

Through the Eyes of a Caretaker

I started a sojourn two years ago, a trip of taking care and looking after my wife, Corky, who has Frontal Temporal Lobe Dementia (FTD). This is rarer than the more commonly known Alzheimer's disease, but the symptoms of each overlap. The loss of memory and cognitive difficulties are the most prevalent. The main difference is that Alzheimer's involves a tangling of the neurons of the brain whereas with FTD there is a loss of brain tissue, specifically a shrinking of the brain in the frontal and temporal lobes. One other distinction is that FTD usually appears at an earlier age – often in the 50's – and is usually more progressive, a misleading term better described by two rhyming words, aggressive and regressive, that define the loss of function.

There is no cure at this time for the diseases that involve dementia. The research that shows promise is putting pacemakers in the brain similar to what is done in the heart. The theory is that this will improve connectivity in the brain. The same studies show that the brain has been under attack for about ten years prior to the first symptoms of dementia, but doctors don't know why or how. The possible solution is to augment the connection within the brain by increasing the voltage in the pacemakers which decline with time.

An ancillary difficulty is that the person with dementia often has anosognosia. This is different from denial where a person can recognize that something is wrong, but won't accept it. Anosognosia is a state where the person does not even recognize there is anything amiss. For my wife this manifests itself with a refusal to go to the doctor, to take medicines that help with symptoms (but not a cure), and not cooperating with home care.

There are both difficult and funny moments in coping. When we went to Riverfest and were entering the gates, the attendant asked to look inside my wife's purse. She refused and just walked on, prompting a call to security. It was a tense, somewhat confrontational scene until I was able to explain to the security guard the nature of my wife's condition. My wife is incessantly setting me up unintentionally for funny comeback lines. Johnny Carson never had it any better when Ed McMahon was his sidekick. One of her common phrases goes like this, "It's either going to rain today or it's not going to rain." My reply, " What's the other option" ? When we went to vote on Election Day , my wife hadn't studied much about the candidates. She received her ballot and immediately spotted the name Elvis Presley, a third

party candidate for Commissioner of State Lands. She blurted out, “ Elvis Presley, he’s dead”, and got laughter and smiles in a room with a fairly serious mood.

For a long time I had difficulty buying into the inevitable which is that my wife will not improve and get better. I went through all the stages of grief (usually associated with death) – denial and isolation, anger, bargaining, depression, and now, finally acceptance of facing the challenge of staying positive. My lowest point – when everything overwhelmed me – was the Sunday I fainted in front of our church and EMT’s were called. I was fine physically in a few minutes, but it was a slap in the face, a wake-up call , that I needed to reach out and seek help. Since then there have been numerous friends who are eager and willing to help , but the key is asking them and letting them know exactly what they can do. My wife has a son in Russellville and two daughters, one in Quitman and the other in Mayflower , who have visited and done as much as possible to lend support. A friend with a handicapped child once told me he looked at his situation as a blessing. I couldn’t understand that then, but it is clear now.

Many people who know us have stated that my wife is fortunate to have someone like me. It’s like the man who had a dog which was hard of hearing, virtually blind, and had a missing leg so he walked with a pronounced limp. An acquaintance asked the dog’s name and the man replied, “Lucky”.

So now I’m at the point where I can tell people I’m the one who is lucky and blessed. I’m fortunate to have a wife who, despite her lessening mental capacity, is totally devoted and loving. In the movie, “A Beautiful Mind”, even after the man is cured of his mental disease still faces an everyday battle to lead a normal life. He attributes his recovery and ability to carry on to the love of a good woman. I can come home after a day at work or even a two hour bike ride , and my wife will greet me at the door with a huge smile and a hug like I’ve been lost in the desert for a month. With that attitude and frame of mind we’ll make it through this no matter what the future holds.