

American Brain Tumor Association

Learning to be Strong and Weak at the Same Time:

# Advice *for* Caregivers

As spouses, parents, children, siblings and friends of people with a brain tumor, we caregivers have a special, and often stressful, bond with our loved ones as they fight the brain tumor battle. My own experience began at the age of 34 when my 34-year-old husband was diagnosed with glioblastoma multiforme. Thrown from a world of positive certainties to a world of grave uncertainties, we had a steep learning curve to tread.

What did I know about being a caregiver? As a thirty-something adult, I never thought I'd be placed into this position until I was much older. But yet, just like so many of you, I became a caregiver instantly, without any warning or preparation.

So what's a caregiver to do? Now, after five years of my husband's unbelievable survivorship, I've found it therapeutic to list some guiding principles that I try to live by. Try is the operative word. Like so many of you, I struggle day-to-day with the roller coaster that is our lives. I am by no means the authority on being a caregiver but I hope you may find comfort and strength in these guiding principles.

## ***Let yourself be in shock***

My shock was instantaneous. From that dreadful, sunny Sunday afternoon in August when we were told of my husband's brain tumor and grim diagnosis, the shock began. It lasted for at least 2-3 months. The world was going on around us but our world had stopped. "Shell-shocked" would be an appropriate description of how we looked and behaved.

## ***Find a way out of the shock***

I can't point to one particular event that brought me out of my shock. I think it was a combination of things: consulting with the best doctors, reaffirming my faith, praying, becoming active in support groups, and lighting the fire of hope. This was now our world. We now had to meet a new set of people, learn a new language of medical jargon, fight the bureaucracies of insurance coverage, and be strong for one another.



## ***Let yourself cry***

Upon learning of my husband's diagnosis, all I wanted to do was to cry. But I had to remind myself that I was the caregiver. I wasn't comfortable crying in front of my husband at first, but I did. I found a "safe place" to cry in my bedroom closet. There I could let out my emotions where my husband or the kids couldn't see. I also cried on a lot of shoulders of families and friends. I cry less, nowadays, and when I do let myself cry, I try not to cry for myself and the prospect of facing life's challenges but instead I cry for my husband and for my children. And I don't just cry - I pray at the same time. Crying helps. It helps us release our fears and stress. Let yourself cry but find a way to end the crying session and to move toward hope.

## ***Reach out for support***

Finding ourselves drifting without an anchor, we reached out to a brain tumor support group to get information and to meet other people like us. In those groups, we found hope in meeting survivors and strength in the exchange of important information. We now had a new second family. We also reached out to a support group for cancer patients and their children. Our daughters, then ages 3 and 6, learned about cancer in terms they could understand. Now we could start learning how to live with cancer rather than to let cancer rule our lives.

### ***Get a second, third, fourth... opinion***

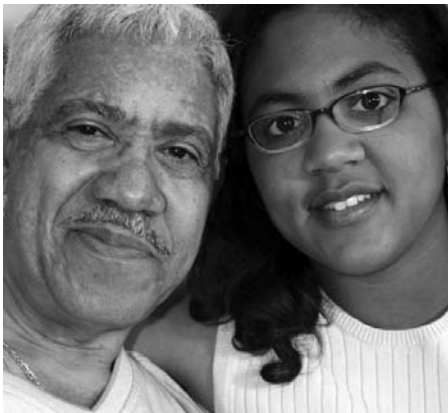
During the shock mode, don't take doctors' words as the final word. Use the Internet to research the diagnosis. Seek out the best hospitals and the best medical professionals for your loved ones to confirm the diagnosis and to discuss treatment options. I've often heard caregivers say that they don't want to pursue a second opinion because they don't want to offend the doctor. Please do not worry about that! Your loved one's health comes first – don't leave it to chance. Be an advocate to ensure the best care. Although many doctors will provide 2nd opinions based on MRI films and medical records that you send to them, we chose to travel to the doctors, sit before them, ask our questions, have them examine my husband, and listen to their recommendations face to face.

### ***Formulate a battle plan***

One of the things that helped me out of my "shell shock" mode was to formulate a battle plan. After seeing the best doctors, my husband and I reviewed the treatment options and formulated a battle plan. While we didn't know at that time how the battle plan would work out in the end, we found strength in having the plan. We now had a lifeboat to float towards hope.

### ***Find Humor***

As strange as this sounds, some of the best laughs I've had with my husband since we've been married have been in hospital



rooms. Maybe it's the fact that we're both working hard to talk about anything other than the obvious. Maybe it's just nervous energy or boredom. But whatever it is, find a way to laugh. Laughter releases so much stress and, for a few moments, gives you a

break from the daunting tasks of a caregiver.

### ***Grow your relationship***

My husband and I had a great marriage before diagnosis but we have an even better one now. Before diagnosis, we were fast-paced professionals with young daughters worrying about the little things. Now we are husband and wife, mother and father first and last. We know what's important in life and we're not about to let ourselves lose perspective again. Focus on how your loved one's relationship has been made stronger by diagnosis.

### ***Don't micro-manage you loved one***

Many challenges are presented to caregivers and caregivers often respond with 110% effort. Yet often that zealousness turns into control. I found myself wanting to "micro-manage" my husband's day



– what he would eat, when he would take his medicine, and when he should lay down for a nap. But I soon learned that he was more than capable of doing those things, and most of the things he did before diagnosis, on his own. But I had to let go of the fear that letting him do things for himself would be bad for him. I've now learned that it's just the opposite – it was (and still is) good for him. If he felt good enough to cut the lawn, who was I to stop him?

### ***Never give up hope***

After we did the research on my husband's diagnosis, we had no hope. But my husband has always been a positive person and so he began his determined quest for survivorship against seemingly unbeatable odds. I became the unofficial "cheerleader" who had hope because she was told to by others. Yet every day of his survivorship brought me genuine hope. Every good test result helped to make me stronger. Reading survivor stories made me strong too. With a little hope, I was able to help us weather the storm that came with uncertain or bad test results. The hope I have now is unshakeable. That's not to say that I don't worry, stress, or cry. I do. But the rational side of me stops me somewhere along the way to remind me that there is hope.

I send my hope, prayers and love to all of you. May all the best come to your loved ones and to you.

This article was written by Barbara Dunn, JD. Ms. Dunn is a member of the American Brain Tumor Association Board of Directors. She also represents the brain tumor community by serving as a Patient Consultant to the FDA. Barbara and her husband John reside in the St. Louis area with their two daughters.



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