning, and others, have improved our localization of these tumors, but there is still no “cure”. The work continues daily at universities and other major brain tumor facilities to help with obtaining the information, which will, in time, allow us to offer a more positive outcome for these desperate conditions.



## **Chapter 5: Sex & Fertility**

### **Effects Of Treatment And Medication**

For the patient undergoing treatment for a brain tumor, a reduction in sexual drive and/or the inability to enjoy normal sexual activity is common. Deciphering the origins of such can be difficult, however, as many factors can, and do, contribute to the problem. While surgery causes postoperative fatigue and temporary physical weakness, chemotherapy and radiation can greatly impact and reduce your desire for sexual stimulation due to adverse effects on hormone production. So too can the medication prescribed for brain swelling, seizures, nausea, anxiety and depression. Physical changes, such as hair loss and weight gain can further undermine one's sense of attractiveness and desirability, deepening the emotional separation from sexual contact. Individually or in varied combination, these side effects to treatment create, in some cases, a daunting puzzle that requires patience and communication to piece together.

Complicating the patient's ability to understand (or prepare for emotionally) the effects of treatment as it relates to a decrease in libido, is often the health professional's discomfort in discussing sex with the same openness and honesty that might accompany a discussion regarding nausea, diarrhea or even one's expectation for recovery. For this reason, patients often find discussing ongoing issues of intimacy beneficial with other members of their care team, such as a counselor or neuropsychologist who, as a medical doctor, is familiar with the impact of brain trauma and the effects of medication, as well as, the emotional toll often carried internally by the patient. While most treatment-associated dysfunction or lack of desire is temporary, being able to openly discuss difficulties and options for sexual intimacy with your partner and medical team is key to managing the extent of disruption, treatment options, and your ability to resume normal sexual relations after treatment.

Depression is common among brain tumor patients; a condition often controlled with medication (antidepressants) called SSRI's (selective serotonin reuptake inhibitors), such as Paxil or Zoloft. However, these medications can reduce libido by interfering with sexual desire. A simple change in dosage or medication may aid in restoring libido and should be discussed with your prescribing physician.

### **Birth Control**

It's important to discuss potential effects of your treatment with both your tumor physician and your gynecologist if you take oral contraception – birth control pills. Chemotherapy may halt menstrual periods temporarily, but precaution against pregnancy must

be maintained due to the devastating effects of chemo to an unborn fetus. Some chemotherapy medications, as well as anti-seizure drugs, can interact with the effectiveness of birth control pills. A thorough discussion with your medical care team is essential.

## **Sex, Surgery and Radiation/Chemotherapy**

In most cases, there are few reasons why one could not have sexual relations while having radiation therapy or post surgery, however, you should always consult your physician regarding any precautions they would recommend regarding strenuous activity, including sex. Fundamentally, both radiation and surgery can result in fatigue, making any strenuous physical activity difficult. As your strength returns, normal sexual activity can resume.

Likewise, unless your physician specifically warns you against sexual activity while undergoing chemotherapy, normal relations are limited only by the precautions associated with the drugs themselves. Chemo drugs can be transferred through sperm, and in some cases, can be harmful to sperm thus damaging to a fetus. Condoms should always be used during both intercourse and oral sex to eliminate the possibility of exposing another to the harmful effects of chemotherapy drugs, either vaginally or orally. As sperm can live for a period of up to three months, it's important to continue with condom safeguards during this time. Although dry orgasms can occur naturally on occasion as men age, chemotherapy can also cause this syndrome to occur. The lack of ejaculation during orgasm is not cause for alarm and should have no adverse effect on pleasure.

Women must take extra precaution against pregnancy during chemotherapy, as birth defects can result in a developing fetus from chemo drug exposure. Always discuss your method of birth control with your doctor, specifically any possible reduction in the effectiveness of your prescribed oral contraception. Chemotherapy can also dry out mucus membranes within the nose, mouth and vaginal area. Non-petroleum, over-the-counter vaginal lubricants, can assist with the temporary dryness associated with chemo, relieving the discomfort and pain most often experienced during sexual relations. Petroleum-based products can irritate the vaginal area, as well as, weaken condoms, so they should be avoided.

Additional resources are available that can help you overcome issues of intimacy caused by fatigue, pain, or limited mobility and include:

*Sexuality and Fertility After Cancer* by Leslie Schover, Ph.D. New York: John Riley and Sons, 1997. ISBN: 0-471-18194-3

*Enabling Romance: A Guide to Love, Sex, and Relationships for the Disabled (and People Who Care about Them)*. by Ken Kroll and Erica Levy Klein. New York: Harmony books, 1992. ISBN:0-517-57532-9

*Sexual Function in People with Disability and Chronic Illness: A Health Professional's Guide* by Marca L. Sipski and Craig J. Alexander. Gaithersburg: Aspen Publication, 1997. ISBN:0-8342-0886-5

## **Fertility**

Radiation to the head, surgery and most medication used in the treatment of brain tumors (excluding chemotherapy drugs) do not pose a threat to fertility. If radiation therapy is aimed at locations other than the head, you should consult your radiation oncologist about fertility concerns prior to beginning treatments. Often, a lead apron can provide adequate protection to sex organs during radiation treatments.

Chemotherapy can have a real and permanent effect on fertility in men, reducing or eliminating sperm production. While reversible in most cases, it may be a number of years before sperm counts return to normal.

In women, chemotherapies can temporarily halt menstrual periods, but normal menses should resume after treatments are concluded. Alkylating agents, however, can affect female egg production (effects worsen for older women), so concerns regarding fertility should be discussed prior to beginning treatment.

Personal concerns and the importance of fertility is an individual decision, and while not always the priority of the physician who is basing his/her treatment on life-saving measures, should be discussed before beginning any form of chemotherapy. If necessary, you should insist upon it.

Fertility experts can advise you about the possibility of sperm banking, in the case of a male patient, or the advancing options for women regarding egg harvesting and fertilization techniques. Sperm banks typically suggest a minimum sperm count to be frozen and used at a later date, but count alone (if low) should not discourage you. A fertility expert can best advise you regarding your chances of success in the case of a low sperm count and other options available to you.

Impotence, while rarely the result of brain tumor treatments, can occur as a result of depression. For those who experience more than the occasional (normal with aging) sexual dysfunction, consult your physician about medication and other available treatment avenues.

Fertility experts or physicians/therapists dealing with sexual problems near you can be located by visiting:

### **The American Medical Association**

**<https://extapps.ama-assn.org/doctorfinder/recaptcha.jsp>**

### **The American Society for Reproductive Medicine**

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

Additional resources are available from

### **The American Association of Sex Educators, Counselors, and Therapists**

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

# Chapter 6: Insurance Management

## Know Thy Policy!

### Understanding Your Insurance

Insurance laws vary from state to state. Additionally, your policy may be under state or federal guidelines depending on where you work, and if your employer is self-insured. Large employers who are self-insured are not considered an insurance company, but rather write their own policies that are in turn, managed by an oversight organization, which may be an HMO, who operates within your state. They (the self-insured policies) are governed by federal laws and even states laws such as California – with strict HMO laws protecting consumers – are not available to those covered by self-insured, federally regulated plans.

Complicating things even further, plans such as HMO's and PPO's often fall under different jurisdictions as well. Your human resources department at your employer can often tell you if your plan is self-insured, governed by state or federal regulations, and the contact information for the proper agency.

Most insurance plans contain a specific list of “**covered**” medications and those that are excluded from coverage, called a “Formulary”, and by law, must provide you with a copy upon request. Many of the drugs used in the treatment of brain tumors are approved by the FDA for other conditions, but are not approved for treatment of conditions associated with brain tumors. When a physician prescribes a medication for a condition that falls outside the FDA approved guidelines, it's called an “**off label**” use, and in many cases, is not covered.

Many states provide an appeal process for challenging an “**off label**” denial that may assist you in obtaining coverage. You may be required (if for no other reason than your immediate need of the drug) to pay for the prescription out-of-pocket, as the process may take several weeks for a decision. If your employer or the insurance company will allow you to upgrade your prescription coverage to one that will allow for off-label medication coverage, you would be wise to do so now, regardless of whether or not you require such coverage at this time – it's likely you will need it in the future. For more information, see Chapter 4, section FDA Approved Chemotherapy Drugs.

**Note:** Request a copy of your insurance plan's formulary and keep it in your treatment binder. Have your physician check the formulary when prescribing a new medication to ensure coverage, or perhaps select a like-drug (if available) from the formulary to avoid unnecessary out-of-the-pocket expense.

Information regarding the laws that govern switching plans during treatment or “continuity of care” issues when policies change with new employment, can best be answered by calling your state’s insurance commissioner office. Many states, such as California, have specific departments for patient’s advocacy that can help you work through these issues, or direct you to the proper federal agency if your plan is governed by federal regulations. Such patient advocates within your state health insurance department can also help you file the necessary paperwork for appealing denials of coverage from your insurance company for specific treatments or medications, or to file complaints.

**The following are some tips for dealing with insurance companies:**

- All communications (from making claims to general inquiries) should be in writing.
- When communicating by phone or in person, be sure to record and confirm your understanding of the conversation in a letter sent certified with a confirmation of receipt and copy of the letter in your file.
- Scrutinize everything you receive from the insurance company and hospital, e.g., bills, payments and credits for mistakes – they DO happen! Do not be afraid to ask for explanations for items that are unclear or unspecified.
- Read your policy thoroughly so that you are aware of what benefits you are entitled to and what items are excluded, paying special attention to areas involving clinical trials or experimental treatments. Be prepared to ask your physician to write a letter on your behalf explaining why you should be allowed coverage for these items. It is helpful to have an “understanding” with your physician as to when consideration of experimental therapies would take place, rather than waiting for that day to arrive, only to find an unsupportive care partner.
- Do not hesitate to ask to deal with a “superior” of the person handling your account and keep accurate information regarding the names of all persons (and their position) involved with your claims.
- Before making a request make sure that the person you are dealing with has the authority to grant it.
- Do not be intimidated.
- Do not hesitate to challenge anything that doesn’t sound right to you.
- If you are unsure about anything, check with the State Insurance Department (see above) and then, if necessary, with a lawyer. If you do not think you can afford a lawyer, you may be able to get low cost or free legal help. Try calling the local bar association to ask about legal

aid (available through non-profit organizations in most major communities) or a local law school to ask if they have a student law clinic.

- Most states have non-profit advocacy organizations dedicated to access and continuity of care issues, able to discuss your legal rights and avenues for contesting insurance decisions on your behalf. You can search the Internet using the words: insurance denials, HMO, continuity of care, or healthcare access along with “+ patient advocates”. In California, *Citizens for the Right to Know* is an excellent resource.
- Set up and keep a file of all correspondence and phone communications relating to your claims. This includes, but is not limited to, bills, payments, claims, letters you send, letters you receive, checks, contacts, and your policy.
- Be sure that all of your premiums are paid on time. You may have trouble getting insurance again if you let your policy lapse.

# Appendix I: Virtualtrials.com Website Features

Virtualtrials.com is the website of the Musella Foundation For Brain Tumor Research & Information, Inc. It is also known by the title: “Clinical Trials and Noteworthy Treatments for Brain Tumors”. Take time to look through the menus – most people don’t realize how large the website is and the breadth of information it contains!

The website is organized into the home page and 6 main menu choices:

- **Home:**  
Information about our website and organization.
- **Learn About:**
  - ***Guide For The Newly Diagnosed*** – This document!
  - ***Brain Tumor Symptoms***: A list of symptoms, as well as a detailed paper about symptoms, and a survey (and results) of our member’s symptoms.
  - ***Noteworthy Treatments***: An extensive list of articles on our website that is important to brain tumor patients and their families. Everyone should read the article, Treatment Options for Glioblastoma and other Gliomas. It is 50+ pages long, written by a 10+year GBM survivor.
  - ***Brain Tumor News***: Listing of news articles about brain tumors, conferences, and events. Note – the articles from our brain tumor news blast are archived here.
  - ***Fundraising For Research***: A list of fundraisers that we are running as well as fundraisers that our members are running for us.
  - ***Frequently Asked Questions***: A list of almost 1000 of the most frequently asked questions and answers. All answers are provided by brain tumor specialists, mostly by Dr. Paul Zeltzer – a word famous neuro-oncologist! You can ask questions here – and if it is general and may be of interest to others, we will post the responses here.
  - ***Common Brain Tumor Terms***: The most frequently used terms.
  - ***Dictionary***: Look up brain tumor related terms here!
  - ***Survivor Stories***: A sampling of stories about people dealing with many different types of tumors. It helps to see other people are managing, even with the worst types of brain tumors.
  - ***Temodar***: An entire sub-section of the website devoted to everything about Temodar. (The most used chemotherapy for brain tumors). There is a review of the literature supporting its use, as well as the package insert and a dosage calculator that can give you a reality check to make sure your dose is in the right ball park – to catch math errors.

- ***Novocure Novo TTF100-A***: Details on this new, FDA Approved treatment for GBMS!
  - ***Brain Tumor Vaccines***: General concept as well as listing of vaccine trials!
  - ***DIPG / Brainstem Tissue Donations*** : This is a new feature about how to donate tissue from these tumor types for research – anyone interested in DIPG / Brainstem tumors should take a look at it!
  - ***Tocagen Toca 511***: An exciting new gene therapy trial
- **Find A Treatment**: Has many ways of locating treatments. Note that the order of the trials listing is determined by how recently the listings were verified, so the ones near the top are current. If you see an old “Last Updated” date – the trial may be closed. If you find a closed trial – let us know so that we can remove it!
    - ***New Trials Listings***: Displays the most recently added or updated trials.
    - ***Keyword Search***: If you know the name of the treatment you are looking for, this is how to find it!
    - ***Advanced Search***: Allows you to specify the tumor type, geographical area, prior history and other factors to narrow down the choices to only the trials you may be eligible for.
    - ***Treatments List***: Displays a list of the commonly used and experimental treatments being used for brain tumors.
    - ***By Tumor Type***: Browse trials that allow your selected tumor type.
    - ***By Geographic Area***: Browse trials by country, state.
    - ***Surgery***: Browse trials that involve surgery.
    - ***Radiation***: Browse trials that involve radiation.
    - ***Immunotherapy***: Browse trials that involve immunotherapies.
    - ***Gene Therapy***: Browse trials that involve gene therapies.
    - ***Chemotherapy***: Browse trials that involve chemotherapy.
    - ***Less Toxic***: Browse trials that involve drugs with fewer side effects than the standard treatments.
    - ***Trials Matcher*** – We partnered with EmergingMed.com to provide a different database of clinical trials, with an easy way to search. No database is complete, but by using our database, the EmergingMed.com database and the ClinicalTrials.gov website, almost every brain tumor trial is covered!
    - ***Tocagen Toca 511***: Trials of this new gene therapy!
  - **Virtual Trial**: The brain tumor virtual trial is a study the Musella Foundation is conducting where we observe, record and analyze what treatments our members are doing and the outcomes. We do not tell you what to do – we just observe. Everyone should join. Participants can view the ongoing results.



- ***What is it:*** An overview of the project.
  - ***Join:*** Sign up for the project.
  - ***Post an Update:*** The project requires that you return once a month to post an update. It is important to post an update even if there is no change! We send you an email reminder to post the updates.
- **Interact**
    - ***Newsletter:*** The Brain Tumor News Blast, which contains news stories about brain tumors (sent out about two to four times a week).
    - ***Feedback:*** You can use the feedback form to make suggestions or ask questions about the website or our organization. We are very responsive to the requests received.
    - ***Video Library:*** An extensive library of over 40 hours of presentations on every aspect of brain tumors. All available FREE and immediately with no registration required.
    - ***Unsubscribe:*** An easy way to remove yourself from our newsletters. Note: you have to remove yourself from each online support group separately. Every message from the online support groups has removal instructions at the bottom.
    - ***Note:*** We have removed the live chat room feature from our website and now use the online support groups (See below) for brain tumor discussions.
- **Resources:**
    - ***Co-Payment Assistance Program:*** The Musella Foundations' co-payment assistance program.
    - ***Drug Discount Program:*** The Musella Foundation's Drug Discount Program.
    - ***Brain Tumor Centers:*** A list of the major brain tumor centers. Some of which (the ones marked with a red asterisk) offer a free scan review.
    - ***Doctor / Hospital Address Book:*** Look up the contact information for most of the brain tumor specialists.
    - ***Online Support Groups:*** These groups work via email. When you send a message to the group email address, a copy is sent to all of the other members, who can then respond. You get a copy of everyone else's messages to the group.
    - ***Links:*** A vast database of links to most of the important brain tumor resources on the Internet, browseable by many categories or searchable by keyword.
    - ***Books:*** Listing of books on brain tumors.
    - ***Brain Tumor Organizations:*** Visit their websites to get a balanced view. Everyone has their own views on the issues facing us and you need to get as many points of views as possible and educate yourself in order to make the best decisions.
    - ***Young Adult Resources:*** Especially for young adult survivors!

- ***Support Groups:*** Listing of “real world” support groups, and each group has a place to post announcements. Try attending a meeting near you. Most of us would never consider joining a “support group”, but when it comes to something as serious as a brain tumor, support groups can be marvelous. You will meet other people going through the same thing as you, and most groups get exciting guest speakers to talk about brain tumors.
  - ***College Scholarships:*** For people who have brain tumors or relatives with brain tumors.
  - ***Memorials:*** Honoring our lost members.
  - ***Prayer List:*** A place to request prayers for those who believe prayer can help.
- **About Us:**
    - ***Musella Foundation:*** How we got started and what we do!
    - ***Research Grants:*** A database of requests for brain tumor research grants. Any organization (or individuals) can fund listed projects – just let us know you do. OR – you can help us raise money for these projects. Also lists recent projects that we funded.
    - ***Recent Additions to the Website:*** The most recent changes to the website. You can get the changes and brain tumor news stories delivered to your desktop via a RSS feed. Check the page for details!
    - ***Privacy Policy:*** Includes our privacy policy, editorial policy, advertising policy and more.
    - ***Our Sponsors:*** These companies provide the resources to enable us to create and maintain the website.
    - ***Awards:*** Awards received by the Musella Foundation.
    - ***Make a Donation:*** You can make a donation using credit cards, PayPal or check. You can now direct donations to research only, patient assistance only or wherever needed the most!

*There are many more features – these are just the highlights!*

*Take a moment to explore the site:*

**<http://www.virtualtrials.com/>**

## Appendix II: The Future

*I know things look dismal now. We have come a long way over the last few years – doubling average survival with the introduction of using Temodar and radiation concurrently. But that isn't good enough.*

*There has been an unprecedented burst of progress in identifying new approaches to the battle. There are new theories on the role of stem cells, new molecular signaling targets, new forms of radiation, new vaccines, anti-angiogenesis, tumor treating fields, gene therapies, advances in surgery and much more.*

*We are in the home stretch. The cure is almost within sight. It is now a matter of time and money. Although the government is now funding brain tumor research at the highest level ever, it isn't enough. Many promising projects go unfunded. Eventually the cure will be found, but for the first time in history – WE have a chance to speed up the process.*

*The Musella Foundation specializes in funding innovative and creative research, with a special emphasis on research that complements, rather than duplicates, the research funded by the federal government. We have funded the development of three new forms of immunotherapy, two of which went on to receive major funding from other sources.. We have given over \$1.6 million to over 45 brain tumor research projects, and we have over millions worth of worthy proposals sitting on our desk just waiting for funding.*

***We need your help to raise money.***

***For details on how you can help us speed up the search for the cure,***

***visit***

**<http://www.virtualtrials.com/fundraising.cfm>**

## Appendix III: Resources

### Brain Tumor and Care Websites:

NAME	PHONE	WEB ADDRESS
American Brain Tumor Association (ABTA)	800-886-2282	<a href="http://www.abta.org">http://www.abta.org</a>
ABTA Palliative Care		<a href="http://www.abta.org/care_support/68">http://www.abta.org/care_support/68</a>
Brain Hospice		<a href="http://www.brainhospice.com/">http://www.brainhospice.com/</a>
Center to Advance Palliative Medicine		<a href="http://www.capc.org">www.capc.org</a>
Get Palliative Care from ABTA		<a href="http://www.getpalliativecare.org">www.getpalliativecare.org</a>
Hospice Foundation of America	800- 854-3402	<a href="http://www.hospicefoundation.org/">http://www.hospicefoundation.org/</a>
Hospice		<a href="http://www.hospicenet.org/">http://www.hospicenet.org/</a>
National Brain Tumor Society (NBTS)	800-770-8287	<a href="http://www.braintumor.org">http://www.braintumor.org</a>
National Cancer Institute	800-422-6237	<a href="http://www.cancer.gov/">http://www.cancer.gov/</a>
National Hospice & Palliative Care Organization	703-837-1500 800-658-8898 (Helpline) 877-658-8896 (Multilingual HelpLine-translates in over 200 languages)	<a href="http://www.nhpco.org/templates/1/homepage.cfm">http://www.nhpco.org/templates/1/homepage.cfm</a>
Palliative Doctors		<a href="http://www.palliativedoctors.org">www.palliativedoctors.org</a>
Pediatric Brain Tumor Foundation	800-253-6530	<a href="http://www.pbtfus.org">www.pbtfus.org</a>

The Children's Brain Tumor Foundation	866-228-4673	<a href="http://cbtf.org/cms/">http://cbtf.org/cms/</a>
The Initiative for Pediatric Palliative Care		<a href="http://www.ippcweb.org">www.ippcweb.org</a>
The Musella Foundation for Brain Tumor Research & Information	888-295-4740	<a href="http://www.virtualtrials.com">http://www.virtualtrials.com</a> <a href="http://www.virtualtrials.com/braintumororganizations.cfm">http://www.virtualtrials.com/braintumororganizations.cfm</a>
Tug McGraw Foundation	707- 255-1884	<a href="http://www.tugmcgraw.org">www.tugmcgraw.org</a>
Voices Against Brain Cancer	212-340-9446	<a href="http://www.voicesagainstbraincancer.org/">http://www.voicesagainstbraincancer.org/</a>

### Support Groups, Publications & Radio Talk Shows:

NAME	SUPPORT	WEB ADDRESS
American Brain Tumor Association	For patient & caregivers	<a href="http://www.abta.org/index.cfm?contentid=48">http://www.abta.org/index.cfm?contentid=48</a>
Brain Tumor Talk Radio	Information on brain tumor diagnosis, treatment options, & other critical information needed to make an informed decision.	<a href="http://www.blogtalkradio.com/braintumortalk">http://www.blogtalkradio.com/braintumortalk</a> Sponsored by Miles for Hope- Moving Towards A Cure!
Cancer Care	Online & face-to-face support groups.	<a href="http://www.cancercare.org">http://www.cancercare.org</a>
Hope with Support	Helping others by providing encouragement & information.	<a href="http://www.hopewithsupport.org/">http://www.hopewithsupport.org/</a>
National Brain Tumor Society	Search by zip code to find a support group near you.  Patient & caregiver peer support group.	<a href="http://www.braintumor.org/FindSupportGroup/">http://www.braintumor.org/FindSupportGroup/</a>  <a href="http://www.braintumor.org/">http://www.braintumor.org/</a> click on Resources and Support
National Cancer Institute	Articles for almost every aspect of cancer information.	<a href="http://cancer.gov/cancerinfo/support">http://cancer.gov/cancerinfo/support</a>

## Clinical Trials:

NAME	WEB ADDRESS
American Brain Tumor Association	<a href="http://www.abta.org/Research_Progress/Find_Clinical_Trials/46">http://www.abta.org/Research_Progress/Find_Clinical_Trials/46</a>
National Cancer Institute	<a href="http://www.cancer.gov/clinicaltrials">http://www.cancer.gov/clinicaltrials</a>
The Musella Foundation for Brain Tumor Research & Information	<a href="http://www.virtualtrials.com">http://www.virtualtrials.com</a>

## Listservs & Chat Rooms:

NAME	WEB ADDRESS
National Brain Tumor Society	<a href="http://www.braintumor.org/Login/">http://www.braintumor.org/Login/</a>
Virtual Trials Chat Room	<a href="http://www.virtualtrials.com/chat1.cfm">http://www.virtualtrials.com/chat1.cfm</a> For a complete listing or to join any of these groups, go to <a href="http://virtualtrials.com/lists.cfm">http://virtualtrials.com/lists.cfm</a>
Brain Tumor Treatments, formerly known as Brain-Temozolomide Group	<a href="http://virtualtrials.com/lists.cfm">http://virtualtrials.com/lists.cfm</a> <i>Originally was for patients/caregivers/doctors interested in the drug Temozolomide (Temodar) for brain tumors. Now we have expanded it to include all medical treatments for all types of brain tumors: malignant, benign, primary and metastatic. No talk of politics, jokes, and religion allowed. For those subjects, use the other groups listed below.</i>
Brain Tumor Community Group	<i>A NON-Medical discussion - for patients / caregivers / doctors interested in brain tumors! THIS IS AN ADULTS ONLY GROUP. Some humor and discussions will be offensive! Use this group for the types of messages that are off-topic on the other groups! Humor and politics are welcome here!</i>
Spinal GBM Group:	<i>For people interested in a spinal GBMs.</i>
Brain - Gleevec Group:	<i>For people interested in the experimental drug Gleevec for brain tumors.</i>
Brain Tumor Virtual Trial Group:	<i>For people who are participating in our brain tumor virtual trial.</i>

Bt-Faith Group:	<i>For discussions involving faith / religion / God among people interested in brain tumors.</i>
Optic Glioma Group:	<i>Discussions involving optic gliomas..</i>
Brainstem Glioma Group:	<i>For adults and children with brainstem tumors.</i>
Choroid Plexus Papilloma Group:	<i>For adults and children with Choroid Plexus Papillomas.</i>
Acoustic Neuroma Group:	<i>Discussions involving Acoustic Neuromas.</i>
<b>Online support groups run by other organizations:</b>	<a href="http://www.virtualtrials.com/support.cfm">http://www.virtualtrials.com/support.cfm</a> <i>Some of the 111 support groups listed on this site.</i>
Brain Surgery Group:	<i>A support website/ mailing lists for brain tumor patients, has been in operation since February 2000. Their purpose is to educate patients, families and medical professionals and to improve the quality of medical care/ follow-up and increase knowledge and awareness.</i>
Pediatric Brain Tumors:	<i>This list is for the discussion of all pediatric brain tumors, primarily by parents and immediate family. However, all medical professionals both involved in the diagnosis and treatment are welcome. We deal with the tough stuff head on. We laugh, we cry, we argue and vent together as we search for answers. For the protection of members, a short bio (a little bit about you and your interest in the group) will be requested after submitting your membership request and before we provide full access.</i>
Bt-finance Group:	<i>For discussions involving financial matters among people interested in brain tumors, including insurance issues, disability issues, prescription assistance plans.</i>
Brain - Activist Group:	<i>An e-mail discussion of legal, regulatory and public policy issues impacting cancer patient rights and benefits in clinical trials, especially brain cancer patients. Purpose of educating and empowering the patient community and especially the brain cancer patient community.</i>
Adult ependymoma mailing list:	<i>An on-line support group for adult ependymoma patients, caregivers and relatives.</i>
Teens of Parent Survivors:	<i>A support group started to allow teenagers who have parents with a brain tumor to discuss issues, concerns, and just talk about everyday life while having a parent who is ill. Please email <a href="mailto:OoLewieoO@aol.com">OoLewieoO@aol.com</a> if you would like to join.</i>

Australian Brain Tumour Discussion Group	<i>OzBrainTumour is a community of support for Australians dealing with brain tumours. Ask questions; discuss treatment options and coping strategies.</i>
Pacific Northwest Brain Tumor List:	<i>For brain tumor patients / caregivers in the United States Pacific Northwest.</i>
Chordoma Support Group:	<i>An online support group for people affected by clival, spinal or sacral chordoma.</i>
Educating Brain Tumor Kids:	<i>An educational resource center for teachers, schools, parents, and social workers to educate children with brain tumors.</i>
Cerebellar Mutism and Posterior Fossa Syndrome:	<i>A support group of parents and friends of children with brain tumors who suffered from cerebellar mutism and posterior fossa syndrome after brain tumor removal. Approved members can access a 52 web-based resource guide.</i>
BT Canada Group:	<i>Supports the treatment of brain tumors in Canada.</i>
Pituitary Tumor Listserv	<i>Designed for patients and caregivers who have, or have had Pituitary Tumors and Disorders. There is no age limit to join, it's for all Pituitary Patients and Care Givers.</i>
Hopkins Meningioma Mailing List	<i>For anyone interested in meningiomas, either as patients, caregivers, friends or doctors.</i>
Meningioma Support Group	<i>Associated with the "<a href="#">Meningioma Support and Information</a>" website to research more information on meningiomas. You can share your stories, hopes, questions, triumphs, and frustrations about meningioma brain tumors. This site is here to help ease the effects of isolation, and to help people get on with their life after diagnosis.</i>
Meningioma Talk	<i>Post questions and answers; problems and solutions; successes and failures; hopes and support about Meningioma brain tumors.</i>
Medulloblastoma Group	<i>A resource center with easy to read information about medulloblastoma. Share your stories and have access to information about medulloblastoma.</i>
Bereavement:	<i>The Bereavement Support Group is an online community to provide support to family members and friends whom have lost a loved one due to a brain tumor.</i>
Hypothalamic Hamartoma Information and Support Share Group	<i>A worldwide group comprised of families with a child or adult that has been afflicted with a HH. Find information about HH, references to medical articles, and the latest treatment developments. Share your stories and experiences by joining the discussion group.</i>
Supreme Crossings:	<i>This mailing list is open to any individual needing support or wishing to provide support in the areas of Brain Tumor End-of -Life, before, during and after as well as sharing and providing home health care support issues.</i>



BT Healthykids:	<i>This is a list created by brain tumor patients and caregivers of brain tumor patients who, in addition to the many demands that come from dealing with a brain tumor in the family, are also contending with the day-to-day joys and sorrows of raising children. There are many extra concerns and stresses with respect to parenting issues, whether they have to do with children's questions about the brain tumor or a simple bee sting.</i>
BT Caregivers:	<i>This is the only forum where brain tumor caregivers can praise and rail, laugh and fume, feel their whole fear and release their stress without the worry of hurting the loved one for whom they offer care. Just as there are things that patients can only discuss with each other, there are things that caregivers can only truly express to other caregivers.</i>

### **Financial, Prescription & Travel/Flight Assistance Resources**

NAME	WEB ADDRESS
American Brain Tumor Association	<a href="http://www.abta.org/Care_&amp;_Support/Financial_Assistance_Resources/49">http://www.abta.org/Care_&amp;_Support/Financial_Assistance_Resources/49</a>
Angel Flight Travel Assistance	<a href="http://www.angelflight.com">http://www.angelflight.com</a>
Cancer Care	<a href="http://www.cancercare.org">www.cancercare.org</a>
Caring for Cancer	<a href="http://www.caring4cancer.com/go/cancer/financial/help-with-costs/DrugAssistancePrograms.aspx">http://www.caring4cancer.com/go/cancer/financial/help-with-costs/DrugAssistancePrograms.aspx</a>
Drug Assistance Programs from Pharmaceutical Companies	<a href="http://www.cancersupportivecare.com/drug_assistance.html">http://www.cancersupportivecare.com/drug_assistance.html</a>
Medicare Rights Center	<a href="http://www.medicarerights.org">www.medicarerights.org</a>
Medicare Prescription Drug Program	<a href="http://www.medicare.gov">www.medicare.gov</a>
Miles for Hope Travel Assistance	<a href="http://www.milesforhope.org">http://www.milesforhope.org</a>
Mission for Maureen Travel Assistance	<a href="http://www.mission4maureen.com">http://www.mission4maureen.com</a>
National Brain Tumor Society	<a href="http://www.braintumor.org">www.braintumor.org</a>
Musella Foundation Treatment Co-Payment Assistance Program	<a href="https://braintumorcopays.org/index.cfm?">https://braintumorcopays.org/index.cfm?</a> Covered treatments include Avastin, Gliadel, Novocure Novo TTF-100 A and Temodar.
Patient Advocate Foundation	<a href="http://www.copays.org">www.copays.org</a>
Supplemental (SSI) & Social Security Disability Insurance	<a href="http://www.socialsecurity.gov/">http://www.socialsecurity.gov/</a>

## Caregiver Support & Resources

NAME	WEB ADDRESS
Cancer Care	<a href="http://www.cancercare.org/tagged/caregiving">http://www.cancercare.org/tagged/caregiving</a> <i>(Stories of help and hope, and podcasts on an array of subjects ranging from financial assistance to stress management for caregivers.)</i>
Cancer Compass	<a href="http://www.cancercompass.com/message-board/caregivers/1,0,122.htm">http://www.cancercompass.com/message-board/caregivers/1,0,122.htm</a> <i>(Caregiver discussion groups and resources.)</i>
Caregiver Hope	<a href="http://caregiverhope.com/">http://caregiverhope.com/</a> <i>(Stories of hope and encouragement as cancer caregivers experience this journey starting with a loved one's diagnosis and learn to face fears, have faith and hope, and learn to embrace life when it changes.)</i>
Caring. Com	<a href="http://www.caring.com/">http://www.caring.com/</a> <i>(Caregiver wellness, money and legal articles, as well as a directory of peer reviewed and rated home health care agencies, nursing homes and hospice care.)</i>
FCA: Family Caregiver Alliance National Center on Caregiving	<a href="http://www.caregiver.org">www.caregiver.org</a> <i>(Addresses the needs of families and friends providing long-term care at home by offering national, state and local programs to support caregivers. The site contains newsletters, fact sheets, caregiving info and advice and online support groups.)</i>
National Hospice & Palliative Care Organization	<a href="http://www.nhpco.org/i4a/pages/Index.cfm?pageID=3254">http://www.nhpco.org/i4a/pages/Index.cfm?pageID=3254</a> <i>(Resources for the caregiver including preparing for caregiving, the planning ahead checklist, caring for the caregiver, and caring for a child with a serious illness. Also has information on advance directives.)</i>
Lotsa Helping Hands	<a href="http://www.lotsahelpinghands.com/">http://www.lotsahelpinghands.com/</a> <i>(This sites provides an answer to the question, "What can I do to help?" by allowing you to organize family and friends for tasks needed via electronic calendars and announcements. It also provides resources for caregivers.)</i>
Miles for Hope	<a href="http://www.milesforhope.org/component/kunena/28-caregiver-support/-3-on-being-a-caregiver">http://www.milesforhope.org/component/kunena/28-caregiver-support/-3-on-being-a-caregiver</a> <i>(Caregiver support forums.)</i>

National Family Caregivers Association	<a href="http://www.thefamilycaregiver.org/">http://www.thefamilycaregiver.org/</a> <i>(Supports caregivers to those with chronic illness or disability by educating the caregiver to strive for good health and well-being. The site is a wealth of information for Tips &amp; Tools for financial &amp; medical benefits, support groups, respite care, newsletters and publications. They have a link to Saturing, which provides you with a free version of online care management. It allows you to manage and monitor care needs by including other friends and family members of your choice to participate in caregiving needs, thus easing your daily responsibilities.)</i>
Strength for Caring	<a href="http://www.strengthforcaring.com/index.html">http://www.strengthforcaring.com/index.html</a> <i>(Featured articles and resources just for caregivers. Share your stories and connect with other caregivers online via message boards.)</i>
Today's Caregiver	<a href="http://www.caregiver.com/">http://www.caregiver.com/</a> <i>(Webinars, resources, support groups, caregiver's stories, conferences and book club. You can also sign up for the free Fearless Caregiver Weekly Newsletter.)</i>
Tumor Free	<a href="http://www.tumorfree.com/">http://www.tumorfree.com/</a> <i>(Created in memory of Kimberley Ann Jaye and Michael John Luparello who both fought a brave battle against deadly brain tumors, this site is dedicated to provide resources, support, and comfort for brain tumor patients, caregivers, and families.)</i>
Well Spouse Association	<a href="http://www.wellspouse.org/">http://www.wellspouse.org/</a> <i>(Addresses the needs of caregivers with blogs, articles, and events on an array of timely, pertinent subjects.)</i>

## **Acknowledgements**

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Grey Ribbon Crusade™*

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The Musella Foundation is a 501(c)(3) nonprofit public charity dedicated to speeding up the  
search for the cure of brain tumors and helping families deal with brain tumors. For brain tumor  
information, to join a virtual trial, to join online support groups or to make a donation, go to  
<http://www.virtualtrials.com/>*

*Call or email with questions or suggestions for this guide!*

*All proceeds from the sale of this book will be used to fund a brain tumor research project  
through the Grey Ribbon Crusade!*

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Virtualtrials.com*

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The information presented in this document is the opinion of the above people, whom are not MDs. Take the information as ideas to explore further with your doctors – not as medical advice.



Please note: The Musella Foundation has no relation to the following organizations. They are listed here because they are important resources and we encourage you to contact them! The Grey Ribbon Crusade is a coalition of brain tumor charities acting as a United Force Against Brain Tumors (UFAB) and we are one of the founding members.

### **MEMBERS (As of 1/1/2013)**

See <http://greyribboncrusade.org> for current list!

Accelerate Brain Cancer Cure	Dr. Marnie Rose Foundation
Aimee's Army	Florida Brain Tumor Association
AITC - Associazione Italiana Tumori Cerebrali ONLUS	Gayle Sheldon Memorial Foundation for Brain Cancer, Inc.
Allegheny Brain Tumor Center	Glenn Alan Miller Memorial Fund
Another Day Another Memory (A.D.A.M.)	Gray Matters Brain Cancer Foundation
Astro Fund	Gunner's Magic Train Pediatric Cancer Foundation
Benny's World	Have A Chance Inc.
Brain Injury Association of Wyoming	Head for the Cure Foundation
Brain Tumor Action Network	HOPE With Support, Inc.
Brain Tumor Fund for the Carolinas	I Could Be Your Child
Brain Tumor Group Of Tennessee	Imerman Angels
Brain Tumor Resource And Information Network	Just One More Day for Love, Hope & a Cure
Brain Tumour (BT) Buddies	Kevin Mullin Memorial Fund for Brain Tumor Research
Brains Together For a Cure	Kyle Daniel Kerpan Foundation
Brown Bag For A Cure	LAAF - Lori Arquilla Andersen Foundation
C.E.V.A.N. Louie Foundation for Brain Cancer	Lauren's First and Goal Foundation
Central New Jersey Brain Tumor Support Group	Leap-for-a-Cure
Childhood Brain Tumor Foundation	Lifestream for Kids
Children's Brain Tumor Research Foundation	Lou Beeler Foundation
Coalition for Children's Brain Tumor Research	Matthew's Miles
Cristian Rivera Foundation	Michael A. DiCarlo Brain Tumor Foundation
Crozer-Chester Foundation	Michael G. Belz Foundation
Cure DIPG 4 Hope	Michigan State University
Cure Starts Now	Miles For Hope
Cure4Chad.org	Mission4Maureen
	Monmouth and Ocean County Brain Tumor Support Group

Musella Foundation For Brain Tumor  
Research & Information, Inc  
National Brain Tumor Society  
Neil C. Harrington Sr. Memorial Fund  
Nicki Leach Foundation  
Ohio State University Medical Center  
Oklahoma Brain Tumor Foundation  
Oligo Fund of Musella Foundation  
PA/PMA Research Fund at Johns Hopkins  
Pediatric Low Grade Astrocytoma Foundation  
Peter A Bednarski Fund for Brain Tumor  
Research Inc  
Preston Robert Tisch Brain Tumor Center  
Raleigh General Hospital  
Rhode Island Brain & Spine Tumor  
Foundation  
Roswell Park Cancer Institute  
Ryan Lamantia Foundation  
Samuel J Foundation  
San Diego Brain Tumor Foundation  
Smiles For Sophie Forever  
Students Supporting Brain Tumor Research  
Tali's Fund  
Team Underwood Foundation  
The Brad Kaminsky Foundation for Brain  
Tumor Research  
The Brain Tumor Awareness Organization  
The Brain Tumor Trials Collaborative (BTTC)

The Brian Bedell 2-Young Foundation  
The Charles Warren Brain Tumor Awareness  
Foundation, Inc.  
The Chris Elliott Fund  
The Claudia Fund  
The Enoch Nkongho Brain Foundation  
The Kortney Rose Foundation  
The Man in the Mirror  
The Ricky Gutierrez Brain Tumor Foundation  
The Michael Overall Benefit Fund  
The Nick Gonzales Foundation for Brain  
Tumor Research  
The Tug McGraw Foundation  
The William Woodyard GBM Foundation  
Tommy Detesco Fund for Adolescents and  
Young Adults  
UCLA Department of Neurosurgery  
UNC Chapel Hill  
University of Connecticut  
University of Pennsylvania Department of  
Neurosurgery  
Unlocking Brain Tumors, Inc  
Voices Against Brain Cancer  
Walk For Kate  
We Can, Pediatric Brain Tumor Network  
Whole Child LA and Whole Child Foundation  
Wylie's Day Foundation



**Who:**

*The Heroes of Hope™ are those willing to be a part of a United Force Against Brain Tumors.*

**What:**

*The Heroes of Hope™ initiative seeks to create dynamic action in the drive for funding of brain tumor research through a synergistic approach.*

**Where:**

*Join our existing charitable organizations, our online community or let us help you bring the Grey Ribbon Crusade to your town.*

**When:**

*Now is the Time to Unite and Fight for a CURE!*

**Why:**

*Because within the next 12 months, over 200,000 people in the U.S.A. will be diagnosed with a primary or metastatic brain tumor.*

**How:**

*If you have your own, or are affiliated with a not-for-profit that currently raises awareness and funds brain tumor research, simply join us!*

***The Grey Ribbon Crusade!***

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

# NOTES



# NOTES