A patient arrives in your office whose health you instinctively know is about to decline. Your clinical experience suggests that the patient’s chronic diseases are increasing both in number and severity, and that the patient is on the verge of acquiring new disabilities. In addition to discussing possible medical treatments, your patient and the family want to discuss options for long-term care services and what they are likely to cost. This article summarizes basic information and references more detailed sources about long-term care.

**LONG-TERM CARE DEFINED**

“Long-term care” refers to the personal care, assistive technologies, and environmental modifications that allow individuals to compensate for physical and cognitive impairments. “Long-term care services” typically refers to the assistance needed to perform 2 types of activities:

1. Instrumental activities of daily living (IADLs): household tasks necessary to live independently in the community, such as using the telephone, preparing meals, shopping, doing light and heavy housework, managing money, and following a medication regimen.
2. Activities of daily living (ADLs): basic personal care tasks such as eating, dressing, bathing, toileting, transferring, and walking across a small room.

Approximately 10 million Americans have an ADL or IADL limitation. Individuals who require assistance with these activities are disproportionately older and female; the majority live in the community.¹

**LONG-TERM CARE SETTINGS**

**UNPAID HELP AT HOME**

More than three fourths of people with long-term care needs (78%) receive unpaid help from family and friends exclusively; an additional 14% receive a combination of paid and unpaid help.¹ There is considerable variation in the types and intensity of assistance provided by unpaid caregivers. One national study found that 44% of caregivers provide fewer than 8 hours of help per week, whereas 20% of caregivers provide full-time constant care.²

Whereas two thirds of caregivers reported they were comfortable providing personal care assistance, the study found that more than one half (54%) of caregivers had not received any formal training, such as how to safely bathe a patient or transfer a patient from a chair to a bed. In addition to personal care and household tasks, 43% of caregivers helped with treatment-oriented tasks, such as providing wound care (19%), assisting with medical equipment (15%), and administering medication (39%). Of the caregivers helping with these tasks, one third had received no instruction in changing dressings or bandages or in operating equipment, and 18% had received no instruction about administering medication. Physicians should be aware of the significant role caregivers play in providing assistance, and physicians and their staff should actively educate caregivers.

In addition to needing clinical instruction, many caregivers also need emotional support. (See also “Maintaining Patients With Alzheimer’s Disease in the Home Environment” on page 297.) Depending on the intensity of the patient’s needs, the physical, emotional, social, and financial costs to caregivers can be substantial. Caregiver burden has been linked to numerous adverse health-related consequences, including depression and stress.³⁴ As the caregiver experiences more difficulty, there is also a greater likelihood that the patient will be institutionalized.³ To help prevent this, the American Medical Association developed a Caregiver Self-Assessment Tool (www.ama-assn.org/ama/pub/category/5037.html) to be used in physicians’ offices to identify caregivers who might benefit from respite or other supportive services.

There is growing recognition of the important role physicians can play in directing patients and their families to community resources. The Administration on Aging recently launched a national program, “Making the Link,” to improve physician awareness of caregiver issues and to
serve as an information and referral source for physicians who want to direct families and individuals to community agencies. More than 650 local area agencies on aging plan, coordinate, and offer services to help older adults remain at home (Table). The “Eldercare Locator,” a simple 3-step search process available online at www.eldercare.gov, generates contact information for local agencies that focus on aging. The site also includes useful links to caregiver resources and a summary of the types of services available in the community.

**PAID HELP AT HOME**

Average hourly rates for home care in 2002 were $18 for a home health aide and $37 for a licensed practical nurse. An individual who requires 2 hours of personal care assistance with daily needs might therefore expect to pay $13 000 annually. Medicare covers only limited home care for individuals who are homebound and who need part-time therapy or skilled nursing care. Medicaid provides medically necessary home care; however, individuals must meet strict financial criteria to be eligible for the program. Because of gaps in coverage, disabled individuals and their families finance more than 60% of paid in-home care; Medicare provides an additional 27%, and Medicaid provides 9% of paid assistance.

Difficulties with access and coordination of paid care are well recognized, even among individuals who have unpaid helpers. Obstacles to paid care include difficulty arranging services (35%), financial barriers (31%), and a lack of awareness of available services (24%). The CareGuide Web site (www.careguide.com) provides useful general information about issues to consider when coordinating home care, including a link to a tutorial for hiring in-home help.

**ASSISTED LIVING**

Assisted living is a residential option for individuals with functional limitations who require help with personal care and household tasks but who do not require extensive medical and nursing services. In the United States, an estimated 33 000 assisted living facilities currently house about 800 000 individuals. Residents are typically women with ADL limitations. The National Center for Assisted Living (www.ncal.org) reports average fees for assisted living are approximately $1900 per month. The primary source of funding for assisted living is the patients themselves; 75% of residents finance their own care or rely on family; 22% rely on Medicaid, Social Security income, and Social Services Block Grants; and just 3% are reimbursed through long-term care insurance or managed care companies. Medicare does not reimburse costs associated with assisted living.

**SKILLED NURSING FACILITY**

Skilled nursing facilities provide a combination of personal, nursing, and medical services to individuals who have the highest levels of disability. An estimated 1.6 million older Americans reside in 18 000 nursing facilities, and approximately 40% of individuals who reach the age of 65 will spend some time in a nursing home during their lifetime. Approximately one half of all nursing home residents have some form of dementia and three fourths need help with 3 or more ADLs.

In 2002, the average annual cost of a semiprivate room in a nursing home was $52 000, and for a private room, $61 000. Medicare pays in full for the first 20 days of nursing home care following hospitalization and for a portion of care for the next 80 days, beyond which Medicare coverage ends.

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**Table. Services Provided Through Local Area Agencies on Aging***

<table>
<thead>
<tr>
<th>Service Type</th>
<th>Services Provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information and Referral</td>
<td>Assistance with information and referral to community services, health insurance counseling, needs assessment, care plan development, transportation services, caregiver support resources, retirement planning and education.</td>
</tr>
<tr>
<td>Community Services</td>
<td>Senior centers as a gathering place for social, physical, and recreational activities; a place to congregate for meals; adult day care services; volunteer opportunities.</td>
</tr>
<tr>
<td>In-Home Services</td>
<td>Meals on Wheels; homemaker services; chore services; telephone reassurance and friendly visiting to homebound older adults; energy assistance; emergency response systems; home health services; personal and respite care services.</td>
</tr>
<tr>
<td>Housing</td>
<td>Senior housing and alternative community-based living services.</td>
</tr>
<tr>
<td>Elder Rights</td>
<td>Legal assistance; elder abuse prevention programs; ombudsmen services for complaint resolution for older adults who live in institutions.</td>
</tr>
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*www.eldercare.gov or 1-800-677-1116.
Because of the high costs associated with nursing home care, many residents initially pay for the services privately and “spend down” to Medicaid eligibility by exhausting all of their personal resources.

The quality of nursing home services varies widely. Using quality care standards, The Centers for Medicare and Medicaid Services has developed “Nursing Home Compare” (www.medicare.gov/NHCompare), a searchable national database that provides information on every Medicare- and Medicaid-certified nursing home in the country. For each facility, the database offers information on 14 quality-of-care measures, deficiencies found on health inspection, and nursing staff hours per resident per day.

WHO PAYS FOR LONG-TERM CARE?

Because traditional health insurance programs such as Medicare do not cover extended home or institutional care, the majority of spending on long-term care comes from either Medicaid or private savings. During 2001, 44% of all long-term care costs were paid by Medicaid, 23% by savings (out-of-pocket), 16% by Medicare, and 11% by private insurers. One study estimated that for the average 65-year-old person, the annual cost of long-term care not covered by insurance would be $44,000—more than 3.5 times the annual cost of prescription drugs not covered. Long-term care insurance has begun to play a more instrumental role in helping people pay for long-term care, and it is likely that the number of people who purchase long-term care insurance policies will continue to increase. However, average annual premiums of $1000 for a base plan (without inflation protection) preclude widespread “take-up” rates for the typical 65-year-old retiree whose only income is Social Security benefits.

CONCLUSION

Because the circumstances surrounding each individual’s needs, preferences, and available resources vary substantially, no single option is suitable for all individuals who need long-term care. While the majority of individuals who require long-term care receive help at home from unpaid caregivers, a growing number of community and residential options exist. Physicians can play an important role by actively supporting family caregivers and referring patients and families to services in the community.

References

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