

What Are We Going To Do With Dad?

A geriatrician stands by during his father's downward spiral into old age, disability, and dementia.

BY JERALD WINAKUR

PREFACE: *America is getting older, and older Americans are living longer. What has not changed is the dysfunction and illness that usually accompany aging. Geriatrician Jerald Winakur looks at the "vast inland sea of elders" that is building and wonders where the doctors will come from to care for them. Writing as the son of an eighty-six-year-old man with dementia, Winakur also details the nitty-gritty of caring for an increasingly debilitated parent. In both of his roles—loving son and highly skilled professional—he is hard pressed to alter a course that punishes his dad and tears at his family. Even as medical science extends life, the future seen through his eyes is fraught with clinical and moral quandaries.*

MY FATHER IS EIGHTY-SIX years old. He was never a big man, except perhaps to me when I was his little boy. At most he was five feet, eight inches tall and weighed 160 pounds. Today he weighs barely 120. Maybe he is five feet two. He teeters on spindly legs, a parched blade of grass in the wind, refusing the walker his doctor recommends or the arm extended in support by those of us who love him. He doesn't know what day it is. He sleeps most of the time, barely eats. Shaving exhausts him. His clothes hang like a scarecrow's. Getting him in for a haircut is a major ordeal. He is very deaf but won't wear his hearing aids or loses them as often as a kid might misplace his marbles. He drives my mother—five years younger—crazy to tears.

My only sibling, the architect, asks me every time we are together (which is often because we all live in the same town) and every time we speak on the phone (which is almost every day because we are a close family now in crisis): "What are we going to do with Dad?" As if there

must be a definitive answer, some fix—say, putting a grab bar in the bathroom or increasing the width of the doorways. Something that is according to code.

He asks me this question not just out of fear and frustration, not only out of a realization that it is time for the adult children of a progressively dementing elderly

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parent to act, but because he figures that his older brother who has been practicing medicine for almost thirty years should know the answer. I do not know the answer. I do not have a pat solution for my father or yours—neither as a son, a man past middle age with grown children of his own; nor as a doctor, a specialist in geriatrics, and a credentialed long-term care medical director.

In the United States today there are thirty-five million geriatric patients—over age sixty-five—and of these, 4.5 million are over age eighty-five, now characterized as the “old old.” The American Medical Directors Association, the professional organization that credentials physicians in long-term care, has certified only 1,900 doctors in the entire country. As we baby boomers go about our lives, frozen into our routines of work and family responsibilities, a vast inland sea of elders is building. By 2020 it is projected that there will be fifty-three million Americans over age sixty-five, 6.5 million of whom will be “old old.” Many of you will be among them. America will be inundated with old folks, each with a unique set of circumstances: medical history and the manifestations of the particular dementing process; medication use; emotional and psychological makeup, including past traumas and present-day fears; family dynamics; support structures; and finances.

Compounding all of this is the sad and frustrating fact that our government appears to have no policy vision for long-term elder care. Our leaders seem to wish—perhaps reflecting our own collective yearnings as a vain, youth-worshipping society—that when the time comes, the elderly will take their shuffling tired selves, their drooling and incontinence, their demented ravings, their drain on family and national resources, and sprawl out on an ice floe to be carried off to a white, comforting place, never to be heard from again.

The Role Of The SNU

FOR THE PAST NINE YEARS I have been the medical director of my hospital's skilled nursing unit, or SNU as we call it. This unit receives transfers from all areas of the acute care hospital when attending physicians feel that their patients have reached a point where they no longer need acute care services yet are unable to return home. Sometimes it is obvious what we have to do: finish out a course of intravenous antibiotics in a patient with an infected wound or provide a few more days of rehab to a competent elder who has just undergone a hip replacement. But more and more, as our patients grow older and more frail, it becomes clear that the attending physicians have requested that their patients come to the SNU because they don't know what else to do with them.

Each week I attend the SNU team care conference. Every staff professional who has a role in caring for patients on the unit attends, so around the tables pushed together in the unit's “activity room,” amid the puzzles and games almost none of the patients has the ability to play, the magazines most no longer have the eyesight or insight to read, sit a registered nurse; geriatric nurse specialist; pharmacist; social

worker; activity coordinator; physical, occupational, speech, and respiratory therapists; dietitian; and myself. We discuss each patient in turn and review each medication list. The nurses provide up-to-the-minute reports on medical progress or setbacks; the therapists discuss the rehabilitation status and whether the patient is proceeding toward goals set the previous week; the patient's weight and diet are reviewed; we hear about the situation at home, the help or lack thereof we can expect from family or other caretakers, and the patient's insurance and what it may or may not provide. Our main goal is to answer one major question: What are we going to do with this patient? Where can we safely send him—given his medical, social, and financial circumstances—and expect him to maintain his highest level of functioning, his remaining dignity? Very often, we don't know.

After we review each patient's case, families are encouraged to attend. Most do not—often, I think, because they are afraid we will tell them there is nothing more we can do. And they are already despondent, overwhelmed by Dad's downhill progress and the acute event that brought him to the hospital (the pneumonia, the

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fall, the stroke), bewildered by his deteriorating course (the mental confusion, the weakness) while there, and angered and frustrated in dealing with the bureaucracy (callous nurses, inattentive aides). Even with the attending physicians, who often drift quickly in and out on their rounds like white-coated apparitions.

So now your dad's physician—maybe the one person you thought could solve all of this, the one person you trusted (although less and less so in these days of “managed care,” because it is hard to trust someone you might have just met or whose name was picked at random from a list of random names)—comes into his room and says, “I don't think there is much more we can do for him here.” Your mind reels. Nothing more to do? In America? Home of the most advanced health care in the world? The land of Medicare and WebMD? You think about all the glowing seniors—continent, smiling, sexually active—in those drug ads on TV or the aging but robust movie stars on the cover of the AARP magazine. Nothing to do?! What, I'm supposed to take him home like this? You gotta be kidding, doc! And anyway, he was just fine until he came to the hospital!

The doctor sighs. She has been through this many times and still doesn't quite know how to handle it. Even though the ravages of aging are not her fault, she feels the stern gaze of Hippocrates on her back and wants to do more. She might remind you—tactfully—that this patient, your father, lying with sallow distorted face, partial paralysis, a Foley catheter now hanging out of his penis attached to a bag clipped to the bedrail, was not fine when he came to the hospital. He was not shanghaied from his home where he sat smoking his pipe and reading the *Wall Street Journal*. Rather, this man, her patient whom she doesn't know what to do

with at this moment, arrived in the ER at 4 a.m. hypertensive and gurgling, brought in by ambulance after he passed out in the bathroom and hit his head on the toilet.

“I think perhaps we can transfer your father to our skilled nursing unit for some rehabilitation,” the doctor says. I say it all the time. Family members are uncertain what this means except that they don’t have to take Dad home just yet and are temporarily grateful. The doctor has postponed answering the “What are we going to do with Dad?” question for a while longer. Every Medicare patient has coverage for one hundred lifetime SNU days if the criteria outlined in thousands of pages of regulations are met. But past the first week or two or three, these criteria usually can no longer be satisfied—not because the patient is well; very few get well once they get to the SNU—but because the patient is “no longer making progress.” The patient is caught in the downward spiral of old age, disability, and dementia.

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From here there is no “progress” except toward the grave. And the next way station is chronic custodial nursing home care. Family members will soon discover, if they haven’t already, this essential Medicare insurance coverage fact: There is no Medicare coverage for long-term custodial nursing home care. Unless, of course, an elderly loved one is destitute, in which case he might qualify for some state-sponsored Medicaid assistance. And this often can be quite problematic depending on the level at which his state reimburses its long-term care facilities.

And, typical of our government, as SNUs are being used more and more (as so many medical practitioners find themselves stymied by the “what are we going to do next?” question), Medicare has cut the reimbursements to these units drastically (not limiting the benefit to the patient, of course, which might anger the consuming public), so that many are closing. My own unit shrank to half its size before being shut down by its sponsoring hospital—even as I was writing this piece. Although the CEO told me that this was done because my hospital needed more “acute care beds”—certainly true—closing the SNU coincided with the change in Medicare reimbursements to SNUs that made it financially advantageous for acute care hospitals to jettison their SNUs in favor of more acute care beds.

The Road To Now

THIRTY YEARS AGO I BECAME A PHYSICIAN. My father, a first-generation American born of immigrant Russian Jews, was then the age I am now. He never completed high school. He was a sensitive man who helped his fatherless family eke out a living through the Depression and then served five years in the Army Air Corps—a member of the “Greatest Generation.” He ended up a man who

was neither secure nor successful, even in this country's most optimistic years. But he was proud of me, a college boy, a medical school graduate.

In my family there was no more honorable profession than medicine, and the highest calling to my generation of physicians was the discipline of internal medicine—to follow in the footsteps of Sir William Osler, an empathic bedside clinician, a skilled diagnostician of the first order. To become a physician who derives great joy from shepherding his practice, his flock of interconnected families and friends through their medical lives, available for those frightening calls in the night, those tense moments in the ER, those difficult days in the intensive care unit (ICU). The one who is trusted to help make the tough choices, the final decisions. The one true patient advocate with broad knowledge, compassion, and unbiased judgment. More than half of the graduates of my medical school class pursued a career in general internal medicine. By 2003, that career choice among all first-year residents had declined to 19 percent.

Primary care, especially geriatric primary care, is time-consuming, excruciatingly detail-oriented professional piecework—all of those visits, those slowly moving, wheelchair-bound, unsteady elders to get onto and off of examination tables. Their pencil-scrawled complaints and medication lists to decipher, to ques-

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tion, to strip down, remake, and remodel at every encounter—a tiny dosage change here, an elimination or substitution there—all the time wondering: What am I missing? What else can I do? Not many young doctors want to preside over this carnage of human obsolescence or be reminded every working day of their own inevitable slide into disability and dementia.

In this work, the arenas change but not the inevitabilities: hospitals after the falls and broken hips; ICUs after the inevitable cascading complications of postoperative strokes, infections, and embolisms. Then the SNU and rehabilitation hospital admissions and, finally, custodial nursing homes. The patients become less responsive, less the people they used to be; their families become more uncertain, more demanding, more shrill from half a continent away. They call, fax, e-mail, wanting details, updates, help, answers. Visit by visit I document declines. After a lifetime of practice, I find myself presiding over legions of chronically ill people—my extended family now—and every week there is another death certificate to sign, another condolence card to send, another funeral to attend.

There are many sexy career choices in medicine today, all the highly paid specialties and their procedures that actually—if all goes well—restore functioning and stave off death and disability, at least for a while. Snap in new knees or hips or shoulders. Laser the grunge out of blocked coronaries. Snip out the polyps that might become cancers. Suck out the fat, prop up the sags, botox the wrinkles,

burn up the spider veins, pop in the new lenses, pump up the withered penis. Resolve the problem at hand, pocket the Medicare payment (or, even better, collect the full retail fee from “uncovered” procedures from your well-heeled patients), tell yourself what a great physician you are, and send your satisfied medical consumers back to their “primary geriatrician” quickly—before they fall, seize, stroke, and become incontinent on the plush-pile carpet of your waiting room.

Hospital Dangers

THREE YEARS AGO MY FATHER, A LONGTIME HEART PATIENT, had trouble breathing and complained of chest pain. He was admitted into the hospital with congestive heart failure. This is the hospital in which I have made rounds almost every day for the past three decades. Many of the nurses and therapists and I call each other by our first names. The CEO is my friend and patient. My father’s physician is one of my young associates, well-trained and eager. I was confident that my father would receive the best medical care he could get in America today. Yet I would not leave him alone in his hospital room. During the day, if I or my brother or mother could not be there, I had a hired sitter by his bed.

It’s rarely talked about, but acute hospitalizations are the most dangerous times for the elderly. Even if they have never before manifested any signs of confusion or disorientation, it is in the hospital—in a new and strange and threatening environment, under the influence of anesthetics, pain pills, antiemetics, and soporifics—where the elderly (competent or not) will meet their match. Add to this the iatrogenic mishaps (caused by the “normally expected” side effects and complications of standard medical procedures) and the human errors (mistakes in drug dosing, the right medication given to the wrong patient)—now multiplying in our modern hospitals like germs in a Petri dish—and it is almost a miracle that any elderly patient gets out of the hospital today relatively unscathed.

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I stayed with my father every night; I slept in the reclining chair by his bed. I got up when he did; ran interference with bedrails, side tables, and IV poles; guarded his every move to the bathroom; looked at every medication that was handed to him and every fluid-filled bag plugged into his arm. I was not afraid to question the nurse or even call his physician. Each day my father descended deeper and deeper into paranoid confusion. He couldn’t rest, he was intermittently unsure of who I was. At first I could calm him with my voice, talking about the old days, reminding him of our fishing trips on the Chesapeake Bay when I was young. Then he needed the physical reassurance of my hand on his arm or shoulder at all times.

Finally, so that he could get some rest, I got in the bed with him and held him, comforting him as he once—in a long-ago life—did for me.

After four days and nights in the hospital, I knew I had to get my father out of there. His doctor came by and told me that his heart failure was better and that his dementia evaluation did not show a treatable or reversible cause. But he didn't like the way my father looked—he was agitated and sleep-deprived and deconditioned, a perfect candidate for some time in the SNU. And, after all, here I was, his senior associate, the medical director of the SNU. Surely my dad would get good care there.

I took my father home. I knew if I didn't get him home at that moment, he would never come home again. The SNU for my dad would have been only a way station to a custodial nursing home. I arranged for a home health agency to come to my parents' house and provide my father with physical therapy to aid in his reconditioning and to assist with his bathing and dressing and grooming—something Medicare covers, but for only a limited period. I went to the pharmacy and filled the eight prescriptions he left the hospital with, and I went back again to buy the blue plastic container divided into daily dosing compartments when I realized that my mother was having trouble reading the labels on the bottles and following the instructions. How long had this been going on?

And Now We Wait

WHEN I VISIT MY FATHER THESE DAYS, if he is not asleep, I sit down beside him on the couch and talk at high volume into his hearing aid, if he has remembered it. Our conversations go something like this:

"How are you feeling today, Dad?"

"Not so good. You ought to come around more often."

"Dad, I was just here yesterday."

"Why are you calling me that? You're not my son."

"Of course I'm your son. That's your wife, my mother, sitting over there."

(My mother: "What are you saying! Of course he's your son!")

"I like you and all, but you're not my son."

"Well, I love you anyway."

"You're older than I am. How could you be my son?"

"I love you, Dad."

"You ought to come around more often."

(My mother: "See what I'm putting up with all the time?")

Yet through the fog of his senility I still recognize my father, and once in a while he will surprise me. "Remember those big rockfish we used to catch off Thomas Point Light?" he might say. And then nothing.

The Medicare coverage for the home health care ran out almost as soon as it began. Between my brother and me, one of us is there almost every day. We have been

fortunate to find two dedicated women to help my mother attend to my father's daily personal needs. My brother and I help with the cost of this—\$1,500 a month, but still only one-third of the cost of custodial nursing home care. I often wonder: Why isn't this kind of care covered by Medicare or Medicaid? After all, when my parents use up their meager savings (which they will), like most families with a demented elder, they will become eligible for Medicaid, and the state will then pay the entire cost of custodial nursing home care. But the longer we can keep my father at home attended by aides, the cheaper his long-term care cost will be to society as a whole.

Drinking the supplemental nutritional feedings my brother brings to the house by the case (another noncovered cost of several hundred dollars a month), my father has actually put on a few pounds. I keep his medicines stocked, and I fiddle with the doses now and then, a tad extra diuretic when I see he is more short of breath, a tiny dose of an antipsychotic when he becomes more agitated. We get him in to see his doctor regularly for follow-up examinations and laboratory testing. And still, every week he gets worse, harder to deal with, more bizarre.

Recently, he has begun to holler at my mother every time she tries to help him change his clothes, which is often because he wets himself. "You're my sister! You're not supposed to see me naked!" he screams at her. He can no longer find his way from the living room to his bedroom in their tiny one-story house.

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Most of us do not recognize when the mental capacities of our spouses or parents are reduced until something happens, something unexpected. My mother just didn't get it that my father was demented; she continued to believe his stubbornness and withdrawal were purposeful acts of belligerence against her. Until the day she realized he could no longer figure out how to unlock the front door by himself, she continued to blame him for his disability. Adult children are often no different in their lack of insight; we expect our parents, after all, to be our parents. Dad is just being cold and distant because he's still angry over something from years before, a son might believe. The sad fact is that Dad forgot about this incident long, long ago.

From my years as a geriatrician and now as the son of an "old old" man, I recognize that there is but one inescapable truth: Our parents will become our children if they live long enough. Perhaps if we looked on our elderly in this way, we would be kinder to them. They will become dependent on us, our stronger arms, our acts of gentleness and caring. We will arrange for their meals, pay their bills, take them to their doctor visits, sit by their bedsides at the hospital and in the nursing home.

I don't know what else to do for Dad at this moment, but I know what is likely

to happen to him if he does not die in his sleep, a heaven-sent coup de grâce that from long experience I recognize is unlikely to occur. There is almost always a great struggle in the end. One day I will get a frantic call from my mother that he is on the floor and she cannot get him up and he is crying out in terrible pain. Wherever I am, I will drop what I am doing and race over there and find that one of his legs is shortened and externally rotated. His hip is broken. From the wall phone in my parents' kitchen, I will call my brother and I will tell him all the reasons why we should not send him to the hospital: He might not recover from the surgery—indeed, might die on the table given his bad heart. But even if he does survive, he will spend days in the ICU, probably on a respirator, until his heart is stable. And then he will be constantly confused and agitated. I don't see him ever being able to cooperate with physical therapy. At best he will end up in a nursing home, bedridden and at the mercy of overworked, underpaid aides. He will descend deeper and deeper into disorientation and delusion, require medications to keep him from harming himself, and die anyway in a few months—or perhaps even a year or two if he is unfortunate and the care is better than average.

My brother will hear my mother crying and my father hollering in the background. He will feel guilty that he is not in the house with me at that moment. He will remember the time our father took us on a summer vacation to the White Face Mountains and we all huddled together on the swinging bridge in the mist, as the Ausable River tumbled and roared through High Falls Gorge. Then he will say, "Maybe it won't be as bad as you think. Maybe we can set up a hospital bed in his room—I think the door is wide enough—and it won't take much to alter the shower to accommodate a wheelchair." There will be a moment of silence. "I don't know," he'll say. "You're the doctor. What do you think we should do?"

I do not tell him that I often, in fitful sleep, dream that when the time comes I go to my father's bedside, quietly fill a syringe with morphine, and stroke his arm as I place the tourniquet. I tell him over and over again how much I love him and what a good father he has been to me as I slip the needle into his antecubital vein. Then I say how much I will miss him and goodbye, Dad, goodbye, as I push the contents into his bloodstream. In this dream I tell my mother and my brother that he has gone peacefully in his sleep.

Yet I have not until now given voice to this dream because I know for certain that in the end, I could never do this. Not to my poor, demented, suffering father. Not to anyone. I know there are some who disagree with me, and perhaps this is one way our society will ultimately deal with its flood of elders in this age of limits. I will by then, I hope, be old and no longer on the front lines. When my time comes—before it comes—I will choose for myself. But for now, as long as I have the will and the strength to practice, I am a physician deeply steeped and firmly rooted in the art and tradition of healing, of comforting.

For my father, on that day, I will tell my brother that I will handle it and hang up the phone. Then I'll pick it up again and dial 911.