

## The Rock-Strewn Road of Early-Age Dementia

*Frustration and denial to diagnosis: the rocky road of Pushing Discovery.*

Part 1 of 3

This is “one of those stories”.

It was 2002, he was 51--a GQ-kind of guy--he had been vital, intelligent, gifted, quick, curious, fun, captivating, involved, ego-less, loving, devoted. He was my husband, and he would be dead in 3 years.

His mother called me long distance the Christmas of '99 wanting to comment on our Christmas card photo. “Bob doesn’t look right in his eyes”. “Oh, Mom”, I said, “he’s fatigued from traveling so much, but he’s fine.”

Only he wasn’t.

What she saw, a mother’s eye, was some of the first visible signals of Early-Age Dementia. His eye gaze becoming flat. Emotional expression blunted. Photos tell that story well.

Other symptoms were there and more cropped up. Why did he say *that?*” or “Why *didn’t* he say anything?” or “Why’d he do *that?*” or “Why *didn’t* he do something?” “What an *odd* reaction.” or “He didn’t *even* react.” The haunting list grew.

He was consulting in the East. Much could be passed off to fatigue, preoccupation, jet-lag...blah, blah. And normally I’d be right. Except it wasn’t any of those things. And I wasn’t right.

There’s always the straw, right? The one that break’s the camel’s back. For me, that straw happened one evening the Fall of 2000. After a bizarre and maddening incident at home, I spoke up. “Bob, that’s it. Either you either face that you have a profound problem, go to the doctor and let’s get to the bottom of these critical changes in you---or there’s the door, and you know which way the knob turns.” He cried. And he’s wasn’t a crier.

Thus began our rocky journey toward a diagnosis.

To state the obvious, diagnosing is a process of elimination. Tests, tests, tests, further tests, repeated tests, bizarre tests, more tests. On and on, fruitless, for more than a year. The doctors became, frankly, exasperating. The diagnosis of early-age dementia was not on their radar. I can’t begin to tell you how excruciatingly wearying it was *not to be heard* by generalists and specialists alike. It was exasperating, ineffectual, and futile. It beat us down.

Bob continued showing more aberrant changes in behavior. Confusing, confounding, befuddling, alarming, maddening behaviors. Who *are* you Bob? Our road was strewn

with rocks obscuring our passageway. No one had answers. Our road looked as if it was impassable. The rocks have names. They're in the frontal lobe. Here are a few:

- Impaired judgment: he over-drunk; he didn't pay attention to work; he took chances in the car--passed on the right shoulder, misjudged oncoming traffic.
- Communication: he distorted facts, came to "off" conclusions; sequencing a story became jumbled and pointless.
- Apathy: he cared little about people, issues, problems, events; stale and corny humor.
- Short-term memory: he couldn't work without a list and belabored the list; remembered only parts of events and jumbled them; asked the same questions continually.
- Spatial orientation: he couldn't pack the trunk of the car; cutting paper wrong to wrap a gift.
- Coordination/sequencing: he became maladroit with simple things like getting into or out of the car, using a ski lift; use of utensils became confounding, using them upside down or saying "what does this do".
- Paranoia/delusions: who's that person in the mirror; bugs on the wall; handwriting on the rug.
- Expressive aphasia: used words that didn't fit; could seemingly absorb a story, but couldn't respond because word-finding was overwhelming; he occasionally used words that were not even language.

I could go on endlessly but won't. To be sure, we all have a blip in our own brains that sound like these rocks, but the rocks on Bob's road stayed, multiplied in his brain and eventually took his life.

We plowed ahead toward a diagnosis. During Thanksgiving weekend 2002, Bob was tested by a neuro-psychologist. Bingo! She really got it. She sat with me and our adult daughter, Erika, to grimly explain (they cannot diagnose) what Bob's brain could no longer do--ever.

She said Bob was profoundly depressed, had extensive short-term memory impairment, delayed recall, spatial confusion, planning/organizing/completing discontinuity to name only a few—all familiar. She drilled into my eyes with hers lest there be any misunderstanding on my part: "There is something gravely wrong with your husband; you must find a doctor to help you; he will never work again; he is very impaired".

What? What???

It was shattering. Where do we go, what do we do?

By a fluke, which later felt like a miracle, we found a doctor who heard us instantly. Prepared with all of the many reports, test results, multiple scans and now with a definitive neuro-psych exam, we saw John Adair in June 2003. He is the guy at UNMH and the VA who works tirelessly in this specialty of neurology. It fits here to say that he

carefully and generously saw Bob until it was clear to all that he could no longer help, as did psychiatrist, Kenneth Bull. They were our go-to guys.

Okay, now we had doctors on board, and a best-guess diagnosis of fronto-temporal dementia. FTD. A humbling diagnosis and one of many dementias that strike the frontal lobe and which move fast and is terminal.

But now what? What meds do we try? Who could we talk to; who has walked this rocky road? Surely there were people who had gone before us, right? People who could lend an encouraging ear and give us advice? Support groups? The answer: no, there was zip.

Community support specific to younger-age dementia (which attacks the frontal lobe, dementes the brain wholly differently than traditional Alzheimer's and brings a swift demise) was non-existent in our state. This horrendous disease, unspeakably frightening and isolating, had no support system for us.

I fall into a weeping heap. Frightened, overwhelmed...where do I turn? Where is help? My partner, always wise and by my side, always a part of decisions is demented. He can't help. He can process very little of this. He's actually in the way of help. He is now the problem.

What is ahead of us? How on earth do we do this alone? How does this disease progress? How does it end? When does it end? How do we adapt? How do we pay for all of this? What happens when the money runs out? What does our medical plan provide? Are there public funds to help? Will he have to be institutionalized? What does a place like that look like? How could I keep him at home? How do I handle the family? What about my job? How do I find out about any of this? This cannot be real, it just cannot be.

Return next month for the second of three parts to this story: *Griping fear and uncharted waters: Bulldozing a small passageway in the rocky road toward Better Understanding.*