Choosing Long-Term Care: Advice From an Expert

By Jane Gross
September 29, 2008 *The New York Times*


(Robb Kendrick/Aurora Photos)

For many of us, elderly parents and adult children alike, nothing is more complicated or consequential than understanding the differences between the many available permutations of long-term care, choosing which is most appropriate for our families and figuring out how to pay for it.

With that in mind, I turned for guidance to Larry Minnix, the president and C.E.O. of the American Association of Homes and Services for the Aging (A.A.H.S.A.), an association of 5,800 not-for-profit providers of aging services including adult day care, assisted living, nursing homes, home-based services, senior housing and continuing care retirement communities (CCRCs).

What follows are my questions and Mr. Minnix's answers. As always, your comments are welcome, as are additional questions. Mr. Minnix has agreed to answer some of them in future posts; please submit your questions in the comments box, but realize that Mr. Minnix will not be able to respond to all of them.

Be sure to check out the story in today's Times, by my colleague Robert Pear, on violations of federal health and safety standards at U.S. nursing homes.

Q.

Do you think coverage of long-term care should be included in Medicare or some other government entitlement program, or should it be an individual responsibility? Some experts in the field point to long-term care insurance as the solution, but many people are already too old or infirm to qualify for a policy, or they can't afford the premiums. Currently, Medicaid is the payer of last resort. But I know what a humiliation it was to my hard-working, upper-middle-class mother to wind up a "charity case." I also know how tempting it is for those who aren't impoverished in the ordinary sense to "game" the Medicaid system by getting rid of money, often in legal if sly ways, and thus qualify for a means-tested program. What's wrong with this picture, and is there any hope of fixing it?

A.

There's a lot wrong with our long-term care financing system, but we do have the power to fix it. As you point out, our current system creates an entire group of "middle-class poor" people who must resist the urge to transfer assets and then impoverish themselves before they can get any help. Many studies show that expanding Medicare to cover all of long-term care is impractical.

The A.A.H.S.A. advocates creating a national insurance trust that would cover all disabled adults, regardless of age. All adults who could afford to do so would pay premiums. All those who need help would receive cash benefits to pay for the services they need, where they want to receive them. We like this idea because it promotes personal responsibility with the premiums, choice with the cash benefits, and fairness because all Americans would have access to it. Most important, it would help people stay at home.

Q.

Regardless of what happens to long-term care financing in the future, there are more and more families stuck in the middle of this right now, beset by huge expenses with no idea of how long they will last and thus no way to budget for them. How can families make wise decisions given the available options and the unpredictable trajectory at the end of life?

It seems to me, based on personal experience, that the best we can do is make educated guesses that often turn out to be wrong.

An example: My mother, who had an early version of a long-term care insurance policy, paid her own way in assisted living for about eight years with the proceeds from selling her home. Then she wound up in a nursing home, again paying her own way until her money ran out and she qualified for Medicaid. At certain junctures, I hired private-duty help for her in the nursing home, which I paid for out-of-pocket, because the insurance premiums went first to the nursing home and later to the government. If I had it to do all over again, I'd likely encourage her to keep her house, avoid assisted living altogether and use her insurance policy to pay for home care. Or I'd have paid the upfront costs of a CCRC, which I thought prohibitive at the time but

now see might have been more economical in the long run and avoided a series of traumatic moves.

But hindsight is always 20/20. How do we make these choices in real time with no information about what the future will bring?

A.

Most decisions about long-term care are made in the middle of a crisis. For example, your father is hospitalized with a broken hip and the discharge planner is pushing him to move to a nursing home and free up the hospital bed. Whatever the case, the most important thing people can do is to acknowledge when they are younger and healthy that they are likely to need care at some point in their lives. In fact, if a person lives to be 65, there is a 69 percent chance he or she will need some kind of long-term care.

So, if you admit you might need care, you can think clearly about what's most important to you and research the best options that are available in your community. As you point out, there are many ways to approach potential needs. Nursing homes, with an average cost $77,745 per year, are often the most expensive and least desirable setting to receive care, but are essential for those with the most complicated health needs. Assisted living is somewhat cheaper, with an average annual cost of $35,628. But if your health declines beyond the basic package of services, you might be looking at a required move or extensive out-of-pocket costs to fill in the service gaps.

CCRCs do have significant entry fees, but many times these fees can be covered with the proceeds of a house sale. Also, most of that entry fee is often refundable when the resident leaves the CCRC or passes away. We find that people who move to CCRCs choose them for the amenities, but value the peace of mind of knowing that all of their needs can be met on one campus.

Reverse mortgages can help people who own their own homes stay at home by providing cash that may be needed for services. But there are drawbacks and fees involved. Depending on how complicated your or your loved one's needs might be, you may want to consider a care manager to coordinate services and help you or your caregivers.

Q.

What is the difference between for-profit and not-for-profit facilities and agencies? This may sound like an idiotic question, but do for-profits actually make money given the short-fall between costs and Medicare/Medicaid reimbursement? And with non-profits, if income exceeds expenses, where does the "profit" go?

Also, what differences, if any, will consumers actually encounter between the two? Did my mother's non-profit nursing home, for example, spend more money on her care than a for-profit would have? Should we assume for-profit care is "bad" because someone is looking to make money?

A.

Any profit that a not-for-profit aging-services organization earns goes right back into fulfilling its mission. Not-for-profit does not mean an organization never makes money, but it does mean that the money is focused on services and supports, and not on raising shareholder value.

Not-for-profits are the research and development labs of aging services. They were established to meet community needs and solve community problems. We find that once not-for-profits have ironed out the kinks of a new service, like adult day care or homemaking services, for-profits are likely to get in the market and try to maximize profits. Even in states with terrible Medicaid reimbursement rates, for-profits often find a way to turn a profit. How they do it, I don't know. This is why we need more transparency, so we can know how the dollars are spent and ensure the majority are spent on direct care.

For nursing homes, there are government data showing that not-for-profit nursing homes have fewer deficiencies and higher staffing ratios. All not-for-profits have boards of directors providing oversight, creating a transparent environment that consumers can examine and scrutinize. Don't get me wrong. There are some wonderful for-profit long-term care providers that are committed to providing quality. But across the board, consumers can be assured that a not-for-profit is committed to people over profits.

Q.

Among non-profits, do most have religious affiliations? Here in New York there are lots of Jewish homes and lots of Catholic homes — though people of any religion are welcome. What is the historical context for religious organizations dominating long-term care? And how comfortable do you think Christian clients are in, say, a glatt kosher nursing home? Or a Jewish client in a home full of religious statuary?

A.

There are no exact data on the ratio of faith-based homes and services in relation to the total number of not-for-profit providers. We estimate that 70 percent of our members, all of whom are not-for-profit, are affiliated with a faith tradition. Many longstanding aging-services providers were established by religious organizations and fraternal groups like the Masons and labor unions who recognized a need to establish services for their aging members. Because of fair housing laws, providers are not allowed to exclude people on the basis of their religion, or race, sexual orientation, etc.

If you're looking around, you should certainly ask how much the faith affiliation influences the program, but I think most people will find that the faith-based orientation is restricted to the chapel and the pastoral care department. One important thing for people to find out is the number of other residents who share the same faith and whether or not there are services and pastoral support to help you stay connected with your faith tradition.

Q.

In long-term care facilities, the staff members who have the most impact on a resident's day-to-day comfort and happiness seem to be the low-level aides. The good ones must be saints, given what they are paid, how they are treated and the nature of their work. Why should they bother to do their jobs well under these conditions? But how will we be able to afford to compensate them fairly without driving the cost of long-term care beyond anyone's means?

A.

You point out an important reason why consumers should look first to not-for-profit facilities for their long-term care: staffing is the key to quality. In general, not-for-profits have more staff and a commitment to career development. Many of our members are on the forefront of expanding benefits packages and professional development opportunities for direct care staff.

Our Better Jobs, Better Care initiative, funded by the Robert Wood Johnson Foundation and Atlantic Philanthropies, examined a number of ways that long-term care organizations can improve staff retention. Numerous studies before it found that the primary reason people leave jobs in long-term care is a bad relationship with a supervisor.

If you're touring a long-term care facility, you can and should ask about their staff turnover rate. Staffing is the best proxy for quality, and I predict it will be one of the hottest issues as we prepare to meet the needs of the baby boom generation.