

Diagnosis Brain Tumor: You Are NOT Alone

WHAT TO DO WHEN YOUR DOCTOR SAYS YOU HAVE A BRAIN TUMOR

If you are reading this, it probably means that either you or someone you love has been diagnosed with a brain tumor. In many cases, you didn't have too much warning --maybe a few headaches, a feeling of disorientation, or some numbness in your arm or leg. Or perhaps you suddenly found yourself in the hospital after suffering a grand mal seizure. Whatever your prior history, you are now in the company of a group of very special people. We like to call ourselves survivors, not patients, because one of the first decisions we made was to do everything within our power to survive the statistics.

Any type of cancer is a serious and traumatic ordeal. But brain cancer can stir up more fears and panic than other types of malignancies simply because of its location. In most other cancers, if surgery or radiation is necessary, surrounding tissue may be affected but it will usually heal without the possibility of permanent alteration of your basic self and without the potential of seizures or serious deficits. If your physician feels it is safer to take an extra inch of colon or a broader excision of breast tissue, it can usually be done without compromising your life or the essence of your being. When the operation is over, you will still be you. However, a brain tumor is different. Everything you are and everything you can do is controlled by the gray matter inside your head. And the dangers increase tremendously if tissue other than the tumor is either excised or irradiated. Because of the wondrous makeup of the human body, the same skull that so perfectly protects you from outside injury suddenly becomes an obstacle. The tumor cannot grow outwards. The only thing it can do, if left untreated, is to grow within the brain, affecting your very essence...your sight, your sense of taste, smell, touch, hearing, emotions, memory, strength, even cognitive ability.

This is why it is so important to become informed and educated about your tumor and your treatment options. You will need to make some of the most important decisions of your life in the next few days, weeks and months. The purpose of this pamphlet is to give you an initial road map to follow so you won't feel so lost. Consider it your road map to recovery.

STEP ONE:
GET ORGANIZED

ESTABLISH YOUR RECOVERY TEAM AND
TAKE CONTROL

There may be times during your treatment when you are not able to act on your own behalf. Examples would be immediately following surgery or when you are recovering from a chemotherapy or radiation treatment. Therefore, it is necessary for you to establish your own recovery team. This team could consist of a spouse, a parent, a grown child, or a close friend. In fact, your team could include all of these people. The size of your recovery team is not as important as its dedication to your total wellness. Of course, one of the most important members of your team should be your doctor. If he or she is not committed to your recovery and well being, the remainder of your team's efforts may be sabotaged. Both you and your team must recognize that you are a survivor. And there is a vast difference between being a victim, a patient, and a survivor. A victim has things done TO them - without consent or control. Patients will usually give consent but sometimes do not opt to take control of their own treatment. As a survivor, you will not have things done TO you, but will have things done FOR you. And these things will be done only after you have taken control and given your consent---your informed consent.

It takes a lot of work to be a survivor. You need to find out as much as you can about your condition. You need to determine the best type(s) of treatment for you. You need to maintain a positive attitude and a deep belief in your ability to help heal your body. And you need to be able to take the necessary steps to heal yourself. Right now, your most important decision to make is to take control of your life, to choose life and recovery. Let everyone who comes in contact with you know: I AM A SURVIVOR.

SET UP YOUR WELLNESS BOOK

Your Wellness Book will become a constant companion during your recovery. You should take it with you everywhere you go. You will record the dates and times of your appointments, your medications, your treatment schedules and every other thing that concerns you and getting rid of your tumor. It is important that the book is set up early and that it is kept up to date. There will be times when you think of questions or concerns between appointments. Write these things down so you will be able to recall them accurately the next time you see your doctor.

GET SPECIFIC DETAILS REGARDING YOUR DOCTOR'S DIAGNOSIS

First, have your doctor fill out the top portion of the attached Fact Sheet. This includes such items as your symptoms, the location of the tumor, the type of tumor, the grade of tumor, and whether or not a biopsy has or will be done. This is part of the proactive process of taking control. You need to know exactly what you are confronting in order to fight it effectively.

Next, discuss with your doctor the basis for his or her diagnosis. Ask questions. Ask how many other brain tumors this doctor has treated. Ask about their success rate with your particular type of tumor. If you do not know the doctor personally, ask about their qualifications. Are they a board-certified oncologist? How sure are they that the tests used to diagnose your tumor are accurate? Does the doctor feel that a second opinion would be beneficial? If a biopsy was performed, from what site was the sample collected? Does the doctor feel that the biopsy report is indicative of the make up of the entire tumor? Don't be afraid to ask questions. They serve a number of purposes. Not only do the answers give you valuable information from which to make your future decisions; they also provide a method of assessing your doctor. Remember that your doctor is a member of your recovery team. You need to be able to communicate with each other. You have to be able to trust the information that you exchange with each other. As a general rule, if a doctor vehemently opposes discussing, for example, the pros and cons of getting a second opinion, it may be time to find yourself another doctor. Keep in mind that you may be fighting for your life. The medical professional(s) that you choose to have on your team should be open and honest. They should be able to explain options and conditions to you in terms that you are able to understand. And if they assert that there is

absolutely no hope for someone with your type of tumor, you need to find a doctor, a recovery team member, with broader experience -- one who chooses to treat survivors rather than victims.

CONTACT A BRAIN TUMOR SUPPORT GROUP AND RESOURCE CENTER

One of the best resources you will encounter may be your local Brain Tumor Support Group. The Central New Jersey Brain Tumor Group and Resource Center is led by Patty Anthony, a Neurological Nurse Specialist and Beth Scheiderman, a Social Worker. The group consists of qualified health professionals and people who have faced the same things that you are facing now. You can be put in contact with other brain tumor survivors. Your recovery team members can talk to members of other recovery teams and learn what they are doing. You will be informed of the various speakers that will be present at monthly meetings. You can be provided with reading lists and organizations that will help provide you with the information you need to continue on your road to recovery. It has been shown in numerous studies that individuals confronting critical illness do better when they are involved with a support group. To find if there is a support group near you, check with your library, The American Cancer Society, or any member of the North American Brain Tumor Coalition. You can also find online information about the location of groups at the following site: www.virtualtrials.com. You want to find a Brain Tumor Support Group, if possible, rather than simply a cancer support group because the problems and challenges faced by brain tumor survivors are considerably different from those faced by most other cancer patients primarily because of the location of the disease.

STEP TWO: DO YOUR HOMEWORK

EDUCATE YOURSELF

You will need to research and assimilate a tremendous amount of information in a relatively short period of time in order to make informed decisions about your treatment and recovery. This learning experience will go on throughout the course of your treatment and hopefully for the rest of your life. It would be impossible to read all of the literature on brain tumors and recovery before making your first decisions. But it is necessary to educate yourself as to basic terminology so you can communicate effectively with your doctor. One of the first things you should read is called "A Primer of Brain Tumors." A copy of this pamphlet should be included with this packet. If it is not, call the American Brain Tumor Association at 800-886-2282 and request that a copy is sent to you.

The second publication that you should read as soon as possible is entitled, "50 Essential Things to Do When The Doctor Says It's Cancer." This book is written by Greg Anderson and published by the Penguin Group. While it is written for people with all types of cancer, many of the suggested actions can apply specifically to brain tumor survivors. The book can be purchased at most major bookstores for about \$8.95.

A third book that is highly recommended is "That's Unacceptable - Surviving a Brain Tumor - My Personal Story". The author, Rebecca Libutti, is a long-term glioblastoma multiforme survivor. She offers practical advice on dealing with the day-to-day challenges of recovery.

Of course, there are many other good books and pamphlets that you will want to read and study. The Brain Tumor Society has compiled a list of reading materials that should be helpful to you.

RESEARCH YOUR TREATMENT OPTIONS

In conventional Western medicine there are basically three ways to treat a brain tumor:

1. Surgery
2. Radiation
3. Chemotherapy

You will find, however, that there are several different types of surgery, there are many different ways to irradiate the brain, and there are numbers of different chemicals that can be used in chemotherapy. Now is the time to ask your doctor to discuss your treatment options with you. Discuss your doctor's recommended treatment and again ask questions. Ask why your doctor prefers this type of treatment. Ask how many times he or she has used it successfully on brain tumors similar to yours. Ask if it is the most current method of treatment, and if it isn't ask why the doctor prefers to recommend it. You or one of your team members should also call the organizations listed at the end of this pamphlet to find out if there are other options that your doctor has not considered. And now is the time to ask about side effects. Remember that your tumor is located in your brain. You will want to consider both short and long-term side effects in making your decision.

You should also ask your doctor about clinical trials that might relate to you. Either you or your doctor can request what is called a PDQ (Physician Data Query). The PDQ was originated by the National Cancer Institute and contains most current treatments that are available for your type of tumor as well as information on clinical trials.

Another topic that should be discussed with your doctor at this time is where you will receive the best treatment. Your doctor may feel that your type of tumor can be adequately treated at local facilities or it might be suggested that the optimum course of treatment can best be obtained at a major brain tumor or neuroscience center. As you are provided with more information, you will need to make more decisions. You may want to contact various cancer treatment centers yourself and get an independent opinion from them. Or, if you are satisfied that your doctor is a proactive member of your recovery team, his or her opinion by itself may be enough to satisfy you.

You should be aware that you have a right to look at and receive copies of all of your medical records. This is a difficult concept for many patients. We are used to simply taking a doctor's word about our physical condition and asking very few questions. But you are involved in perhaps the most serious struggle you will ever encounter, and that is why it is necessary for you to change from a patient to a survivor.

INVESTIGATE COMPLEMENTARY OR ALTERNATIVE THERAPIES

What is called conventional Western medicine encompasses some of the most refined and advanced surgical and patient care procedures in the world. But there is more to recovery than surgery, radiation, or chemotherapy. Each one of these particular disciplines is designed to focus specifically on the tumor. However, you are more than a tumor. You are a complete human being who has a tumor in one small part of your body. And since it has not yet been determined exactly what causes a brain tumor, it may be safe to assume that something in your entire body made it possible for these abnormal cells to take hold and grow. We are all exposed to outside factors that cause abnormal reactions inside our bodies. Usually, however, our own defense systems are strong enough to counteract and defeat these invaders. For some reason, this time your body could not repel the attack, and a tumor resulted.

Part of your recovery, therefore, should be to strengthen your body and your immune system to provide the best opportunity for total healing. Many conventional Western doctors have not been adequately trained in fields such as diet, exercise, meditation, and natural curatives. Those items are not their specialties. But those items can have a definite effect on your recovery. For instance, the very goal of most chemotherapy is to kill the tumor. The chemicals that comprise most protocols are toxic. They have to be in order to accomplish their goal. They cannot, however, be contained to the area of the tumor. They infiltrate your entire body and can have drastic effects on your temporary well being. The same holds true for radiation. That is why you will need to have blood tests during your treatments. One of the things that the doctors will be looking for is the state of your white blood cells, your platelet count, and your general condition.

There are a number of herbs and natural substances that can help bolster your immune system and stabilize your blood counts. It may, therefore, be wise to add another member or so to your recovery team. This could be a practitioner of alternative or complementary therapies. Both Native American and Eastern medicine have been in existence for thousands of years. The treatments used by these societies have endured and are still used in many instances today. This is another area in which either you or a member of your support team will have to do some homework. You need to investigate. You need to ask questions. You need to find out if an herbalist, nutritionist or homeopathic practitioner can help you restore and maintain a healthful body so your conventional treatments stand the best chance of succeeding. **It should be noted that each person who becomes a part of your recovery team needs to be aware of what the other members have suggested and what course of treatments you, as the person in charge, have decided upon. Be very aware that both traditional and natural treatments can have serious side effects and can interact negatively with other substances.**

Other areas you should research include such topics as meditation, visualization, diet and exercise. You need to know that your mind and your body work together to comprise the unique entity that is you. And because something has been out of balance to allow this tumor to grow, you must now call upon all of your resources, mind, body, and spirit to banish it.

REVIEW YOUR INSURANCE COVERAGE

The costs of treating a brain tumor can be extremely high. You are looking at the possibility of surgery, extended radiation therapy, chemotherapy protocols, periodic diagnostic procedures (such as Magnetic Resonance Imaging (MRI) and Positron Emission Tomography (PET) scans), possible physical or occupational therapy, new medications and a number of other expenses. Therefore, one of the first things either you or a team member should do is to contact your insurance company. You need to ascertain exactly which procedures are covered under your policy. Some insurance companies have representatives that deal with potential major claims such as yours. If possible, have a specific representative (or advocate) assigned to your case. That will facilitate communications and pre-approvals, if necessary.

You might also look into the possibility of Medicare. You can usually make inquiries and application through your local Social Security office.

Write all of your insurance information down on the second page of your Brain Tumor Fact Sheet and make sure the information is filed in your wellness book.

STEP THREE: MAKE AN ATTITUDE ADJUSTMENT

ADOPT A POSITIVE OUTLOOK

The effect that the mind and the spirit can have on the body is an established fact. Let's face it, we all know that stress, for example, can make you physically ill. And we know that laughter makes you feel good. In fact, it has been shown that laughter causes real biochemical changes in your body. When you were first diagnosed with a brain tumor, you probably felt that there would never be anything to laugh at again. But that was before you decided to be a survivor. Your tumor is a challenge. It is, to be honest, a life threatening challenge. But you are much more than just a tumor. You are a living, breathing, thinking human being. And you have the support and dedication of your entire recovery team. You are in control and you have the power to make the decisions that will give you the best chances to expedite and effectuate your recovery. Knowing this should help you maintain a positive outlook.

That doesn't mean that there won't be times when you just feel overwhelmed. That is a natural response to all that you have been confronted with. But you should also remember that the resulting depression is counterproductive to your recovery. So much has been discovered about the direct correlation between your mind, your emotions and your body's ability to heal. You owe it to yourself to deal with your emotions in the most constructive manner possible. You should look at the possibility of including a mental health professional on your recovery team. This gives you the opportunity to deal with your feelings honestly and to use them to your benefit. But, as stated earlier, seriously question anyone you are considering. You need to select a counselor who has worked with people with cancer before. You need to feel comfortable and safe in talking to them. And you need to know that they respect and concur with your decision to be a survivor.

DEALING WITH THE STATISTICS

You may hear a lot about survival statistics during your recovery. This may start with your very first doctor's visit and proceed from there. Many publications, in an attempt to provide complete information, will include statistics about mortality and survival. And of course, you will probably run into many "friends" who just can't wait to tell you about their "poor Uncle Theodore who died of a brain tumor twelve years ago." Dwelling on these numbers can be very depressing. If you need to study the statistics, there are several things you should take into consideration.

First of all, you should question the demographics on which the statistics are based. Then you need to know how current the data is. Next, you should be aware of who has compiled the numbers and whether or not they have a vested interest in what the statistics project. And of course you will need to know the type and extent of treatment for each person who is represented by the numbers. In other words, statistics are only as good as the data on which they are based. Yes, it is true that having a brain tumor is a serious situation. Yes, it is true that people die from brain tumors. But it is also true that the number of survivors has increased dramatically as medical techniques have improved. And as we more fully understand and implement the connection between treating a specific part of the body and healing the entire being, we find that the number of survivors increases.

So if someone confronts you with mortality statistics, realize that these numbers represent, at best, what has occurred in the past. These numbers do not represent the present or the future, and these numbers do not have to represent you. You have chosen to be represented by survival statistics.

TAKE TIME TO SMELL THE ROSES

As you proceed along your road map to recovery, realize that you are a very special individual. You are facing and dealing with some of the most serious situations anyone could possibly imagine. You will probably be encountering a number of medical procedures that are not always pleasant. There will be days that you feel just lousy. There may be times when you question why this had to happen to you. You may wonder how much more you have to put up with before you feel good again. You may get tired of taking medication and supplements.

All of this will be difficult to deal with. That is why one of the most

important things you can do to aid in your recovery is to be good to yourself. Do the things that you enjoy doing as often as you can. Find the activities that relax you and please you. Enjoy the beauty of a sunset or the miracle of a child. Even though this is a critical time in your life, don't be afraid to laugh. Reach out to other people and give them your strength and let yourself draw strength from them. And above all, realize that you are not alone. You do not have to make this journey by yourself. You are traveling a road that others have traveled before you and you can make it through. You are a survivor.

STEP FOUR: COVER ALL THE BASES

AT THE DOCTOR'S OFFICE

Your doctor represents one of the most important members of your recovery team. It is vital that you understand and remember what is discussed at your appointments. Therefore, it is a good idea to bring someone with you to all appointments. In addition to providing an extra pair of ears to hear what is being said, you might ask that person to be responsible for taking notes so you are free to concentrate on listening and asking questions.

Another suggestion is to tape your doctor's appointments. More and more physicians are recognizing this as a viable way for survivors to retain a record of what is discussed regarding their treatments.

Between visits, be sure to write down any questions or concerns you have. It is difficult, if not impossible, to remember everything that has crossed your mind unless you have something in writing to jog your memory. And please, don't ever be afraid to ask a question because you feel it might be silly. You are fighting a battle for your life and well being and you need to know the answers to whatever questions you have. You might even ask your doctor to draw simple illustrations to explain certain things about your tumor and treatment. Never indicate that you understand what your doctor has said if any part remains unclear. Remember that this is a new world for you and it's unrealistic for anyone to expect you to grasp all of the medical jargon. You have a right to know what is happening to your body. You have an obligation to understand prospective treatments so you

and your team can make informed, intelligent decisions. This is not a dress rehearsal - this is the real thing and sometimes you get only one opportunity to get it right.

KEEPING ACCESS TO VITAL RECORDS

Not so long ago, a patient would have never thought to ask to look at their medical chart or to review actual MRI's with their doctor. The sense was almost as if those things belonged to the doctor and all you needed to know was what you were told. That was the philosophy of the "patient."

On the other hand, you are a "survivor" and you need to realize that these are your records. You have a right to see them, read them and even have a copy, if you wish.

You should definitely have your own copy of your MRI's and scans. If you ask for an extra copy either when you make your appointment or right before the MRI, the technicians are usually very amenable to providing one at a small cost or even no cost at all.

Having these records in your possession is extremely important if you want a second opinion or you are applying for a clinical trial or you need emergency treatment. You should also obtain a copy of the doctor's written interpretation of each MRI.

GETTING A SECOND OPINION

You may have all the faith in the world in your primary doctor. Being able to communicate with him/her and having a bond of trust is very important. But remember that the invader you are fighting is inside your skull. It is not easily seen and the tests and procedures used to identify it can be open to interpretation. Therefore, it is usually wise to obtain a second opinion. Most reputable doctors have no problem with patients seeking a second opinion. They realize it is not an act that casts doubt on their expertise but, rather, a way to explore all of the options that are open to you. The second opinion should be obtained from a major neuroscience or brain tumor center. Some will ask you to send your MRI's, biopsy slides and other test results. Some will want to see you in person. You need to select the course of action that seems right for you - AFTER you have been made aware of all your options.

GIVING AND RECEIVING

Strange things happen when people learn that you have been diagnosed with a brain tumor. Some people will seem as though they have disappeared from the face of the earth. They won't call, they won't visit, they won't even write a letter asking how you are. The reality is that some of these people are just insensitive and you are better off without them. Some are in a state of denial and are unable to believe that something this serious can happen to someone they know and care about. Others are simply afraid. Afraid for you and for themselves. They don't know what to say to you. They may feel that by saying the wrong thing, they will cause you even more pain and suffering. Some of your friends, relatives and neighbors may visit frequently at first and then slowly drift away. And some people will stand by you throughout your battle.

There are a few things that you can do to help people feel more at ease around you. Start by asking them if they have any questions about brain tumors and your specific diagnosis. Make certain that they are aware that you are a survivor. Let them know that their friendship is valuable to you and you appreciate their concern. You empower yourself by giving the gift of love to other people. Spend at least a small part of the conversation talking about what is happening in their lives. Let them know that having a brain tumor does not preclude you from caring about the outside world. And even though it is important to maintain as much independence as possible, find ways that people can help you. Accepting love and concern from people who care about you is tangible proof of your positive feelings for them.

When people say "I'm so sorry. Call me if I can do anything," have a list of things they can do. Have them do research on the Internet for you. Ask them to go to the park with you and enjoy the beauty of the day together. If you become fatigued during treatment, let them do the grocery shopping or pick up the dry cleaning. The important thing is to allow people to contribute to your survival in ways that are beneficial to both of you. Cultivate the positive energy of those who want to help you in your battle and just let the others bask in their ignorance.

HANDLING DEFICITS

Throughout various aspects of your treatment you may experience certain

deficits. Some will be temporary and some you will have to live with. Most of these conditions will depend on what portion of your brain the tumor or treatment may have affected. Some of the more common deficits are fatigue, short-term memory loss, and difficulty communicating. Remember to be gentle with yourself. You may feel that you should be able to do everything you used to within a relatively short time after surgery or other treatment. Don't be frustrated if everything isn't exactly the way it was before. The truth is you probably will not be the same person you were before diagnosis. Most of our life experiences change us to some degree and the diagnosis of a brain tumor is a huge life-altering experience.

If you feel overly fatigued, work with your doctor and physical therapists to find ways to minimize and deal with it. If you experience short-term memory loss, find ways to help you remember the important things. Working with a neuro-psychologist can be beneficial in learning coping strategies. There are mental exercises that may help.

If you have difficulty with communication, you need to understand that you may need a team effort to help overcome this deficit. Ask your doctor if speech pathology is an appropriate option for you. Encourage people to be patient with you while you find and express the right words. To minimize frustration, have a prearranged signal set up with your team members that will indicate to them when you want their help in expressing yourself.

Working your way through the jungle of post-treatment deficits can be frightening but you can learn to make the best of the situation. It's part of the skills you need to acquire as a survivor.

A NOTE FOR CAREGIVERS

Being a caregiver makes you a very special person who has the opportunity to share in an extremely important part of a loved one's life. Every survivor is a unique individual and will react differently to their illness and treatment. While it is impossible to prepare you for everything you might face, there are certain things that you should keep in mind. Sometimes you might feel totally alone and wonder how you can possibly handle everything. The following items might help you in being a positive productive partner of your loved one's recovery team.

1. Feel honored that you have been asked to participate in this important journey. It is an indication of both love and trust that you have been selected to be an integral member of the team. You should do everything possible to ensure that you honor that love and do nothing to violate that trust.
2. Consider it an opportunity, not a chore. Facing and overcoming the challenges you and your loved one will encounter is a unique experience. You will need to demonstrate a high degree of creativity and concern to surmount some of the obstacles you will face.
3. Never make a survivor feel like they are a burden. If you feel burdened, you are not ready for this job. The statistics for brain tumors are far from optimistic. It is a difficult struggle to choose surviving over succumbing. Remember, it is not your life that is in the balance, it is their life. Making someone feel like a burden is a selfish, negative act that detracts from the possibilities of healing. Of course, there will be times that you are exhausted and frustrated. Please remember that this is because of the work, not the person. Include as many people as you can to help with the work so you are freer to fill your heart with joyful giving instead of resentment.
4. Do what you can to find substitutes for a survivor's loss of independence. For instance, get books on tape if the person's vision is impaired. If seizure activity makes driving impossible, find another way to supply a feeling of empowerment. Let them place the order at the restaurant or make the selection of gifts for relatives' birthdays. Realize that brain tumors can sometimes take little bits of independence and capability from a person slowly but steadily. Discuss ways to provide as much of a sense of wholeness as you can.

5. Give your love and care with a joyous heart. You are building memories with this person. Sometimes the memories you create will have to last a lifetime. Never be afraid to touch your survivor if this is something that is comfortable for both of you. Tell them how precious they are to you. Reinforce their sense of worth. Don't be afraid to take photographs even when there are scars or hair loss or Cushing's syndrome. Connect on a heart-to-heart level and you will be able to experience the true meaning of unconditional love.
6. Do acknowledge the losses he or she feels. Don't downplay them - they are real to the survivor. Don't dismiss them by saying things like "we all have our bad days". The truth is we all don't have brain tumors. Instead, as mentioned before, try to find alternative ways of dealing with the deficit.
7. If possible, find opportunities for your own "downtime." Have a friend, relative or neighbor visit while you take a 20 minute bubble bath or a walk. Learn to accept help that is offered. Keep a list of errands handy so that when people say "if there is anything I can do..." you are able to tell them specifically what they can do to help out.
8. Realize that this is not a dress rehearsal. What you say, how you respond, what you do is the ultimate reality. You will be inundated with ideas and suggestions from friends and relatives and even the doctors. All you can do is make the most informed choices you and your survivor can. And then move ahead. Live your lives to the fullest and don't put off doing special things just because of the brain tumor.
9. Understand that sometimes the tumor changes the person you love. The location of the tumor can alter almost any facet of their physical being or personality. Surgery, radiation and chemotherapy can also cause changes. Some medications can induce drastic personality swings. These changes should, of course, be reported to your doctor because many of them are treatable. But you may have to live with them for a while. So do what you can to love the new facets of your loved one.
10. Share in the vision of hope. The person you love has made the decision to be a survivor. If you are doing a lot of the research, you will become aware of the depressing statistics regarding brain tumors. First, read the section of this booklet on statistics. Then open your mind and your heart and invest in the hope your loved one feels. Practice things together like relaxation and visualization. Draw a picture of a brain with a tumor. Each evening gently erase a portion of the tumor together. Keeping your

hope viable will facilitate the loved one's being able to maintain a positive, healing attitude.

RESOURCE LIST

Central New Jersey Brain Tumor Support Group and Resource Center

Phone Number: 908-685-0917

Contact: For general information about the group, call Stan or Virginia 908-685-0917

Facilitators: Patty Anthony, RN - Neurological Nurse Specialist:

Beth Scheiderman, CSW, LPC; Our Social Worker.

Meetings are held the first Thursday of each month at 7:00 PM

Location: St. Luke's Catholic Church

300 Clinton Avenue

North Plainfield, NJ

Notes: The group is comprised of qualified health professionals, brain tumor survivors, and recovery team members. Frequent guest speakers ranging from long term brain tumor survivors to practitioners of complimentary therapies to neuro-oncologists are featured. The group has a lending library and listings for obtaining other resource information. There is no cost for membership.

American Brain Tumor Association

2720 River Road

Des Plaines, IL 60018

Phone: 708-827-9910 or 1-800-886-2282

The Association is a member of the North American Brain Tumor Coalition. Their quarterly newsletter is entitled "Message Line." Publications provided by ABTA include:

A Primer of Brain Tumors

Coping With A Brain Tumor

Living With A Brain Tumor, A Bibliography

Radiation Therapy of Brain Tumors, Part I: A Basic Guide

About Glioblastoma Multiforme and Malignant Astrocytoma

About Medulloblastoma

About Meningioma

About Oligodendroglioma

Chemotherapy of Brain Tumors

Radiation Therapy of Brain Tumors, Part II: Background and Research Guide

Shunts

The Brain Tumor Society

124 Watertown Street, Suite 3H

Watertown, MA

Phone: 800-770-8287

The Society is also a member of the North American Brain Tumor Coalition. They publish a quarterly newsletter entitled, "Heads Up." The Society also provides pamphlets and information on request, including a book list and "Color Me Hope."

The Children's Brain Tumor Foundation
35 Alpine Lane
Chappaqua, NY 10514
Phone: 914-238-1656

National Brain Tumor Foundation
414 Thirteenth St, Suite 700
Oakland, CA 94612
Phone: 1-800-934-CURE or 415-284-0208

Also a member of the North American Brain Tumor Coalition, this foundation's quarterly newsletter is called, "Search." They also publish the following:

Brain Tumors, A Guide
Brain Tumor Support Groups in North America
Gathering A Life: A Journal of Recovery

Brain Tumor Information Services
University of Chicago Hospitals
Box 405, Room J341
5841 S. Maryland Avenue
Chicago, IL 60637
Phone: 312-684-1400

CHEMOcare
231 North Ave W
Westfield, NJ 07090
Phone: 908 233-1103

This organization provides information and assistance in dealing with issues relating to cancer. They may provide one on one emotional support by matching the newly diagnosed patient with a cancer survivor. The object is to provide living proof that cancer survival can be a reality. They also provide match ups for other family members.

National Familial Brain Tumor Registry
The Johns Hopkins Oncology Center
600 North Wolfe Street, Room 132
Baltimore, MD 21287-8936
Phone: 410-955-0227

American Cancer Society
Phone: 1-800-ACS-2345

You should look in your phone book for the telephone number of your local chapter. ACS can provide general information and pamphlets. They can also arrange for transportation to and from medical appointments, if necessary.

Cancer Information Service

Phone: 1-800-4-CANCER

The Cancer Information Service provides information on cancer to patients, their families, health professionals and the general public. This organization can provide you with information on clinical trials and the most up-to-date treatments for your type of tumor.

You can obtain a PDQ from the Cancer Information Service.

National Coalition for Cancer Survivorship

1010 Wayne Avenue, Suite 300

Silver Spring, MD 20910

Phone: 301-585-2616

This organization specializes in job and insurance discrimination problems for those with a brain tumor diagnosis.

National Institutes of Health

Office of Cancer Communications

Bethesda, MD 20892

Phone: 1-800-352-9494

This organization can provide you with a listing of comprehensive, clinical, and consortium cancer centers that are supported by the National Cancer Institute.

National Organization on Disability

910 Sixteenth Street, N.W.

Washington, DC 20006

Phone: 202-293-5960

Physicians Data Query

9000 Rockville Pike

Bethesda, MD 20205

Phone: 301-496-7403

You can obtain one free computer printout covering clinical research trials for your specific tumor type. Before calling, you need to know your tumor type, grade, and location.

Social Security Disability

1-800-722-1213

Call this number for general information on possible social security benefits and medicare.

Online Resources

This is compiled by Kathy Knight <kathy1024@WEBTV.NET.

She updates it periodically and puts it out on the BRAINTMR list.

B.T. SURFING SITES -These are sites to start with, by no means a complete list.

The Healing Exchange Brain Trust T.H.E. BRAIN TRUST (includes the BRAINTMR list) <http://www.braintrust.org>

AL MUSELLA'S SITE VIRTUAL TRIALS <http://virtualtrials.com>

JIM KENZIGS SITE A list of brain tumor links (over 650 of them)
<http://www.virtualtrials.com/btlinks>

MEMORIAL-SLOAN-KETTERING Hospital has an overview of Brain Tumors:
<http://www.mskcc.org/document/WICBRAIN.htm>

DAN COLILLA'S BRAIN TUMOR INFORMATION WEB SITE
Dan Colilla-- [father dx gbm] <http://www.erols.com/colilla/>

M.D.ANDERSON CANCER CENTER M.D.Anderson Information Line 1-800-392-1611 (Option 3 For information about M.D. Anderson) <http://www.mdacc.tmc.edu>

Anderson Network 1-800-345-6324 (To talk with another patient with the same diagnosis)

CANCER INFORMATION SERVICE 1-800-4-CANCER For up-to-date cancer information--literature and/or counseling

The ABTA, the NBTF, and probably TBTS will send a primer and booklets.

Be sure to check the ABTA-American Brain Tumor Association, <http://www.abta.org>
ABTA PRIMER URL -- 7th. ed. <http://www.abta.org/primer/index.html>
Phone: 800-886-2282

NBTF-National Brain Tumor Foundation,
Email: <mailto:nbtf@braintumor.org> WEB: <http://www.braintumor.org>
National Brain Tumor Foundation
414 Thirteenth Street, Suite 700 Oakland, CA 94612-9260
Patient Services: 1-800-934-CURE

TBTS-The Brain Tumor Society <http://www.tbts.org>

You can reach them from links above. There are literature, counseling, pen pals, newsletters, phone pals, etc., available. Phone: 800-770-8287

SOUTH FLORIDA BRAIN TUMOR ASSOCIATION Has many links to other sites --
<http://www.angelfire.com/fl3/SFBTA>

Subject: CONTACTING DOCTORS.

KEITH BLACK, M.D. -- LOS ANGELES,, CALIFORNIA, USA

<http://www.csmc.edu/nsi/contact.html>

Cedars-Sinai Neurosurgical Institute Phone: 1-800-CEDARS-1 (1-800-233-2771)

Deirdre K. Heimer, B.A., B.S., PA-C

<http://www.csmc.edu/nsi/default.html>

The Maxine Dunitz Neurosurgical Institute at Cedars-Sinai

8631 W. Third Street, Suite 800E; Los Angeles, CA 90048

Neurosurgical Physician Assistant Phone: 310.423.7900 310.423.0777 fax

PETER BLACK, M.D. -- BOSTON, MASS.

[http://www.boston-](http://www.boston-neurosurg.org/faculty/black.html)

[neurosurg.org/faculty/black.html](http://www.boston-neurosurg.org/faculty/black.html)

Neurosurgeon-in-Chief at both Brigham and Women's Hospital, and Children's Hospital, Boston, as well as Chief of Neurosurgical Oncology at the Dana Farber Cancer Institute, and Professor of Neurosurgery at Harvard Medical School.

Boston Neurosurgical Foundation <http://www.boston-neurosurg.org/index.html>

HENRY FRIEDMAN .M.D. -- oncologist --

[mailto: fried003@mc.duke.edu](mailto:fried003@mc.duke.edu)

<http://www.canctr.mc.duke.edu/pno>

DUKE Room 047 Baker House, South Hospital, Trent Drive, Durham NC 27710

Phone: 919-684-5301

Duke University Medical Center <http://www.mc.duke.edu> 1-800-MED-DUKE (1-800-633-3853) *(There is also a Dr. Alan Friedman, a neurosurgeon, be sure to use the correct first name.)

FRED EPSTEIN, M.D.

[mailto: FEpstein@bethisraelny.org](mailto:FEpstein@bethisraelny.org)

http://www.bethisraelny.org/professionals/staff/f_epstein.html

Phone: 212-870-9600 Fax: 212 870 9810

ROBERT FINK, M.D. - <mailto:rafink@ibm.net> or

<http://www.dovecom.com/rafink/>

("Bob" on the BRAINTMR list)

Neurological Surgery 2500 Milvia Street Suite 222; Berkeley, CA 94704-2636 USA

Phone: (510) 849-2555 FAX: (510) 849-2557

JEFFERY WILLIAMS, M D. email: jw@jhu.edu <<mailto:jw@jhu.edu>

web: <<http://www.med.jhu.edu/radiosurgery>

Director, Stereotactic Radiosurgery Department of Neurosurgery;

The Johns Hopkins Hospital, Harvey 811 600 North Wolfe Street Baltimore, MD 21287-

8811 Phone: 410-614-2886 Fax: 410-614-2982

SAN DIEGO GAMMA KNIFE CENTER; KENNETH OTT, M.D.

<http://www.sd-neurosurgeon.com>

9850 Genesee, Ste. 770 La Jolla, CA 92037 (619) 297-4481

From Jan McCormack (with the NBTF)

Dr.MIKE McDERMOTT UCSF (San Francisco) - (specializes in meningioma & Gamma Knife)

DR. MITCH BERGER MD Anderson (Houston)

DR. RAY SAWAYA Sloan Kettering (New York)

Dr. PHIL GUTIN (formerly at UCSF)

Dr.ROLANDO DEL MAESTRO (London, Ontario Canada)

WALTER A.HALL, M.D., M.B.A -- MINN.. <mailto:hallx003@maroon.tc.umn.edu> or <http://www.neuro.umn.edu/default.htm>

University of Minnesota Department of Neurosurgery

Box 96 UMHC 420 Delaware St SE, Minneapolis, Minnesota 55455

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Professor of Neurosurgery, Radiation Oncology, and Radiology at the University of Minnesota.

MOFFITT--TAMPA,FL <mailto:obadiamc@moffitt.usf.edu>

http://www.moffitt.usf.edu/clinical_programs/nonc/index.htm

STEVEN BREM, M.D. (on the BRAINTMR list)

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JON OLSON, MD <mailto:olsonjmd@bigfoot.com>

NeuroMedical Center, 7777 Hennessy Blvd Suite 10000; Baton Rouge, LA 70808

Phone 225-769-2200 FAX: 225-768-2161

MEDICAL COLLEGE OF VIRGINIA

Virginia Commonwealth University, Richmond, Virginia

Neurosurgeons: WILLIAM BROADDUS, MD and HAROLD YOUNG, MD

RANDALL E. MERCHANT, Ph.D. (on the BRAINTMR list)

Professor of Neurosurgery and Anatomy

Contact Person for CLINICAL TRIALS Phone 804-828-2746

Seizure Information

Generalized seizures -a seizure that affects both hemispheres of the brain.

Types of generalized seizures:

Absence (petit mal) seizures, usually seen in children.

Symptoms include altered awareness or responsiveness. Staring episodes occur lasting for about 2-15 seconds. May see motor phenomena (eye blinks, lip smacking, changes in muscle tone)

Atypical Absence Seizures.

Staring episodes with only partial reduction attention. May see eye blinking or lip smacking.

Myoclonic seizures.

Characterized by short, abrupt muscular contractions of arms, legs and/ or torso. Possible brief loss of consciousness.

Tonic seizures.

Abrupt stiffening of the body, arms or legs. Loss of consciousness can occur, lasting 30 seconds to several minutes.

Clonic Seizures.

Quick, bilateral severe jerking movements. Usually lasts less than one minute.

Atonic Seizures.

Abrupt loss of muscle tone. Referred to as drop attacks.

Tonic Clonic Seizures (Grand mal).

May begin with a high cry caused by air being forced through abrupt closure of epiglottis. Loss of consciousness. Characterized by stiffening of arms and legs. Jaw may snap shut. Breathing may decrease or cease. Usually short lived. Followed by quick, bilateral severe jerking movements of the arms and legs. Usually lasts less than one minute. May include drooling or foaming and excessive saliva production. Loss of bladder and bowel function. Biting of tongue, lip and cheek. Postical Phase (period of time after seizure) Consciousness gradually returns. May be lethargic and confused for minutes to hours or often falls asleep.

Partial seizures:

Simple partial (focal ,Local)seizure.

Consciousness not impaired. May have aura (feeling, sensation, smell or taste prior to onset of seizure). Characterized by abnormal movement of arms and legs, feelings of numbness and tingling in fingers, hallucinations, changes in heart or breathing rate.

Some may experience psychic seizures feeling of deja vu state, dreamy state.

Complex Partial seizures with impaired consciousness.

Begins as simple partial - progresses to impaired consciousness or can start with impaired

consciousness. Automatic movements occur - i.e.(repetition of words, walking, picking, grunting, chewing, etc.)

Status Epilepticus seizure that lasts more than 30 minutes.

May be convulsive or Non convulsive. Convulsive state must be treated promptly.

First Aid for:

Tonic / Clonic seizure-

Move hard or sharp objects from area, or move patient.

Loosen tight clothing, such as collars or ties.

Place something flat and soft, like a shirt, underneath the head.

Turn the individual on side to keep the airway open. (some may salivate or vomit)

Do not place anything hard in mouth.

Do not attempt to hold the tongue. (A tongue cannot be swallowed).

Do not restrain the individual's movements.

Remain with the individual until consciousness returns.

Do not attempt artificial respiration unless breathing has stopped after muscle jerks cease.

For Complete partial seizure:

Remain calm

Guide individual away from danger.

Do not restrain the individual's movements.

Remain with the individual until complete awareness returns.

Emergency situations:

Immediate emergency help should be summoned if:

1. the seizure lasts longer than five minutes or a second seizure begins soon after the first seizure has ended.
2. the seizure occurred in water.