Introduction

My Perspective

DISCLAIMER: The information within this site is the author's perspective. You should always consult with a health professional before adopting any form of treatment regimen.

"You have three to six months to live."

Those were the words that tripped from the mouth of my radiologist some twenty+ years ago.

That might hold to make sense from the physician's perspective if you get caught up in the hurdle called statistics. Statisticians use this tool to eliminate variance and predict the norm.... that which is normal.

I have yet to determine what is normal about brain tumors. They are all different in shape, size, density, grade, mass, location, etc.

With statistics, I can tell you how often Mickey Mantle will drive in a runner on second base with two outs.

We use his past performance, and other variables...the bat and ball are pretty much the same, but the pitcher will differ. With brain tumors, the tumor will be unique to any tumor ever seen before...the physician much as the pitcher does, will play a significant role. But unlike the bat, the surgeon's tools are improving all the time (but no corked scalpels!☺). So what might have been a strikeout two years ago, might be a ground rule double today.

At the date of this revision, I have lived 46 times longer than my doc expected (276 mos vs 6 mos)... to put that in perspective, it would be the equivalent of living to be 3,220 years old! Talk about wrinkles!! God will have the final say in how long each one of us lives… and He does not wear a white coat or a green mask.

Don't sit around and wait to die. (But if you do, then demand buckets of good chocolate-cherry mocha ice cream). ☺

Make a decision... either get on with living or get on with dying.

Don't let statistics run your life. You must have some hope that things will work out:

YOU will be the exception!

You need to have confidence that your physician is not God, and cannot put you in a grave while you are still breathing...

You must embrace the hope that you are in control of your life and can demand treatment for your body regardless of how a physician or insurance company rules. Hope never gets old and hope never dies. (**Do** find a kick-ass physician and put your trust in them, but **don't** turn your *entire* life over to them.)

Each moment of our life is precious. Learn to love the time. http://www.cdbaby.com/cd/dmbailey98

Face each new hurdle face-on with grit & determination to survive and keep on keeping on!!

There are no guarantees in life. You have to step up to the plate to win. Sure you might ground into a double play, but if you don't step up to the plate, you'll never hit a home run. In my book, if you choose not to play, you have already lost. Life has no room for benchwarmers! (didn't we learn that in tee-ball?)

I suppose if I had just accepted my six-month prognosis as the gospel and just rolled over, I might not be here today. But how we live our life is just as important as being alive.

So get on with living. (hmmm…sounds like a 1990's movie…)<wink>

Second Opinions

Treatment Centers Of Excellence

> The single most challenging problem is the nihilism, which most physicians have-they believe a patient with a gbm is dead. Only with the use of the newer more scientific approaches will there be progress. We have too many survivors to ever adopt this give up before you start the fight philosophy.
>
> We've got a lot of new weapons and we really believe that the slate is blank - that you can make a path that doesn't necessarily have to follow the old, traditional land mine of 'dead in a year.' And we meld that to hope.
>
> The biggest problem is that people make the assumption that if you have a lethal disease, you're going to die no matter what you do. So they act accordingly and fulfill their own prophecy.
>
> If instead you try newer, more creative ventures and if you've got good ideas, you'll keep chipping away at the problem. You can't just sit around and hold somebody's hand and sing Kumbaya.
>
> **---- Duke Univ. Neuro-Oncologist: Dr. Henry Freidman, MD**

(This quote is 15 years old… imagine where we must be now as you are reading it!! At that time Henry was seeing about 100 new pediatric and 600 new adult patients each year--400 of which were adults with gbm.)

There are many **high volume** treatment centers of excellence. While it can be a difficult decision knowing which center is the best for you, it is **more** important to get to a center than knowing which one is the best. In some cases, location may be more of a factor in making a decision. Some patients may choose to stay in their region so they can benefit from continued support & interaction of friends and family. Others may choose to fly to a center across the nation, as I did.

Even at the poorest center of excellence, you are likely to get better more specialized care than at most of your general care facilities (like your garden-variety local hospital) that attempt to offer you brain tumor treatment(s).

Brain tumor treatment could be compared to major amusement parks like Disney World. Those roller coasters are too expensive to build one in every little town. The tools and equipment to effectively treat brain tumors are also expensive. A state-of-the-art operating-suite microscope for brain tumors starts at $200K! As such, it is more economical to bring patients to a center, than to try and have such specialized equipment at every general care hospital. Most of those garden-variety facilities simply could not justify it based on the small number of brain tumor patients they treat annually. You want a center that sees a high volume of brain tumors!!

Moreover, these centers of excellence work as a team in treating the patient. You will be seen by neuro-specialists in surgery, oncology, radiology, pathology, psychology, etc.

> "I think there's no doubt the team approach works better, the patients do better--they live longer. Their best chances of a cure come from that team approach, and at some point every [patient] should have a team of compassionate doctors taking care of them for this kind of a brain tumor problem. It's a big, huge multidisciplinary problem, and no one specialty has dominion over it."

- **---- Dr. Allan J. Hamilton, MD, FACS**
Chief Director of Neurosurgery, Univ. of Arizona

If I were personally in need of treatment, these are the centers I would consider first. They are listed alphabetically: (You should of course, discuss all treatment decisions with your physician).

- **"A Premier Institute for Neurological Surgery"**

  CEDARS-SINAI -- Maxine Dunitz Neurosurgical Institute (Los Angeles, California) Located in Los Angeles, Cedars features one of the premier neuro-surgeons in the world: Dr. Keith Black. Keith has been featured in a slew of magazines, including Time, and has been featured on PBS numerous times. Both an outstanding clinician and a force to be reckoned with in the research laboratory, Dr. Black may best be known for his work in disrupting the blood brain barrier and the development of a brain tumor vaccine. Furthermore, he is a compassionate, gentle physician.

- "At Duke There Is Hope"

  DUKE UNIVERSITY (Duke, North Carolina) Their motto: "At Duke, There is Hope." This may be best attributed to having Dr. Henry Friedman, a neuro-oncologist on staff there. Henry an outstanding clinician, known for his exceptional bedside manner. Don't be surprised if you see Henry doing rounds in jeans, he feels that white coats only distance physicians from their patients. It is not uncommon for Henry to phone patients as late as 10pm. He is a credit to the fight against brain tumors.

- "Making Cancer History"

  Univ. of Texas - MD ANDERSON (Houston, TX) This center is nestled in amongst some other outstanding hospitals in the Houston, Texas area. It is perhaps, the premier treatment facility in the Mid-West. I absolutely love the people at Anderson, they are my extended, extended family. Chief Neurosurgeon Dr. Ray Sawaya is a gem.

- "The Best Cancer Care. Anywhere."

  MEMORIAL SLOAN KETTERING (New York, NY) Located in New York, Sloan Kettering is an excellent center. It features Dr. Phil Gutin, MD as their chief of neurosurgery. Formerly of UCSF, Dr. Gutin is an outstanding clinician.

- "A Comprehensive Cancer Center Designated by the N.C.I."

  Univ. of Calif. at SAN FRANCISCO (UCSF) (San Francisco, CA) A top notch brain tumor facility, UCSF has been a leader in brain tumor care for decades. Their chief of neurosurgery, Dr. Mitchel Berger is excellent. Furthermore, their Neuro-Oncs: Dr. Michael Prados & Dr. Susan Chang are top-notch clinicians.

An excellent resource for locating a TCE is the address book found at: http://www.virtualtrials.com/btcenters.cfm

We all would prefer to be treated by the best physicians at the very best treatment center. And surely this exists...but your objective should be to get to a center of excellence, not necessarily the best one. Even the "worst" of these centers will be able to offer you expertise and treatment options that are not available at a typical "garden variety" community

hospital. There are many good centers, don't limit yourself to the five listed above. Insurance &/or regional preferences may factor into your decision. Whether you go to a UCLA or an NYU is somewhat negligible...just get to a center!! As you become more educated about various centers, treatments, clinical trials, you may want to align your treatment somewhere else.

Other centers to consider are the ten Member Institutions of The North American Brain Tumor Consortium. NABTC conducts clinical trials of therapy for adults who have newly diagnosed or recurrent malignant glioma.

The NABTC consists of:

- **Dana Farber Cancer Institute (Boston)**
- **University of Pittsburgh Cancer Center**
- **Memorial Sloan Kettering Cancer Center (New York)**
- **University of Texas MD Anderson Cancer Center (Houston)**
- **University of California, Los Angeles**
- **University of Texas San Antonio (Pharmacology Core Laboratory)**
- **University of California, San Francisco**
- **University of Texas Southwestern (Dallas)**
- **University of Michigan (Ann Arbor)**
- **University of Wisconsin (Madison))**

http://www.nabtc.org/physician.shtml

For pediatric tumors, I'd still consider these centers (remember I was a ped when I was diagnosed), you might also check into:

St. Jude (Memphis, TN)

St. Jude has one of the largest brain tumor programs in the country and is devoted to providing the most up-to-date therapy for patients and families. Children are not just small people. Their anatomy and physiology, and the disorders that affect them, require a specialized team to provide the optimal care, which is what you get from St. Jude's brain tumor team. St. Jude families never pay for treatment not covered by insurance, and no child is ever denied treatment because of the family's inability to pay.

Clinical Trials

On The Cutting Edge Of A Cure

A Clinical trial is one of the final stages of a long and careful research process. Studies are done with brain tumor patients to find out whether promising approaches to brain tumor prevention, diagnosis, and treatment are safe & effective.

The medical community considers it ethical to try unproven treatments (i.e., clinical trials) only after proven treatments have failed or when used in addition to proven treatments, but not instead of proven treatments.

Yet typically, temodar & radiation are considered the standard treatments for gbm. There are even limitations with how long a patient can be on temodar. Hence, the emphasis & need of exploring the options available in clinical trials.

Keep in mind that the primary purpose of a trial is not to save lives--that is the role of the best standard treatment. Clinical trials are used to determine whether a treatment is effective so that it can be used to save lives in the future. Some clinical trials have just as much chance of causing harm as of helping.

> "But for my money [in treatment], I don't want doctors who read journals; I want doctors who write them."

---- Ed Nugent, gbm survivor, 2000

It is my belief, that some clinical trials actually increase the chance of survival over the best standard treatment. Of course, this is something that you should discuss with your physician(s) before adopting any form of treatment regimen.

Brain tumor patients can benefit from clinical trials. In treatment trials, for example, participants receive high-quality brain tumor care -- and will be among the first to benefit if a new approach is proven to work. Through a process, called informed consent, you will learn about the study's treatments and tests, and their possible benefits and risks, before deciding whether or not to participate.

NOTE: Because of the need to be able to derive unbiased scientific results from trials, patients that have had previous treatment may be ineligible for certain trials. For example, if you have had radiation and are looking at getting into the chemotherapy ‘abc’ trial, you might be disqualified for the trial because the results might be clouded as to whether the chemo worked or it was the radiation. This does not mean that you should presuppose that you will not qualify for a trial. Leave that to the docs. Apply for several trials if you can find ones that you want to participate in.

- **virtualtrials.com**

  Your first stop in any on-line brain tumor information search. The Musella Foundation's website, virtualtrials.com, is considered by many, to be the single most authoritative brain tumor clinical trial site. This site, literally, revolutionized website brain tumor information. It has clinical trials information readily available, as well as an address book that includes many of the top physicians & treatment centers of excellence.

- **braintumor.org**

  The National Brain Tumor Foundation offers links to clinical trial databases. They also offer step-by-step information on how to use those databases. http://www.braintumor.org/patients-family-friends/treatment/clinical-trials/finding-clinical-trials.html

> **Be kind to yourself in the education process. Realize that you are being required to learn, in perhaps weeks or months, information it has taken the medical field in its entirety over a century to learn. Give yourself a pat on the back for being able to pronounce some of the foreign terms you have learned and give your brain credit for making new creases in the gray matter to accommodate your new found knowledge. Specialize in your tumor; get to know what is necessary to survive it.**

---- Rebecca L. Libutti, brain tumor survivor & author;
That's Unacceptable © 1997

Support Groups

Strength in Numbers…

…the right attitude! Fight like hell and don't ever stop!

david m. bailey, 14 yr gbm brain tumor survivor

Fear is a useless emotion, unless it motivates you to do something positive.

Rebecca L. Libutti, brain tumor survivor (dx 1993) & author; That's Unacceptable © 1997

There is a wealth of help and information available in these groups... the stuff the doctors overlook or don't know to tell you--other patients & caregivers will.

If there is a brain tumor support group in your area, you should join. If not you should join a cancer support group, if available. If neither is available, start your own brain tumor group...if you are looking for one, you can be sure there are others that will be anxious to join your group. Organizations such as ABTA, FBTA & NBTS can provide information on starting a group and will even mail a notice to people currently in their database that live in your area.

Connecting with others will enrich your life and theirs too.

Studies have shown that cancer patients who participate in support groups actually live longer than those who avoid these groups. Reaching out to others who are experiencing a similar diagnosis is not only very supportive, but can be crucial to your treatment and recovery.

You may want to also consider joining the largest support network for brain tumor patients: BRAINTMR. http://www.braintrust.org/braintmrlist.htm

Locate a support group:

- Virtualtrials: Support Groups
- NBTS: Support Groups Listing Click "Resources & Support”
- BRAINTMR: an on-line support group.

BRAINTMR

An On-Line Healing Support Network

The BRAINTMR mailing list is a listserv for the brain tumor community. "The list", as it is referred to, is a group of brain tumor patients/survivors; caregivers; and medical professionals who exchange messages via the internet.

- Everyone is welcome to join.
- There are NO fees and you can leave the group at anytime.

It works via email. When someone from the group sends a message to the server, it is redistributed to each member in the group. If you reply to the message, it gets sent back to everyone else in the group.

This is an excellent resource especially for newly diagnosed patients who are looking for information.

To learn more and/or sign up for the list, follow the link below:

http://www.braintrust.org/braintmrlist.htm

Conferences

Survivors Meeting at the Intersection of Life

I have been attending brain tumor conferences for over 20 years. I have met other long-term gbm survivors at these events…so don't single me out as the only long-term gbm survivor you have heard of. WE ARE OUT THERE – a fact I wish more neurosurgeons knew about… pass the word along to yours!!

Attending brain tumor conference(s) can have tremendous benefits on a brain tumor patient & their family. It provides one with the opportunity to chat with the top clinicians, nurses & physicians in brain tumor treatment from across the country. Plus there is a wealth of information available in workshops, lectures, vendors, etc.

Ideally, every newly diagnosed patient would be exposed to the information provided by the speakers at these conferences--a toolbox of information!!

The best reason to attend a conference is to meet the other survivors, caregivers, & clinicians in attendance. It is a very powerful forum to be surrounded by others that really understand what it is to have had a brain tumor. You are given the reassurance that you are not alone in the journey from the largest support group you shall ever experience. You will build an invaluable network of friends and health professionals.

Many of these conferences also offer 15-minute consults with the physicians that are speaking at the conference. These are the top neurosurgeons, neuro-oncologists, etc. The consults are free. Come prepared with scans and reports in hand to share with these docs.

There is a growing number of regional conferences by various medical centers, and organizations. Often limited scholarships are offered to help those in financial need attend. If you can't find info on this, be sure to ask.

- **American Brain Tumor Association;**
  Des Plaines, IL

Two or three times each year, ABTA hosts *Sharing Hope* Meetings for Patients/Families/Survivors in various cities across the country. They also host a biennial Patient, Family, and Survivor conference in the Chicago area. This conference is held in years ending with odd numbers (e.g, 2011, 2013).

- **National Brain Tumor Society;**
  West Coast & East Coast Offices in US

NBTS Patient and Family Conferences are held in cities across the United States. Traditionally, the NBTS has co-hosted a conference in conjunction with MD Anderson in Houston, Texas. This biennial event is usually held during the Spring in years ending with odd numbers. They may also offer regional events, workshops, teleconferences, and webinars.

- Florida Brain Tumor Association;
  Coral Springs, FL

FBTA holds a conference in South Florida during January. They typically have a conference every year alternating between the west shore (e.g., Tampa) in even numbered years and the east shore (e.g.,West Palm Beach) in odd numbered years.

Links

Support…Education…Hope…

- **virtualtrials.com**

  Dr. Al Musella's virtualtrials website is considered by many to be the **premier site** for newly diagnosed patients, as well as survivors. You are already here, be sure to check out the other pages. He would also appreciate a donation that helps to keep my story on-line as his is the only organization to promote my story of survival and this gbm resource guide. ☺ Thanks, Al!!

- **Brain tumor link index**

  This site is a good clearinghouse of links for brain tumor information.

- National Brain Tumor Society

National Brain Tumor Society offers top-notch resources and caring support for everyone affected by brain tumors. NBTS provides education and information to help patients, families, and caregivers make informed decisions and develop strong support systems during every stage of the journey.

- **The Healing Exchange Brain Trust**

  T.H.E. BRAIN TRUST helps to provide, promote, & improve communication opportunities & tools for people whom are personally affected by or who professionally treat or study localized neurological disorders and subsequent or related health concerns. They are the heart of the matter.

- **American Brain Tumor Association**

ABTA provides brain tumor information, treatment explanations, support resources, & research updates. ABTA is highly recognized as a resource for comprehensive information and compassionate support for the brain tumor patients, families and caregivers who are living with this disease.

- **david m. bailey**

david (1966 - 2010) is well-known as a 14 yr survivor of a gbm that was to have killed him in 6 months. His amazing story of hope and survival has inspired thousands of fans all over the world. david was a great friend and my mentor. Sadly we lost him after fourteen years; these were some of the most enriching years of my life. A wonderful songwriter, be sure to check out his music and definitely buy his inspirational cd’s focused on life, peace, hope, and love. Good stuff!

BECOME AN ADVOCATE

The Most Qualified Case Manager

Be prepared for the nihilism that still exists with many physicians who see a gbm diagnosis as a death sentence. They will quote you the bleak statistics.

You have the ability and right to get a different doc and always seek second/third opinions.

The Internet is full of information on clinical trials…just because your physician gives up on you, does not mean you must do so…just use caution on-line. ☺

If you are not at a high volume treatment center of excellence that uses a team approach, you may have to coordinate communications between your physicians: neurosurgeon, neurologist, oncologist…etc. For example, I had to be the intermediary between my docs at UCSF and my local NS and oncologist. *For some reason they teach these guys (in medical school) to never to call other physicians themselves!?! NOT!* ☺

This may seem like an unfair burden while walking the path of treatment. Champion your cause, and accept this new roll as medical coordinator. Haste makes waste. Get on a first name basis with office managers, nurses, radiation & lab techs, etc. These are people you are going to have to interact with for awhile, remember to be as pleasant as you can, as you may need them to go to the well for you sometime when you are in a pinch.

Educate yourself about brain tumors, treatments, seizure meds, etc. Communication is sometimes a burden, and it helps when you are on the same page as your physician(s).

***Demand the best care from your physicians and be an informed patient. Your docs will slow down and take more interest in your case when they see you are informed and interested and asking good questions. Never be afraid to advocate for yourself!! (except in a Mexican jail!! ☺)

BIO

Matthew Fullerton

In September 1987, a senior in high school, Matthew, 17, began experiencing headaches with nausea upon waking. His family physician was able to see pressure when looking in his eye, ordered scans leading to a prompt diagnosis. Diagnosed with a glioblastoma multiforme (gbm), in the right frontal lobe, a radiologist gave Matthew three to six months to live. The tumor was encapsulated, well circumscribed, about the size of a man's closed fist.

After all gross tumor was surgically debulked, Matthew received the maximum dosage of standard "beam" radiation. Matthew entered a SWOG clinical trial for intra-arterial cisplatin. The procedure had to be aborted due to risk of stroke after a capillary was nicked just mm's away from the tumor. The cisplatin would have assuredly left Matthew blind; perhaps this was God’s swift intervention.

Matthew was fortunate to have a great local neurosurgeon who focused on providing Matthew with both quantity & quality of life. He made arrangements to enroll Matthew in a brachytherapy* clinical trial at UCSF. Dr. Michael Edwards & Dr. Michael Prados, guided the placement of the I-125 radioactive seed implants in Jan. 1988. 14 months later, it was necessary to return to UCSF for a craniotomy to debulk the radio-necrosis caused by the brachytherapy. This had a positive flip side, as these docs had seen better survival results in the trial with patients who had required the necrosis removal.

*NOTE: It is unlikely that brachytherapy will be available to you. It gave way to the more widely used Gamma Knife, X-Knife and other focal radiation delivery methods. Still you can always inquire about it.

Matthew enjoyed a long period of remission, during which time he graduated from college. A recurrence was detected in a routine follow-up MRI in Nov. 1993. Matthew returned to UCSF, where Drs. Michael McDermott & Prados repeated the brachytherapy, pushing Matthew's accumulated dosage of radiation to 170 Gy.

In the summer of '94, Matthew began having complex partial seizures. After several AED "cocktails" failed to control the seizures, Matthew explored surgery as an option. In November '98 Matthew underwent a pair of craniotomies at the Univ. of Minnesota, under the care of Dr. T. Walczak, to retract his seizures. Testing revealed his right temporal lobe had suffered radiation damage and was the focal point of the seizures. The faulty temporal lobe was removed and Matthew was seizure free for nearly three years before his seizures returned. This time, however, the seizures were less debilitating than before the surgery.

September 11, 2004, Matthew celebrated his 50-50 (having lived exactly half of his life pre-gbm diagnosis and half post-diagnosis.) Matthew still relies on medication for his seizure control.

In 2005, Matthew's local neurosurgeon retired. During Matthew's final examination, the doc proclaimed that Matthew's chance of recurrence at this stage was probably now equal to the chance of anyone being diagnosed with a gbm. Beating a tumor is certainly an uphill battle, but living through and with a brain tumor diagnosis has its own challenges too.

On Sept. 11, 2010 Matthew's celebrated 23 years of survival with continued remission and generally good health. He is convinced of several positive factors that have lead to his long-term survival: 1. age of diagnosis 2. prompt diagnosis 3. proactive aggressive treatment incl. treatment center of excellence/clinical trials and 100% debulking 4. prayer and God's hand 5. location of tumor 6. UCSF!.

Matthew continues to advocate for other brain tumor patients-survivors, and persons with epilepsy. He reminds them to never let anyone in scrubs steal their hope.

In October 2010, Matthew lost his inspiration when fellow long-term gbm survivor, performing songwriter and friend david m. bailey passed away. david reminded everyone to live life to the fullest by 'loving the time.'

david's attitude took him a long ways and impacted many lives. Ultimately old-age was not in the cards for david, but he loved the time all the way. Anyone who lives life to the fullest will indeed beat their gbm like david no matter what the clock says.

Required listening to all faced with this challenge; his songs are available at: http://davidmbailey.com/ (start with love the time, my favorite cd)

Keep On Keeping On!!

How Do You Get More Dates?

"I've learned a thing or two in my 30-something years,
Life is short so stay awake before it disappears"
-david m. bailey, gbm survivor

Jan 1st; Jan 2nd; Jan 3rd…

- **Diet/ nutrition**

  People often ask me if I made any changes to my diet in fighting my gbm… to which I sheepishly reply "No."

  Not that I shouldn't have. The better off your immune system the better you will be able to fight any disease. I am not aware of any research that shows if I eat more vegetables, cut back on my red meat consumption and walk around the block 12 times a day that it will keep my brain tumor away…but then again I am not aware of research that shows it won't.

- **Lifestyle**

  My recommendations:

  1. **Stop** hooking the battery charger up to your head when you go to bed. It is not going to make you any smarter or give better dreams.
  2. **Avoid getting stuck** at a traffic light next to the guy who has made his car into a stereo with wheels & a steering wheel--so many speakers at such a high volume that even your windows are rattling!
  3. **Laugh More.** Here I know they have research that those endorphins scat-a-doodling around thru your blood are helpful. (Those that know me, know I laugh often and have a screwed up sense of humor..(oh, but you know that already! ☺). I'd call it helpful, maybe a key component to my survival.
  4. **Adopt a Survivor Attitude**

     More of what I have learned has been through observation of other survivors, than my own 20+ years walking the journey.

CONGRATULATIONS!!

You have made it this far in my guide, so here is the secret to survival…

The key to surviving is being a survivor. Duh... sounds redundant, I know...but my point is you have to want to live...and I mean really, really want it...regardless of how any insurance co. rules, what any doc tells you, or any statistic or any bad mri... you still have to truly desire to live... if you give up ‘cuz a doc has given up, you may well fulfill that destiny. <insert raspberry here>

But this is most important of all: If you don't know Monty Python's lumberjack song by heart...there isn't any hope for you... you are destined to follow the course of the Norwegian Blue parrot!! ☺
Beautiful plumage! LOL Here’s an excerpt:

...I'm a lumberjack and I'm okay
I sleep all night and I work all day
I cut down trees, I skip and jump
I like to press wild flowers
I put on women's clothing
And hang around in bars...

Prayer, good treatments, good doctors are all essential components of your journey...but if you lose the fighting attitude & desire to live there isn't going to be much medicine can do for you.

My Survivor's ToolBox

- **For the Mind:**

  - **http://www.virtualtrials.com/**
  - **American BT Association**
  - **National BT Society**
  - **Steven De Pesa's gbm Guide @ http://home.earthlink.net/~sdepesa/**

    > *Finally, brethren, whatever is true, whatever is honorable, whatever is right, whatever is pure, whatever is lovely, whatever is of good repute, if there is any excellence and if there is anything worthy of praise, let your mind dwell on these things. - Philippians 4:8*

  - **"Change Your Brain, Change Your Life"**

    by Daniel Amen, MD [clinical neuroscientist]

    This is by far one of the best resources I have found for survivors. Dr. Amen's groundbreaking work at the Amen Clinic for Behavioral Medicine uses SPECT imaging technology in examining behavior as related to deficiencies in the brain. And since most of us with tumors are left with some deficiencies, I think most anyone who has survived a tumor can benefit from part of his book.
    Not only does the text offer insightful information, but Amen even offers exercises and "prescriptions" to help you quell anxiety & panic; fight depression; curb anger; conquer impulsiveness; learn to focus; &/or stop obsessive worrying, etc.. . The book is readily available at all major bookstores, and/or on-line. (paperback : ~$15.)

- **For the Heart**

  - **"That's Unacceptable" - Surviving a Brain Tumor…. My Personal Story**
    by Rebecca L. Libutti

    In this book from my friend, you will walk with Rebecca through her journey of diagnosis, treatment and survival. This powerful narrative will provide strength & hope as you are uplifted by Rebecca's indomitable spirit.

  - "Magic & Loss"

    By Greg Raver-Lampman

    When diagnosed with a brain tumor, Greg feared that he might not live to see his three-year-old daughter, Emmy, grow up. Greg began writing letters to her. Greg rediscovered life, and emphasizes how hope and an abiding desire to live are an essential to survive.
    *Available at Amazon.com

- **For the Soul:**

  - **Music of Hope & Peace**

    david m. bailey
    A gbm survivor, david's masterful acoustic songwriting has a unique power and grace. When I am having difficulty staying on course and feeling down… david's music always reminds me of the blessings and beauties of life.

  - **Dan Steven**

    Thoughtful and honest observations of daily living and the struggles of people to find peace--remarkable music by a young man with a wisdom considerably beyond his years. (reminds me of myself LOL) NOT!

- The Scalpel and the Soul

A book by distinguished neurosurgeon Allan Hamilton, MD, he covers a lifetime of unusual mind-body encounters he experienced in his years of neurosurgery. He addresses the powerful idea of hope in a patient’s mind.

Disclaimer

You are advised to seek professional diagnosis and treatment for any medical condition, and to discuss information obtained from this website with your healthcare provider(s). The opinions appearing in this website as well as the free advice herein, while based on 20+ years of experience as a brain tumor survivor, are solely the opinions of the author and do not necessarily reflect the opinions or guidelines of the Medical Community. Furthermore, this author is not a physician (some quotes are from physicians -- but that's their problem), therefore the advice offered herein does not constitute medical advice. While every effort has been made to achieve perfection, neither does this author warrant or guarantee the accuracy of his opinions or the efficacy of his advice; No warranty is offered or implied. What's more, the reader assumes all risk for acting on or interpreting said free advice (for which the reader has paid nothing). This makes it easier for the author, and harder for the reader - which, in the author's opinion, is precisely how it should be in a free society (where free advice is offered freely).

Keep on keeping on.