

Frontotemporal Dementia Sucks by Robin Albright

My name is Robin Albright. I'm a Visual Corporate & Life Coach and a speaker. I coach employees and individuals on topics such as fulfillment (for instance - Be Your Own Super Hero) and goal setting. I own a company called Zinger Zanger, Inc. and have been doing this since 2008. The reason I'm sharing my profession with you is because I spend time helping others choose perspectives that help them shift out of feeling trapped and frustrated. But last year, I felt both in the biggest way EVER.

For the first half of 2012, my husband Dave, fought what we thought was low testosterone, depression and what I assumed was a big horrible case of mid-life crisis. He acted weird on so many levels. This all began "officially" in February, but now that I understand FTD, I can see signs and symptoms back a few years.

In February, Dave seemed distant and had this weird look in his eyes. I noticed that he would stop and stare at himself in the mirror. He stopped talking to me and rarely looked at me unless it was an empty stare. I, like the wife of 32 years I'd always been, began "opening up communication." I would pry and poke at topics hoping to understand what he was feeling or going through. In years past, this worked but not now. Dave became angry and frustrated. I'd ask what was wrong and he had no answer. I was certain that he must have another woman or was looking. I remember saying, "If you're not with ME, then who are you with?" We almost divorced, spent that spring going to the general practitioner, a psychiatrist, a psychologist and a marriage counselor trying to cure his "depression" and our supposed marital problems but nothing seemed to help. The worst part of it all was that no one wanted to believe me - or so it felt. I felt incredibly alone.

Summer of 2012 hit, and Dave's boss sent him a disciplinary letter. Dave, the man I married, was always the breadwinner of our family. He always made me feel safe and loved and cared for. He worked hard and didn't miss a beat going to work and caring for his family, so I knew that something was up. In an attempt to create a "plan of action" for his boss (something he'd done for years) and save his job...it was obvious that Dave couldn't do it. He couldn't follow through with thoughts or sentences.

That week, he ended up on short-term disability and in the hospital to "switch around his depression meds." I asked that a neurologist be called in and reluctantly, the psychiatrist did so. I'll never forget the call I got from the neurologist that week. It was, "Mrs. Albright, I know that you feel as if your husband has stopped loving you but I believe that his brain has stopped working in that area. I think that he has Pick's Disease or FTD is the newer name for the disease." I'll never forget the feeling during that phone call... sadness because Dave had this horrible thing and happiness because for once, it felt as if someone was validating ME...and finally giving us an answer that made sense. I cried and cried that night.

This was the beginning of the second part of our nightmare...because now we began dealing with FTD testing and our insurance companies. While our neurologist was certain that the symptoms led to behavioral variant frontotemporal dementia, the tests (MRIs and neuropsych testing) didn't always support that diagnosis. January of 2013, Dave had a PET scan, which showed a decrease

in metabolism in the frontal lobes, but couldn't define it as FTD, but also couldn't rule it out. We got a five-minute second opinion, and he gave the diagnosis of "possible FTD." It has been a constant battle with insurance companies (or so it felt) trying to prove that Dave was disabled so we'd continue to be fed.

During all of this, I continued to coach clients (unbelievably so) and take care of my 89-year-old mom who lives on the other side of our duplex... all the while trying to be successful at a sales job I'd grabbed in the fall of 2012 to help create a little security. I lost that sales job in the spring of 2013, simply because I couldn't keep up with the sales goals and the doc appointments for Dave, my mom and myself (my body began responding to stress with problems here and there).

In June of 2013, our short-term disability ran out and long-term disability wasn't fast at approving our claim, so we had no money coming in. We, for the first time in our lives, stood in lines to get help. We'd already claimed bankruptcy in order to simplify our financial obligations. I was in survival mode, trying to figure everything out. We applied for social security, pulled together letters from people that know Dave, copied articles and literally became the lawyer, trying to prove to the insurance companies what I was seeing and hearing. It was exhausting.

It dawned on me that I had a voice and that I was hiding behind my fears rather than using it (something I'd often point out to clients). So I designed a video to put on YouTube, explaining our story. I hoped that it would catch the attention of the insurance companies, but also that it would help someone else who may be suffering from the typical FTD nightmare. The responses I've received are amazing. I've read story after story of other families/caregivers who have experienced the same sort of heartbreak and frustrations.

So now, we've gotten word that our Social Security has been approved and our long-term disability is kicking in. Finally, it feels as if we can breathe again. I realize that the road ahead may not be any easier than the one behind us, but the one thing that I know is that there is a healing power in using our voice. Whether it's to shout to the world our story or merely validate quietly what's going on, our words can release us from feeling trapped and alone. With this, I plan to volunteer and offer our story to anyone and everyone who may want to hear it, with hopes that it will create more awareness and fewer tears for other families affected by FTD. I'd encourage you to do the same.

The Video Link:

<http://www.youtube.com/watch?v=QakWMJQeIuE&feature=share&list=FL0HFaDzFR4DQMJB CBWvrjMQ>

For questions or comments please feel free to contact me at 309-261-0934.

♥ Robin