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What Are We Going To Do With Dad?

No Pat Answers For the 'Old Old'

By Jerald Winakur

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My father is 86 years old. He was never a big man, except perhaps to me when I was his little boy. At most he was 5 feet 2 inches tall and weighed 160 pounds. Today he weighs barely 120. Maybe he is 5 foot 2. He teeters on spindly legs, a parched blade of grass in the wind, refusing the walker his doctor recommends or the arm extended by those of us who love him. He doesn't know what day it is. Shaving exhausts him. His clothes hang like a scarecrow's. He is nearly 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, an architect, asks me every time we are together (which is often because we all live in San Antonio) 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.

He asks me this question not just out of fear and frustration, but because he figures that his older brother, the physician, 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 specialist in geriatrics who is also a credentialed long-term care medical director.

In the United States today there are 35 million geriatric patients -- defined as over the age of 65. Of these, 4.5 million are older than 85, now characterized as the "old old." Yet the American Medical Directors Association, which credentials physicians in long-term care, has certified only 1,900 such doctors in the entire country; only 2 percent of physicians in training say they want to go into geriatric care. 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 there will be an estimated 53 million Americans older than 65, 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 and financial.

Compounding all of this is the sad and frustrating fact that our government appears to have no policy vision for long-term elder care. It's as if our leaders wish -- perhaps reflecting our 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.

For the past nine years I have been the medical director of my hospital's skilled nursing unit, or SNU. This unit receives patients from other parts of the hospital who 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 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 referred their patients 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 patient care attends. The nurses provide up-to-the-minute reports on each patient's medical progress; the therapists discuss whether the patient is meeting goals set the previous week; we hear about the situation at home, what help we

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can expect from family or other caretakers, and what the patient's insurance may or may not provide. Our main goal is to answer one 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.

Families are encouraged to join us after our review. Most do not -- often, I think, because they are afraid we will tell them there is nothing more we can do. They are already despondent, overwhelmed by Dad's (or Mom's) decline and the acute event that led to hospitalization (the pneumonia, the fall, the stroke); bewildered by his mental decline (the confusion, the weakness); frustrated in dealing with the hospital staff (the inattentive aides, the callous nurses, the harried attending physicians who often drift in and out like white-coated apparitions).

So now your dad's physician -- maybe the one person you trusted to solve all of this (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 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? 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?! 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 draining his urine into a bag clipped to the bedrail, was not fine when he came to the hospital. He was not shanghaied from home while smoking his pipe and reading the Wall Street Journal. Rather, he arrived in the ER at 4 a.m., hypertensive and gurgling, brought in by ambulance after he passed out 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 but 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 100 lifetime SNU days if the criteria outlined in thousands of pages of regulations are met. Past the first few weeks or so, these criteria usually can no longer be satisfied -- not because the patient recovers; very few get well in the SNU -- but because the patient is "no longer making progress." No documented progress, no Medicare reimbursement.

Much of the time, 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 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 typical of our government, even as many medical practitioners are using SNUs more and more in answer to the "What are we going to do next?" question, Medicare has cut the reimbursements to these units drastically (but not decreasing the benefit to the patient, of course, which might anger the consuming public). As a result, many hospitals are closing them. My own unit shrank to half its size before being shut down by its sponsoring hospital last year, even as I was working on this article. 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 that made it financially advantageous for acute care hospitals to jettison SNUs in favor of more acute care beds.

Three years ago my father, a longtime heart patient, was admitted into the hospital with congestive heart failure.

This is the hospital in which I have made rounds almost every day since the mid-1970s. 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 available in America today. Yet I would not leave him alone in his hospital room. If my brother or mother or I could not be there, I had a hired sitter by his bed.

It's rarely talked about, but hospitalizations are the most dangerous times for the elderly. Even if they have never manifested any signs of disorientation, it is in the hospital -- in a strange and threatening environment, under the influence of anesthetics, pain pills, anti-emetics and soporifics -- that many elderly will meet their match. Add to this the treatment 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 relatively unscathed.

Every night, I slept in the reclining chair by my father's 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 and every fluid-filled bag plugged into his arm. Yet each day, my father descended deeper into paranoid confusion. He was restless, and 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 and held him, comforting him as he once -- in a long-ago life -- did me.

After four days and nights his doctor 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 -- agitated, sleep-deprived and deconditioned, a perfect candidate for time in the SNU. And, after all, here I was, his senior associate, the SNU medical director. Surely, my dad would get good care there.

Instead, I took my father home. I knew that if I didn't get him out of the hospital at that moment, he would never come home again. The SNU would have been a way station to a custodial nursing home. I arranged for a home health agency to provide my father with physical therapy and to assist him with his bathing, dressing and grooming -- something Medicare covers, but for only a limited period.

I went to the pharmacy and filled the eight prescriptions he was given as he left the hospital. Then, when I realized that my mother was having trouble reading the labels and following the instructions, I went back again to buy a plastic container divided into daily dosing compartments. How long, I wondered, had this been going on?

When I visit my father these days, if he is not asleep, I sit down beside him 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, shouting at my father: "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."

Once in a while, though, he will surprise me: "Remember those big rockfish we used to catch off Thomas Point Light?" he might say. And then nothing.

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 in attending to my father's daily needs. My brother and I help with the cost -- \$1,500 a month, but still only one-third of the expense 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, just like most families with a demented elder), they will become eligible for Medicaid, and the state of Texas 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 nutritional supplements my brother brings to the house by the case (another non-covered cost of several hundred dollars a month), my father has actually put on a few pounds. But 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.

At first, my mother didn't believe that my father was demented. Most of us do not recognize the reduction in the mental capacities of our spouses or parents unless something unexpected happens. My mother continued to see his stubbornness and withdrawal as 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.

From my years as a geriatrician and now as the son of an "old old" man, I recognize that there is 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.

I don't know what else to do for Dad at this moment, but I can imagine what is likely to happen to him if he does not die in his sleep (a heaven-sent coup de grace that I know, from long experience, is unlikely to occur). One day I will get a frantic call from my mother that my father is on the floor and crying out in terrible pain. I will race over there. I will find that one of his legs is shortened and externally rotated. His hip is broken.

I will call my brother and tell him all the reasons why we should not send him to the hospital: He might not recover from the surgery -- indeed, he might die on the table, given his bad heart. If he does survive, he will spend days in the ICU, probably on a respirator. At best he will end up in a nursing home, bedridden, at the mercy of overworked, underpaid aides. He will descend deeper into disorientation, require medications to keep him from harming himself, and die anyway in a few months -- or perhaps 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. He will feel guilty that he is not there with me. He will remember the time Dad took us on a vacation to Whiteface Mountain in the Adirondacks, and we all huddled on the swinging bridge in the mist, as the Ausable River 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, and it won't take much to alter the shower to accommodate a wheelchair." There will be a moment of silence. He'll say: "I don't know. You're the doctor. What do you think we should do?"

I do not tell him that often, in fitful sleep, I dream that when the time comes, I go to my father's bed, quietly fill a syringe with morphine and stroke his arm as I tie the tourniquet. I tell him 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, in the end, I could never do this. Not to my 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 firmly rooted in the art and tradition of healing, of comforting.

So instead, 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.

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