

# The Long-Term Care Maze: Getting Care While Getting Older

Preparing for the possible costs of future impairment and long-term care is, regrettably, a task that everyone faces as they age. Losses in a person's ability to function day to day is a natural part of the aging process, and those losses become more severe as people get older. Twenty percent of America's elderly (those age 85 and older) are what some people call the "oldest old." Among this group, over half of them have physical or mental impairments and require long-term care—the personal assistance that enables impaired people to perform daily routines such as eating, bathing, and dressing.

# Aging and Long-Term Care

Impaired people who need long-term services and supports usually need it for a long time—in some cases, until they die. But people may also use the same kinds of services constituting long-term care for relatively short periods, such as during their convalescence from a hospitalization or from an injury or illness. That characteristic of long-term services and supports tends to complicate an understanding of the issues related to long-term care financing.

For example, health insurers cover certain long-term care services, such as home health care, to aid beneficiaries in recovering from specific medical events. But they generally do not cover long-term services and supports that are needed because of either nonspecific cause related to aging or as a result of chronic, or "long-term," impairment.

When the elder's needs for long-term services and supports can no longer be met either inside the home or without the intervention of paid providers, the elder enters, as we like to say, "the long-term care system." (Sometimes, we call it "the maze.") The elder, and the elder's family, are now embarking on an arduous journey through murky waters.

Let them begin their journey with the observation that the current system in our country for addressing long-term services and supports is a non-system, a hodgepodge of services that fails to meet the needs of the elderly and disabled in the variety of long-term care settings. It is economically inefficient, and it fails to assure the quality of services that are provided.

The "system" does not fund most long-term services and supports at all, or sporadically, or requires people to "spend-down" to eligibility; and the system provides home health care in a hodgepodge fashion. Medicare includes gaps in coverage, especially outpatient prescription medication. For people who need chronic care at home, almost no funding is available to help them in the day-to-day self-management of their illness. As a consequence, the system for financing long-term services and supports

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is biased in favor of providing extended care in an institutional setting, which usually means a nursing home.

Currently, elderly people finance long-term services from a variety of sources including private resources—personal savings, care donated by friends and family, and longterm care insurance—and with assistance from public programs such as Medicaid and Medicare.

# Limited Money, Limited Benefits

Underlying the set of decisions a person makes in preparing financially for future extended care needs is the availability of publicly funded programs for long-term services and supports, primarily Medicare and Medicaid, and, for some people, benefits provided by the U.S. Department of Veterans Affairs. Medicare does not cover long-term services and supports *per se* but has become a *de facto* financier of extended acute care services through its coverage of care in skilled nursing facilities (following hospitalization), its home health care benefit, and, increasingly, its hospice benefit.

Medicaid is the dominant public insurance program for long-term services and supports. Not only does it cover the extended custodial care needs of people with very low income, but its eligibility rules permit middle-income people—even older persons whose income in retirement leaves them fairly comfortable—to qualify for coverage by exhausting, or "spending down," their income and assets.

#### Home and Community-Based Care

For people who want to remain in their homes for as long as possible, the government may provide some limited assistance. Likewise, for persons who decide to move into an assisted-living residence, in which they receive assistance with activities of daily living, such as bathing, dressing, food preparation, and the like, the government may provide some help.

In most cases, however, assistance is limited and is almost never "24/7 personal care." Most care at home is provided or paid for by family. The legislature has decided this type of care is personal care, not health care, and therefore the eligibility criteria for personal care is typically very strict and is typically limited to supplemental care.

## Medicare and Health Care

Some people think that Medicare pays for long-term services and supports, such as personal care at home or extended care in a nursing facility. Medicare pays for health care, not personal or custodial care. For example, Medicare provides limited benefits for short stays in skilled nursing facilities.

Similarly, hospitals are under increasing pressure to shorten inpatient stays under Medicare's inpatient hospital payment system. Patients who are not ready to go home may instead be discharged to skilled nursing facilities. As a result, most nursing home residents either stay for a short period of time on Medicare skilled care or exhaust the benefit during the course of their stay.

# Medicaid and Nursing Home Care

For persons who have to have nursing home care, the legislature has likewise decided this type of care is personal care, not health care. Most nursing home residents begin their stay on skilled nursing care (which is health care, paid for by Medicare and health insurance), and then are taken off skilled and put on intermediate care (which is extended custodial care, paid for privately, with long-term care insurance,

#### and Medicaid).

Despite the costs, there are advantages to paying privately for nursing home care. The foremost is that it may be easier to get into a nursing home. In Tennessee, and probably in other states as well, few nursing homes do not accept Medicaid residents and only accept residents who are private pay. For a resident who resides in a nursing home that does not accept Medicaid, getting admitted to a Medicaidcertified facility may be difficult: the individual may have to be on a waiting list or be admitted after a hospital stay. Planning for Medicaid eligibility may therefore limit choices among nursing homes.

# How People Pay for Long-Term Care

A person preparing for his or her extended personal care needs has several options from which to choose. One alternative is to "self-insure" by setting aside personal savings and assets and then supplementing those personal resources with the donated, or free, care of family and friends. In fact, the majority of impaired seniors rely on donated care and their own savings. The value of donated care probably exceeds that of any other category of long-term care financing but is difficult to quantify in dollar terms.

An individual who self-insures retains maximum flexibility and control over his or her savings and assets but must bear the full financial risk of impairment, which will depend on the extent and duration of functional losses. Significant impairment can leave little, if any, wealth for bequests or other uses.

When it comes to paying the cost of longterm services and supports—whether in a nursing home, assisted-living, or homeand community-based care—there are, therefore, really only two choices: (1) private wealth or (2) public benefits.

These are not mutually exclusive. Seldom will the public pay all costs of someone's care, at least not for an extended period of time. In fact, most public benefits programs in the United States have a cost-sharing or co-payment component. For example, Medicare's skilled nursing facility benefit pays all costs for the first 20 days; for the 21<sup>st</sup> to 100<sup>th</sup> day, the patient pays a copayment of over \$200 a day. Medicaid requires that the nursing home resident pay all of her income to the nursing home, less certain allowable deductions such as the Personal Needs Allowance.

# Private Wealth

This consists of the individual's money, his family's money, and borrowed money. It may include what we call "liquid money" such as money in the bank, CDs, and savings bonds; and it may also include "illiquid money," which includes the value of real estate and business interests. It also includes insurance.

It is important to remember that private wealth can be both assets and income. Why is this important? Because disabled or near-disabled persons typically do not need assets (a potful of money); instead, they need an assured income stream to maintain their standard of living. In our planning, the distinction between assets and income is often critical.

Sources of income include Social Security retirement, Railroad Retirement, VA compensation, pension, rents, royalties, immediate annuity payments, interest, dividends, alimony, installment note payments, reverse mortgage payments, line of credit, and earnings from employment.

## **Public Benefits**

We have already looked at Medicare and Medicaid. There are few other public benefits available to pay for long-term care.

To summarize:

- Medicare: Pays for health care, such as hospital and doctor bills, rehabilitation in a skilled nursing facility, and hospice care.
- Medicaid: Pays for intermediate care in a nursing home, provided that the Medicaid recipient meets minimum assets and income levels and exemptions. (In Tennessee, through its "CHOICES in Long-Term Services and Supports" program, Medicaid pays for some home- and communitybased care in addition to intermediate care in a nursing home.)
- Medicaid: Pays for health care for persons with limited assets and income; or pays health insurance through the Affordable Care Act ("ObamaCare").
- Veterans benefits: Pays or provides health care and some long-term services and supports depending upon the facility and the status of the veteran or the veteran's spouse/widow.

# Supplemental Care

Often, our clients and families who come to see us do not want the cost of their loved ones' nursing home care to impoverish them. They seek our help in attaining Medicaid eligibility for themselves, or for their loved ones.

Medicaid provides a limited bundle of benefits, however. It finances care that must include certain required elements, including, among other things, nursing home care for residents in a manner and in an environment that promotes maintenance or enhancement of each resident's quality of life. Each resident must receive and the facility must provide the necessary care and services to attain or maintain the resident's highest practicable physical, mental and psychosocial well-being, in accordance with the resident's comprehensive assessment and plan of care.

There is, unfortunately, no compelling reason to assume the elder's needs *will be* met in a nursing home. The shortcomings in nursing home care are well known. Studies indicate that nursing homes are challenged to provide consistent, highquality care. Adequate staffing seems to be a system problem for these facilities.

In short, we cannot rely on a financing system that provides only minimal benefits in order to meet all of the needs of our clients. We must do more, if we can; and where resources are available, we can do more, but only if we put in place a plan that provides supplemental care services for our Client-Elders.

Accordingly, our agreements with our Client-Elders typically include a paragraph that looks something like this:

**Elder-Centered Approach:** We are an Elder Law firm. We will not knowingly take a position that harms an Elder and it is our goal to improve the quality of life for those Elders we serve. By entering into this Agreement with us, you expressly authorize us to act in your best interests at all times.

First and foremost, our planning efforts are directed towards bettering the lives of our clients – who are the Elders and not the Elder's children or other expectant heirs. Goals of the Plan are in this order of priority: (1) supporting and maintaining the good health, safety, well-being and quality of life of our Client-Elder; (2) assisting the Elder and his or her family with health care and long-term care decision making; and (3) preserving family wealth – first, for the benefit of our client, and second, for the benefit of our clients' heirs.