

The Rock-Strewn Road of Early-Age Dementia
Part 4 of 4
Hanging on for Dear Life:
Bob's Crossing

Bob's Crossing, is your last access to his life. This once vibrant, infectious, devoted, smart, funny, clever, intellectually curious and deeply loving man finds himself on the last road of his journey. In this last part, you can observe Bob's rapidly-advancing disease clock and our attempt to "go for it"---to throw caution to the wind--to travel, experience, see people important to Bob, and then observe and feel our setbacks and challenges that almost, but not quite, take us down.

My email journaling (they are long and detailed) will take you to the end and a bit further. Come with me. Walk our path. Learn from our clumsiness and ineptitude as we relentlessly thrash our way to understand and stay competent. Hurt with us, be dejected and inundated with us. Feel the mountain-tops of joy and hope, and the valleys of despair and hurting. It's not an easy passage, but I welcome and challenge you to experience this with us. Thank you, dear and favorite reader.

And so we begin: *Bob's Crossing*.....

- 6/03 here's a mountain top if you've ever seen one! We went to Europe thanks to my dear brother's generosity. We went to their home in Monte Carlo (can you believe!) and did day trips into Italy and France, even saw the Grand Prix from the balcony of their apartment which overlooked both the Mediterranean (deep sigh...), one of the straight-aways and two of the hairpin turns. It defies description. Daughter Erika (then 31), through the generosity of her employer for time off, was able to join us for some time in Monaco, and then we all traveled to London for the theater and more sight-seeing.
- Erika had not seen her daddy for 5 months. She was stunned and shaken at the changes she observed in her Daddy.

One fact of note: traveling with Bob in multiple foreign airports, tons of luggage (those days are gone!) was a mess. This was 19 months before his death. I envisioned he could help far more than he could. (I lost him once for more than 5 minutes—an eternity with managing two luggage carts and not knowing where on earth to look. It was a scene out of *I Love Lucy*, for sure.) He could not help, could not follow my simplest directions. He was quite overwhelmed with all the chaos around us. I collapsed in tears once I found him and there were no understanding souls who stopped to help. Just think hard before tackling what I did.

- 7/03 I have mentioned about my email updates. Below, I have cut and pasted the update I wrote after we returned from Europe. From my heart, for you to read, unedited, dear reader.

Several people have asked me to write about how I am doing. It is hard to put into words, so if you are faint of heart, skip the next paragraphs. I will be plainspoken. There remains tremendous love, bond and trusting comfort between Bob and me. Unfortunately, what is going, and to some extent has already gone-----no matter what sparkling circumstances may be before us like on the Mediterranean coast, the Provence vistas, our backyard view, London plays, historical tours, fabulous food and great company around us---is the ability to relate and discuss and share thoughts with each other in the rich ways of the past. His thoughts are often (not always) disjointed, a bit jumbled and a

little off kilter. He has a real struggle expressing himself or describing situations/things. We lack the ability to have the riveting conversations, the deep introspection, the speculation or exchange of advice. His responses lack his usual good judgment and often, frankly, seem inarticulate and sometimes frivolous. Many of you have enjoyed him as intellectual equals in those pithy discussions. That ability is just flat gone. We too often feel "alone", empty and sad for what is already lost. Other times we're defensive and cranky----and who wouldn't be. All of these behaviors follow the outlook described in the medical research. So just "doing life" daily is marred, skewed and somewhat goofy for us. We certainly make the best of it with stiff upper lips and all that, but then we come to a point where we let down and talk about "where we are in the moment" and what's transpired since our last deep talk. I have begun being more honest about the rip-off I feel, how I despise the disease and it's robbing from us of our relationship's basic nature, essential qualities, sum and substance--the core and pith of who we were as a communicating entity. That oneness of interplay and interchange. And he responds likewise. We end in tears, but they are always healing. And then we just get up and go on.

- There is gradual decline, the disease marches. Meds are tweaked; our life is accommodated for 6 months.
- July 03 to April 04. There is constant but gradual decline, the disease marches, robs Bob and he gets worse and worse. Meds are tweaked, we adjust and our life is accommodated over a 9-month period. We did what we termed "family and friends tours" all through California where Bob was born, raised, went to school, worked and then married me. These were precious times for him, not to mention the joy he brought to those we visited. People reached both into him (and me) and around him in love and support. It buoyed us both. Here are two specific things we did:
 - September 03 – a nagging question kept at me: Is there more I should be doing? Is there research to press the boundaries of possible treatment? I knew from voracious reading that NIH had money for early-age dementia research. Are there any studies out there that could benefit Bob and future Bobs?
 - We ultimately ended up going to the quickest repplier at Indiana University. Martin Farlow, renowned neurologist, and Bernardino Ghetti (a brilliant Italian with an amazing heart) neuro-pathologist were interested.
 - We traveled there, spent two days interviewing and testing. It was blessing beyond blessing. They listened, they heard, they validated, they encouraged. Dr. Ghetti gave me his home phone number. Imagine. There was nothing happening that Bob could participate in, but they diligently followed Bob beyond death.
 -
 - Erika and I were determined to bathe Bob in some of Nature's best. So Thanksgiving 2003 we went to the Big Island of Hawaii for 10 days. Mind you, I could not have pulled this off without Erika. While we flew separately (and that was hard), she was with me the balance of the time. We took him on a helicopter tour of the entire island. We were amazed and thrilled at this experience. Sadly, we got little expression from him. Flat Affect had taken over hugely. We took him parasailing and got a little more expression. He also got to swim with the dolphins (see photo) and he was charmed and riveted in that experience.

- May 04 – It's my birthday. Some caring soul had taken Bob to buy me a birthday card earlier in that week. He could never have read the calendar, understood the calendar, or related to a notation that I was gaining yet another year. You see, I was 4 years his senior, so he delighted in razzing me and wouldn't miss this opportunity if only he was not diseased.
 - I observe Bob that morning. I do a lot of that those days--become the "clinician" and fly above it all in my mental hovercraft to accurately survey how he is on any given day. Small tasks, such as this, have become big ordeals. Handwriting is not something he can do well, if at all. But I so appreciate his determination. Shortly, I heard a loud thud and ran downstairs calling his name. I can still hear myself, panicked.

From my email journal.

Bob fell, the EMTs came and Bob was hospitalized for a non-displaced, fractured pelvis. Many diagnostics later, it was determined to be a syncope event (fainting), due to low heart rate, which necessitated a pacemaker implant.

- *5/17 pacemaker surgery; I stayed overnight with him most nights*
- *5/17 delirium events assuming from anesthesia, medicated for psychotic episodes, thus had to be pulled off his refined "cocktail" of meds supporting his brain*
- *5/20 released to Rehab facility for pelvis, reinstated some meds*
- *5/21-22 reacted with more delirium from reintroduction of old meds, so discontinued some of them (this is crazy and so hard on him and it eviscerated my heart))*
- *5/24 doing well physically in rehabbing pelvis, but rushed back to hospital fearing a cardiac event, presenting very high blood pressure and pulse*
- *5/26 after much testing, determined nothing physically wrong; instead determined to be extreme agitation and inability to cope with mental stresses of (to him) busy, noisy, overwhelming and alien Rehab environment (he had not been able to verbally express any of how he was feeling. They had even netted him into his bed to control him. That about did me in. So...*
- *5/27 released to home for rehab*

This is day 5 at home. I am fighting tooth-and-nail for insurance coverage for rehab at home. They won't. I became a screaming banshee to whomever I could get to talk to me. I fight and fight.

It has been a very, very rocky road for all involved in caring for Bob and for Bob himself. Bob is still without many of the meds that formerly supported him so well. This means he has pretty wide swings in his feelings and responses. To manage his heightened periods of agitation he is presently medicated with Seroquel. It helps, but I am eager to find some way to support him even better. We see his doc tomorrow. (And he upped the Seroquel which helped)

We have had in-home physical therapy which has rehabbed his pelvic fracture. He is walking today without any devices and with minimal assistance on stairs. Home health care has been here 24/7 since his return home. I've described our situation as having newborn triplets. Two sets of hands are not enough. Our family and friends here have pitched in. Bob's brothers from CA and Erika came for the first phase of in-hospital time; this second phase at home is being supported by his mother and one angel, disguised as a friend, from CA who came to help me in my office for two days (that way I didn't have to go postal on the insurance company). She worked through a good portion of the morass of paperwork dealing with 4 reporting/paying entities including the government. She

helped manage and direct the hoards of people coming through here to sign us up for one thing or another and the mountains of questionnaires, etc, thank you precious Karen. For Bob it was worse than Rehab, and I only barely kept my cool. I must take up that paperwork battle again tomorrow where she left off.

Bob has lost a lot of ground. His expressive aphasia is profound. His grasp of what you say and how to respond is much more limited than pre-event. It is even hard (but not impossible) for him to mimic the therapist with exercise movements. I pray that he regains some of what he's lost during this time of incredible stress on him. He still has occasional delusions and periods of over-interest (perseveration) in things and people. He is residing downstairs in the large family room with hospital bed and other accoutrements to support him until he can regain enough (continence, lack of agitation periods, etc.) to move back upstairs with me. This allows him a lot of freedom in the house and outside on the deck. He enjoys that immensely. It is calming and soothing to him to stare at the watermelon mountain and watch the tram run its loop.

We again ask for your prayers and good thoughts. I have seldom been this fatigued, so bear that in mind as you read and digest. We are hanging in as best we can. Sometimes my fingernails have been blue from barely hanging on, but I've not slipped yet. God is faithful and true. It is hard, but not impossible. This too shall pass, and we'll be on to another phase of Bob getting better.

- June 04 email journal:

Greetings from us of great joy and thanksgiving,

Sounds like a holiday greeting, but it's actually better. I am so glad to report that Bob is doing better. Here are a few details for those who like detail:

- *Bob's fracture is healing well and now at 3.5 weeks of recovery he is using a cane comfortably and his pain is tolerable with over-the-counter meds. He developed some back spasms which aggravated his overall comfort, but muscle relaxants are unwinding that as well.*
- *Bob has recovered continence almost 100% and that is an enormous victory medically and says a lot for the near future*
- *His heart rate and blood pressure are in a normal range daily for three days now.*
- *His times of delirium and paranoia are much reduced and any of we caretakers can "bring him back" easily*
- *His bouts with acute agitation are being managed well with the increase in medication which has led to the betterment of his overall sense of well-being*
- *We see much more of "Bob" now and less of the results of all of his trauma*

His physical therapy continues, but he is walking stairs as his main exercise. That demands bearing his entire weight on his bad side, but he is doing it well and feeling gratified with his own progress. We will do some speech therapy which will overlap into occupational therapy. He is re-mastering some fundamentals of daily living and am told that speech therapy often reorganizes some of the brain processes that he needs. It's a long shot, but worth a try.

His expressive aphasia is still a struggle, but he understands completely whatever is said. He may not be able to tell you that he does, or comment in specifics, but gets what's going on and often can express appropriately. If things go on too rapidly or if there are too many things at once, he struggles. All in all, he has made stupendous progress and I am extremely heartened. A good friend doc has kept a close eye on him and was over last night to observe and visit with him. He feels we've made great strides

and all signs point to possibly even some more ground being gained. It takes time and patience.

Eliminating the initial chaos was helpful. We are now more rested and the house has become more orderly and routine with caregivers. It won't be long before we can trim some of that help and even get Bob back upstairs with me at night.

Let me share a few of the things that we've learned through great struggle that might be beneficial to you or someone you know. We'd like to eliminate your struggle by sharing the information.

- *Did you know that health insurance companies can assign Case Managers to an extensive or expansive claim? (These are 3rd party people, obviously hired for the company's benefit, but they are able to get things done quickly that could take hours from me if I could affect it at all.)*
- *They can assist you in bringing non-network providers into your network.*
- *Failing that, they can renegotiate rates to make non-network providers less expensive out of your pocket.*
- *Hospice is not just for advanced elderly, imminently dying or even 6-month before dying benefit anymore. Up to two years ahead of death, Hospice can provide amazing resources, equipment and personnel to assist. This has been a big benefit for us.*
- *Inside Hospice is speech therapy, home health care daily, skilled nursing weekly or more if required: social workers, chaplains, bereavement counseling (did you know there is something called anticipatory grief bereavement counseling?)*
- *Access for emergency allocation thru Medicare*
- *State capabilities for those with terminal disabilities*

Bob's mother remains here as a true help and source of joy for him. Erika will return for Father's Day celebration. Friends have brought abundant food for our tummies, food for our souls, counseling and listening, advising and generosity beyond belief. We are blessed in every way.

We ask for continued prayers of healing for Bob, resilience for his mother and strength & focus for me. As a good friend recently wrote, "Doesn't evidence of His love for you continue to amaze". Indeed.

August '04 Email Journal:

Hello to each and every one of you,

Some of your are regularly in contact by one means or another, some are rarely, so this email will be new news to some and somewhat redundant to others. Please bear with us. It has been a long number of weeks since my early June update on Bob's health and well being, thus a lot has happened. I'm able to bring you both good news and the other side of that coin as well.

I will begin by telling you in general how he is, and then for those who like details, I'll bullet-point the salient issues. I hope this format works for most of you. When I use the term "we", it includes Erika, who has been here basically every three weeks, sometimes more often, to steadfastly tend, love and care for her adopted Daddy whom she loves deeply. He is her hero, the man who redeemed fatherhood for her and marriage for me. He is slipping from her adoring grasp. He peers intensely into her eyes, willing her to

know of his devotion and care for her, his sorrow and grief in leaving her, and his desperate inability to defy this demonic disease.

For us all, the good news is that since his fracture he now walks without aid, with only a slight favoring of his right side. Also, his sense of humor and his tender heart remain quite readily accessible. Further, it seems to us he can mostly comprehend what is said to him. He may not be able to act on it or even appropriately respond (more on that below), but I am assured that he "gets" most of what is said to him.

To tell you the not good news, I am going to be brutally honest. I just can't sugar coat things and still be true to Bob, his struggle and the Truth.

The disease continues its iron-fisted, merciless and unyielding grip on Bob's frontal and temporal brain lobes, and perhaps some of the rest of his brain as well. No medical test or scan known to man can show us what is happening at the cellular level, and at one cell at a time, it is depriving us of him. As a result, Bob is in a steady, relentless decline. All of his faculties are impaired and several of them are gravely impaired. We are sad to report that he has lost much ground mentally.

Here are some of the details (and I'll use where I left off in June as a reference for beginning), and then we'll talk about how we're coping and where our eyes are looking.

- continence, while he gained ground initially, is again giving way (accidents multiple times daily)
- delirium and paranoia are manageable with the med Seroquel, an antipsychotic used commonly and well tolerated by ailing brains (he can become very fearful and primally protective, including lashing out, which happens very infrequently with the meds)
- agitation is managed with the same drug, and with lots of rest, but is not controlled, especially as the day wears on (he naps and sleeps more hours at night)
- his ability to access words and speak what he wants to say (expressive) is profoundly hampered (aphasia)-- (this is frustrating for him and me, and periodically wears thin on us both)
- his short term memory is also thoroughly impeded and disrupted (he retains almost nothing which then requires tedious repetition of information)
- his long term memory is being invaded as well, but gladly less so to date
- he cannot write almost altogether, he cannot read aloud almost altogether, he does not read and retain at all, thus he reads almost not at all
- his attention span is strikingly diminished (he has little, therefore, to occupy his time, but never seems bored, however does wander, which can be unsafe)
- his swallow response has begun being affected
- his gait has drastically slowed, tends to somewhat shuffle, and moves more cautiously (things come at him too fast to process)
- he needs 1:1 cueing for most everything, even dressing, showering, (he's a 185 pound toddler in his abilities)
- he often confuses identity of items, or cannot name something at all, he often cannot read even a digital watch, has no idea the day, month, season or year, his SS#, where we live, etc. I will say more about the "march" of the disease below....

Erika has just read this and comments that it is nigh-on-to-impossible to capture for you the deterioration and diminishing of this formerly vibrant, capable man.

These are the main points. It is a long, painful (and incomplete) list to write and for him to endure and for me to care for. Thankfully, his brain debilitation includes a stunting of his own emotional reactions to his status. He knows his situation "factually", but it has little effect on him. The downside is that he is not able to exude his emotions outwardly either. His facial expressions remain quite "flat". He even has a downcast countenance now, and yet he will answer that he is happy and fine.

It's a grim picture. I know. It is a grim reality, but I've tried to never whitewash the facts. So where are we, how are we coping and what's ahead in the march of the disease and where do we go from here?

Where are we:

- we have help from Hospice each morning to shower and dress Bob*
- we have a companion hired to come twice weekly for 4-5 hours to give me a break*
- we have Jerry & Sharon (I so appreciate) who will take Bob for early evenings when I have a church commitment, and other occasions*
- we have other friends who generously spend periodic time with Bob*
- we have an utterly superb medical advocate, friend and supporter who tirelessly supplies what is needed for question answering, clarification, and mental sustenance, and who keeps us from losing courage or stability and who champions Bob in the face of opposition and odds, and who has helped me carve a team of doctors to care for Bob*

How are we coping:

- good, not so good, lousy -- just depends. The fatigue factor of 24/7 monitoring is all-encompassing to me. I am exhausted a lot of the time. He is like a 2-3 year old in judgment and compliance.*
- our faith is the under girder of every moment of every day; it is Bob's mainstay as well*
- joy is here more often than you might think*
- we hold on very tightly to one another; our love is truly conquering all*
- we have great support from near and far from our family, friends, church community, and greater faith community--and we continue to need that and more*
- we have had many out of town visits from dear family and friends; we welcome others. He enjoys so much the visits from familiar friends and family. It is quite a shock and adjustment for people when first exposed to his changes.*
- we have grown in faith, in personal maturation, in perspective, in tolerance, in compassion, in stamina -- we have learned and are eager to learn whatever lessons we each have to learn through this demanding and insatiable time, lest it be a waste. I pray that I don't miss any of the lessons.*

What's ahead:

- we are advised that if we are to travel to visit in any meaningful way, it should be now*
- we leave for the Bay Area on 8/17, visiting family and friends there and on our way to our Lake Tahoe cabin, returning 9/13 if all goes well. It is pretty clear that this will likely be our last time.*
- the disease will soon completely rob Bob of his ability to express thoughts*

- *the next step is that he will begin not comprehending what is said (I see bits of that in just the last two weeks, I hate to say)*
- *when that happens, other things physical and mental will begin*

Where do we go from here?

- *just about anywhere, hopefully to visit brother Mike & Charlotte in Montana/Oregon, early in the Fall*
- *hopefully to Atlanta for Thanksgiving*
- *short jaunts here and there -- Bob has little stamina physically, but looks good*
- *live in the moment*
- *employ more in-home care as the situation warrants*

If you are in the Bay Area or on our way to Tahoe and want to see us, call my cell phone 505/450-9084.

So. How do I sign off? Let me say this from my heart and soul:

It is remarkable, actually, to be in our position. We get to see the hands of God, the feet of God, the eyes of God, hear the words of God, feel the embrace and assurances of God right here where we stand. He lives luminously in every helper, every phone call, email, goodie brought by, card in the mail, yard work done, paint touched up, caretaker respite, invitation to dinner, breakfast or whatever, on and on. Thank you for supplying much of what we need. If you ever doubt that God is, come visit our home and experience the awesome grandeur of Grace, Peace, Mercy and Love. We hurt, we cry, we mourn. It is altogether a very lonely disease process. Sometimes it owns us for a while, and the despair is like a boulder we cannot crawl out from under or a hail storm where we can find no shelter, relentlessly pelting us with the harsh reality of the loss.... but not for long. We prevail.....almost daily. And we will continue to, by His strength and your support.

*With our love and grateful thanks,
Gretchen -- for us all*

October '04 email journal:

Greetings to All,

I am choosing to stop watching the 2nd presidential debate. I finally realized it was giving me both a stomach ache and making my teeth hurt.

It has been a long time since I've written a "global broadcast" update on Bob, so tonight seems like a good moment to bring things current. Bob just finished a walk with one of our caregivers and it was a beautiful 73 degree NM Fall day. There are many things that drive me batty about NM, but the stunningly mild, welcoming weather is one of the main reasons we live here. Balloon Fiesta is in full force as I write.

We did go to California as planned, I'm pleased to report. We were able to see a lot of family and friends, just not all that we envisioned, as the end of the trip was cut short. For week three, went to our home in Tahoe and on 9/3 Bob had a major seizure. Long, long story short, he spent the day in the ER. Bottom line, we got him loaded on Dilantin (anti-seizure med) made sure nothing in him was broken, and brother Craig accompanied me home to Albuquerque via Reno the next day. Our medical team here in Albuquerque was like no

other in making sure things went well both in the hospital and preparing us for the plane trip home.

Since then, but leveling out the last 10 days, it was a mini-version of some of the struggles in May when Bob fractured his pelvis (poor sleep cycle, medication problems, rapidity of decline and adjustment thereto). I'm glad to report that he is now reliably sleeping through the night again, medicines have been adjusted, and we're adjusting to his new levels of functioning. It has been a challenging and trying 5 weeks.

Briefly, some of you may be wondering why he suffered a seizure. I understand that the scarring of the brain by the disease interrupts the electrical flow, and often, but not always causes seizures.

So where is Bob now, you may be wondering. I'll do the bullet point thing so that I stay briefer.

- the expressive aphasia advances -- there are days that he is almost mute (the norm), and then days when he is more interactive (the exception)*
- complete incontinence of both bowel and bladder -- we manage this pretty well*
- agitation, aggression and disinhibition are quite present -- we are close to maxed out with the reliable med (Seroquel) that has kept Bob more "even" than not, so will be making more adjustments very shortly*
- more memory decline*
- almost no attention span*
- he is wandering and is a wandering safety risk (he has lost all concept of judgment), so we never allow him to be more than 10' away from one of us*
- swallow response worsening but gradually*
- posture is hunched and slower, halting gait*
- 100% need to cue for all tasks and all activities of daily living*
- Feeds himself about 25% of the time, well at breakfast and then diminishing over the day, some days better than others*
- still has some periods or moments of delirium -- talking back to the TV or answering something that I've asked someone on the phone, are some of the more benign examples, pronounced startle response, confusion-- e.g., thinking we're in the wrong car, or another house is our home*
- when the doorbell rings, Bob may answer it, and if he does, he will approach and greet you and that will be the extent of his active interaction or meeting your eyes*
- his phone conversations are now quite stunted, and he may not be responsive at all*
- he is extremely hyper-vigilant (perseveration), and by the end of the day, it is a behavior that saps me*
- the disease is cruel and unbending in its progression; he continues to succumb to the invasion and decimation of his once brilliant and agile brain.*

So what does all this mean in our daily life, you might be asking? Let me try to translate it by telling you specific accommodations we have made.

- Hospice care for daily showering remains in place*
- Hospice nurse sees him 3 x weekly in our home*
- Hospice responds to any issues we have almost instantaneously, same day med delivery (these people are breathing, walking, talking angels on earth for us)*
- Hospice professionals (advance bereavement counselor; social worker who does wonders; chaplain who is amazing) including doctor staff*

- 24/7 non-hospice trained aides caregiving in 12-hour shifts since we arrived home on 9/4, probably from now on (we have a good team in place for days and nights; they save me daily from the tide of overwhelm)
- Family and friends, near and far, supporting as they can
- email support from many people
- formal and informal church community support on several levels (thank you Stephen Ministry)
- our almost-in-residence physician/friend/chef/counselor continues to keep very close watch over the welfare of both Bob and me, and there is no earthly measure by which to express the value, meaning and significance of what Dr. David brings to us mentally and spiritually in addition to overseeing Bob's processes

Speaking less specific, I'll address how we're coping:

- prayer is the only thing that is able to sort out and funnel me through each day
- I sigh a lot and cry often when I stare into the too-often vacant eyes of my husband
- I delight a lot and feel joy to my toes when I, not often enough, can stare into the not-vacant eyes of my husband and can see and feel his connection
- I don't know what I'd do without this professional team around us
- this home we purchased for very different reasons, accommodates as to not fall over each other with triple and more the traffic inside, ministers to us with spaciousness and comfort to accommodate Bob's vigilance, allows the need for me to be elsewhere during the night yet accommodate overnight family visiting, and it offers vistas and visiting wildlife to still delight his eyes and ears (and mine).

Where do we go from here? Good question.

- I do not see anymore traveling. He can't manage the over-stimulation involved, and he doesn't readily comply. I can't manage when he can't be managed, so our hoped for jaunts are out.
- Visitors are welcome, but I suggest only a few days. Do not wait to come.
- Keep this home environment comfortable and safe for Bob -- for the duration, I might add
- No heroics will be employed in his care, but all comfort will be (including a flu shot!)

I've said in past emails that I want to be able to see the silver lining in this cloud, the rainbow at the end of all of this, or in my vernacular, the glory which God promises will come from all suffering. I do not know much these days, but I do know that we can do this walk. All of us. We can walk this walk with Bob and do it well for him. I have small glimpses of that Glory. I get small nudges of insight. And I believe.

I will close with this lovely vignette. Brother Jerry is on the foundation board of one of the local hospitals. There is a whole renovated and new section recently completed. It is called the Center for Spirituality and Health. It contains the chapel, the chaplaincy services and two new areas created: Healing Sounds and Healing Garden. These two new areas are being formally dedicated by Jerry & Sharon to Bob (and me). The service will be early next week. Doesn't that clutch at your heart? It should. That is part of the Glory. I hope you believe as well.

We send our dearest love across cyberspace.
Gretchen -- for us all

December '04 email journal:

Dear All,

It is late on Saturday evening, and I face a long night alone. That fact is tempered because we expect my main night caregiver to be a first-time daddy by morning! Lots of balance in this life if I look carefully enough.

We are sending our Greetings of the Season via e-mail this year. Somehow a newsy letter and requisite photo doesn't seem appropriate. We are Christmassy around here, however. Stockings are hung by the fireplace with care, the tree (thank you, thank you, Bruce, Lynn & Nichole!) is up, house is festooned, Luminaria light the drive and walkway, the pine trees and bushes are lit in white lights, the aspens in colored lights. All in sheer determination to feel more normal than not.

Bob delights in the décor. He watches the tree rotate for hours and stands looking at the Luminaria with a smile in his eyes. Much family ate Thanksgiving dinner at our table. Bob was able to make it down the stairs albeit with great help and slow going.

We had a thank-you gathering for my entire Circle of Trust friends, all caregivers and our hospice family. The glaring exclusion was Bob. He could not come downstairs, literally. He isn't venturing from our bedroom suite at all. But he is very comfortable with his recliner lined with sheepskin, his hospital bed and his big-screen TV.

Since our last e-mail Update in October, we have remained right here at our home. Traveling days are behind us, but former trips hold wonderful and lasting memories. Many of you reading this have been a part of those treasured times.

As I re-read my October note, I am further stunned at the changes in Bob. Can it only have been two months ago? In order to bring you up to date, I will elaborate below, and will stick with the bullet-point format and a summary ending. I know many of you keep these and refer back to them to understand the path we've taken.

The current status on Bob is as follows:

- Bob still knows faces, voices, old stories recalled, and retains some humor response. This is a huge blessing to us and anyone who comes to see him.*
- Bob is emotionally based, meaning he wants to be physically connected to someone constantly. Touch is huge, much as a baby requires to thrive.*
- He is loving in his encounters with family and friends.*
- Bob is also primally based, meaning his main focus is to have his every day living needs met. Little beyond that is of sustained interest to him.*
- He is content and peaceful most of the time, even watching TV, which two months ago was a rare and agitating activity. He does not particularly comprehend what is happening on the screen, but he is "entertained" by the animation. Slower things like ice skating, golf, or tennis are more to his liking, but football and the cartoon channel are also pleasing to him.*
- The expressive aphasia continues to advance. This is not galloping, thankfully, but edging downward. He says very little, but does occasionally speak up, sometimes greatly surprising us.*
- The agitation/aggression/hyper-vigilance is mercifully almost gone. This has been accomplished through both proper med choice, dosing, and unfortunately, also by the advance of the disease. It has given way to the peace mentioned above.*
- Bob's meds have been greatly curtailed. He takes only the anti-psychotics and anti-seizure meds.*

- *His gait has changed. He has become very tentative about stairs, especially walking down. Whereas in October he could still be cued to do things, he is 80% unable to comply with directions. He must be directed and assisted to accomplish most all tasks, even eating. He feeds himself less than 5% now. If you put a slice of apple in his fingers, he will eat it. If you put it in his hand, he won't. Isn't the brain a conundrum?*
- *Bob is experiencing much more confusion and delirium, but it does not frustrate him. Amazing.*
- *His startle response has moved from slight to significant. Also manifesting is abrupt jerking (not tremor, which he has as well), and I am assured this is not treatable, but is just bad frontal brain.*
- *Bob is sleeping a large part of the day in addition to a long night's sleep--more of the disease advancing.*

Our accommodation to these changes has necessitated adjustments in helpers. We have a superb team of Hospice aides, nurses, social and spiritual counselors, and an occasional doctor. In addition, we have an outstanding team of 24/7 aides under our own hire. Each of these devoted caretakers has a true affection for Bob and cares a lot about what matters to me. Interestingly, that is not an easy combination to find and/or keep. Grace.

Hospice remains dedicated to us for the duration, and pending personal emergencies, so does each of the caretakers. We consider them part of our inner circle and have experienced both deaths and births in even that circle. More Grace.

Our family near and far supports as they can. Our friends, near and far, do likewise. We've had rich, meaningful visits from many. Such support and devotion to us actually blows my mind a lot of the time. Additionally, the amazing support of our Dementias of the Frontal Lobe Support Group cannot be measured. We have seen a family through one death and another is imminent. These people are true heroes. More amazing Grace.

Bob's medical team is superb. Topping the list of supporters and medical advisors, unequivocally, is our friend Dr. David. His heart beats with Bob's as he compassionately cares for him medically. He generously opens that care to me in counseling, consoling, candid perspective, unvarnished truth along with caring validation and encouragement. He tips the heavily-weighted, negative scale to the positive when it comes to me "keeping balance" in my outlook. He also cooks and makes us laugh. Grace without measure.

Foundational to all the above is Bob's and my deep and abiding faith. Without it he would have no hope, and I would be bitter. Profound sadness notwithstanding, there is hope eternal, and I am not bitter. It is hard to see our once symbiotic paths now so divergent. Perhaps that is yet another blessing to be found in the process of this awful disease. There is time to adjust, and time to reflect, and time to discern, time to peek and know that there is life on the other side of this for both of us.

What's ahead?

More of the same and different as well. Parts of this walk get harder and harder. Other parts get easier and easier. It is fatiguing and sapping, often confounding and confusing. The flat affect of the disease almost totally robs us from seeing pleasure on Bob's face, but his contentment is evident.

The adjustments required of us by the disease are insatiably demanding. There are days I am spent. There are days I feel kicked in the stomach. On the other hand, there are days I

am invigorated. Thankfully, Bob's overriding needs are now primitive in nature and, with proper overseeing, are easily satisfied. He is "happy" most of the time.

The road in front of us is formidable. I get a rock in the pit of my stomach if I look ahead too far. A dear friend and neighbor brought me a gift. It is a small, luscious pillow with same color stitching which reads "One Day At A Time". That rather overused phrase has dramatically striking meaning in our lives. It is the only mantra that makes any sense. I am prudent and planning ahead, but too much focus there is untenable, and certainly unsustainable.

Many have asked for specifics:

- The cost is staggering. But I believe it to be manageable.*
- Bob will remain at home, which is critical and not open for discussion; no heroics, but all comfort and palliative care will be employed.*
- Help will remain status quo.*
- Visitors remain welcome.*

May you be blessed, each and every one, by the depth of the meaning of this Season. Even in death, the gift of life anew for me and the gift of life eternal for Bob.

*Love,
Gretchen (for us all)*

The very end of January '05 email journal:

Loving Greetings to All,

I am writing with a heavy heart and will make this brief. Late yesterday Bob began a fever which persisted and increased through the night into this morning. After discussions and examinations, we find that he has a quickly blooming, fast progressing and significant pneumonia. This is an unwelcome but not an unexpected event. Because of his reduction in lung capacity and inactive state, he is susceptible to aspiration pneumonia. And here we are.

I have done much fact gathering and soul searching, and had expert discussions. I have replayed Bob's discussions with me numerous times. We will not employ measures to try to remedy the pneumonia. Should we employ even the most aggressive measures, we are not assured of recovery. And the reality remains, recovery to what "quality state". Bob's quality of life in just the last three weeks has taken a dramatic and apathetic downturn. Further, he would surely repeat with the same problem very shortly again. He is very, very tired of this fight.

He is extremely peaceful, content and comfortable. We will keep him that way. While miracles do happen, we do not expect him to recover from this dreaded turn of events. Where before we were thinking in terms of a few months, we are now looking at a week or less. Bob is mute but he knows us. I am promised he will remain like that.

We ask and thank you in advance for your prayers for his continued comfort and peace.

*With love from all of Bob's family to you.
Gretchen*

Dear and favorite reader, thank you for making it to this paragraph. You have read *so much* thus far; it takes real guts and determined interest to stick with me and now to come forward to 2010. It's almost over, dear reader. You can sense that, can't you? I know.

Bob died 7 days later, on February 5th at 2:10 a.m. in the morning, just days after this last email entry. Family and friends were here with me. The coroner came to lovingly collect Bob's body and with detailed instructions to begin the harvest of Bob's fresh brain to be transported to our esteemed doctor, researcher and friend, John Adair, MD, here and to Indiana University to Bernardino Ghetti. Their teams would analyze and write to us their findings of the exact pathology of his dementia.

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. Irrespective of what organism was the destroyer, there is only one course of treatment for dementias of the frontal lobe—so it matters not, actually. His pathology results showed beta amyloid protein. That is Alzheimer's Disease. At 54. Imagine.

We don't think of a person like Bob when we think of Alzheimer's Disease. Why is that? It is because we think of the profoundly old and a person who recedes into nothingness, vacant and void, because the disease destroys primarily the old brain. Today we know far more than we did 8+ years ago.

- Nationally there is a greater commitment to educate and inform the public about dementia diseases of the frontal lobe via the Alzheimer's Association.
- Doctors think about it as a causative agent far more than they did in 2002 when we were desperate to understand what was happening to Bob. But still not enough.
- There is a stronger commitment in Washington to find a cure.

All of this advancement is heartening but cannot come fast enough for those who are becoming victims as I write. The Baby Boomer generation is lurking and will be the largest mass of humanity ever to age in our country's history—many will succumb to this devastating disease process. How will we respond to them and their families?

Our support group helps to keep sane those who can find us. They come via the local ADA, bless them, and through personal referral. We began very small and now we flourish—an odd word to use here, but it's true—we flourish. Why?

- Because we've now walked this abysmal walk for 7 years with so many, many families. We have helped them to remove, step over or blow to smithereens the rocks strewn on their roads.
- Because of our collective wisdom about all phases of this disease from diagnosis to death, we've compiled a small but worthy data bank.
- Because we know the outstanding practitioners since we constantly update through our Group's experiences.
- Because we know support organizations and places to find money, both private and public, some completely obscure.
- Because we know websites and reference compilations.
- Because we know the establishments, who with competence, commitment and care, are an alternative when being at home isn't feasible anymore.
- Because we **know** how to help--period. We've been there.

In the years since Bob's death, the dementia-aware community has changed. It is not sweeping change, but it is significant change.

- There has been more national press taking note of the aging demographics.
- There has been more attention focused on the staggering increase in all dementias.

- There is the medical research community which is receiving more funding from gifts from you, from grants, and from the government's stronger commitment to find a cure.
- There are selfless people like Maria Schreiver and her 2009 HBO special which educates and also helps to nullify the stigma of all dementias.

Thank you for traveling our journey with us. I am exhausted again, 8 years later, from all this writing and revisiting the pain, but I am wide awake to the cause. If you or others want to contact me, email is ggshiple@comcast.net; phone is 505.823.1554.

Awareness is raised. Now it needs to be raised through the roof. Whoever you are, dear and favorite reader, will you help?

Vaya Con Dios,
Gretchen