

## OUR JOURNEY WITH ALZHEIMER'S DISEASE

A Sermon by Rev, Mike Morse, preached at UUCF on July 21, 2013

When Carl called and told me of the emergency with his mother and asked if I could preach on Sunday, my heart went out to him and I responded positively and immediately. He suggested I pull an old sermon. I have about 2000 of those, but I have always had a problem with old sermons. The problem is that they are Old sermons!

I thought I would like to do something that I have never done before with a sermon, an experiment of sorts, and take you on some of the pathways I have travelled in recent years with my beloved Carol who is now in the 6<sup>th</sup> stage out of a total of 7 of Alzheimer's Disease. I trust you get the impact and import of those two numbers, 6 and 7. The journey is a personal one, yet in many ways it contains ingredients that I think are of supreme importance for all of us who are human beings and who live in relationships whose integrity is maintained by the use of words, whose feelings gain their substance through the use of memory and habit, and whose essential meaning embraces the ability to make decisions that are useful, worthy, and even sacred. If I have learned anything in the past seven years, it is how precious memory is, how mysterious and sacred it is that we humans can use words, formulate ideas, give verbal expression to abstract feelings like love, and hope, and joy, and sorrow, and pain, and frustration, and anger, and disappointment, and pride, and thanksgiving, and a myriad of other emotions. Think of it! And what I hope you take away from this tale, if nothing else, is the resolve to never again take your brains for granted, or, to put it positively, to treat your brains and what they give to you every day, as a sacred trust, to be nurtured, honored, and cherished.

It was almost three years ago that I began writing about this journey, although onset of the disease was at least three years before that. My effort was prompted by a somewhat difficult episode triggered by Carol's doctor who had suggested that Carol get a mammogram. We went to the lab, and in spite of some confusion the experience went smoothly. A day later the lab called to say that her left breast showed some abnormality and they wanted to repeat the imaging. There was much confusion and anxiety. "Why do I have to go?" she asked. I tried to explain, but to no avail. I then said that I would call Dr. Broderick and talk with her about options. So, I did. Dr. Broderick was concerned and said that it is always better to catch a problem in early stages. Then she suggested that she might talk to Carol. She did, but Carol did not really track with the conversation, but did agree that she would go back to the lab for more tests. She handed the phone back to me and I finished the call with the doctor. I turned to Carol who was now crying quietly. "Everyone gets a say, but me," she said. And I knew that she was right.

I continued to reflect on this episode in my journal. We have crossed another threshold with this latest experience. What bothers Carol, frightens, terrifies, is not so much going to the doctor, or getting an exam, or enduring whatever ordeal that might come along. It is the loss of control over one's destiny. It

is sitting, as it were, on the sidelines as a third party while others make decisions about your life. It must be feeling like a three year old being told what to do, what to wear, how to behave. "Everybody gets a say but me. How true. And not having the ability to understand why it is this way. If the meaning of life is intrinsically linked to our ability to think, to reason, to weigh differences rationally, and thus make decisions, then it is meaning that is slipping away.

It was also about three years ago that I took note of another milestone in our journey. Carol had stopped reading. There are between 600 and 700 books on shelves in her library that is in the L part of our bedroom. She has always treasured books and, indeed I associate her with reading. There is a favorite picture in our piano room of a woman sitting quietly in a red wicker chair reading. Her legs are crossed and she is finely dressed with her hair done up and wearing high heeled shoes. Carol doesn't wear her hair up, nor has she ever worn high heels, but in tone and demeanor, that painting IS Carol. She was a voracious reader, and not in any cursory sense. I don't know if she read even the index in books, but I wouldn't be surprised!

When she was in college and thinking that she would be a foreign language teacher, she read all of the works of the Spanish philosopher, Unamuno. In Spanish! She wrote a 50 page thesis that overwhelmed her professor because of its depth and insight. And that was two years before we were married! Knowing all of this, one cannot help asking why? Why are great and wonderful minds wasted to this disease? I have come to understand the science answer, but that does not stop me from asking the existential question when it is part of my own personal journey.

The brain weighs about three pounds The cerebrum fills up most of the skull. It is the location of memory, problem solving ability, feeling, movement control. The cerebellum sits in the back of the head and controls balance and coordination. The brain stem sits beneath the cerebrum and controls such things as breathing, digestion, heart rate and blood pressure. The brain is nourished by by a vast network of blood vessels, about 25% in our body go to the brain. The real hard work of the brain goes on in individual cells called neurons. There are about 100 billion of them in a normal brain, with branches that then connect about 100 trillion different points. (I'm sure that Carl's brain has over 200 billion neurons). This is often referred to as the neuron forest. Neurons are what get destroyed in Alzheimer's. The signals that move through the neuron forest are electrical charges and these charges connect with one another at synapses where tiny bursts of chemicals are released called neurotransmitters. They, in turn, travel across the synapse, carrying signals to other cells calling forth a particular activity. Alzheimer's disrupts both the electrical charges and the activity of neurotransmitters. In the vernacular, the disease causes the brain to go haywire and shrink, quite literally!

The horror of the disease is that it moves so slowly in most cases. Though I should say, as a matter of general information, that once you have seen one Alzheimer's patient, you have seen one Alzheimer's patient. Each case is different, so that a caregiver might experience vast personality changes as the disease progresses, for instance, or not. In Carol's case the sweet, gentle, caring and tender person she was for 66 years or so, has remained in tact, and is even more pronounced than it ever was. It has made the task that I have, as well as our family, much easier, and at points even joyous, as we have travelled this difficult road to its inevitable conclusion.

The episodes I described earlier took place nearly three years ago and would be characterized as typical of stage 4 of the disease, where there is a pronounced inability to perform somewhat complex functions. In our case it included difficulty in putting items away in their proper place, or choosing appropriate clothing to wear. So, for instance, I have found a computer cord tucked away in the dish cupboard, or a loose sock in with kids coloring books, a cookie wrapped up and placed in the bookcase. Episodes with clothing have sometimes been hilarious, what with items pulled out of the hamper, or six or seven changes within a period of an hour. One has to laugh and be amused, for the tears of anguish are just beneath the surface. They are the therapy alleviating the pain of knowing with certainty what is coming next on the journey. Alzheimer's moves only in one direction. At least that is the case so far.

Stages 4 and 5 of the disease are replete with such things as disorientation, or knowing what season it is, for instance. Two years ago we travelled to Michigan and arrived at my sister's home in East Lansing. We have been there hundreds of times. At four in the afternoon, we drove into the driveway and Carol said, "Where are we? Why are we here?" That night as we got in bed she leaned over, kissed me and said, "Thank you for taking care of me."

The following morning my Uncle and wife arrived and we joined them in travelling to northern Michigan for a tour of old childhood haunts. On the way we stopped at a very nice gas station where my sister took Carol into the restroom. My Aunt Dawn stood with me waiting and cautiously asked me if I thought Carol was aware of what was happening to her. It's a question I've often asked and for which I have no certain answer. I told Dawn what had happened the previous night and then suggested that maybe in that moment Carol knew, but I couldn't be sure. Dawn started to cry, for her own mother and several Aunts died of Alzheimer's. Dawn's question was not for the purpose of idle conversation. It is worth probing because it suggests that it makes a difference in how we deal with at the personal level with the patient.

Now it is nearly August of 2013. Gone is the ability to identify by name most of the people seen daily, even those in our close family. Gone is the ability to get dressed and undressed alone. One cannot put a bra on feet first! Even I know that! Gone almost is the ability to speak coherently. Bathroom issues are beginning to manifest themselves. Present is the terrible fear of being left alone. The threads of sheer survival have become thinner and thinner by the day. Yet, the counterpoint to being left alone is the delicious desire she has to be in the company of many people. She speaks often of being *together* with others and how nice that is.

At the risk of sounding self-serving, let me say some things about myself that have become part of the journey.

Without a doubt I have become more understanding and sensitive to people's needs. One of Carol's strongest virtues has been her patience. I am far behind, but I have travelled far in that department. It is a lesson the disease has taught me.

I have also learned to separate the person from the disease. Not always, but most of the time. I cannot tell you the number of times I have caught myself up short when I was about explode with frustration over not being able to find something, or when all the items I had set aside for income tax work got lost, and I have talked to myself and said, "Mike, she can't help it. You need to laugh." And then I do! I realize that Carol's reality is different from mine, that her's is impaired and lives somewhere in the past, that it changes from day to day as the disease progresses

I have learned to listen more attentively. And I have learned that listening involves watching body language, especially the expressions in the eyes and on the face. This is becoming more important as Carol's language facility drops off dramatically. Reading the wrinkles and understanding the nuances is imperative. And I have come to realize that how I say something and in what tone of voice makes all the difference. It's useless to argue or criticize or to correct, or to reason. It just doesn't work

As I have intimated at several points, humor is important. Fortunately, Carol can be humorous, too. And we are still able to play a little bit.

I hope that in telling some of our story you have been moved somehow to work to find a cure for this terrible disease, or ways to prevent it from occurring in the first place. I have always encouraged my grandchildren, especially the female ones, to learn everything they possibly can about this disease, for in our family, at least, it seems to run in females.

Together, with the support of so many friends and family, Carol and I will move soon into stage 7, the last stage of this disease. On the journey there we will try to create special moments of peace and love. There will be times of laughter and joy, and especially tender moments because of who Carol has been and still is. And there will be tears, not just of sadness and pain, but of thanksgiving for a journey that has revealed so much truth and goodness, full of sacred mystery and happiness.