1 Long-Term Care: An Overview

- What Is Long-Term Care?
- When Is Long-Term Care Needed?
- The Growing Need for Long-Term Care
- Long-Term Care Services and Settings

What You Will Gain from This Chapter

As a result of the reading, research, and thinking you do in this chapter, you will be able to explain what long-term care is and describe the indicators of a person's need for long-term care, the growing need for long-term care in the United States, and where and how long-term care is delivered.

What Is Long-Term Care?

Long-term care is a broad range of services provided over a prolonged period, the purpose of which is to minimize or compensate for a person's loss of physical or mental functioning resulting from an illness, disability, cognitive impairment (such as Alzheimer's disease), or simply the frailties of old age.

To understand long-term care, it is helpful to understand how it differs from acute care:

- Acute care is a medical intervention lasting a relatively short time. Acute care is intended to treat or cure an individual with a critical illness or injury and restore previous levels of functioning. Acute care is provided by physicians, nurses, and other medical professionals, and it normally takes place in a hospital.

- Long-term care, unlike acute care, is not primarily intended to cure or treat a medical condition. Instead, it focuses on coping with a person's reduced level of physical or cognitive functioning over an extended period, sometimes indefinitely. Some long-term care services are rendered by health care professionals such as nurses and therapists, but long-term care is more often provided by nonprofessional personnel such as home health aides, or by informal caregivers such as family and friends.

Coping with a person's reduced level of functioning, the focus of long-term care, can include medical treatment, skilled nursing care, and therapy of various sorts. But it more typically involves assisting a person with the following:

- basic functions, such as bathing, dressing, getting out of bed, going to the toilet, and eating;
- household chores, such as meal preparation and cleaning;
- life management, such as shopping, money management, and taking medications; and
Long-term care can take place in a number of different settings. These include nursing homes, residential facilities (such as assisted living residences), community-based facilities (such as adult day centers), or the home of the person receiving care. And as mentioned above, long-term care is provided by a variety of individuals, including health care professionals such as nurses or therapists (who provide skilled care) as well as nonprofessional personnel, family, and friends (who provide personal care—that is, assistance with basic living functions and household chores).

Research

To read more on the definition of long-term care, visit the web site of America’s Health Insurance Plans (AHIP), www.ahip.org. Go to the “Consumer Information” section, click on the “Guide to Long-Term Care Insurance,” and read the first section, “What Is Long-Term Care?” You can download the AHIP guide from the web site, or you can order copies through the Federal Citizen Information Center by calling 888-8PUEBLO (888-878-3256) (order item #331M, $1.00 each). Bulk orders of the guide are available to financial services and insurance professionals through the Life and Health Insurance Foundation for Education (LIFE) at www.life-line.org/catalog or by calling 800-268-7680.

You may want to use a search engine to locate other definitions of long-term care on the Internet.

Thinking

Based on what you already knew and what you have learned about long-term care from your reading and research, write down what you would say to help someone understand what long-term care is.

When Is Long-Term Care Needed?

Whether a person needs long-term care and what care he or she needs is determined by a health care professional. An important part of the process is an assessment of the person’s ability to perform simple, everyday activities. There are two sets of such activities that are generally assessed—activities of daily living and instrumental activities of daily living.

The activities of daily living (ADLs) are basic activities that a person must be able to perform to take care of herself. The inability to perform ADLs is the most reliable and objective indicator of the need for long-term care services. The following six ADLs are commonly used to assess this need:

- bathing—washing oneself by sponge bath or in either a tub or shower (including getting into and out of the tub or shower);
dressing—putting on and taking off all clothing items and any necessary braces, fasteners, or artificial limbs;

- toileting—getting to and from the toilet, getting on and off the toilet, and performing associated personal hygiene;

- transferring—moving into or out of a bed, chair, or wheelchair;

- continence—being able to maintain control of bowel and bladder function or, when unable to maintain control, being able to perform associated personal hygiene (including caring for catheter or colostomy bag); and

- eating—feeding oneself by getting food into the body from a receptacle such as a plate, cup, or table, or by a feeding tube or intravenously.

These ADLs are listed above in the order in which people lose the ability to perform them. This order is very predictable, and interestingly, it is exactly the reverse of the order in which children acquire the ADLs. For instance, eating (picking up food and putting it in the mouth) requires only gross motor skills and a limited range of motion. It is the first ADL children acquire and the last adults lose. In contrast, bathing and dressing are very complex tasks that require fine motor skills (to manage buttons and zippers), balance (to stay on one leg while putting on pants), and an extended range of motion (to reach back to pull on a sleeve). These are the last ADLs children acquire and the first adults lose.

In some cases, a person is physically independent and able to perform all activities of daily living but still needs long-term care because of a cognitive impairment, a condition (such as Alzheimer’s disease) that causes a substantial diminishment of reasoning, intellectual capacity, or memory and results in confusion, disorientation, impaired judgment, or memory loss. Individuals with these disorders need supervision to ensure their health and safety and may or may not also need help with ADLs.

An early indication of the possible need for long-term care is difficulty in performing instrumental activities of daily living (IADLs), activities a person must be able to do in order to function independently in the community. IADLs include the following:

- grocery shopping,
- meal preparation,
- laundry,
- housework or handyman work,
- using the telephone,
- getting to places beyond walking distance,
- managing medication, and
- managing money.

The Growing Need for Long-Term Care

Concern about long-term care is growing as the population in need of such care increases. This increase is largely a result of the greater numbers of elderly people in our society. It is true that not all of those in need of long-term care are old, but it is also true that as people grow older the need for assistance with activities of daily living increases significantly. For example, as of 1999,
those age 75 or older were more than three times likelier to have an ADL limitation than those age 65 to 74.\textsuperscript{3}

Thus as the elderly population grows, the need for long-term care increases. And in the United States today, the elderly population is increasing rapidly both in numbers and as a proportion of the total population. For example, in 2000 individuals age 65 and older made up just under 13 percent of the population; by 2030 this figure is projected to increase to almost 20 percent.\textsuperscript{4}

This increase in the number of elderly persons results in part from people living longer because of improvements in living standards and advances in medical science. In 1900 the average life expectancy was 47 years; for those born in 1950 (who will turn 65 in 2015), the average life expectancy is 68 years; and those born in 1999 can expect to live to the age of 77 on average.\textsuperscript{5}

Another cause of the growth of the elderly population is the aging of the baby boom generation. The more than 76 million baby boomers born between 1946 and 1964 form a bulge in the U.S. population, and in 2011 these people will begin turning 65.

In summary, the elderly have become our society’s fastest-growing age group, and as a result, the need for long-term care is growing rapidly. In fact, many experts question whether our current delivery and financing system will be able to adequately cope with the sheer numbers likely to require long-term care in the future.

**Research**

Go to the web site of the National Center for Health Statistics, www.cdc.gov/nchs, and see what you can find out about the growing need for long-term care among aging Americans. The “Aging” section under “Initiatives” is a good place to begin looking. You also might see what is in the “News Releases and Fact Sheets” sections.

Write how you would explain the growing need for long-term care in the United States.

**Long-Term Care Services and Settings**

Today, thanks to new technology and new arrangements for care, there is a wide variety of settings in which long-term care can be delivered. Improved technology means that services once provided only in hospitals and nursing homes can now be delivered at home or elsewhere. Innovative care settings include assisted living residences, adult day centers, and others. In the remainder of this chapter, we will look at the many long-term care services and settings.

**Long-Term Care at Home**

For most people, home is the preferred setting for long-term care. Remaining at home reinforces a person’s sense of independence. The person can maintain her accustomed habits and daily routines. Surroundings are familiar, and accumulated possessions call to mind lifetime memories. For someone with diminishing cognitive abilities, this familiar environment can provide “cues” for cognition, and a person with reduced physical functioning can arrange her own home in a way that makes coping with her particular limitations easier. In contrast, a nursing home resident lives in an unfamiliar place and must usually follow institutional regimens. And indeed, most people receive long-term care at home, rather than in a facility.
Traditionally, home care meant that a person was taken care of by a family member, usually a woman who was not employed outside the home. The elderly person either moved in with his family caregiver or was visited by her in his own home several times a day. However, this situation is becoming less common, as a majority of women in the United States now have full-time or part-time jobs. Today, while most family caregivers are still female, almost 40 percent are male.\(^6\)

Still, many women and men with jobs also provide care to aged or disabled family members. Indeed, 59 percent of family caregivers are employed, most (48 percent) full-time.\(^7\) But caring for a person with a severe functional impairment at home can be overwhelming. While almost half of all family caregivers report spending no more than eight hours per week on caregiving, one-fourth spend more than 20 hours, and for 17 percent it is a full-time job, consuming more than 40 hours a week.\(^8\)

Family members who help elderly people with a severe disability also face a higher risk of serious illness and mortality themselves. Over one-third of those meeting the highest caregiving demands experience physical and mental problems as a result of caregiving, and they describe their own health status as only fair or poor. And over one-third of all caregivers report an emotional stress level of four or five on a five-point scale (where five is “very stressful”).\(^9\) For those who are also raising children (just under 40 percent of all family caregivers\(^{10}\)), the burden is particularly great. These members of the “sandwich generation” often feel caught between the care of their children and the care of their parents, not to mention the demands of their jobs. They often find that they have too many responsibilities to meet and too many needs to satisfy.

In summary, most people hope to avoid entering a nursing home and want to live as independently as possible in their own homes or some other homelike setting for as long as they can. At the same time, family caregivers, who often make continued residence at home possible, are frequently overwhelmed by the demands of providing care. In response to this problem, a new approach to long-term care has developed, called aging in place. Aging in place means that the person stays at home, and needed services are provided there or in the community. These services help the person avoid entering a nursing home and ease the burden on family caregivers. Aging in place is made possible by the following:

- **home health care providers**, which provide nursing care, personal care, home health aide care, therapy, and homemaker/chore services;
- **community-based care**, which includes adult day centers, senior centers, and congregate meal sites, as well as transportation services and home-delivered meals; and
- **residential care**, which allows the elderly to maintain their own independent living spaces while also having access to needed personal care and household support services. This includes assisted living residences and continuing care retirement communities.

These services and facilities, as well as nursing homes, are described below.

**Home Health Care Providers**

Many families call on a home health care provider when a person needing care prefers to stay at home but requires services that cannot easily or effectively be provided solely by family and friends. Home health care agencies serve recovering, disabled, chronically ill, terminally ill, and cognitively impaired persons, and they deliver at home a wide range of services, including medical, nursing, or therapeutic treatment; assistance with the activities of daily living; and supervision. There is also a growing number of independent home health care providers—nurses, the-
rapists, and home health aides who provide similar care and services but who are not affiliated with an agency. Some states certify or license these independent providers.

A physician, care manager, hospital discharge planner or social services coordinator, or a local Area Agency on Aging can help families locate home care providers in their area. State departments of health, aging, or social services can provide a list of licensed home health care agencies. In evaluating providers, family members should always ask questions and choose carefully, taking into consideration the following issues:

- How long has the provider been in business?
- Can the provider supply references?
- Does the provider supply literature explaining its services, eligibility requirements, fees, and funding sources?
- Are the patient’s home care needs evaluated by a nurse or therapist?
- Does the provider include the patient and her family members in developing a plan of care?
- Is the patient’s course of treatment documented, detailing specific tasks of the provider?
- How does the provider select and train its employees?
- Does the provider assign supervisors to oversee the quality of care?
- What procedures does the provider have in place to handle emergencies?
- How does the provider bill for services?
- How does the provider ensure patient confidentiality?
- Is an independent provider licensed or certified (if this is required by the state in which he is practicing)?
- Can an independent provider demonstrate that he is qualified by training and experience, and can he provide references?

**Research**

The above questions are based on a list appearing on the web site of the National Association for Home Care, www.nahc.org. Go to that site and browse to find more information. Click on “Consumers” on the menu to the left of the screen to get to the guidelines on how to choose a home care provider.

**Adult Day Centers**

**Adult day centers** have become an increasingly popular way of providing community-based assistance in meeting the needs of functionally or cognitively impaired adults. These centers run on the same principles as day care for children. They are open during customary business hours, allowing caregivers to work during the day and care for their family member during evenings and weekends. They provide supervision, personal care, help with managing medications, and other supportive services. A variety of social, recreational, and educational activities may also be offered to participants. Many are run by nonprofit agencies, and the cost is sometimes based on the ability to pay.
Respite Care

Respite care is long-term care provided during a limited period for the purpose of giving a family caregiver a break. The period may be for a few hours so that the caregiver can take care of personal business, or it may be for several days to allow him to take a vacation or just relax. Respite care is provided by home health care agencies, independent home care providers, assisted living residences, and nursing homes for a fee. There may also be community-based services that provide respite care on an informal basis in homes.

Thinking

Given what you have learned about home care and the support available to family caregivers from your reading and research, write down what you would say to explain to someone the home care options available to them.

Nursing Homes

Nursing homes (also called skilled nursing facilities or convalescent care facilities) provide a wide range of services, including 24-hour nursing care, supervision, assistance with ADLs, and rehabilitative services such as physical, occupational, and speech therapy. Some people stay in them for a short period of recovery and/or rehabilitation after a serious illness or operation and then return home. But the traditional role of these facilities is providing long-term care for the chronically ill or disabled. Typically, families seek nursing home care when a relative’s condition reaches the point where it is no longer possible to safely care for him at home, even with professional help, or when the cost of round-the-clock care at home becomes too great.

Nursing homes are highly regulated. They must be licensed by state governments, and in order to receive Medicaid and Medicare benefits, they must also be certified by those programs. Licensure and certification are intended to ensure that residents are cared for in a safe physical environment and that they receive high-quality care from qualified providers, and regulators closely monitor facilities. However, quality can and does vary from one nursing home to another.

There are some guidelines that can help a family select a facility. The family should obtain basic information about the facility. They should ask to see the current licenses of the facility and its administrator, and they should ask the following questions:

- Is the facility Medicare and Medicaid certified, and does it accept other forms of insurance?
- What is the daily rate, what does this daily rate cover, and are there any additional fees for laundry, supplies, medication, therapy, or other services?
- Are there any vacancies? If not, are vacancies anticipated, and how long is the waiting list?

The family should inspect the facility and ascertain the following:

- Is the facility clean and odor-free throughout?
- Is the facility well lighted and homelike in both common spaces and private quarters?
• Does each resident have ample closet space, a comfortable chair, a reading light, and a locked drawer with a key?
• Does every room have a window?
• Are private telephones and televisions allowed?
• Is there a working call-bell at each bed, toilet, and bathing area?
• Are the common areas of the facility wheelchair accessible, and are the lavatories conveniently located?

Research

The Medicare “Nursing Home Compare” web site, www.medicare.gov/NHCompare/, is a good place to get more information about nursing homes. The site allows you to search for nursing homes by name, within a certain geographic area, or based on other criteria. At www.medicare.gov you will also find articles providing general information and advice on selecting a nursing home. Information about finding a nursing home or assisted living residence is also available at www.longtermcareliving.com.

Assisted Living Residences

Assisted living residences are designed for those who need help but not the level of care provided by a nursing home. Residents of these facilities live in their own individual apartments (or sometimes individual rooms), but they also enjoy the support services that a community setting makes possible. These services include:

• up to three meals a day;
• assistance with personal care;
• help with medications, housekeeping, and laundry services;
• 24-hour onsite staff to respond to emergencies; and
• social programs.

Facilities of this type are known by many different names. Their cost also varies widely depending on geographic area, the size of the community, the services offered, and other factors. Assisted living residences are regulated in all states, but states’ requirements vary.

Research

Several web sites have information on selecting an assisted living residence: One is the site of the Assisted Living Federation of America (ALFA), www.alfa.org. In addition, “A Consumer Guide to Assisted Living and Residential Care Facilities” can be found at http://www.longtermcareliving.com/planning_ahead/assisted/assisted1.htm. While you are at these sites, browse for additional information about assisted living. Also visit the web site for the Center for Excellence in Assisted Living, www.theceal.org.
Continuing Care Retirement Communities (CCRCs)

Continuing care retirement communities (CCRCs), sometimes called life care communities, offer several levels of care in one location. For example, many CCRCs offer independent housing (for those who need little or no supportive care or services), assisted living housing, and a nursing home, all on one campus. An individual can obtain different services as his needs change, without having to move to a new community. Thus a resident who loses his ability to live independently can move from the independent area to the assisted living area, or he can receive home care in his living unit. And if the resident's condition worsens, he can enter the onsite nursing home.

Research

The web site of the American Association of Retired Persons (AARP), www.aarp.org, is a good place to get information about CCRCs and advice on choosing one. Enter “CCRC” in the search box and click on “Go.” While you are there, familiarize yourself with the other resources on the AARP site.

Adult Foster Care

Adult foster care is much like foster care for children. Elderly adults who need help functioning or who cannot live safely on their own live with a foster family. Foster families provide room and board as well as 24-hour supervision and assistance with ADLs, either to an individual or a small group. Sometimes those receiving care pay for these services. In other instances, a government program pays for foster care. State licensure of this type of facility, as well as the terminology used for it, vary greatly.

Board and Care Home

Board and care homes (also called residential care facilities) are usually small residential facilities, with 20 or fewer residents. Residents receive all meals as well as personal care and 24-hour protective oversight. They are not appropriate for individuals who need the level of care available in a nursing home, since nursing and medical attention are usually not provided on the premises. As with adult foster care, terminology and state licensure vary greatly.

Hospice Care

Hospice care provides services and support for the dying and their families. Usually, hospice patients have a life expectancy of six months or less. The purpose of hospice care is not primarily to treat the medical condition of the patient, which is incurable, but rather to improve the quality of life for the time that remains. Care focuses on pain and symptom management, social services, and emotional and spiritual support for the terminally ill and their families.

Hospice care may be provided in the patient's home or in a facility. Care is provided by a team that includes registered nurses, licensed professional nurses, home health aides, social workers, therapists, chaplains, and bereavement counselors. Volunteers are also involved. Hospice services are generally fully or partially covered by Medicare, Medicaid, private insurers, and prepaid health plans.
A source of information on long-term care resources in your area is the local Area Agency on Aging or Council on Aging. Look it up in the phone book and call for an appointment to visit with the director. This office should be able to give you a directory of long-term care organizations and information on costs in your area.

Thinking

After you have done your reading and research, write down what you would do and say to help someone find the appropriate long-term care setting for a family member in your area.

What’s Next

In the next chapter, we will survey ways of paying for long-term care—private savings and assets, family assistance, the Medicare and Medicaid programs, and various forms of private insurance. In the following chapters, we will examine these alternatives in greater depth.

Key Terms
Activities of daily living (ADLs)
Acute care
Adult day center
Adult foster care
Aging in place
Assisted living residence
Board and care home
Cognitive impairment
Community-based care
Continuing care retirement community (CCRC)
Convalescent care facility
Family caregiver
Home health care provider
Hospice care
Instrumental activities of daily living (IADLs)
Life care community
Long-term care
Nursing home
Personal care
Residential care
Overview

Respite care
Skilled care
Skilled nursing facility

Review Questions

1. What is long-term care?

2. What are the major distinctions between acute care and long-term care?

3. Who provides skilled care? Who provides personal care?

4. What are the activities of daily living (ADLs)? What are the instrumental activities of daily living (IADLs)?

5. What is a cognitive impairment?

6. What are some community-based services in the area of long-term care?

7. What types of services do home care providers offer?

8. How does an adult day center help a family caregiver cope?

9. How does respite care help a family caregiver cope?

10. What services are provided in a nursing home?

11. What is an assisted living residence?

12. What is a continuing care retirement community (CCRC)?

13. What is adult foster care?

14. What is a board and care home?

15. What is the purpose of hospice care?

Answers

1. A broad range of services provided over a prolonged period, the purpose of which is to minimize or compensate for a person’s loss of physical or mental functioning resulting from an illness, disability, cognitive impairment (such as Alzheimer’s disease), or simply the frailties of old age.

2. Acute care is intended to treat or cure an individual with a critical illness or injury and restore previous levels of functioning; long-term care focuses on coping with a person’s reduced level of functioning. Acute care is provided by physicians, nurses, and other medical professionals; long-term care is usually provided by nonprofessional personnel such as
home health aides, or by informal caregivers such as family and friends. Acute care lasts a relatively short time; long-term care is provided over an extended period, sometimes indefinitely.

3. Medical professionals such as nurses and therapists provide skilled care; nonprofessional personnel, family, and friends provide personal care.

4. The activities of daily living are basic activities that a person must be able to perform to take care of herself; the instrumental activities of daily living are activities a person must be able to do in order to function independently in the community.

5. A condition (such as Alzheimer’s disease) that causes a substantial diminishment of reasoning, intellectual capacity, or memory and results in confusion, disorientation, impaired judgment, or memory loss.

6. Adult day centers, senior centers, congregate meal sites, transportation services, and home-delivered meals.

7. Nursing care, personal care, home health aide care, therapy, and homemaker/chore services.

8. They are open during customary business hours, allowing caregivers to work during the day and care for their family member during evenings and weekends.

9. Respite care allows a family caregiver to take a break, which may last a few hours so that he can take care of personal business or several days so he can take a vacation or just relax.

10. Twenty-four-hour nursing care, supervision, assistance with ADLs, and rehabilitative services such as physical, occupational, and speech therapy.

11. A long-term care facility in which residents live in their own individual apartments (or sometimes individual rooms) but also have support services available.

12. A community that offers several levels of long-term care (such as independent housing, assisted living, and a nursing home) in one location.

13. In adult foster care elderly adults who need help functioning or who cannot live safely on their own live with a foster family that provides room and board as well as 24-hour supervision and assistance with ADLs.

14. A small residential facility in which residents receive all meals as well as personal care and 24-hour protective oversight.

15. To improve the quality of life of the terminally ill for the time that remains, with a focus on pain and symptom management, social services, and emotional and spiritual support for patients and their families.

NOTES


6 National Alliance for Caregiving and AARP. April 2004. *Caregiving in the U.S.*

7 Ibid.

8 Ibid.

9 Ibid.

10 Ibid.