

The Long-term-care Puzzle

Sorting out fact and fiction about care and coverage • by Anne Stuart

FEW PEOPLE UNDERSTAND IT. Nobody likes thinking about it. But at some point, it touches nearly all of us.

Demand for long-term care (LTC)—the medical and personal services people receive when they're no longer able to care for themselves—is on the rise. Already, 60 to 70 percent of Americans who live to age 65 will require such assistance at some point in their lives, according to research by the American Society on Aging and other organizations. Demand is expected to grow as we move deeper into the twenty-first century, for several reasons.

We're getting older. Overall, the U.S. population is maturing from youth to middle age. According to the Census Bureau, the median age (meaning half those counted were younger and half older) has increased from 23 in 1900 to 35.2 today. That benchmark is expected to rise as the baby boomers, the 77 million Americans born between 1946 and 1964, move into their sixties, says Robert J. Blendon, professor of health policy and management at the School of Public Health.

To put it another way: In 1920, less than 5 percent of the U.S. population was older than 65. By 2000, that share had doubled. During the next two decades, it's expected to double again, growing from about 35 million to 71 million. Says Blendon, "As the baby boom generation starts pushing into retirement, that has very broad policy implications" for everything from Social Security to housing, health insurance, and long-term care.

We're living longer. Overall, U.S. life expectancy grew from 47 years in 1900 to 77 years in 2000, according to the National Institute on Aging (part of the National Institutes of Health). In a few decades, the average lifespan will exceed 80 years, thanks to con-

tinuing scientific and medical advances, and researchers predict that many Americans will survive significantly longer. "Not only will it be relatively normal for people to live to 100...they may live to reach the 'natural cap' of 120 and up," Paul Hodge, director of the Generations Policy Institute at the Kennedy School, writes in the debut edition of the *Harvard Generations Policy Journal*, a publication exploring age-related policy issues. And even though many of those long-lived people will remain healthy for most of those additional decades, others will require years of assistance.

We work more. Until a few decades ago, women traditionally cared for their aging parents and other relatives, Blendon points out. With the rise of the two-income household, working women can no longer serve as full-time caregivers. Many women start families later, meaning they're busy raising their own children just as their elders need help; in addition, they often live hundreds or thousands of miles away. Finally, whether by necessity or by choice, many Americans now tend to work until much later in life, making them unavailable to care for their even older relatives (see "The Next Chapter," January-February 2004, page 24A).

Those changes have created a raft of new questions about how to provide—and how to pay for—long-term care, which, even at the lowest level of service, costs thousands of dollars annually. The good news: In recent years, Americans have gained more options than ever before in terms of both care and cost. The key is thinking about it before it's needed.

"No matter what your age or financial status or health is now, there are steps you can take to ensure that you'll have long-term care down the road," says Marilee Driscoll, founder

of the Long-Term Care Learning Institute in Plymouth, Massachusetts, and author of *The Complete Idiot's Guide to Long-Term Care Planning*. "The tragedy of long-term care is that most people don't even consider what they're going to do until they're in a crisis."

A good place to start is to educate yourself about exactly what long-term care is. Sometimes called "custodial care," the term refers to the services people require when they can no longer perform "activities of daily living"—such as eating, dressing, using the bathroom, or moving from a bed to a chair—by themselves. That need can arise suddenly, due to injury or chronic illness, or gradually, due to physical or cognitive decline. Whatever the reason, services are intended to maintain the patient, rather than to cure the condition.

Unfortunately, that definition may be the only straightforward thing about long-term care. The subject is rife with misconceptions about who needs assistance, who provides it, how much it costs, and who pays for it. So the first step toward long-term-care literacy is simply separating fact and fiction. Several common myths about this complex, constantly changing issue follow, each paired with the actual story.

Myth: Only the very old need long-term care.

Reality: Anyone can require assistance at any point, for any number of reasons.

Debilitating accidents, occupational injury, strokes, or a chronic illness such as multiple sclerosis or Lou Gehrig's disease can strike long before retirement. In fact, according to research by the National Alliance for Caregiving and by AARP, 40 percent of people currently receiving long-term-care services are adults 18

to 64 years old, among them actor Christopher Reeve, paralyzed from the neck down at age 42 in a riding accident.

"If you're over 18, you're not too young to think about this," says Phyllis Shelton, president of Long-Term Care Consultants in Nashville, Tennessee, and author of *Long-Term Care: Your Financial Planning Guide*. Marilee Driscoll agrees. "It should be part of everyone's retirement planning," she says. "To not plan is to leave your finances and your family vulnerable."

Myth: Long-term care is a synonym for "nursing home."

Reality: More than 80 percent of such care is provided in other settings.

In fact, most care still happens at home. Researchers say up to 70 percent of older LTC recipients still live in their own homes or with families or friends, relying on that network for help. Others receive part-time care from home healthcare agencies or adult day-care centers. A growing number are turning to assisted-living facilities, a residential option for people whose limitations aren't severe enough to require constant nursing attention. All these options serve people "who need a lot of help to get through the day, but don't need a doctor or nurse to provide it," Driscoll says. (That is why hospitals and rehabilitation centers don't provide long-term care.)

Myth: Medicare pays for long-term care. If all else fails, I can rely on Medicaid.

Reality: Only for short periods or under highly restricted conditions.

Medicare (federal health insurance for those older than 65) covers only "medically necessary" skilled-nursing care, only for a limited period of time (the maximum is usually 100 days), and only following a hospital stay. It offers only minimal benefits for home-based skilled-nursing care. Medicare doesn't cover any assistance with daily living.

As for Medicaid (government health insurance for low-income Americans), coverage varies from state to state and benefits are typically available only to those who have "spent down," or depleted, most of their own resources.

Myth: My health insurance or HMO includes long-term-care coverage.

Reality: That's probably not the case.

Most insurance plans and programs cover hospital, doctor, and prescription expenses related to illness or injury. Typically, even the most comprehensive won't pay for assistance with daily-living activities. The only private coverage available for such services is a policy specifically designated as long-term-care insurance.

Myth: The disability insurance I receive or buy from my employer covers long-term care.

Reality: It doesn't.

People commonly confuse disability coverage with private long-term-care insurance, Driscoll says. Actually, "disability insurance replaces earned income that's lost because you're hurt or sick," she explains. It doesn't cover nursing-home, assisted-living, or

home-health-care expenses; unlike health insurance, it doesn't pay for medical care.

The shortcomings revealed by these reality checks indicate that the United States has a long way to go toward resolving the long-term-care question, says Harvard economist David Cutler. "It's an example of how our medical system is set up to deal with acute problems," he explains. "When it comes to dealing with chronic illness, we're very, very bad." But individuals can take steps to resolve the issue for themselves by following Driscoll's advice: stay informed and be prepared. ■

For selected books, websites, and other resources, see "Learning about LTC" at www.harvardmagazine.com/LTC.

An Overview of Long-term-care Insurance

WHAT FOLLOWS is a summary of information about long-term-care insurance (frequently abbreviated as LTCi). For an inexpensive brochure on buying LTCi, call the National Council on Aging at 800-373-4906. For details on rating LTCi providers' financial stability, call Weiss Ratings at 800-829-9222. For more resources on long-term care, www.harvardmagazine.com/LTC.

Benefits: Benefits are expressed in terms of cost per day, with the buyer selecting the amount at time of purchase (obviously, higher benefits cost more). Current payouts average \$140 per day nationwide, but can exceed \$250 in areas with higher living costs.

Coverage period: Buyers also decide how long they want their benefits to last; choices range from one to five years or lifetime coverage. Longer policies mean higher premiums.

Start date: LTCi companies offer an optional waiting period between the date policyholders become eligible for benefits and the date payouts actually begin. Such waiting periods, which lower premium rates, last from one month to one year; again, it's the buyer's choice.

Cost: Premiums vary based not only on

the factors cited above, but also on the buyer's age at the time of purchase. Based on a recent rate survey, consultant Phyllis Shelton offers the following sample premiums for three policies providing benefits of \$140 per day.

For a three-year benefit period, the annual premium is \$853 if the policy is purchased at age 40, \$1,039 at age 50, \$1,605 at age 60, and \$2,601 at age 70.

For a five-year period, the premium is \$1,093 at 40, \$1,316 at 50, \$1,879 at 60, and \$3,810 at 70.

For a lifetime (unlimited) benefit period, the premium is \$1,514 at 40, \$1,822 at 50, \$2,625 at 60, and \$5,222 at 70.

Payouts: Benefits begin when a doctor certifies that a policyholder needs help with at least two "activities of daily living," such as walking, eating, or bathing.

Those contemplating the purchase of LTCi should also remember to:

- consider what, if anything, you're willing to spend out of pocket for care and determine how much you can comfortably afford to pay for premiums.

- compare quotes from three or more companies.

- check competing insurers' ratings with respected evaluators such as Weiss Ratings Inc.

- look for "inflation riders," which