

## Watching the Lights Go Out

### An Autobiography

I have Alzheimer's disease.\*\*

I've probably had it for about two years, but it's still pretty early in the illness. Most other people don't notice my illness yet, although my memory is starting to move from a normal "bad memory" that lots of older people have to an abnormal "there's-something-wrong-with-his-memory." I don't feel abnormal, at least not yet. But, in addition to the memory problem, I'm certainly slowing down. As a retired physician who has seen his share of mentally declining patients, I know what's most likely in store as the disease gets worse: A long, progressive mental decline (to the point, for instance, where I don't recognize my family), nursing home care, and early death from complications of the disease.

I'm writing because it may be helpful for people to know what one person's process is like from inside the diseased mind. Most of us are scared of Alzheimer's disease. Our fear may arise because of the deep unknown of the disease. Demented people seem so pitiful. Is that my future?

But, at least for me, the fear is of shame and abandonment. At least it was for me. I know my own reaction to a demented person. What do I say to him? How do I respond when he asks me my name for the fourth time in fifteen minutes or repeats a story he just told us? As a result, I'm afraid, I find one way or another to abandon the sufferer, not because I want to but because I don't know what else to do. That's certainly what I usually did. But abandonment is what I now fear the most. I want those of you who don't have the disease to know something of what it's like to be in this position so that it's *not* so difficult, so you can allow yourself to find your way into the world of the Alzheimer's disease sufferer, find your way back into relationship and won't have to abandon me or others so easily.

I'm also writing for those of you with early Alzheimer's yourselves. I understand that you may not want to know what your future has in store for you, but I remain convinced that the more we know and the more we accept what is coming, then the less suffering we will experience. I don't know what my future holds, either, but I must say that, so far, it's been an interesting ride. So far, my relationships have become closer. So far, hard as you may find it to believe, my life has been better than before I knew the diagnosis.

It will probably be useful to know something of my previous history. So this introduction is about. Each of us with this disease comes with a unique history that profoundly affects how we will experience it. I am a physician. I practiced for seven years as a general practitioner in a rural area of northeastern Minnesota and then for ten years in the inner city of Washington. I considered myself a good doctor, smart and well-liked. I became a writer—publishing three books and many articles—a frequent lecturer, and a teacher. I'm an intellectual, so a large part of my self-image is invested in my intelligence, insight, and perceptive analysis of political, economic and social forces. I have become accustomed to the privilege that comes from being smart and educated, and I took for granted that it was my birthright. Many of the capacities that I will be losing over the next years will be precisely those that have been essential to my identity. It's going to be hard!

So here's the story. I was born in 1945. My father was a Protestant pastor and my mother a nurse who later worked full-time at home (and half-time as a pastor's wife). I had two sisters and a brother. I didn't recognize that I was academically gifted until the end of my senior year in a large suburban high school when I was shocked to find myself valedictorian. Yale College was just beginning to offer scholarships to public school students to integrate its upper-class environment. Combined with a National Merit Scholarship and ten hours a week working at the college, I had a free ride through college.

To be honest, all I did during my first two years at Yale was go to class and study an additional eight hours per day, seven days a week. I was driven, pushing myself academically to the point of physical exhaustion and emotional imbalance. There was actually no point to it: I was not aiming toward a prestigious medical school after graduation but toward a small denominational seminary after college; I simply didn't need exceptional grades. I had no friends and no life outside of the classroom. I was miserable. It was only in mid-adulthood that I or anyone else recognized that it was an organic depression that drove both my need to prove myself and a deep unhappiness. The intermittent depression was to bedevil me for thirty more years until I finally got appropriate medication.

My academic intelligence, strongly supported by my obsessive study habits, led to an academic place within the top 1% of students. You'd think such recognition would relax me and allow me to work less compulsively. But I remained depressed, unhappy, and feeling little self-worth. In my sophomore year, I continued the same pattern of monomaniacal work, on the basis of which I was admitted to Phi Beta Kappa in my junior year, an exceptional academic honor at Yale which gave me little comfort, self-confidence or sense of meaning.

I'm embarrassed to tout my intelligence in this way, but as I write this blog while my mental faculties decline, I want you to know what I'm starting with and how it's shaped my identity. I'm heading into uncharted territory in which my primary sense of self will fall apart quickly. And I will remain in this now unfamiliar territory for years.

My mother committed suicide in the spring of my sophomore year at Yale. Nobody—herself least of all—recognized her depression. She was admired as a competent, humble and happy pastor's wife until her first suicide attempt in the fall of 1963. After several other unsuccessful suicide attempts that autumn, she was finally successful in hanging herself in April of the following year. It was only much, much later that my father and I could go back and piece together the signs of depression stretching back to her adolescence that nobody had recognized. My assumption is that she was unable to recognize her feelings for what they were, process it, or to receive any help from others. Suicide, I suspect, seemed eventually the only way out. Unbelievably, her suicide gave me no understanding of the depression I was suffering.

Despite having had a close relationship with my mother, I had little emotional reaction to her suicide... then or ever. My tendency toward unemotional responses to the most emotional of events confuses me to this day. Even after eight consecutive years of twice-a-week psychotherapy, I'm no closer to understanding my emotional distance from reality.

After my depression finally started interfering with my school performance in my junior year, I finally managed the wisdom and courage to leave Yale for a year and live in Munich in Germany, working first in a library for the blind and then later for an optical company packing eye glasses. In the intervening summer, I hitchhiked around Europe. My depression disappeared, my drivenness dried up, and I experienced one of the happiest years of my life.

Returning to Yale I was able to live something of a normal college life, getting decent, but not exceptional, grades, and being a little less depressed. I became deeply involved in the anti-war movement and discovered drugs and sex, although never heavily into either. Having lost my Christian belief in two excellent philosophy courses, I didn't see much point in going to seminary, but I didn't know what else to do, either. So, after college, I drove taxi for a year, became involved in the Human Potential Movement of the 1960s and led small groups of people exploring their emotional sides. When I discovered myself at twenty-three leading a "sensitivity training" group for middle-aged black ex-cons—who needed to learn to *control* their feelings rather than *express* them—I realized I was in

way

over my head. I wisely stopped leading groups and worked as a postman for a while. Feeling at a loss for something to give meaning to my life, I decided to go to medical school, more to find some discipline in my life than to become a doctor. I fantasized eventually working at the intersection of mind, body, and spirit. And medical training seemed like a good background for any career I would want to try. Anything to get me out of my own head.

During those three years before medical school, my depression waxed and waned. Not recognizing it for what it was, I was more confused by it than anything else. Since the externals of my life gave no reasons for unhappiness, I figured that my inability to be grateful and happy was some sort of character defect. Why couldn't I just pick myself up and be more joyful? My inability to do that didn't do much for my feelings of self-worth.

One good thing that happened during those years was the developing relationship with Marja and our subsequent marriage. For Marja, she now says, it was love at first sight when she came from Finland as an exchange student to my high school. It took me a bit longer. In that senior year in high school, we eventually started going together for a couple of months before she left to go home, we corresponded weekly while I was in my first year at Yale, and I traveled over to Finland to visit her in Finland after my first year. I remember my dad trying to counsel me to "be careful," by which he certainly meant not getting Marja pregnant. I marveled at how little he understood me, how minuscule the chances of Marja and I having sex that summer.

In fact, after a month together, I called our relationship off. I think it's fair to say that I had no idea what was going on emotionally or its relationship to my still unrecognized depression. We saw each other two years later while we were both in Germany. Two years after that, she wrote about coming back to the US for a while to see some other part of the country. We were both avoiding acknowledging the caring we had for one another (at least I was). I arranged for us both to spend the summer after my graduation in a small civil rights project in Alabama, teaching high school students. Thrown together not only in our daily teaching but also in our isolation in a county with virtually no other white people, it didn't take long to rekindle our feelings for one another. She left at the end of the summer but returned in the fall. We lived together until we married a year-and-a-half later. We honeymooned on a backpacking trip out west in the month before our marriage and celebrated the ceremony with family and a few friends around a campfire in rural Wisconsin. In the fall of 1969 I started a year of pre-medical work and she prepared to get her Master's degree in teaching. On weekends I drove cab again while she waited on tables at a pizza place.

I quite enjoyed medical school. I was a good student and this time I didn't need to study

obsessively. In fact, I read somewhere that the average medical student spent fifty-five hours a week on his studies. I figured I was at least average, so every week at the end of my fifty-five hours, I took the rest of the week off. I don't remember being very depressed.

Marja and I lived in an intentional community of twelve people in a large house in St Paul, Minnesota. The rest of those in the community founded and taught in a tiny alternative high school for students who—after the student strike following the invasion of Cambodia—didn't want to return to their classes in “the system.”

After the first two years of medical school, I had been seduced by medicine and acknowledged I was here for more than intellectual reasons. I wanted to be a doctor. I was accepted into a unique program that allowed students to get credit for their entire third year while working as an apprentice in a rural community. Instead of having to pay tuition, we were paid \$10,000, an enormous sum back then. In 1972, we moved with our one-year-old Laurel to Grand Marais, MN, on the North Shore of Lake Superior.

It was an unbelievably exciting year! After a while I saw patients of my own supervised by my mentor Roger MacDonald. Working in the clinic, emergency room, and the hospital I was pretty much on my own ... except that Roger was always available, supervising unobtrusively, gently relieving me of ultimate responsibility. We were over a hundred miles from the nearest specialists in Duluth, and Roger and his partner were the only doctors in a county the size of Rhode Island. The county had residents 4,000 residents but that filled with perhaps 20,000 people during the summer to canoe in the Boundary Waters Canoe Area, a huge wilderness that for practical purposes extended well into Canada. I loved it; the depression was nowhere in sight. In the spring Roger allowed me several weeks off to join a group of others to traverse Mt McKinley, up one side and down the other. We returned to Minneapolis and the last year of medical school. I was stunned to be voted by 300+ fellow students as one of the two most promising clinicians in the class!

While depression had certainly been a part of my life after my second year of college, it had not been a dominant part. That was about to change.

We moved to a Duluth hospital for a year's internship where a second daughter, Karin, was born. Then, along with a classmate, Bill Gallea, I rejoined Roger as a partner in 1975. It seemed an ideal situation. My patients and the other Grand Marais residents were grateful for our presence and appreciative of our care. Roger was at least as smart as I was and Bill much

more so; more importantly we liked each other, worked well as a team, and gave each other a lot of support. It was a beautiful wilderness area. During the three months of winter I could cross-country ski the three miles down to work in the morning and the three miles back up in the evening. I began marathon cross-country ski racing, became quite good at it for an amateur, and got into prime physical shape. Halfway through our sojourn there, our son Kai was born.

But except for that first student year, I was never comfortable as a physician. I felt continuously on edge, anxious, sometimes almost terrified to return to work after a weekend off. Perhaps it was the frequent overnight call that could be overwhelming in the summer with all the tourists. Perhaps it was realizing that as a rural doctor, I routinely practiced beyond the limits of my capacity and sometimes made serious mistakes. Perhaps it was my awareness that, at my best, I was meeting only a small fraction of the needs my patients brought into the office. Probably much of it was the still unrecognized depression rearing its head again, exacerbated by those difficulties in practice. I tried working three days a week; I tried taking off three months every year; I did everything I knew to make possible a medical career. I knew I was a good doctor; I knew my patients thought me more than competent; I knew how important the relationships I had with my patients were to me. I knew I was a good father, deeply in love with Marja.

Yet I was miserable. After seven years in Grand Marais, our family left to take a year's sabbatical in Hämeenlinna, Marja's hometown in Finland. Six months before we left, Roger took me aside and asked me if I would take anti-depressant medication. I may not have known I was depressed, but he did. Those early medications didn't help me much and gave me side effects I didn't want to tolerate. I wasn't really convinced the diagnosis was depression.

The year in Finland was the best in my life. Marja's parents had a summer cabin on a beautiful lake within biking distance of Hämeenlinna. We spent a magnificent summer there, playing with the children, taking frequent saunas, and enjoying the beauty of the area and one another. When it began to get cold we moved back to Hämeenlinna where Marja worked as a teacher and I as the househusband. During the long winter, I skied over two hours a day. While not in the same class as the Finnish amateurs, I loved skiing the international marathon from Hämeenlinna to the national ski center 75 km away.

I began work on my first book, *Healing the Wounds*, because I needed to write to help me explore what had driven me away from my rural medical practice. The book turned out to be stories about the contradictions of being a physician. I didn't realize my writing was as good as it turned out to be. The *New England Journal of Medicine*

, the most prestigious medical journal in the country, published one of the chapters about the medical mistakes.

*Harpers*

magazine picked up it up from there, and Tom Engelhardt, an editor from

*Pantheon Books*

called me to suggest we work on the book together. Publishing the book in 1985 was very rewarding, especially when some medical schools began using the book as part of their regular curriculum.

Although we had planned to return to Grand Marais, I was terrified of returning to the demands of rural general practice. In the summer of 1983, we came back to the States to join a small, ecumenical faith community, the Church of the Saviour, that had an extensive set of ministries to the inner-city poor of Washington DC

Both Marja and I had always had a deep concern for justice. Part of the reason for moving to Grand Marais was the poverty of the Indian reservation on one end of the county and the families on the other end who were periodically unemployed for longer and longer periods as the iron processing plant repeatedly shut down and reopened depending on the price of iron. In Washington we would get a chance not only to live near and work with the very poor but also to do it within the context of a supportive faith community: the small, ecumenical Church of the Saviour.

Work in an inner-city clinic with specialists a mile or two away is in most ways much easier than the work of an isolated rural doctor. Not recognizing the real reasons for my intolerance of medical practice, I thought I would enjoy the practice in the city. And things *were* certainly easier. Many friends and relatives assumed that the inner-city practice and all of the poverty-associated symptoms would be more difficult than my Grand Marais practice with its mostly middle-class population and idyllic environment. But my clinic at the Community of Hope was actually much less overwhelming, and I was grateful for it.

I was initially concerned that a white doctor moving into an impoverished, African-American community would arouse suspicion and charges of paternalism. But it never seemed an issue. Especially once people figured out that I was sticking around for more than the usual two years, I was welcomed and my patients were grateful for my presence.

Like my practice in Grand Marais, it was rewarding work. Not only was my medical care

deeply appreciated within the community but I was also appreciated. People shared their struggles with me and we developed close relationships. I was respected and admired. It should have all been good. But the still unrecognized depression would have its way. I became more and more burdened by the work, less and less capable of dealing with even the straightforward issues the clinic patients brought in. I felt the same double existence I'd had most of the rest of my life: externally blessed and, internally, emotionally chaotic.

I entered long-term psychotherapy and began to see the role of depression in my inner life. Many others in the faith community were involved in ministry to the impoverished, too, so they could offer not only support but also good counsel. A group of us from the church founded Christ House, a 34-bed medical recovery shelter for homeless men with temporary illnesses. The patients were cared for and lived downstairs, and the three of us doctor families and some social workers lived in community upstairs.

In 1990, after five years at Christ House, our family began the most intense years of our lives. We wanted to live in closer community with those we were caring for. AIDS was moving into the impoverished community, and, at Christ House, we couldn't take care of people who were dying, so we founded Joseph's House, a home and community for homeless men with AIDS. Our family had our bedrooms on the top floor, the men had their rooms on the second floor or in the basement, and the first floor kitchen, dining room and living room were common spaces for all of us. Our hope was to be not so much an institution as a home and community. Recognizing lines of race and class, we wanted to live together without ignoring them. Could white and black, rich and poor, sick and well actually live together in a common community that was not dominated by our differences but by our common humanity?

There are many stories to tell from that time at Joseph's House, but the most important for me is PeeWee's. Coming to Joseph's House, I certainly believed intellectually that the men and I were peers, but—to be honest—that wasn't my emotional reality. Emotionally, I was still on top, vaguely superior, and "they" were still on the bottom, downtrodden. Pee Wee was a man my own age who had been a wealthy drug kingpin, ruling his fiefdom with violent discipline. Now he was homeless, dying and utterly abandoned by friends and family. I was a doctor, a writer, a parent with a great family ... a success. Whatever I believed, what I ***felt*** was that I could never be as broken as PeeWee was.

At one point after we'd moved into Joseph's House, my depression became overwhelming. I was terrified—looking into the abyss of mental illness, unable to see either the bottom or the other side. Figuring that the men knew something was going on, I decided at a community meeting to share with them the intensity of my illness and my fear. I asked them just to allow



me to live there without a formal role. Immediately PeeWee spoke up. I'll always remember his three sentences. "That's cool, doc," he said. "We been noticin' somethin' wrong. You just take as much time as you need, and we'll still be here for you."

I didn't realize it immediately but what PeeWee was saying to me was: We're in this together. I got AIDS; you got depression. We need each other. Over the next few days the wall between us crumbled. We were just human beings, engaged in human struggles.

As life-changing as Joseph's House was, after three years my depression would not allow us to stay. In 1993 we left for another year's sabbatical to Finland. I began work on a second book, *Not All of Us Are Saints* about my life doctoring in the inner city. While in Finland, I realized that I needed to leave the practice of medicine completely. The combination of the normal stresses of being a doctor along with the depression had wiped me out emotionally. Despite the knowledge that I was a good doctor doing good work, despite the often deeply rewarding relationships, despite the admiration, despite all the perks of being a physician, I had been trying unsuccessfully now for seventeen years to find joy in my work. It was time to stop hitting my head against the wall.

When we returned from Finland in 1994, I returned to Joseph's House as the director but found that too challenging, also, and eventually became the "Chief Operating Officer," in my case a glorified name for the bookkeeper.

At about this same time, new medications for depression had come on the market. A psychiatrist put me on Wellbutrin. After a few days, I was utterly astounded: So *this* is what normal people feel like! The fog just lifted. In that particular case, the effect lasted only three months, but a few years later, we found a combination of drugs that holds me mostly steady. I will take them for the rest of my life.

Even after the antidepressants guided me to new mental health, I've never been tempted to resume medical practice. Partly, I think, I was burned by all those years of pain; I've just been too scared to try it again. And I'm quite sure that my unhappiness as a physician was not due solely to my depression. I tried long enough to make it work. There was a great deal of *grief* in letting go of all the rewards of medical practice but no temptation to return.

Nevertheless, I continued my work lecturing and teaching at medical schools. At first, I was asked to talk about the contradictions of medicine I described in my first book. But I gradually turned to speaking about inner city poverty and the responsibility of the medical community to provide care to everyone. I was certainly never famous, but, within certain medical communities, I was well known and respected for my work.

In the late 1990s I began to explore yoga and meditation, and I have continued a regular practice of both until this day. Although I am committed to Christianity, I have found a great deal of value in Buddhist teachings: quiet, centering presence in the here-and-now, non-attachment to either failure or success, equanimity within happiness and sorrow, non-judgmentalness of myself and others, and acceptance with what I've been given. Perhaps the most important has been the recognition of "non-self": There is no constant and immutable self within me, and every attachment that I have to a particular sense of self only leads to suffering. So even before the Alzheimer's, I was beginning to let go of the illusion that any one characteristic defined me: I was not only an intelligent thinker and writer, not only an athlete who kept his body well conditioned, not only a husband and parent, not only a member of a community, and not only a depressed person. It's been an important preparation for this time.

I became much more active in my church, the Eighth Day Faith Community, part of the Church of the Saviour. I'd always felt myself to be on the borders of Christianity, never able to believe in the supernatural aspects of the faith or the claim to exclusive salvation. But I'd always hung around the edges not only because the social gospel was able to explain for me the imperative towards solidarity with the poor but also because liberation theology had suggested that moving into that solidarity was a path toward deeper knowledge of God for which I yearned. Fortunately Eighth Day valued diversity in all its aspects and was happy to accept me despite my borderline Christian beliefs as part of their community. I valued the theological diversity, too; I was happy to be part of a community with a wide range of ways of thinking about God—from quite traditional to inexpressible—yet a common commitment to peace and social justice.

The most important parts of my belonging to Eighth Day were, first, the love and support of the community and, second, the recognition of my "prophetic voice." I preached within the Eighth Day community and spoke regularly to the outside world about the injustice and inequality of our society, the sin of American empire, the coming fall of that empire, and how we Americans might prepare for what was coming. The community affirmed that voice.

In 2002, just before the beginning of the Iraq war, I traveled with a peace group and spent two weeks in Baghdad in order to demonstrate solidarity with the people of Iraq who were about to

experience the indescribable tragedy of years of war. A year later after the war had begun, I returned, for another two weeks to see for myself the American destruction of that society. My visit only intensified my belief in the ongoing collapse of our society.

I spoke to large and small groups, I preached at different churches, I created this website, to share my speeches, sermons and writings. In October of 2008, I formally retired at age 64 with the intention to continue writing and speaking full time.

I had a place in my community and in our larger society. I believed that my intellectual capacities; my commitment to peace and justice; my speaking, writing and teaching abilities; were making a difference in the world. In large part, I defined myself in those terms. I hoped that would continue.

But hasn't quite worked out that way. Gradually, about two years ago, I began to find writing more and more difficult, and I found myself taking more and more excuses not to write daily. Although I didn't identify it clearly then, I felt increasingly apathetic about writing, wondering what I had to say.

At the same time, I was beginning to feel bored and restless. I had changed life-course several times in my adult life. Going to medical school; deciding to become a rural doctor; leaving and going to Finland; coming to Washington and work in the inner city; becoming an author lecturer and teacher; starting Joseph's House; leaving the practice of medicine; becoming a bookkeeper; leaving Joseph's House to devote more time to writing and teaching. Now I had started to feel it was time to change again. I was ready for a new adventure, but, unlike previous times, I had no idea what adventure was coming. I couldn't have guessed it would be the uncharted waters of gradually losing my mind.

In June 2010, I experienced a disturbing event. For a decade or so I'd been driving two or three times a year down to southern Virginia to visit a friend, Jens Soering, who was serving a life sentence for two grisly murders he almost certainly didn't commit. This time, because Jens had been transferred to another prison, I would have to figure out how to get to a new place in an isolated rural area. Jens sent me the rather complex directions for which I had to carefully study the Google map to avoid getting lost.

During my visit with Jens, the prison chaplain stopped by to say hello. I introduced myself, but he said something like, “Yes, I remember you from last time.” I’d had a terrible memory for names and faces since forever, so I’d developed a coping mechanism in these circumstances. I faked it. After the chaplain moved on, I asked Jens whether the chaplain had moved from his previous prison where I might have met him. Jens seemed a bit confused by my question and told me that I’d met the chaplain during my last visit to this new prison several months earlier.

I was absolutely certain I’d never been there before. The route planning had been meticulous. It was a complex 3½-hour trip to the prison. I would have visited with Jens for four-hours and drive the 3½-hour trip back? I couldn’t possibly have forgotten it!

But I had. To this day I remember nothing about that forgotten trip. Nothing remotely similar had ever happened before (or since, actually). When it didn’t recur, I pushed it to the back of my mind, rationalizing that if it was a completely isolated event, a doctor would not be able to make much of it.

Months later, however, I was working on a spreadsheet for my church’s next year’s budget. I needed a relatively complicated formula that I’d developed in previous years. Since I’d enjoyed working on spreadsheets, I decided to recreate the formula from scratch. Not only was I unable to recreate it, however, but, when I went back to old spreadsheets and looked at the formula, it was too complex for me even to understand! Even looking at it in some detail I couldn’t figure out what I’d done. What was going on?

Perhaps I didn’t want to know, but I did ask my wife Marja and several close friends if they had noticed any strange symptoms that might indicate decreasing mental function. They hadn’t, but I asked them to tell me if they did. No one ever said anything.

In late summer of 2011, however, just to put my mind at rest, I made an appointment with a neurologist to get a professional opinion. After interviewing me and administering the appropriate tests, he told me that given, my previous IQ and professional history, I should have scored higher on the screening test for mental function. Even though my scores were not yet low enough to warrant an official diagnosis of dementia, I had a “mild cognitive impairment.” But he didn’t seem very concerned either about my worsening memory, forgetting the entire visit with Jens, or the difficulty with the spreadsheet. He asked me to come back in a year “just to check.” Although he probably guessed what was coming, he didn’t seem too concerned.

Somehow I was reassured. Given what I know about dementia, however, even a “mild cognitive impairment” should have sent off warning signals and I should have pressed him harder for his impression. In retrospect, I’m amazed I wasn’t more concerned.

Over the next year I became more apathetic about my writing and chastised myself repeatedly for not just “making myself do it.” But writing is a fickle gift, so I certainly didn’t put it in the context of the cognitive impairment. Once again, though, I asked around to see if anyone else had noticed anything. They hadn’t.

Over that next year there were small events that I didn’t tie in with the earlier symptoms. Three times within a few months, I left my hat on the Metro and my backpack once. On my way out to visit my daughter Laurel in California, I left my belt pack in an Amtrak bathroom. These are *tiny* bathrooms. How could I not notice a belt pack when I left? I got my belt pack back (although not about \$200 in cash).

Ten days later, while still at Laurel’s, I lost it again. Ordinarily when I lose something, I have some recollection of how and where it happened. But not this time. I retraced my steps but had no memory of doing anything with it. I went back to every location I’d visited in those few hours. Nothing. We never found it.

I continued to lose things. My typing slowed down and I made many more mistakes. I thought perhaps it was age, but since I was then only in my mid-sixties, it seemed awfully early to be losing so much. After all, Fred Taylor, my eighty-year-old friend, seemed not to have lost a step. This level of impairment was certainly not normal.

I got lost in downtown Philadelphia. I attributed it to a city I didn’t know much about, and I did eventually find my way back on my own. I had had a good sense of direction all my life and nothing like this had ever happened before.

What bothered me the most was my failing memory. I was frequently embarrassed by what I forgot, yet I had been able to explain it away to myself and others as my chronically bad memory, so no one, as far as I know, recognized my symptoms for what they were.

In retrospect, I knew even then that something important was going on. But I'd asked my friends, I'd visited a specialist, and I'd had no symptoms that couldn't be at least reasonably confused with normality. In retrospect it all seems obvious, but I didn't tumble to it until the one-year follow-up visit with the neurologist. As part of the cognitive exam, he showed me a three-dimensional cube and asked me to reproduce it in the space next to it.



I couldn't do it.

This is not a difficult task; the model was right there in front of me, but I couldn't get all the lines to connect. I had administered similar tests to patients before. I knew immediately what was this meant. A knot quickly formed in my gut, and I felt almost sick. I realized that my mind was going.

So when the doctor told me I had a "progressive cognitive impairment," I wasn't really surprised. Stunned yes, but surprised, no!

I have journaled almost every day after that and then have taken from my journal entries some things I can make public. It might seem strange to want to make something so intimate public. But I'm a writer. This is how I process my own reality. My first two books had their origins in my attempt to understand, first, the contradictions of practicing medicine in a rural area and, second, the pain and joy of doctoring in the inner city. Carol Marsh, a good friend and writer, has agreed to edit my writing. As the dementia worsens and I can no longer write, I hope we will be able to talk and I can communicate through her. In my imagining, I will not be the one to finish this chronicle. In the end she will be writing *about* me, describing who I become.

It may seem surprising that I feel almost no apprehension about exposing my mental decline and my reactions to it. The value of my books on rural practice and on inner-city doctoring, after all, lies in my willingness to report candidly, so I have some experience in sharing the messy details. In my lecturing, speaking and teaching, I have tried to be open about my depression, believing that the millions of people who are shamed into hiding their diagnosis should have some models for self-revelation. Likewise, I hope that others with an early diagnosis of dementia and those who are in relationship to a person with dementia (including medical

people) will find my experience helpful.

**\*\* As of Oct 30, 2013, the diagnosis is much less clear. (Click [here](#) .)**