Greetings and a Happy New Year to all! Here is a long overdue update on Susan’s journey and the status of our Fronto-Temporal-Dementia (FTD) experience. Our “four-page” format is inserted here in case you want to jump to one “page” quickly and skip the rest. (I always intend “short” and end up “not-short.” I doubt it will ever change!)

Update “Pages” (not to scale!) Ctrl+Click to jump to the page you want.

Page 1: Life

Looking back, we had a busy year. Since the last update we took a family trip to Colorado, and a couple visits to Kansas City, Jefferson City, and Texas. But the main victory is keeping up with the daily routines and doctor appointments. (I always note how young the docs are and ignore how old I am!). The Girls and their families are in their prime doing great things, and the Grandkids are growing smart and strong! Incredibly proud of all of them!

The Crew at Christmas! I am a rich man; just no money!

We do get out together, but mostly here in town. I’m thankful for our Church, Pulpit Supply opportunities, Veterans groups, and Community events that willingly accept us moving in tandem and understanding Susan’s situation. The computer and internet are my lifeline, allowing me to still participate in the larger world while sitting at my desk. I’ve spoken at webinars, joined conference calls, completed online courses, and more. I’m trying to practice what I preach to others… *“It’s not about what you can’t do with what you don’t have, but what you CAN DO with what you DO have!”* We’re not dead, so we’re not done!

Page 2: Susan

As I explain when people ask, Susan is on a long plateau with a small, declining angle or slope to it. One of the reasons for the infrequent updates is that there is simply not much new or different to share. And yet, the downward angle moves things forward over time—and at increasing speed.

There is an element to this disease of the brain that is entertaining and amusing at times—like finding cookies in odd places or spreading orange peelings throughout the house. But the reality behind these curiosities is her increasing loss of cognitive function and awareness of her actions, feelings, and sense of self.

A variety of symptoms have emerged over the past year. These include shadowing (always being where I am for security), emotional mirroring (matching the mood of those around her), agitation (reflected in self-talk and tapping of feet and hands), sundowning (the emergence of greater symptoms as the day progresses), and an increased need for sleep (the brain is simply tired and needs restoration).


Just got tired in a hurry!

These are the normal and expected outcomes of this terrible disease where one brain cell and its myriad connections slowly dies, breaks those connections, and takes its 'neighbor-neuron' down with it! Fewer and fewer cells then work harder to compensate, but inevitably *those* neural networks break down, too. So, time is my friend in terms of being together, but time is her enemy as she faces relentless progression. We're grateful for that extended plateau but fighting that downward slope.

The "joy-moments," as we call them, are still there. The intuitive and emotional side of positive experiences, along with responsiveness to music, are connected throughout the brain (as I understand it) and not immediately affected by the "Frontal/Temporal" geography of our mysterious design. We still enjoy many moments together in the daily routine, even though there are continual minor adjustments and changes over time.


Abby cares for Susan's hair after a shower.

Since August we have been blessed with in-home support from our special neighbor, Maddy, and helper Abby, a newly married CNA in Joplin. She is working at a hospital while her husband, John, completes his college degree and then she will continue on to become an Occupational Therapist. Her friend, Sherry, has also come our way and they have been a blessing to Susan and a great help to me! Both have come our way when not working at the hospital and have certainly saved the day many times.

But Susan's needs continue to increase, so I am currently arranging more frequent in-home support on a regular schedule. We'll see how that goes! So, when you pray for Susan, ask for those rich joy-moments to brighten her day as we navigate new changes and challenges. Thanks.


Sherry provides a manicure!

Page 3: Gary

The role of “Caregiver” is a new one for me, and for many, many others as well! We’re hearing a lot more about the impact and hidden costs of home caregivers thrust into this role as the boomers age and the numbers skyrocket!

Veterans Day

We had opportunity to attend a support group near Springfield and meet others on a similar journey, and thanks to Mark Applegate, the Senior Age Dementia Care Specialist for Southwest Missouri, we’ve started a support group here in Mt. Vernon at our Veterans Building. So that is positive!

This past year has been a steep learning curve in the caregiving world. Not just the daily chores of food preparation and laundry and home care, but the medical issues, financial questions, insurance companies, and critical decision-making that comes with this role. It’s a jungle out there, and there is no map.

I’ve struggled with the word “every.” It’s now attached to “everything!” Every decision, large or small. Every idea, every clothing choice, every moment, every penny (er, nickel!). It’s everything every day.

I know that each of you reading this care for us, and that knowledge is priceless to me! Thank you! Many of you have offered to come and help, and the offer is priceless, too! But reality is that setting things up and managing multiple schedules just adds to the “every!” [I WILL call when something specific is needed, but knowing you are “out there” is what we need most right now.] So, our in-home helpers, Walmart/Amazon deliveries, drive-through banking, Facebook, and emails & texts, etc. are working well right now.

Page 4: Lessons

I read somewhere that Caregiving is an inward journey, focused on quiet moments nobody else will ever see. Those moments prompt inner reflections that yield life-lessons. And those lessons build a character.

One Christmas present received last week was a Caregiver's Devotional book—a few paragraphs a day written by a fellow pilgrim on this journey. In fact, it's titled "Grace for the Unexpected Journey," and its theme is modeled on Hebrews 11:8 describing how, by faith, Abraham obeyed God's call and *"went out, not knowing where he was going."* The point here is that you don't need to know where you are going, just Who you are with.

Our Thanks and Love to you all!

Gary & Susan Gilmore