

The Rock-Strewn Road of Early-Age Dementia Part 2 of 3

*Gripping fear and uncharted waters:
bulldozing a small passageway in the
rocky road toward Better Understanding.*

Welcome back.

Last month, I left you with my frightened and horrified plea: “*This diagnosis cannot be real; it just cannot be.*” My passionate plea to the Universe and all that is Holy was constant for a long time—it’s called denial, and it’s normal.

Denial takes many forms and, unfortunately, reappears continuously. It is a huge part of what we feel when facing an early-age dementia diagnosis. Why? How shall I make clear to you, my dear and favorite reader, how nearly impossible it was for me to “get it”-- to be able to wrap my head around this grotesque, horrific disease process and the death sentence it brought.

We wafted in and out of denial for a very long time. It sounded like this:

- “He’s seems better--just tired and overwhelmed with work and travel. Am I wrong?”
- “He was good tonight. Maybe it’s me; maybe I’m over-reacting.”
- “If we saw even more doctors, maybe we’d get a different diagnosis.”
- “So many say to me, ‘He looks fine; I don’t see a problem with him.’ So am I nuts?”
- “Why can’t I drive? I’m fine. You’re trying to take away my freedom.”
- “I think something’s wrong with you, not me.”

But when truthfully facing myself in the mirror, I couldn’t hold onto that defiant denial because *I knew* in my heart of hearts it was real. Too real. Bob often said, “I’m fading away and my brain’s turning into Swiss cheese, isn’t it?” I could only nod and choke back tears. Fear and sorrow gripped.

That turmoil surrounded all the intimidating questions still hammering at us.....take a deep breath, favorite reader—there’s a lot ahead of you.

- **What is ahead of us? How does this disease progress? How does it end? When does it end?** I need facts. I must flip these unknowns into self-educated facts like maybe the Internet, organizations dedicated to dementia, finding others like us...and, what else...
- **How on earth will we do this alone?** We cannot. I must share the facts with family and friends. I must enlist support for us. That astute and wise saying came to mind: *There is no virtue in doing it alone.*
- **How will we adapt?** I don’t know. I don’t know. I cannot fathom.
- **How do we pay for all of this?** We have insurances. How do they work?
- **What does our medical plan provide?** Do you know? I hadn’t a clue. (And I used to sell the stuff---go figure).
- **Are there public funds to help?** If I didn’t feel challenged and overwhelmed already, the mere thought of wading into this question made me weep.
- **Will he have to be institutionalized? What does a place like that look like....and cost?** And weep some more.
- **How could I keep him at home?** Is this a possible option....is it even feasible?
- **What happens when the money runs out?** I must look at this---Bob’s care and my future. I must. But I don’t want to.
- **How do I handle the family?** This wrenched my heart. Both parents are alive and active. How, oh how....do they bury their first-born son?
- **What about my job?** Deep sigh.....

- **How do I find out about any of this?** *This diagnosis cannot be real; it just cannot be. Denial again rears its ugly head and takes control.*

Denial occupied me too often. But I could only cry, eat and look out the window with rage for so long. The payoff for that dwindles. So....I shook it off, climbed into my mental bulldozer and began carving a pathway of Facts, pitching the strewn rocks out of my way. Thus began our journey toward Better Understanding.

Here are the Facts, as I found them: the beginnings of our “Better Understanding”.

Fact:

What was ahead of us was grim. The disease is hard to keep up with much less stay ahead of. It is progressive; the decline is fast; it is debilitating and demoralizing for all. And it is terminal. It marches through “stages” which are not cast in stone but are helpful as general predictors of what lay ahead of us. This is a very helpful list, but not exact—nor can it be.

http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp?WT.mc_id=stages_02&qclid=CLGuhKyXsqECFSZHagod6iYy_w#stage1

Bob’s disease process would rob us of who he was. What made him, him. It took away his intellect, his wisdom, his reasoning, his discernment, his sharp wit, his emotional empathy and compassion, his motor functions, problem solving, spontaneity, short-term memory, language, initiation, judgment, impulse control, and social and sexual behavior. This website is a good illustration of the frontal lobe and its functions. It helped me look ahead.

<http://www.neuroskills.com/tbi/bfrontal.shtml>

However, and these are two important and, oddly, good “however’s”. First, he lost his expressive reactions, much of what made him him. Emotional responses became blunted, stunted, dull—but strangely, it was a good thing for him if you think about it. He didn’t have to profoundly grieve his own losses. Second, Bob retained his most primal essence. He never forgot me or others close to him. He lost his languaging and naming skills for who we were, but his eyes never forgot. Thank God I was always able to see the tender love in his eyes--and others did too. The windows to his soul. He let us know.

Fact:

To over simplify, early-age dementia is known by many names. Pick’s Disease; Dementia with Lewy Bodies; Vascular Dementia; and Early-Age Alzheimer’s are the most common. (To my surprise, more than one of these diseases can combine themselves in a brain.) Their symptoms present similarly, and are nominally treated the same. They are often collectively called “frontal lobe dementias”. Here’s a good summary site if you’re interested.

<http://www.mayoclinic.com/health/frontotemporal-dementia/DS00874>

Of note: very, very smart people disagreed sporadically on Bob’s *exact* diagnosis. Exact diagnoses cannot be definitively made until a brain is biopsied at death and its pathology identified under a microscope. (more next time)

Fact:

All of these diseases are terminal! That word – *terminal* – shook my world. I had to keep saying it lest I not believe it. Bob would die, and it would be early--early, meaning a few years. It is not “a long goodbye” like the traditional Alzheimer’s dementia of older people which attacks the old brain. Bob died three years after diagnosis. That is not dissimilar to other victims.

Fact:

Adapt: *become accustomed, get used to, familiarize yourself, get a feel for, acclimatize, find your feet, settle in--*those are all the words for “adapt” in the Thesaurus. But how?

Here's how. I learned the language of this disease process. Study/knowledge somewhat abates fear for me. It de-mystifies. I exhausted the Internet (There is so MUCH more available today on-line—one of the best sites was in Britain, go figure.). I talked to anyone medical that I knew. I drained his doctors. I read and read. I contacted the Alzheimer's Association. (more next time)

I enlisted 5 doctors: an internist, neurologists x 3 (a practitioner; a local researcher to track Bob for national data bases and brain donation [more next time]; and a non-practicing doc who took a personal interest in Bob--too convoluted to explain) and a psychiatrist for med management. We tapped into them off and on throughout the illness. In a word, too many and too much—we know much better now. (more next time)

Bookmark this!! I went to all doctor's appointments over-prepared. Adopt this behavior, and it will garner much, I promise! Always, I pre-faxed a simple, bullet-pointed list of my observations, Bob's changes and a list of questions for the doc. At the end of each fax, I made a numbered list of "What I want to leave with today". This approach rocked. It focused me prior to the appointment and focused the doctor during the appointment. It eliminated trying to remember things and emotionally babbling my observations, concerns and fears—and leaving out important things! The docs were appreciative which also meant they took me seriously. This is a critically effective and efficient method for you, my favorite reader, to adopt as you adapt.

Fact:

Funding the disease is a nightmare. Work the systems = push, push more, push harder. Then persist even further. If you don't like the first answer, ask for someone else. Go higher and higher until you are 100% satisfied. The system will beat you down if you let it. Don't!

This will be my first mention of helpers (more next time). An angel friend literally flew to me with the sole purpose of wading through oodles of paperwork, much of which intimidated me. She "became me" on the phone and got gobs done in just a few days. May she be seated at the right hand of God. Find this angel in your life--they are there.

Specifics. The first line of defense is your medical insurance policy. Sorry, but you have to actually read the blasted thing. Do it with liquor---applied liberally. I jest but not totally. Know what you are entitled to and use every single dollar of it.

Apply quickly for Social Security Disability Benefits. Do so with exceptionally prepared paperwork. Thanks to many who have gone before you, dear favorite reader, you won't have to fight to receive this benefit. We did. Not long ago, they added our diseases into their system for automatic approval. All paperwork to submit is on line.

Military: Veteran's Affairs have several programs which will fund if you qualify. You may think that you know all of them. Likely, we have found, you don't.

City, County and State programs are also available to help you. Find them. Call Senior Affairs, call the local Alzheimer's Association. Go to caretaker's conferences, pick up brochures, make the calls. Find every dollar.

Do you have long term care insurance? Do you have personally-owned or group-funded disability insurance? Is there perhaps a professional association membership which offered benefits? Find every dollar you can; you will need them.

Fact:

In-home care? Institutional care? A combo—when & how? Every family and every situation is unique, favorite reader. As for us, I had a splendid career as a life and disability insurance salesperson to self-employed professionals, and my parents lived

through the Great Depression. It is no surprise, then, to learn we owned whatever insurance it took to appropriately transfer risk away from us. I was able to keep Bob at home because of 3 insurance policies, a large chunk of our savings, SSDI and because I wanted to. In total truth, however, at that time we almost no “real” alternatives. (Those options are far, far better now which helps others have more choices.) I felt I would be able to manage things in our home with the right personnel. Thankfully, I was right. But it was a huge challenge, make no mistake.

Fact:

Handling (preparing/informing/answering questions our family and many close friends living too far away. We, the family of Bob, had several long talks. Would everyone trust me to care for him throughout his decline, including his death? Did they have confidence in me for the hard decisions? I needed to hear this up-front lest I come to a fork in the road and be second-guessed. I needed their commitment from day one. And I got it. Bless them.

I started an extensive email list of family and friends. I sent very regular mass updates on Bob—the good, the bad, the terrible, the ugly, the fearsome and the funny. Laughter, in spite of this heinous disease, allowed us to be even better connected across the miles. It also kept phone call updates to a minimum. What a blessing that people felt “in the know” and satisfied with our emailing-information system. It also, for me, was a cathartic outlet. I was raw and frank in the emails.

When Bob’s reading abilities deteriorated, I read to him. Among those readings were responses to our updates, which meant a lot to him, especially if he could laugh.

Fact:

Working and driving, my work, oh my. Bob could no longer work, but his increasingly impaired judgment precluded his full acceptance of that fact. The same acceptance issue surfaced when it came to giving up driving. His slowed reaction times, bizarre traffic judgment, brain processing impairment and our increasing liability demanded he stop. Ultimately he agreed to both, but it was extremely hard.

I continued to work for a while which was a good thing. I felt confident I would know when it was time for me to be at home full time, and I did.

While I am frank and factual about these things, please know dear and favorite reader, that each was enormously hard, often protracted and filled with angst. Is it any wonder that after years at this, most caretakers need anti-depressants? My doc told me I was running on fumes, my tank empty. I heard him.

Here’s the good news! Thanks to the fact gathering above, many of my stifling fears were made more manageable. As you have read, many questions were wholly or partially answered. I began to build a disease-and-home management structure of money, people and organization. *I had plowed a small passageway of Better Understanding.* Halleluiah!

Bob’s disease process would periodically coast. We took full advantage of those times, only to have it abruptly resurface and slam us like a rogue ocean wave again and again and again. Absorbing each of Bob’s new losses was grave, devastating and cruel. Still, I *had* to adapt and adjust. There were no choices about that. And I did. We did.

It was about then that it began to dawn on me that I wasn’t enough. I couldn’t do it all, be it all. How could I find more support? How could I build a group of nearby people around me who understood at a gut level what we faced daily? How could they help shore me up and I them? Surely I could find that---couldn’t I? Couldn’t I?

Return next month, dear and favorite reader. There are some crazy outcomes. Join me for *Part 3: The Rock-Strewn Road of Early-Age Dementia: Excavating crushing stones to produce a grass-roots emergence of support! Our passageway to a Refuge of Knowledge, Answers, Comfort and Understanding.* Until then, be well.