CHAPTER 1

I Have a Brain Tumor

Newly diagnosed brain tumor patients are like people who don’t know how to swim being thrown into deep water with no flotation device.

Kathleen, aunt to Kyra, a child with a brain tumor
WHY PREPARE AND BE ORGANIZED?

Here you are. You, your spouse, your child, or loved one has a serious illness. It is a disease with a medical name that you may not recognize, something you thought only other people got. It is a BRAIN TUMOR.

The diagnosis makes it sound like “it’s all over.” You may feel numb, helpless, and unsure of where or to whom to turn. Your family and friends stare in disbelief. Your primary doctor, on whom you trust and depend, is not familiar with its treatment; so you are sent off to a specialist at a well-known medical center or institute. Now what?

Brain Tumors – Leaving the Garden of Eden will help you – as patient, caregiver, or friend – to
• Feel more in control of the situation and less like a victim.
• Organize your strategy for traveling the difficult road ahead.
• Identify the right “experts.”
• Navigate through the maze of specialists who you will encounter.
• Ask the right questions about your diagnosis and tests to ensure that you receive the proper care.
• Find important facts and answers, so that you can make informed decisions about your treatment options. (Yes, there ARE options.)

My secretary, Kimba, tells me that brain tumors are “funky, unpredictable things.” It is precisely because of this that you will need to develop a strategy and organize. You will find out exactly how to get started in Chapters 2 and 3, but first let me give three reasons to explain why you need to prepare and get organized.

REASON 1
BRAIN TUMORS CAN BE DIFFICULT TO DIAGNOSE CORRECTLY

One of my colleagues, Dr. Jonathan Finlay of the University of Southern California, conducted a clinical study of almost 200 patients with malignant gliomas (also called astrocytomas) from the U.S.A and Canada who were diagnosed at their local hospital. We submitted all their pathology slides to an “expert” panel of neuropathologists (physicians who specialize in diagnosing diseases of the nervous system through analysis of brain and spinal cord tissues.) Guess what? The experts disagreed 25 percent of the time on the exact diagnosis; and some patients placed on the study had low grade, not more malignant tumors. This points out that a second opinion may
be essential to your treatment. Often, the treating doctor does not think about questioning the diagnosis, especially if it is a low-grade tumor. This is why you must ask questions to ensure that you receive the care that you need and deserve.

**Reason 2**

**These Darn Things Are Not Always Predictable**

I usually refrain from statistics because they apply to populations, not individuals. However, there is one fact that I want you to remember: no matter how smart any doctor or healer may be, no one can predict for how long any one person will live! We are capable of predicting what will happen to hundreds of people with brain tumors, but we cannot predict what will happen to you.

Prognosis is what a doctor says might happen. It is the odds. This can be based on true statistics or a physician’s personal experience. However, when looking at one person, it’s like flipping a coin. In 100 tries, the theoretical odds are 50-50 heads/tails each time. In actuality, we may get six straight heads; hence, the attraction to gambling. There are many accounts of people beating the “statistics” with successful fights against brain tumors.

Even with the same pathology, what happens can be markedly different among patients. For example, two of my patients, Evan and Jeanne, have the most malignant type of astrocytoma called a glioblastoma multiforme. Both tumors look identical under a microscope. After surgery and other treatments, Evan’s tumor responds to treatments for over 10 years. He becomes an acupuncturist and helps a lot of people with cancer. Jeanne’s tumor initially responds but then grows in spite of treatment. This is only one of many examples of how brain tumors can behave differently.

How can the course of the same type of brain tumor be so variable? Until a few years ago, we did not understand why similar-looking tumors behaved differently. New research suggests that within each brain tumor cell there are “messenger” molecules that activate growth signals inside it. The amount and type of these may differ among tumors that look alike. Understanding the “messengers” may be the key to new therapies. What your tumor cells look like under the microscope may not be the whole story.
REASON 3
BRAIN TUMOR TREATMENT CAN BE COMPLEX

In the “normal world,” a doctor will have a thousand patients. In the brain tumor world, you may have a thousand doctors – and it might seem like that many healthcare professionals! After surgery you may see neurosurgeons, radiation oncologists, neuro-oncologists, neuro-ophthalmologists, rehabilitation doctors, nutritionists, therapists, audiologists, radiologists, as well as other healthcare providers. Excellent organization ensures that the correct medical information is shared and it establishes you as the CEO (chief executive officer) of your body (Chapter 3).

You may be thinking, “This author is so calm, but I am the one with the brain tumor… and I am panicking!” Remember, this book did not spring from an ivory-tower view. I based it on real and successful experiences of many families. My examples include successful appeals to reverse HMO or insurance claims and other successes in coping from the actual patients.

Did every patient live to a ripe old age? No. Did tumors come back? Yes, sometimes. But these families learned to do everything they could; they did not let this “thing” tear away at their fabric. They had weeks, months, and years living fully, with the tumor taking a back seat. And yes, many lived much longer than any expert of statistics would have predicted.

Don’t just take my word for it. Go to the Internet, click on www.tbts.org or http://www.virtualtrials.com/survive.cfm and read stories written by people like Ben Williams, or M.L. Dubay, both of whom have had brain tumors and traveled the path you are on right now.

In the previous section I gave examples of how being prepared will help you regain control. But you may still be feeling like this tumor is some form of punishment and the whole experience has left you powerless and out of control. On the first page of this book, Kathleen’s words likened a brain tumor diagnosis to being tossed in water without a flotation device. This made me think of a famous painting of Noah and the FLOOD (Figure 1-1). In it there is a churning river awash with people struggling to take a breath; others are drowning. Floating in the middle is a plain wooden ark-no rudder, no windows, with a large lock on the door, being carried along by the torrent. One man is trying to climb up on it for safety. Many of my patients have told me that is exactly what their struggle felt like – in a torrent being
tossed around and hoping to find a place to get out from under the storm. They also secretly felt like this brain tumor was a kind of punishment. We are so used to things being under our control. Akin to a cataclysmic flood, a brain tumor changes that and puts us in the middle of a torrent, out of reach from the Ark.

So, where is your Ark? How can one regain control? When we are ill, we want to find the key, unlock the ark so we can climb to safety and wait out the storm. In the past, the medical system – the hospitals, doctor, nurses – could let us in. Today’s health care system has put us more on our own; but we have ever increasing opportunities to help ourselves with knowledge.

In this book, *Brain Tumors – Leaving the Garden of Eden*, I detail basic information about brain tumors – from getting organized, to diagnosis, second opinions, and health professionals you will meet along the way. In the companion book, *Brain Tumors – Finding the Ark*, I include more problem-solving approaches to understand and deal with specifics of treatment, insurance companies and HMOs, special considerations for children, long-term effects, and understanding effects and side effects of your medications.

Remember that you were a person – not a patient – before your symptoms alerted you to a problem. Apart from doctors and the medical system, you are still a person with a life that may include family, loved ones, a pet dog or fish. There is still someone who inside is whole and well – capable of pursuing life, love and things that feel good. As that person, you have choices. They may not be the choices that you want, but you do have choices. You can choose whether to go on a clinical trial. You can choose how to spend each day in hope... or with fear. The power to make choices is still yours.
One of the choices patients and caretakers may make is to connect with others. This can be one-on-one, in a local support group, or even through a computer-based Internet group. For many, the discovery of not being alone on this journey is freeing. One can share the doubts, angst and fears as well as celebrations of small successes that only people in the same situation would understand. The feeling of being connected and genuinely heard cannot be underestimated.

Before we end this chapter, let me say something about attitude. One of my patients, Al, a retired Los Angeles area career fireman who had saved more lives than I, taught me something about his brain tumor. He regarded it as just a “thing” with no more status than that. “It could make me sick, cause seizures, and weaken my limbs,” he reflected; but “it alone did not have the power to cripple my Love, corrode my Faith, or kill a Friendship. It might kill me but not my spirit.” He regarded his situation like, “OK, what can I do now?” Al lived a lot longer than anyone thought he would. Food for thought.

Yes, brain tumors are serious, but take a deep breath and pause. There are many long-term survivors of brain tumors, even of the type that you have. A number of survivors have gone on to become directors of brain tumor foundations and societies. You have time to learn and plan so as not to let this tumor rule your life. You will learn to preserve wholeness and gain control over your situation through knowledge and awareness. My hope is that this book, and the resources that can be accessed through it, will bring you to quieter, safer waters until the storm calms down.

It is time to begin the climb and learn more about brain tumors in general and your tumor specifically. Then you can ask the right questions and understand the choices ahead.