

Shopping For Long-Term Care

A daughter questions market theories after watching her parents make decisions about long-term care.

BY DEBORAH STONE

PREFACE: In a rational world, all of us would make decisions about the kind of long-term care we want in our later years while we are of sound body and mind. In reality, most people find it difficult to contemplate old age, let alone to predict our future health needs or select from a confusing array of options once the time approaches. The result is a nation of elders who in their last, most vulnerable years are likely to experience resignation and entrapment rather than choice. Deborah Stone, a political scientist and health policy expert, debunks what she calls the “myth” of “consumer-driven care” choices for ill elderly people like her mother, who in her prime might have been a savvy shopper but is no longer in a position to make appropriate “market-based” decisions about her long-term care. In our second story, physician Danielle Ofri also derails a myth: the assumption gleaned from her academic medical training that routine blood tests should not be conducted on healthy patients, lacking hard evidence that the benefits outweigh the costs. She relates a lesson she learned years ago while working in a New Mexico clinic about the need for flexibility in testing and treating patients.

BEFORE DEMENTIA CREPT UP, Mom was a consummate shopper. She has impeccable taste; she savors clothes, furniture, kitchen gear, plants, and most of all, contemporary art. She used to spend her days keeping in touch with friends, gardening, visiting galleries and museums, and shopping. I doubt there was a day of her life, save a few spent in the hospital, when she didn't shop. I inherited the gene, and shopping is one of the things we most enjoy doing together.

People like my mother should be perfect candidates for the kind of rational decision making about their long-term care that the market approach to health policy suggests. They have the mindset: Know your goal; compare, evaluate, and choose the best option at the lowest cost. Yet when the time came for Mom to shop for long-term care, it held no appeal. She'd lost her husband of sixty years. She was slowly losing her mind, too, and she knew it. The mother who'd never before uttered a word to me about being lonely or depressed now told me she was both. I naïvely thought that our shopping bonds would help us through this rough patch, but at the mere mention of options—part-time help, a live-in caregiver, a driver, just going to look at assisted living residences—Mom shut down and cut off the conversation.

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The Wise Consumer Myth

ACCORDING TO MARKET THEORY, consumers monitor quality and prices and choose goods that best meet their needs, preferences, and budgets. Supplier competition for these savvy consumers automatically directs resources to their best use, far more efficiently than government regulation. From the Capital Beltway to the Ivory Tower, long-term care policy—like the larger health care landscape—is inspired by market thinking. The answers to every problem (cost, quality, loss of autonomy) are to be found in consumer sovereignty. Call it “consumer choice” of insurance plans, as in Medicare+Choice. Call it “informed consent” or “informed decision making.” Call it “consumer-driven care.” All of these variations on the consumer-sovereignty theme come down to the same thing: Toss the problems back to the people who need care and their families; let them make the decisions; perhaps give them a little money, a voucher, or a budget to allocate—and poof! Costs suppressed, quality monitored, and freedom regained.

It’s fairy-tale magic, this market story with Wise Consumer as its hero, and it revolves around fairy-tale characters. I don’t know any real people, especially frail elders, who are motivated or think much like *homo economicus*. When I read the policy literature on long-term care, I have to wonder whether the nation might envision better long-term care policy if all the analysts and politicians spent a little more time listening to their parents and a little less listening to each other.

Both my parents stayed blessedly healthy and fit through their seventies. They kept their considerable marbles, too. Dad had run a manufacturing company with great success, then he “retired” to a career in public service. He read ravenously in politics, economics, science, education, and even health policy. Mom, too, is a person of keen intelligence and quick wit. She is well-organized, well-read, and prodigiously talented. My parents are the ideal, best-we-could-hope-for health care

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consumers. Dad even relished a good epistolary brawl with Blue Cross. They both completed living wills and health care proxies more than a decade ago. But over the past ten years I have helped my father through four hospital stays and my mother through two. I have accompanied them on numerous doctor visits and helped them think through their choices. Trust me, they never thought or behaved like *homo economicus*.

Each time Mom or Dad was in the hospital, somebody brought them a clipboard with lots of papers to sign on the morning of their discharge. Dad usually scrutinized documents to uncover the hidden traps in bureaucratic language and, more often than

not, fired off a few letters of protest to his congressmen. Not so the discharge papers. He'd sign them without so much as a glance, muttering to the discharge planner, "If this is what I have to do to get out of here..." Mom didn't have the same habit of studying legal forms, but, like Dad, she understood that she needed to sign to get sprung, and that was all she needed to know to apply her John Hancock.

Protective daughter that I am, I would ask to read the forms *ex post* signature. They were clearly meant to protect the hospital by documenting that it hadn't put anybody out on the streets without their consent. The discharge papers also had a disclosure to the effect that Mom or Dad had been offered home health services to be arranged by the hospital, that such services might be provided by an agency owned by the hospital, and that Mom or Dad acknowledged and accepted any such cozy financial relationship. My parents could have cared less.

Real Behavior

THE GURUS OF LONG-TERM CARE hope that people like my parents can be trained to make decisions about their care and perhaps even to manage their caregivers. For instance, Robert and Rosalie Kane have suggested in this journal (Nov/Dec 01) that since a hospital stay often triggers a change in an elderly person's living and care arrangements, we could help consumers like my parents to make decisions that are more in tune with their preferences by "training discharge planners and case managers, and allowing sufficient time—that is, paying for longer [hospital] stays—to grapple with the subtle and complex issues involved." "Hell, no!" I can hear my parents grumble. "Just get me out of here." If my parents are any indication, the hospital stay is hardly a teachable moment.

The first time Mom had surgery for lung cancer, her doctor ordered follow-up home care. She was still groggy from anesthesia when Dad and I got her home. Dad told her that the visiting nurses would be coming later on. "Who asked them to come?" she demanded to know. "I don't need a nurse." If she hadn't been wiped out from major surgery, she never would have accepted home health care, even minimal, no matter how blue in the face some discharge planner might have gotten explaining its benefits to her.

By the second time Mom had lung surgery, Dad had passed away. She was living alone, still in mourning, and she was even less able to manage than she had been five years before. This time I took matters in hand. To supplement the home care time that Medicare would cover, I lined up twenty-four-hour aides from the private-pay side of the Visiting Nurses Association (VNA). I would have done it anyway, but one of the hospital nurses told me that Mom couldn't go home unless she had someone with her around the clock. I knew the nurse's "couldn't" was an empty threat in this era of sicker-and-quicker discharge. But I also knew that she was telling me that full-time care was medically indicated, and I welcomed her exhortation as ammunition against my mother's resistance.

I spent a great deal of time explaining to the VNA's care coordinator that Mom opposed having aides, so we needed people skilled at dealing with elders' resistance. About an hour after I got Mom home from the hospital, the agency's admitting nurse and an aide showed up. We all sat down at the kitchen table, Mom full of energy and elated to be home. The nurse gave Mom a notebook, opened it to a page headed "Patient Rights and Responsibilities," and proceeded to tell her six ways to Sunday that she had a right to refuse services. Mom could ask an aide to leave at any time—it was her house, after all—she didn't have to let anyone in if she didn't want, and she could call a toll-free number at any time to end services. "Please tell me the number again," Mom asked. If I hadn't been there, she would have sent the VNA packing right then.

When the nurse was through, I walked her outside and refrained from strangling her while I asked why she had fairly invited Mom to refuse home health care.

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"It's the new patient privacy regulations," she explained, mentioning some Health Insurance Portability and Accountability Act (HIPAA) regulations that were about to go into effect. "We have to tell patients their rights." A few hours later Mom asked the aide to leave. The aide came to find me in another room. "What do I do?" she asked. "You stay," I said. "I can't," she replied. "If the patient asks me to leave, I have to leave the house." I was incredulous. I thought that I had hired these people, not my mother.

The aide allowed, "I *am* supposed to phone the agency before I leave and tell them the patient has asked me to go." My siblings and I managed to get Mom to accept a few hours of home health aides over the next week by telling her that "they're for us, Mom, we need a break." But after a week she put her foot down, phoned the agency, and called it quits.

Finding A Compassionate Solution

THIS IS WHAT PASSES FOR "CONSUMER EMPOWERMENT." All of the regulations that supposedly empower my mother to make her own choices about long-term care in fact incapacitate the VNA and any other Medicare-certified agencies subject to these consumer-protection follies. I sensed that if I wanted people who could persuade Mom to accept help instead of accepting her refusals at face value, I needed to hire private caregivers or work with agencies that are not beholden to Medicare regulations.

I phoned a private geriatric case manager and asked if it was possible to find caregivers who would interpret patients' rights more flexibly than the VNA did. Patrick told me a story. One morning an elderly woman with dementia refused to

let her long-time aide in the door. The aide went to her car, sat for fifteen minutes, then knocked again at the door and said cheerily, “Hi, I’m here.” “Oh, I’m so glad to see you,” the client gushed. My siblings and I hired Patrick. We knew that Mom couldn’t live alone any longer, but Patrick wisely said that she had to reach this decision herself. He patiently guided her through scenarios, asking her to imagine “what if” she encountered this or that difficulty. What would she like to have happen? Where would she like to be? Over the course of six weeks, Mom went from adamantly refusing to consider even a few hours of part-time help to begging for a twenty-four-hour live-in caregiver.

Mom’s decision making was a profoundly sad kind of consumerism. Shopping in boutiques and anticipating where you’ll wear a new outfit, hang a painting, or use a new gadget are pleasures. Planning how you’ll get by if you can’t walk anymore or remember how to use the microwave is not something anyone wants to think about. You can tell my mother that she’s in control, but she’s too smart to be fooled by empowerment bunkum. She knows that the point of this exercise is that she is losing her powers.

We eventually hired some part-time caregivers for Mom. She asks me alternately, “Can’t I have someone here nights, too?” and impatiently, “How long is this going to go on with these babysitters?” Her ambivalence about help is typical of frail elders and defies the economics assumption that people hold consistent preferences. I suppose that the consumer-sovereignty advocates would say that my mother exemplifies their hopes. After all, she came to the decision herself, counseled by a skilled geriatric care manager. She did so, however, with her back up against a wall. Patrick didn’t so much clarify Mom’s options as force her, albeit gently, to stare her future in the face and admit to needing help. I believe his conversations made her feel cared for, not because he “informed” her about services but because she valued his attention, his time, his visits, and his kindness. Most of all, he took the burden of decision making off of her shoulders. He told her, “You don’t need to worry about how you’re going to cope. From now on, your children and I will worry about everything.” Mom said she was relieved.

To be sure, Patrick made Mom feel her wishes would always be respected. He assured her that no one would force her into anything, even though she would be ceding control over her life to others. He gave her autonomy in small and symbolic ways to compensate for the big and real autonomy she is losing.

Services Unwanted But Not Unneeded

THE MARKET MODEL IS ALL WRONG FOR LONG-TERM CARE because it imagines care as a good or a service that people want, like a steak dinner or a massage. “There is a real problem with long-term care,” wrote economist Mark Pauly in *Health Affairs* (Nov/Dec 01). “Most of the services are not the medical services that healthy people would want to avoid but, rather, are the ‘low-tech’ or

‘servant’ services that anyone would find helpful, whether well or ill.” But most elders find the very idea of services humiliating, demeaning, intrusive, and a mark of defeat before they come to find the services helpful. For my parents, and I dare say for most postpubescent humans, care is a “bad.” No one wants to need it.

Because economists regard care as a good, they are convinced that people want to consume endless amounts of it. If public policies make long-term care free or relatively cheap, the argument goes, elders will break the bank in their eagerness to get all they can. To control “overutilization,” policymakers impose cost sharing, asset spend-downs, and other economic deterrents to seeking care. They cut home care budgets and set per case caps so that providers, too, have incentives to stint on services and terminate them quickly. These policies subtly denigrate care and punish people who ask for it. Pride and shame are already deterrents to appropriate use of care. Policy thinkers ought to worry more about how to persuade people like my parents to accept help and less about how to suppress their demand.

The market model is detrimental, too, because it sets up a competitive, almost adversarial, relationship between patients and providers. It is unfashionable these

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days to advocate the kind of proactive, protective, and, yes, paternalistic, care that we and Patrick are now giving my mother. But caring for my parents has convinced me that this approach to care is more effective, compassionate, and caring than the approach that starts with *caveat emptor*. Patrick’s sensitive and therapeutic alliance with my mother has nothing in common with the threatening, isolating disclosure notices and rights recitations we now offer elders in the name of informing them and enhancing their autonomy. True care has to start from a painful truth: Someone who needs care is dependent.

Pretending that people who need care have only to push their shopping carts around the aisles of life is a cruel hoax on them and an evasion of our moral responsibilities as family members and citizens. My mom seems to know all this: Now in her last months, she repeatedly tells me, “I hate shopping.”