

ORIGINAL ARTICLES

Me and my “benign” brain tumor: Musings of a patient

Brigitte Rieger

I was in constant state of severe pain. After undergoing many tests, I was diagnosed with a brain tumor. The assessment at that time was that the tumor was benign, so it sounded like there was nothing to worry about. The tumor was operable but surgery would carry some risks, and it was thus recommended that the tumor be monitored.

However, the reality of my benign brain tumor led to drastic changes. Not only was my life turned upside down, but suddenly I felt like I was having conversations in a foreign language. All of a sudden, I felt that this thing in my head was terrorizing me and that it wasn't fair. I felt cheated out of the chance to fulfill my dreams and to live the life I wanted.

I was embarrassed and ashamed, but as an energetic, independent and very strong woman who was successful in a male-dominated industry, I was determined to handle the situation all by myself. I really didn't want anything from anybody, and I refused to let anyone be a part of my life as it was. In my mind, I thought that if I could tough it out and pretend everything was fine, no one would worry about me. I refused to cope with my tumor and didn't want to know anything about it. I chose to put a wall around myself that kept me completely alienated from my own feelings, emotions and pain. My philosophy was that, basically, my life was not going to change.

However, my situation went from bad to worse, and my constant severe pain only intensified. It felt as though I was losing everything: my independence, my dignity and my health. Everything that could go wrong went wrong—one thing after another. It seemed it would never stop—like being on a runaway train. Worst of all, I felt like

I was going insane from all the pain.

Finally, I came to a point where I didn't want to live anymore. I no longer cared about anything. It was the first time in my life that I was willing to give up on myself.

On one occasion, I had the most severe pain attack I have ever experienced—it really felt like I was being stabbed in the face with an ice pick. Combined with the headaches, it felt like my eye was being pushed out of its socket.



I thought I was having a stroke and my body was shutting down. Up to this point, I had always been able to hold on to whatever piece of furniture I could find to keep from hitting the floor, but this time I did end up hitting the floor and passing out.

After that point, my thoughts grew desperate and I just wanted to check out of this world, not because I wanted to die, but because it was the only way I was able to control the pain. I didn't think that a human being could possibly suffer through this kind of pain and survive. It was at that time that I experienced a personal disaster: it was a catastrophic defeat.

On the other hand, at that moment I felt totally encouraged and inspired by my role models, the former and active members of the

German Federal Police Elite Special Forces Unit, the GSG 9. I gained my strength from their personalities, courage and expertise as well as the unit's unwavering dedication to every job they undertake – viewing their work as a calling. The duties and operations of the GSG 9 range from rescuing hostages and combating terrorism and organized crime, to saving people's lives in cases of particularly serious violent crimes. Actually, at that very moment the former and active members of the GSG 9 challenged my way of thinking and empowered me step-by-step to believe in myself and to believe, once again, in life in general.

I will tell you how the positive inspiration of the GSG 9 empowered me to turn my hopeless situation around. Actually, some people who know me personally would rather compare me with Mohandas Karamchand Gandhi or Mother Teresa, than with the GSG 9 - for them my personality seems a real contradiction. But it isn't. Very early in my life I realized that evil is real and is all around us. During my childhood and teenage years, I was looking at it from the outside, so to speak: I witnessed violence against family members and at the age of 10 the Munich Massacre, followed by Germany's most evil and violent murders since the Nazi Regime: those committed by domestic terrorists, who were responsible for slaughtering, injuring, victimizing or traumatizing numerous people and carrying out hundreds of bomb attacks, acts of arson and other aggressive and violent attacks, like kidnapping, terrorizing, humiliating and intimidating innocent people. Then as a young adult, I saw it from the inside, when I decided to get out of an abusive relationship. The very first time the situation got out of control, I confronted evil and made it known that I would not tolerate such violent behavior. But at the very moment when I challenged my abusive partner's perceived level of total control and misunderstood power, it became a violent attack. Realizing that evil exists and what evil is eventually capable of doing triggered the power within me to take control of my actions by pushing through fear, in order to get myself to do what I wanted to do –it meant successfully escaping this violent attack at gunpoint.

Please don't get me wrong. I can't physically "wrestle a bear to the ground", so to speak - but I did find meaning in the whole event, afterwards. My strengths are not in fighting physically but in learning from events and living in a centered and harmonious way. I think at this point it is important to note that even in extreme survival situations, it's not the physically strongest who usually survive, the

ones that are the most centered, with the mental ability to go beyond their physical ability. Gaining that centeredness and mental strength, the power within me, is my joy in being alive.

The GSG 9 was founded following the Munich Massacre, the so-called Black September in 1972, when Palestinian terrorists used the Summer Olympic Games to kidnap 11 Israeli athletes, resulting in the tragic deaths of those athletes and one policeman. After this unthinkable tragedy, which no-one was prepared for, the GSG 9 was founded under the leadership of Ulrich Wegener. The GSG 9 has proven itself in more than 1500 operations. The unit became known world-wide especially through the release of the hostages from the Lufthansa aircraft "Landshut" on October 17th 1977 in Mogadishu, the capital of Somalia.

I believe that the members of GSG 9 were a natural choice to be my role models. Consciously and unconsciously throughout my teenage years and, of course, my adulthood I modeled my beliefs and activities on their bravery, courage, and unwavering dedication to saving lives that seemed impossible to save. I developed a kind of guide to my own behavior towards violence and victimization. I believe that it is not only what we say but more importantly the life that we lead that shows what each of us is made of: Having the courage to speak one's opinion, to stand up for what is right, to face tough issues head on, to pick someone up after an injustice, and to not necessarily do as everyone else does. As a result, I have tried to take leadership on the issues I believe in, an approach which is built on integrity, self-respect, self-worth and love for myself and others, as well as respect for the rights of others. Mahatma Gandhi stated, "When I despair, I remember that all through history the way of truth and love has always won. There have been tyrants and murderers and for a time they seem invincible, but in the end, they always fall — think of it, always."

Since my initial diagnosis, my fear of the unknown and my denial of the facts had blinded me to the fact that I was living my life in a totally primitive, helpless and hopeless position. This kept me powerless and vulnerable. My sense of security and control was taken away, and my ability to feel anything or make sense out of life's experiences was gone. Through this denial, I created more pain and frustration. I was literally using all my power to protest and fight against the "benign" tumor. I was trying to wrestle "a bear" to the ground, but I wasn't able to defend myself very well. The outcome was physically as well as mentally losing this self-

created battle: my personal catastrophic defeat. In actual fact, since my initial diagnosis I had made myself a victim of my own actions - I who believed that victimization would never ever happen to me! Since my initial diagnosis, I had chosen to be a bystander to my own life - I asked myself why it was necessary to be engaged in such a powerless and vulnerable fight with a "bear" at all. The fact is that when I turned 40, I felt that my life was under attack, as no one is prepared to receive the diagnosis I had been given. At the time, the easiest way was to listen to and believe the negative voices inside and outside my head, the voices which were telling me, "It's all over - this is a death sentence on the tumor's terms". Gradually I realized and I was able to admit that I was the victim of a tumor which was ruling, terrorizing and taking advantage of me and my life.

Acknowledging that felt like a powerful explosion, which triggered my ability to get myself to do what I wanted to do – at that very moment to reach out and to face the reality of the "benign" tumor– I knew one thing for a fact: if I stay quiet, I can pretend nothing ever happened: if I talk about it, it will become real. With that inside I knew I had to take some positive steps to change my life: going from feeling and being treated like a victim to being a victor. Learning from the event and gaining back my centeredness and my strength, the power within me - my joy in being alive. I decided to dare to be an active participant in my present life; I chose to win back my life!

As I look back over my past, I clearly see the truth of "What goes around comes around". In my case it was from my role models the former and active members of the GSG 9 and from the people I was possibly meant to meet during my compassionate and satisfying life path, as I always strove to be an anchor and a voice for those in desperate need. I've dedicated a part of my life to being an advocate on behalf of victims of crime and abuse through helping them to rebuild their lives. I feel I've been doing good things for the right reason, and I do think there is a special gift you get back from giving: a satisfaction, centeredness and a feeling of fulfillment. Giving is really strengthening; it motivates you and gives you peace of mind. At the most difficult time in my life, both my role models' powerful inspiration and my modeled "guidelines", gained from my dedicated life path, gave me the confidence to push through the fear. I very quickly began to recognize what a negative impact the wrong attitude and fear could have on my mind and

thoughts. I believed that change was possible, but that I also had to make a personal effort to get my life under control.



Since my initial diagnosis, I had forced myself into living a life with an underlying fear of "what if I tell someone what is going on ...what if I let them know about the pain that has suddenly gone from making some kind of sense to making no sense at all ...who would believe me ... possibly no one and I would end up in a mental institution" running through my head. My mind was totally controlled by these fearful, negative feelings and as a result, I had limited myself. Realizing these mental limitations in fact prevented me from being in control of my actions, I finally found the courage to confront the underlying fear, and eventually I overcame it. I began to face the "what if" I had worked so hard to avoid, since my brain tumor had always been benign anyway. As a result, I reached out to my husband, my friends and my medical team and let them know about the pain that had suddenly gone from making some kind of sense to making no sense at all. I soon received clarification about my pain condition; I denied being depressed and I learned that my constant burning and stabbing facial pain and my severe pain conditions were real and were caused by my misleading labeled "benign" brain tumor; in fact, "benign" is relative and only refers to the infiltration because the tumor cells do not invade the surrounding tissues.

This event in my life has taught me valuable lessons, as unexpected life circumstances of different kinds happen to all of us. At the end of the day, it doesn't matter if the "tumor" is a benign or malignant i.e., a cancer diagnosis or - is a person who is bullying his way through life, perhaps a terrorist, a parent, or in some cases even a person who you consider a friend. We can't change unexpected and sudden life circumstances resulting from all kinds of "tumors" - but we do have a choice in terms of how we respond.

They are like scars, and these scars remind us of where we've been, but they don't have to dictate where we're going

Having a physical limitation resulting from a "benign" brain tumor is one aspect; having the mental ability to go beyond these "limitations" is a completely different aspect – a quite challenging one – but it was the beginning of proactively living my life for the first time since my initial diagnosis.

I realized that just because I have to live with this tumor, it doesn't mean I am weak or vulnerable. In fact, it is just the opposite: it speaks to the strength inside me, and I'm forced to become stronger because of it.

The label brain tumor is not a "death sentence" nor is it that the tumor is ruling my life or terrorizing me. It is quite the opposite: it is a "life sentence"- that every day is going to be more valuable and we should live every day as fully, responsibly and proactively as we can. The quality of life for people with a brain tumor is extremely important. In that regard, I often use the analogy of a rescue operation: people suddenly find themselves in an unexpected and unwanted situation. Then they are rescued, the rescuer brings them to safety, and they get medical help. Still, they are shaken up and traumatized from the fearful event - they need care and psychological help, as well as many other types of support, motivation and encouragement. At a time when my world was shattered, my husband, my friends and my very skilled and dedicated medical team immediately responded to my need to heal. They treated me with dignity and respect - and as an individual. I felt that they listened to me, believed in me, and trusted me. Everyone offered to help me in my healing process and supported me unconditionally in adapting to my new affliction. My medical team immediately implemented a chronic - pain management model (featuring one-on-one counseling with emergency care access and opportunities to address pain concerns between visits), a variety of medication trials, therapies and techniques, combining Western and Anthroposophic Integrated medicine with forms of alternative medicine, such as homeopathy, Chinese medicine and acupuncture, as well as intensive patient education and advocacy. In fact, we created a unique patient-centered approach to establish my goals and treatment plan, which takes into account all aspects of my psychological, physical and social needs.

In the aftermath of this diagnosis, I faced the challenge of reconstructing my life and, when

exposed to triggers, coping with my constant and severe pain condition. From that point on, the symptomatic pain, which will remain for years to come, became my most significant concern. I suffered from many of the problems experienced by people living with a symptomatic pain condition—my case being what is probably the most painful condition known to mankind. It makes me almost immobile and unable to do any activities until the pain subsides. I have had my share of experiences with overusing painkillers, including narcotics (in reality all they ever did was dull the pain), antidepressants and several frustrating trials with anticonvulsants, which were either ineffective or intolerable.

My life was difficult enough before I got sick, but it became much more difficult when I had to leave the "old me" behind. Mentally as well as physically, I couldn't just turn my back on the independent, active, responsible, rewarding and satisfying life that I had been living until this time. But I certainly understood my desire to heal and, from the moment I accepted my new lot in life, I had the power to work towards this desire and need to heal. Step by step, guided by the various training materials of my mentors, the former members of the SAS (the SAS is a British Army Elite Special Forces Unit, the members of which are the best and most highly trained experts in surviving extreme situations, such as torture) whose survival skills and techniques in extreme situations enabled me to develop a mental ability and strategies with respect to how I want to react to this kind of "torture" in my future, even if I'm not in the hands of the enemy. Assimilating their professional advice, expertise and knowledge, I was able to train my mind to stop paying attention to my constant pain and worked very proactively and responsibly towards dealing with the frequency and severity of my pain attacks. I educated myself on the severity of my pain condition, and learned to be more understanding and more patient in accepting some of the limitations caused by this condition. With ongoing inspiration, encouragement, support and understanding, I have adapted well to my new situation.

As many great philosophers have noted, with great loss comes the possibility of many gains. For people like me who are living with constant symptomatic pain, the challenge is how to make our lives worth living and find a sense of purpose and hope when there aren't any cures, when the root of what causes this symptomatic pain cannot be treated, or when death isn't likely in the near future.

At times, my life feels like a bitter pill to swallow. I can't function 100% of the time, I'm mostly confined to my home, and I'm unable to work. This "benign" brain tumor has taken a lot from me.

Living year after year with the label "benign," whether consciously or unconsciously, has had an impact that goes far deeper than my physical pain. The biggest challenge I have faced in adapting to this misleading label was dealing with feelings that were, at times, beyond anger. However, my anger was possibly the energy that has driven me to "let the tumor go", forgive myself and move on. I realized that if I fixated only on the misleading label and on the tumor in general, I would disappear! Letting the tumor go doesn't mean I was actually surrendering to it or that I had given up fighting. It



meant that from the moment I "let the tumor go," I had the power to work towards my need to heal, instead of making the same mistakes I had made earlier, when I used all my power to protest and fight against it. Indeed, these experiences had a great effect: I recognized the mistakes and wrong decisions I had made since my diagnosis.

I knew they were valuable experiences because I learned the most from the things I had confronted since finding out about my new life circumstances. Until this time, I had always denied that I was taking any risks because I had incorrectly interpreted a risk as being a physically dangerous act or an act that infringes on the rights of other people. In my opinion, these types of acts are not really empowering. Neither integrity nor the love for oneself or others is behind these acts, so that's why I hesitated and denied that I take risks. Now I was ready to take the risk of accepting myself because this "risk" was, in fact, built on integrity, self-respect, self-worth and love for myself and others, as well as respect for the rights of others.

Throughout my journey, I often sensed a kind of frustration and skepticism wearing down both the afflicted person and the health care professionals. No one is prepared to receive the diagnosis I was given. I had difficulty pronouncing or spelling it. Nine years ago my inner voice spoke up and tried to tell me that something was wrong. Five years later, my inner voice spoke up again, but this time it was an urgent wake up call to listen to my body's physical and mental signals and to learn what my body was telling me. At the end of the day I knew one thing for sure: I had nothing to lose but much to gain in the future—a new outlook, so to speak. The idea of the holistic approach was introduced to me—a unique patient-centered approach to establish my goals and treatment



plan, which takes into account all aspects of my psychological, physical and social needs—helping me to think in a proactive and responsible way about my future and how to make my future turn out the way that I want it to be. It's a challenging outlook I have to admit, but as a matter of fact, this new outlook introduced me to my healing process and it was the key to my success. I achieved what I had once believed was impossible: to lead a "normal life" again. In maintaining a healthy balance of realism and cautious optimism, I am now able to manage and to understand what I need in order to live with my tumor and the resulting symptomatic pain.

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My success and my achievements are gratefully dedicated to the memory of Thomas Hafenecker, Michael Newrzella and Tobias Retterath and are a tribute to the rare and special people who have

inspired me, kept me optimistic, and cheered me on. They are my hero of a husband, my role models, my mentors, my dear friends, my extremely skilled and dedicated medical team and members of the community. They never gave up on me - or gave me the sympathy I was looking for; rather all of them kept encouraging me to change my attitude and supported me unconditionally in my healing process, in adapting to my new affliction and in achieving what I once believed was impossible: leading a "normal life" again, in which no one knows I'm in constant pain if I don't tell them so — for these special gifts I'm thankful beyond words.

My heartfelt and special thanks to my cheering squad— you really pushed me to my limits and out of my comfort zone by encouraging me to go public with my story.

ABOUT THE AUTHOR

Brigitte Rieger (age 49) was in a constant state of severe pain, after undergoing many tests; she was diagnosed in 2002 with a brain tumor. The assessment at that time was that the tumor was operable but surgery would carry some risks, and it was thus recommended that the tumor be monitored. Due to her severe pain, her medical condition was re-evaluated, showing that her brain tumor had increased in size by 5 mm. To stop the tumor from growing, she was treated in 2006 with the Gamma Knife Radiation Treatment. In 2007 on top of her constant state of severe pain, she experienced the most severe pain attack. She reached out to her husband, her friends and her medical team and let them know about the pain that had suddenly gone from making some kind of sense to making no sense at all. After undergoing many tests and talking to several highly specialized experts in the field, she received clarification about her pain and medical condition and was diagnosed with occipital neuralgia, symptomatic trigeminal neuralgia and left hemi-cranial pressure resulting from a benign brain tumor (a meningioma, which is affecting the left trigeminal nerve, acoustic-facial bundle and is mildly compressing the middle cerebellar peduncle) in the left cerebellopontine (CP) angle and with chronic daily headaches. A resection of her lesion is possible, however the risks of having surgery includes death, stroke, heart attack, bleeding, infection and CSF leak and the surgical risks of removing her cerebellopontine (CP) angle meningioma includes facial nerve palsy, facial numbness, hearing loss, gait & balance problems and double vision. A unique patient-centered approach to establish her goals and a treatment

plan were created, which took into account all aspects of her psychological, physical and social needs. With ongoing inspiration, encouragement, support and understanding, Brigitte has adapted well to her new situation - Brigitte's assessment of her medical condition is that her meningioma appears to be stable. Her symptomatic pain has been under control with various therapies, and she currently does not require any specific treatment in that regard. Her chronic daily headaches were consistent with medication overuse. They have fully resolved and require no further intervention.

"There is no formula for success except perhaps an unconditional acceptance of life and what it brings."
- Arthur Rubinstein