STRUGGLES WITH A “BENIGN” BRAIN TUMOUR
Brigitte Rieger

When I was diagnosed with a brain tumour, I entered a world that I knew nothing about—suddenly I felt like I was having conversations in a foreign language. No one is prepared to receive the diagnosis I was given. Meningioma—I had difficulty pronouncing or spelling it. It was called a “benign” growth, one in which the tumour cells do not infiltrate the surrounding tissues, but the torture I experienced because of it was far from “benign”. It was explained to me that the tumour constantly compressed or distorted the trigeminal nerve, which caused the facial numbness and the constant aching pain and the severe attacks with exposure to triggers.

I had my share of experiences with overusing painkillers, including narcotics (all they ever did was dull the pain), antidepressants and several frustrating trials with anti-convulsants, which were either ineffective or had intolerable side effects. It challenged my sense of purpose and hope knowing that the cause of the problem could not be treated. The pain immobilizes me until it subsides; I’m unable to work and I’m mostly confined to my home, so this so-called benign brain tumour has taken a lot from me. Living year after year with the label “benign” has had an impact that goes far deeper than my physical pain. Adapting to this misleading label has meant dealing with feelings that were, at times, beyond anger.

It felt like the tumour was terrorizing my life. I lost my independence, my dignity and my health. It seemed it would never stop, like being on a runaway train. On one occasion, I had the most severe pain attack I have ever experienced—it felt like I was being stabbed in the face with an ice pick. 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 would be able to control the pain.

I reached out to my role models, who challenged my way of thinking and empowered me step-by-step to believe in myself and to believe, once again, in life. I quickly began to recognize what a negative impact the wrong attitude and fear had on my condition. At a time when my world was shattered, my husband, my friends and my medical team immediately responded to my need to heal, treating me with dignity and respect. The team implemented a chronic pain management plan including one-on-one counseling with emergency care access, a number of medication trials, alternative medicine such as homeopathy and acupuncture, as well as education sessions. We created a unique approach considering my goals and treatment wishes, taking into account all aspects of my psychological, social and physical needs. Maintaining a healthy balance of realism and cautious optimism, I am now able to live with my tumour and the pain.

The author would like to acknowledge the memory of Thomas Hafenecker, Michael Newrzella and Tobias Retterath.

Author Biography
Brigitte Rieger (age 48) was diagnosed with trigeminal neuralgia resulting from a meningioma in the left cerebellopontine angle. She was treated in 2006 with gamma-knife radiosurgery. Her pain has been under control with multi-modal therapies. “I have found purpose and value in writing. I know that by sharing my experiences and my change in attitude towards my circumstances, I can give other people hope that change is possible in times when the world seems as though it is falling apart.”