Fighting the Good (and not so good) Fight…

"I do that all the time," my friends say, when I tell them how often I forget, how I can't remember from one moment to the next what I have just said, what I was doing, where I was going, what I was thinking. They mean to comfort me and sweep away my fears. But in truth this comment somehow diminishes me and my fear, leaves the former (me) uncomforted by leaving the latter (my fear) unacknowledged. My friends would be stricken if they knew that is how I take in their remark. And I would never tell them because they have been beside me since this ordeal of the hidden enemy in my head began, fighting the good (and not so good) fight with me.

One of the difficult things to do when an ill friend, family member, loved one, speaks her/his pain is to simply listen and not rush in to try to relieve that pain. For often that is what we need to do, to let the wound bleed free, to let the poison flow out, and by doing so, somehow lessen the pain.

Acknowledging that, what the person who had been wounded experiences differs from what the unwounded does. Acknowledging that the pain of the patient differs from the pain of the caregiver, though each has her own burden to bear, takes nothing away from the burden caregiver bears. Can't the person who is not the sufferer understand that and stand back and acknowledge this and simply accept the bewildered loss of the loved one? I don't know. Perhaps there is something I don't understand, and I am expecting something that is too much.

Friday, September 19, 2014

I am listening to my beautiful wife play the piano, the music flowing, her voice rising and falling, lovely. Fortune favors me here. To have found this woman. Beautiful inside and out, with such talent, caring, standing by me, may her music heal us both.

We move forward toward the day when instruments will pierce my brain, searching out the intruder, to slice it, carefully, cm by cm, from where it clings, to free me, to free my mind. How much of me will it take with it? How much of me will be lost? I fear the answer. Yet what choice is there but to go forward for this is no life I am living now, bound to my home, circumvented, unable to stretch out, unable to run, unable to leap forward, unable to soar!

But then, did I soar before? If not, it is time to try! When they free my brain of this weight, by god, it is time to try. For what will there be to fear then that could compare to what I will fear when I go under the knife, the very soul of me, the very heart of who I am, my mind, laid bare, to be whittled upon, and possibly reshaped into something not quite like myself?

Brain Freeloader

Yes, it's I again on me! Just an update on what's happening with this freeloader in my brain. I can't remember where I left off with everyone so to summarize:

The doctors have determined that this invader is

1. a glioma (tumor), not something else

2. there were signs of it in a 2011 MRI I had

The MRS seems to have produced a mixed reading, so we still don't have a definitive answer about malignancy. In that case, I have decided to think **benign** because I can until someone tells us differently!

The doctors are at last pushing for action, the next step being a WADA test to determine what kind of “deficit” would result for me if they go in and remove the entire tumor. In other words, will I be a blithering idiot if they just go in and cut it out!

OK, maybe not quite that, but the tumor is in a difficult area, involving language and speech, so very vital for anyone, not to mention it's also my career. Suffice it to say it is going to be lots of fun for me and involves a day in the hospital. At least it's Zoe's hospital, Hoag, not LA, so it's more convenient and Barbara lives just around the corner and can come over and make Zoe go get something to eat!

It's going to be a couple weeks before they do the WADA test as they have to wean me off the Topamax (thank god, I hate that drug, which makes me look like a druggie from the '60s), which hospital doctors had me on to prevent seizures. The new, improved doctor I'm seeing has me on a much better drug, so he's now accelerating the withdrawal schedule to get me off the demon drug.

Once the WADA test is done, then the doctors will know how they can approach the actual surgery. There is no doubt the tumor is in a tricky location, so it's not going to be easy, no matter how much of the tumor is excised.

So I suggest all of you be very, very nice to me over the next few weeks because afterward I may end not remembering who the hell you are anyway!

Love to you all,

Jarelle