

The Rock-Strewn Road of Early-Age Dementia Part 3 of 4

*Excavating crushing stones to produce a
grass-roots emergence of support!
Our passageway to a Refuge of Knowledge,
Answers, Comfort and Understanding.*

Welcome back, dear and favorite reader to Part 3. Yes, I lied--I have added Part 4, and it will be posted simultaneously. So much to share, so little ink.

Part 3 is the history of finding support—how it was birthed, what it became, and why it continues today. Part 4 is explained at the end of Part 3.

Last month, I left you with yet more unanswered questions (frankly, the questions never end, but asking them becomes less daunting). I also promised you “more later” in several places. Sadly, too, I also left you with yet another sobering realization: *I cannot do it all; I cannot be it all.*

It's called Overwhelm. It was a constant resident in me. It strips my stamina, grips my heart, gives me a gut-ache, and leaves me mentally and emotionally paralyzed. That paralysis feels like a reeling maze of numbing mind-chatter. A going-nowhere mental spin.

Some wise person sometime-or-another in my life said, “*When you get into a mental spin, write it all down. Write until there's nothing left to write. Don't think about spelling, grammar, punctuation--nothing. It's not for anyone else. Just write.*” That is truth; it works; it has served me well.

So I wrote. And wrote. My mind settled a little. My stomach aches receded. My heart un-gripped a bit. I gained some stamina. I found breathing room—literally. And perspective. And I slept better. From that mental dump I made lists. Now I had a place to begin, but whom to begin *with*.....?

I mentioned earlier, dear and favorite reader, the value of learning the language of this disease process. I could “talk the disease”, so why not start at the top to find help.

In early 2003, I went prepared to fact-find at Bob's next neurological appointment with Dr. Adair. He was generous with me always. But this time I got zip. “What? No support group oryou're kidding?” He was on the Board of the NM Alzheimer's Association—there just wasn't; not for this type of dementia. “Well then....where on earth do I turn, Doc?” He held that if I could generate interest, he would be willing to help. Bingo!

I talked to the Association; they would do the mailing! I did the verbiage; I named a future Sunday at their headquarters; I offered up Dr. Adair as the speaker. Our purpose was to form a support group of those interested in dementia diseases of the frontal lobe.

People came. Not in droves, mind you, but they came. Dr. Adair, fresh from knee surgery, had slides, talked technicalities, answered questions and selflessly gave. He came through gangbusters, and I will never be able to thank him enough, not ever. I did follow-up calls, set a meeting time, and had three people show. Our first official support group meeting happened! And of those, Arlene was the only one who persisted, but guess what? Turns out that was all I needed.

My cherished and beloved friend, Arlene. She has never wavered as my rock, my fount of wisdom, my comforter, my encourager, my backboard, and my touchstone. Together

we have done this sacred thing for lo these many years, adding families, facing deaths and families move on, adding more families, more deaths and the beat goes on....

Along the way we've had task-helpers join (thank you Jo!) and then move on as well. It's okay; it's the nature of things. Barbara is one who has remained since 2006. She is our roster keeper, sender of my plethora of emails, helpmate in research and friend.

Favorite reader, you may be asking right about now: Why have a support group? Isn't everyone whiney and all touchy-feely? Well.....no, quite frankly. The group is for the caregivers, dear reader. We're driven by and never shrink from the tough solution and hard truths, but always with compassion and empathy. We are true help to one another. We unflinchingly support each other while they--often to their detriment--support their loved one. *No one else does that. We've walked in their moccasins—to the very end—many times. No one else has. No one else “gets it” like we get it.*

These support group members are awe-inspiring in their tough-minded determination to have the right docs and meds on board, in their unwavering resolve to have good and responsive care at home, in their steadfastness for safety and comfort of their loved one, in their super-human advocacy for quality of life and surrounding love. Then, if and when, it is not workable to have 100% home care, the choice to move their loved one to new surroundings is meticulously decided. These folks get it done. All of it. And then some.

To be more precise about these persons, they come together once a month to listen to each other. They hear and honor the challenges, the pain, the sadness, the loss, the frustration and helplessness. They offer timely and sensible suggestions, generous encouragement, consolation and true support. Under-girding all that is spoken stands the tenet of telling Truth: to one another, to family, and despite the sting and hurt, we resolutely help keep denial at bay—mostly.....denial is one mean and tenacious fiend.

And.....we laugh. It may sound odd, but if you can't find laughter in the bizarre, the uncanniness, the wackiness, you will surely become a statistic of the disease too. We laugh a lot. They are my heroes. And I love and have loved every one of them.

To be more precise about us in leadership, we know how to help from diagnosis to getting medical and legal paperwork done, to overcoming defiance in the family, to help sort out how to resolve or re-direct difficult behavior, ways to put a stop to driving, wandering and anger, to find respite care, to monitor medications that work and don't, to finding the better docs and institutions in town, and to inform about home health care and hospice. We brainstorm unique issues. We confab on problematic matters. The Alzheimer's Association has lauded us for exemplary work as a group. We work hard together. The trust is bonded tightly.

Post mortem, what happens? When they lose their loved one, they may decide to leave the group for a while or forever, but that doesn't mean that we lose complete touch. We bond for life in many cases; they often remain on our e-mailing list. It's wonderful to witness that people can find "life after dementia". We talk about that in the group. It's critically important to have hope. And *there is hope*, my dear and favorite reader--there is.....*life after dementia*. We help keep hope alive.

On the larger scene, it's heartening to tell you dear reader that national awareness is growing. The national press has developed greater curiosity and understanding. There is less stigma and more accurate information "out there". (Blessings and thanks to Maria Schreiber's 2009 HBO dementia special). Docs seem to diagnose somewhat sooner, but we've got a ways to go on that one. Want to help? Let's talk.

Back home: having Bob's doctors in place, his meds in sync and now having our support group: Arlene, Nato (my precious friend) and the entire Sanchez family to lean on, and the newcomers to the Group—those who can talk the language, understand the infuriating and exasperating process, and who don't shrink from the ugly, made a huge difference. We weren't alone anymore. They knew.

With all prepared, and doctors willing to be on call, it was time to focus on what we as family and friends of Bob could do together before he could no longer travel or participate with people in a meaningful way.

So dear and favorite reader, I hope it's okay with you, because next I am taking you more intimately into our journey. I so hope this is helpful to you. Many people to date have said this "emptying of ourselves" is helpful to the reader. And you, favorite reader, are the best and deserve any help I can offer.

In part 4 you will have access to all I reported via email to friends and family. And it's a lot. In trying to shorten, to brutally edit, I concluded in a heap of emotional frustration the following: I will not select out what we went through; I will not delete the massive complete truth of the details. I have no idea who you are, dear and favorite reader, or why you are reading these postings. But on the off chance that you are looking for validation of what you are seeing in yourself, in a loved one, on behalf of a friend who is concerned, or you are someone right now caregiving to a victim and looking for help on this website, I owe you, whoever you are, the raw, unedited truth from our perspective and experience. I owe it to you to say what *you* can expect as things progress and ultimately end. This is a terminal disease. There is no turning back. May you be blessed in noticeable ways for taking the time to read and learn about the final piece of *Bob's Crossing*.

