

Greetings All! Trust you are preparing for Easter!

Page 1: Life

Writing you from Cleveland, Ohio, tonight... far afield from the house, but things are GOOD!



Hats off to the Gilmore Girls for making sacrificial efforts to be with Susan, allowing me to attend a Public Health National Conference as part of the Missouri State Emergency Management team. It's my privilege to represent the Volunteer Chaplaincy we've been working on for the last five years! (More information on "Page Three!") We're sharing this concept with the entire nation!

Amy, Abbey, and Amanda have worked together to make sure Susan has care and company at home. We talk on FaceTime each day and the girls have done a super job! I considered this week a "test" of the family-care-plan and am very relieved that we/they have proven we/they can do whatever is necessary to care for Susan.

This Sunday (EASTER!) Susan and I head back to WashU for the annual "look" for the research study. The trip and time together will be good, and I am hopeful that we will learn more about our current situation and about the current research on the disease.



Page Two: Susan

Susan doesn't talk as much as before... often a one- or two-word response to a question. When she attempts an observation the thought escapes before the sentence is completed. I usually can get the intention, so I reflect that back to her and get a yes/no. It is still communication, but not the long talks we used to enjoy. And there is still a variety of "affect" (emotions or overall mood) ranging from sitting contentedly on the couch almost dozing to joy and excitement (especially with the grandkids!). It varies from time to time. Again, I hope we will learn more next week during the testing.



And just another observation I have called the "Teddy Bear" effect. Whenever we go somewhere, it's important for Susan to have something in her hands-- usually a notebook and pen or Scripture

cards and colored pencils for her to work on. And now, nine times out of ten, she does NOT color or use the notebook but STILL must have something to hold. There is a supply of stuffed animals at our house for the grandkids but, as the picture shows, the Lion has been a part-time companion recently! (I think it's the sensory "touching" that is important... not the coloring activity or the "thing" she's holding, but the tactile feel of things and the "responsibility" or security of managing something. Interesting!)

Tina Fulbright noticed Susan's love of bright colors and made a personalized quilt for her! What a precious gift!



One other thing that is part of our new reality is that Susan's brain is working harder but processing slower. This leads to hesitancy and uncertainty, and a much slower pace. Even in familiar places—like church or rooms in the house or getting into the car—there is a cautious examination of the situation and a slowness in moving into a room or social encounter. She remembers them, eventually. But it involves intense focus. She will follow me... but I feel rude when I enter the room first instead of holding the door for her! So now I go first and turn back to guide her inside afterwards. Lots of little things!

Page Three: Gary

In reading the Facebook group posts of other spouses dealing with FTD, caregivers seem to go through certain stages of grief. There is the initial hit of the diagnosis, followed by a growing awareness of the implications. Home responsibilities increase, and there is the daily loss of the little things. So it is a journey, to be sure. And so much depends on the "progress" of the disease... which follows a very generalized path at best and will ultimately take its' course.

We are through this first phase of adjusting to the realities of the process. But in time, another issue begins to emerge for the caregiver. Simply put... what kind of life do I have now and in the future?

I have stayed engaged with projects at home and the Veteran and Chaplain causes that have been part of my world for many years. And this is healthy! I won't be trotting off to conventions on a regular basis, but the Girls felt this was a needed break for me and sacrificed to make it possible. Again, so grateful to the family for their support!

But I DO continue to do what I can from home using the computer and the local opportunities that abound. The hometown and Lawrence County efforts are just as important as the "national" ones, and I've upgraded the computer capabilities to literally "stay connected" to my new ministry opportunities!



And bottom line: the HOPE of EASTER assures me that Susan is okay in the Lord's hands. And I am, too! Nobody ever said we would not walk "through the valley of the shadow of death." But because of Christ, it's just a valley and just a shadow! So, we will keep walking. Together. With the support of family and friends and with important work yet to do for each other and the Lord.

HAPPY EASTER!

Gary