

# Caregivers and Settings\*

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care continuum

Long-term care is provided by caregivers and delivered in specific settings. Among the caregivers and the settings, there is a progression of care from less intensive to more intensive as the care delivered moves from family members to professionals and from the home setting to supportive-living arrangements. This progression is often called a *care continuum*. A care recipient's level of independence and the care options that satisfy his or her needs and match a family caregiver's availability and capacity determine the care recipient's place in the care continuum. Thus, although the home is usually the best care setting in which to maintain independence, it may not be the option selected. A supportive-living arrangement may better correspond with a family caregiver's limits and more completely satisfy the care recipient's need for social interaction.

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## CAREGIVERS

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Formal and informal caregivers are the two main types of caregivers. In addition, respite caregivers, care coordinators, and even daily money managers provide long-term care services.

### Informal Caregivers

informal caregiver

An *informal caregiver* is an individual who voluntarily cares for a long-term care recipient without pay and without formal education and training in long-term care. Informal caregivers include immediate family members, such as spouses, children, brothers, and sisters, and others related to the care recipient by blood or marriage, such as aunts, uncles, cousins, and in-laws. Friends, neighbors, and volunteers from churches, charities, and community groups may also be informal caregivers. The informal caregiver with overall responsibility for a person's long-term care (usually a family member) is called a *primary caregiver*. All other informal caregivers are *secondary caregivers*.

primary caregiver  
secondary caregiver

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\* Reprinted from *Meeting the Financial Need of Long-Term Care*, 2d edition (The American College Press, 2005) by Burton T. Beam Jr., and Thomas P. O'Hare.

## **Formal Caregivers**

### **formal caregiver**

A *formal caregiver* in a long-term care setting is an individual who provides care as a profession or occupation and earns a living by rendering services to long-term care recipients. Formal caregivers include physicians, nurse caregivers, other licensed medical personnel, and nonlicensed personnel. Families may retain formal caregivers on an individual professional basis. However, formal caregiver services other than those furnished by physicians and other doctors are often obtained through home care agencies that assist informal caregivers in the home care setting.

### ***Physicians***

### **geriatric physician**

Physicians are formal long-term caregivers because they usually authorize and direct the medical care and other necessary services provided to long-term care recipients. Physicians may treat long-term care recipients directly for acute illness, such as pneumonia, or medically manage a chronic condition, such as Parkinson's disease. A *geriatric physician* specializes in the treatment of the aged. Chapter 6 explains physician certification of an insured as eligible for long-term care insurance benefits.

### ***Nurse Caregivers***

### **nurse caregiver**

A *nurse caregiver* is a registered nurse, licensed practical or vocational nurse, or nurse assistant (aide) who is responsible for the medical treatment of actual or potential health problems with the goal of rehabilitating a care recipient or stabilizing his or her medical condition. A registered nurse supervises the conduct of nursing services that may include custodial services in conjunction with medical care. Thus, nurse caregivers also direct the services provided by nonlicensed personnel. Nurse assistants in the home care setting are called home health aides. Nurse caregivers are principal providers of skilled and intermediate care (discussed in chapter 1 and mentioned later in this chapter).

### ***Other Licensed Medical Personnel***

Other licensed medical personnel are those with special health care skills obtained through training and experience, such as therapists, speech-language pathologists, social workers, and dietitians. These professionals often work together, sometimes in teams, to care for their patients and advise nurse caregivers and physicians on important aspects of patient care.

therapist

**Therapists.** A *therapist* is a trained medical specialist who commonly performs one or more of the following services:

- physical therapy—treatment of physical impairments through the use of special exercise, application of heat or cold, and other physical modalities
- respiratory therapy—treatment that maintains or improves the breathing function through the administration of medications and oxygen and/or the use of ventilator equipment
- infusion therapy—introduction of fluids, electrolytes, or drugs directly into a vein, tissue, or organ
- occupational therapy—functional enhancement of people who have physical, social, and emotional deficits arising from physical injury, illness, emotional disturbance, congenital or developmental disability, or aging

speech-language  
pathologist

**Speech-Language Pathologists.** A *speech-language pathologist* is a professional with advanced training and education in human communications, its development, and its disorders. Individuals with these skills measure and evaluate language abilities, auditory processes, and speech production and treat those with speech and language disorders. Speech-language pathologists often work with stroke victims.

social worker

**Social Workers.** A *social worker* is an individual with advanced education in dealing with social, emotional, and environmental problems associated with physical or cognitive impairments.

dietitian

**Dietitians.** A *dietitian* is a professional trained in the application of the principles of nutrition to the planning, preparation, and serving of foods to promote health and treat disease. For example, proper nutrition can be used to control high blood pressure and diabetes—two conditions that increase with age and affect many seniors. Monitoring weight gains and losses and planning special diets for people on tube feedings are also a dietitian's responsibility.

### ***Nonlicensed Personnel***

nonlicensed  
personnel

*Nonlicensed personnel* are employed to assist long-term care recipients with nonmedical tasks that usually relate to activities of daily living (ADLs), such as bathing and feeding, and instrumental activities of daily living (IADLs), such as cleaning, laundry, meal preparation, shopping, paying bills,

and completing other chores. In the home setting, these nonlicensed personnel are called homemakers, companions, and chore workers. Although these caregivers are usually unlicensed, some states require that certain categories of personnel be certified. Personnel at this level may receive training in geriatric care, including helping persons with cognitive impairments.

### **Respite Caregivers**

**respite caregiver**

A *respite caregiver* is an alternate caregiver who provides long-term care services to relieve a primary caregiver from the physical and emotional stress of rendering care over a long period of time and/or to allow the primary caregiver to have some period of personal time. This service is called *respite care*. Respite care may occur in a number of settings and can be provided by informal and formal caregivers. Respite care can be relatively brief. For example, a neighbor who relieves a caregiver for an hour a day several days a week provides respite care by giving the primary caregiver the opportunity to take a break or pursue personal interests. Respite care can also have an extended duration. Usually, the longer the period of respite care, the more likely it is to be provided by formal caregivers. For example, a care recipient living at home could receive services from a home care agency or be placed in an assisted-living facility or a nursing home for a week or two when the caregiving family takes a vacation.

**respite care**

### **Care Coordinators**

**care coordinator**

A *care coordinator*, also known as a care manager, geriatric care manager, or care planner, assesses an elderly patient who exhibits some degree of physical or cognitive impairment to determine the care needs and to develop a care plan to meet those needs. The plan also identifies and assesses the care resources available from the family (including financial resources) and resources available in the community. The plan effectively places the care recipient in the care continuum by recommending the proper care setting and the appropriate caregivers (or combinations of caregivers) in a manner that respects the care recipient's independence and needs and the informal caregivers' availability and capacity. A social worker typically functions as the care coordinator and develops the care plan. The charge for this service is usually on a fee-for-service basis and costs about \$100 per hour.

A family caregiver or physician may request a care coordinator's services, or the care coordinator may be part of the certification process to determine eligibility for benefits under a long-term care insurance policy (discussed in chapter 6). The primary family caregiver or the coordinator can

manage the plan by monitoring the quality and effectiveness of care and making changes as the care recipient's and caregiver's needs change.

### **Daily Money Managers**

**daily money manager  
(DMM)**

A *daily money manager (DMM)* assists clients who, for any reason, may have difficulty conducting their routine personal financial affairs. Services that DMMs provide relate to budgeting, paying routine bills, and keeping track of financial matters. In addition, DMMs may balance checkbooks, make bank deposits, organize tax records and other paperwork, and confer with creditors. Many persons retain these professionals because they may simply have little time for or interest in managing their routine daily money matters. However, DMMs in effect serve as long-term caregivers when they assist a person with physical and/or cognitive disabilities, usually precipitated by aging, that inhibit the ability to manage one's own finances. These disabilities include limited vision, arthritis or other conditions that hamper writing ability, and cognitive impairments that reduce the ability to complete tasks. The goal is to help persons with such limitations continue living independently. An adult child of an older person may seek the assistance of a DMM if the child does not have the time or ability to manage a parent's financial affairs.

Most DMMs charge for their services on an hourly basis. Some local government agencies, church groups, and other not-for-profit organizations provide referrals to DMMs and may offer reduced fees or free services for low-income clients.

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## **CARE SETTINGS**

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**care setting**

A *care setting* is an environment in which health care services may be given to care recipients. Long-term care settings also occur along a care continuum that begins with home care provided by informal caregivers. They advance to supportive-living arrangements outside the home with the use of formal caregivers. As the care recipient's needs become more intensive and complex, informal caregivers often need support to maintain the home as the care setting. Although supportive-living arrangements outside the home may indicate that the care continuum requirements exceed the home environment's capabilities, these care settings are often an alternative to the home environment when they involve independent living and assisted-living facilities. As supportive-living settings progress from independent living through assisted living and to nursing home care or Alzheimer's facility care,

they also represent a care continuum. Because the nursing home or Alzheimer's facility setting provides the most intensive and complex form of long-term care using formal caregivers, these facilities often constitute an end point on the care continuum. Hospice care, which can be offered in many settings, and hospital care also mark the end of the care continuum for some long-term care recipients.

The key to the appropriate placement of a care recipient within the continuum of care is to select the setting and level of services that best meet the care recipient's needs. At the same time, the care recipient should maintain a maximum degree of independence and as normal a living situation as disability or declining health permits. In other words, the assistance should meet, but not exceed, the care recipient's needs and should allow as independent a life as possible. Because there are alternative settings that might be suitable, individuals and their families should discuss the settings for future care in advance of its need.

aging in place

*Aging in place* is a term that is frequently used to summarize this approach to placement in the care continuum; care recipients avoid nursing home care by receiving care where they live, usually at home and in the community, through a combination of formal and informal caregiver services.

## Home Health Care

home health care

*Home health care*, as the name implies, takes place where the care recipient resides and encompasses virtually any home environment outside of a nursing home. Home may be the familiar family residence of many years or a new residence acquired by spouses for their retirement. The proximity of family members and reduced home maintenance and repair burdens are often the reasons seniors relocate, especially as they become less independent or after the death of a spouse. The care recipient's home may also be in a family member's residence, an independent living facility, or assisted-living facility.

The spectrum of long-term-care services available in the home setting is quite broad, encompassing medical and custodial services that use both informal and formal caregivers. These services are provided to the extent and in the combination necessary to meet the recipient's changing needs and the family caregivers' availability and capacity. Nationwide, an estimated 22.4 million families are providing physical and emotional assistance to older loved ones. Caregivers spend about \$2 billion each month out of pocket on groceries, medicine, and support services.<sup>1</sup> More than 10 million Americans over age 65 live alone, and many have no one to turn to if they need help.<sup>2</sup>

Most care recipients and their families view the home as the ideal care setting, at least at the beginning of the care continuum when care needs are

more easily managed. With familiar surroundings, possessions accumulated over a lifetime, and proximity to established neighbors and friends, the care recipient can flourish and function at a high level of independence despite a disability or chronic condition. To the extent recovery is possible after an illness or injury, it is often quicker when care is delivered in a preferred setting, such as at home. In the home setting, family members, to the extent they are available and have the capacity to do so, may provide the needed custodial services by assisting with activities of daily living, instrumental activities of daily living, and home maintenance. Assistance may be hands-on or in the form of supervision to make sure these tasks are properly and safely completed.

Many elderly with some disabilities live by themselves and need only minor assistance at the beginning and end of the day. Although the ideal location is the care recipient's own residence, the care recipient may move into a family member's home to make it easier for the family caregiver to provide assistance.

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**Example:** Jane's mother, Dorothy, recently widowed at age 78, remains in reasonably good health, but she is becoming increasingly frail and suffers from macular degeneration that restricts her vision. Jane visits her mother two or more times a week to pay bills and to handle financial matters that are now beyond Dorothy's current abilities. When she visits, Jane brings her mother groceries and other necessary purchases. Jane also closely monitors her mother's routine daily activities, such as dressing and bathing, to make sure that she is completing them without major difficulty. Jane's husband cuts the grass, shovels snow, and keeps Dorothy's house in repair.

Jane, as the primary caregiver, and her husband are able to take care of Dorothy's current needs quite well as her informal caregivers in Dorothy's home where, despite some limitations, she maintains significant independence. They are giving Dorothy long-term care at a relatively low level in the care continuum by assisting with the IADLs and the ADLs, frequently on a stand-by basis, and performing home maintenance.

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As care needs change with increased dependency, a family caregiver may have to seek additional assistance to maintain the care recipient at home. This assistance can include a range of support through home health care agencies, adult day care centers, and community services. The services that these groups provide allow a family member to maintain a relative in the home care setting when the relative's increasing needs exceed the informal caregiver's availability and/or capacity. In the absence of these services, the family caregiver would have little choice than to turn to supportive-living arrangements.

### ***Home Health Care Agencies***

**home health care  
agency**

A *home health care agency* is a private company that specializes in care to the elderly and disabled. Many of these agencies employ a range of formal caregivers that frequently includes those previously listed under the headings of nurse caregivers, other licensed medical personnel, and nonlicensed personnel. These agencies can provide medical and custodial services. Specifically, they may provide intermediate nursing services; help the care recipient with bathing, dressing, and meals; and offer socialization and housekeeping. Some agencies, however, provide little medical care and specialize in home health aides (nursing assistants) and nonlicensed personnel (such as homemakers, companions, and chore workers) who may maintain and repair a home. These agencies are more appropriately referred to as home care agencies.

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***Example:***

To continue the previous example, Dorothy falls and breaks her hip. After release from the hospital and a less-than-30-day stay in a nursing home, she returns home to complete her recovery. A home health care agency now provides medical services in the form of nursing care services and physical therapy three times a week. A home health aide visits every weekday to help Dorothy with dressing, bathing, and transferring in and out of bed and chairs.

Jane has just received a letter from Medicare informing her that Dorothy's recovery is now complete to the extent that she no longer requires nursing care. The services of the home health aide who assisted Dorothy with her ADLs are also no longer covered because Medicare does not pay for custodial care in the absence of a need for intermediate nursing care.

Because Dorothy is left with limited agility after her surgery and is becoming more frail, Jane and Dorothy agree to retain the home health care agency's services for a few hours every weekday to assist with dressing, bathing, and personal hygiene while Jane and her husband are at work. On the weekend and sometimes during weekday evenings, Jane and her husband continue to care for Dorothy as they did before her accident. However, her needs now include hands-on assistance with ADLs that the home health aide provides during the week.

Dorothy has returned to a lower level of care than when she required nursing care during her recovery from surgery. Nevertheless, although Dorothy remains at home, her increased dependency and the continuing services of a formal custodial caregiver have clearly advanced her along the care continuum beyond the point at which Jane and her husband began to care for her.

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Home health care agencies are usually state licensed, but regulation varies widely among states and by the type of services provided. However, only about one-half of licensed home health care agencies meet the standards to receive the federal certification required for payment of services under the Medicare and Medicaid programs. The National Home Care Council, the Joint Commission on Accreditation of Healthcare Organizations, and the Community Health Accreditation Program are three prominent standard-setting organizations that accredit home care agencies. State licensure, federal certification, and accreditation are important indicators of the home care agency's staff qualifications and, therefore, of the quality of its services.

### ***Adult Day Care Centers***

**adult day care  
center**

The *adult day care center* is a relatively new care setting that provides social, medical, and rehabilitative services to people with physical and mental limitations. These centers are designed for the elderly, who may be severely impaired but live at home and whose family caregiver is unavailable to stay at home during the day because he or she is working. Without the services these centers provide, many people could not remain at home.

Adult day care centers are usually open 5 days a week from 6 to 12 hours per day and typically offer a full range of long-term care services. Custodial care is provided. Indeed, most of those receiving care at adult day care centers are frail and need help with the activities of daily living. Many have cognitive impairments, including the early stages of Alzheimer's disease. The centers also provide meals under the direction of a dietitian and meet social needs through recreational and educational activities. Many programs offer transportation between home and the center. Medical services include nursing care, as well as physical, speech, and occupational therapy. Not all centers provide medical services, however. Daily charges range from around \$50 to over \$100 if medical services are provided. These centers are frequently sponsored by community service agencies.

Insurance industry representatives often use the terms "adult day center" and "adult day services" to describe this form of long-term care, thereby avoiding the words "day care," which seniors may find offensive.

### ***Community Services***

Community services include community-sponsored programs and services funded by the Administration on Aging.

***Community-Sponsored Programs.*** Almost every community, through volunteers, community groups, charities, churches, and the government, provides various arrays of services that support family caregivers and enhance a care recipient's ability to remain at home. Indeed, the development of adult day care centers discussed above demonstrates the important role community services can play in long-term care. Many communities offer organized classes ranging from art to exercise. Other social services include group sightseeing, scheduled transportation to local shopping facilities, and regularly scheduled movies. These services keep seniors not only physically active, but also mentally engaged. The significant variations in specific services that communities sponsor are beyond the scope of this text. However, a review of the categories of services funded by the Administration on Aging identifies the services that are common across communities.

***Services Funded by the Administration on Aging.*** The federal Older Americans Act established the Administration on Aging (AOA), which supports local area agencies on aging (AAAs) through funds provided to each state. Nationwide, over 650 area agencies on aging receive funding from their respective states. The AAAs contract with public and private groups to offer services, or they may provide services directly to support in-

home and community services for individuals aged 60 or older. There are several categories of these services<sup>3</sup>:

- in-home services—meals-on-wheels, homemakers, chore services, telephone reassurance, friendly visiting, energy assistance and weatherization, emergency response systems, home health services, personal care services, and respite care
- information and access services—information and referral/assistance, health insurance counseling, client assessment, care management (coordination), transportation, caregiver support, and retirement planning and education
- community-based services—employment services, senior centers, congregate meals, adult day care services, and volunteer opportunities
- housing—senior housing and alternative community-based living facilities
- elder rights—legal assistance, elder abuse prevention programs, and ombudsmen services for complaint resolution

Each community determines its own priorities for the services it offers within these categories and the extent to which they are offered. Consequently, services may differ markedly among adjacent communities. Eligibility requirements may relate both to income levels and care priorities, such as the homebound elderly with no family caregiver. Community services, even those with federal funding, do not constitute an entitlement program like Medicare or Medicaid. Budgets are limited; often, there are waiting lists for those who are otherwise eligible. In an effort to expand the reach of their services, agencies are accepting payments that vary and extending income eligibility requirements above their traditional thresholds.

Families are encouraged to contact local agencies to determine the specific services offered in their communities, as well as eligibility and payment requirements. AAAs are listed in telephone directories, usually under city or county government headings. With funding provided by the AOA, the state and area agencies on aging have established an Eldercare Locator administered in cooperation with the National Association of State Units on Aging. The Eldercare Locator helps elderly adults and their caregivers to find local services for seniors through a toll-free service at 800-677-1116; some locator features are available through the Internet at [www.eldercare.gov](http://www.eldercare.gov). Many churches also have volunteers who are valuable resources for finding local caregivers.

## **Supportive-Living Arrangements**

With advancing age, many seniors—although they continue to be in generally good health or have only minor limitations—become less willing to maintain a traditional home, especially if they live alone. They may need some degree of assistance from time to time or at least want the security of knowing that it is available. In addition, they may feel isolated living at home and miss the companionship of others, often after the death of a spouse. At the same time, they wish to remain as independent as possible for as long as possible before entering a nursing home. Supportive-living arrangements for these individuals are available in settings across a care continuum that ranges from independent housing to an assisted-living facility and eventually to a nursing home. Which setting individuals or couples may enter is directly related to their level of independence. Because these living arrangements are often available through unrelated facilities on a stand-alone basis, they are described separately. However, in many other cases, a combined facility may offer two or more shared-living arrangements. This discussion excludes adult retirement communities that are typically designed for younger retirees in good health who must provide entirely for their own medical and long-term care needs.

### ***Independent Housing***

#### **independent housing**

*Independent housing* is a collective term for the array of supportive living arrangements for seniors in a domestic or homelike environment. Residents are free to come and go as they please and do not require facility-based care (described in the following sections). The support these arrangements afford may range from companionship when desired to special meal and recreation programs. Local transportation to shopping and community events may also be available. Limited assistance with daily activities, if offered under these arrangements, is provided on a scheduled basis, not on demand.

Examples of independent housing are shared residences, senior apartments, home sharing, and accessory apartments. In a shared residence, a number of seniors live in the same house as a family, usually with each resident having the privacy of a separate bedroom. A senior apartment is a unit in a “seniors only” complex that provides a sense of community and security. Shared housing is an arrangement in which a person, known as the host and usually elderly, agrees to share space in his or her own home with one or more elderly guests. The housemates can provide companionship and assistance to each other and the host may receive additional income from the guest(s). An accessory apartment is a separate living unit that is constructed,

often for a family member, in a single-family home. Such a unit is called an elder cottage if it is built as a separate structure on the property of the single-family home.

Frequently, community, religious, and other charitable and not-for-profit organizations facilitate and/or operate independent housing programs. Although many of these living arrangements are licensed, the regulations governing their operations vary widely, as does the quality of the housing and services provided. Zoning requirements also regulate the construction of accessory apartments and elder cottages.

**assisted-living  
facility**

***Assisted-Living Facilities***

An *assisted-living facility* provides supportive-living arrangements for older residents who, despite some degree of impairment, remain independent to a significant degree but require continuing supervision and the availability of assistance on an unscheduled basis. There may be separate sections of assisted-living facilities devoted to caring for individuals with such cognitive impairments as Alzheimer's disease.

Residents may have single rooms or their own apartments with kitchens, or they may live in separate units. Services usually include meals, laundry, housekeeping, personal services (such as a hairdresser or a barber), and transportation outside the facility. Services also include assistance with one or more activities of daily living, and medication monitoring is routine. A nurse may be called for an assisted-living resident who needs limited amounts of nursing care. If constant nursing and/or custodial care is required, the resident may no longer qualify as a candidate for assisted living. Facilities, however, may use an aging-in-place approach in the assisted-living-care setting and avoid relocation of a resident to a nursing home or to another unit by allowing a higher than normal level of care in certain situations, such as when hospice care is needed.

Assisted-living facilities may serve as many as several hundred residents, but most are smaller. Although costs also vary widely, average annual costs are approximately \$30,000, or about half the cost of a nursing home. Board-and-care homes and adult foster care are much smaller in scale than assisted-living facilities, yet provide similar supportive services.

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***Example:*** To continue the previous example further, Dorothy's deteriorating condition impairs her independence to the point where the home care agency visits that assist her with bathing and dressing are insufficient to meet her changing needs. Dorothy can no longer be left home alone.

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After performing an assessment, the care coordinator Jane hired agrees that Dorothy needs a higher level of care that includes continual supervision and hands-on assistance with bathing, dressing, and transferring in and out of bed and chairs. The coordinator recommends either an assisted-living facility or an adult day care center in the community if Jane is able to take care of Dorothy's needs after work and on weekends. Both options require Dorothy to give up her home of many years. Because Dorothy prefers the independence of a home-like setting, she decides to

move to Jane's home, rather than an assisted-living facility, to allow her daughter to care for her on a daily basis. Jane is willing to meet the additional care needs, and having her mother live with her makes it possible. Dorothy applies and is accepted at the adult day care center. Jane and her husband adjust their work schedules to accommodate the center's hours. They are pleased that Dorothy receives care and supervision throughout the day, makes new friends, and is more active than she was previously.

This arrangement continues successfully for quite some time until Dorothy's needs at home increase to the point that they are more than Jane and her husband can handle. Somewhat reluctantly, Dorothy moves to an assisted-living facility where she receives supervision and the availability of support services on a continuing basis.

Dorothy continues to advance along the care continuum. Initially, a higher level of care at the adult day care center met her increased needs; the home remained the care setting, and informal caregivers provided more care. With the move to the assisted-living facility, both the setting and the dominant involvement of formal caregivers indicate that Dorothy is now at an even higher level on the care continuum.

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### ***Nursing Homes***

nursing home

A *nursing home* is a state-licensed facility that provides skilled, intermediate, and custodial care services; the care recipient's condition

determines the combination and extent of services provided. Nursing homes typically have separate sections or units for each level of service. Nursing homes are classified as approved skilled-nursing facilities when they meet the accreditation criteria required for reimbursement of services provided to Medicare and/or Medicaid patients. Not all nursing homes that offer skilled-nursing care services seek Medicare or Medicaid approval.

Hospitals usually discharge patients to nursing homes to complete their recovery from an acute illness or injury. Indeed, approximately two-thirds of people discharged from nursing homes were admitted from a hospital and stayed for 3 or fewer months.<sup>4</sup> Those who stay longer are often chronic long-term care recipients who enter a nursing home when they need more care than a home care setting or assisted-living setting can provide. These care recipients need around-the-clock care at least for custodial care and possibly nursing care. Other factors that affect the decision to enter a nursing home are

- the absence of a willing or available family caregiver
- limitations on an available family caregiver's capacity to provide home care even with the support of community and professional home care services
- the determination that the cost of home care needed to meet the recipient's needs makes the nursing home a more economical option

Nursing homes frequently represent the highest level of care and an end point on the long-term care continuum. They provide the most intensive long-term care services in both care setting and the array of formal caregivers available on a 24-hour basis.

### ***Alzheimer's Facilities***

Individuals with Alzheimer's disease and other serious forms of dementia often need specialized or unique forms of care that are not given to all patients in most nursing homes. This care requires a high level of staffing to provide the social interaction, close monitoring, and significant personal assistance that these generally mobile patients need throughout the day. As a result, the *Alzheimer's facility* has been developed to furnish care to Alzheimer's patients and other persons with similar needs. These may be stand-alone facilities, but most Alzheimer's facilities are separate units of nursing homes or assisted-living facilities that are devoted to this type of care.

An Alzheimer's facility has a staff that is specially trained to deal with persons who have dementia. Such facilities are physically designed to alleviate the stress of disoriented patients. For example, the facilities may have few

#### **Alzheimer's facility**

doors and a traffic flow to minimize dead-end corridors. There are numerous activities for patients and high levels of security—other than medication and restraints—to keep patients from harming themselves or wandering away.

### ***Combined Facilities***

**continuing care  
retirement  
community (CCRC)**

A combined facility offers two or more shared-living arrangements that offer the same housing and services described previously under separate supportive-living settings. Some combined facilities provide independent and assisted living, while others provide assisted living and nursing home care. In both of these situations, the combined facility usually gives no assurance or guarantee to the resident regarding access to or the cost of the next level of care, should it be required. By contrast, a *continuing care retirement community (CCRC)*, also known as a life-care facility, offers the full continuum of supportive-living arrangements and is obligated to provide access to housing and defined long-term care services at each level of care for the life of the resident.

Typically, CCRC residents must be capable of fully independent living upon entry, but they are assured of assisted living and nursing home levels of care as their future needs change. In some facilities, the residents may receive occasional home care services when they reside in their independent living accommodations. When a resident needs continuing supervision, he or she is usually required to move to the assisted-living unit of the CCRC. If, however, care needs escalate to the point where skilled care or custodial care is required on a continuing basis, the resident then moves to the CCRC's nursing home facility. Return to assisted living or independent living remains a possibility if the resident's/patient's condition improves. A resident spouse capable of independent living remains in the independent accommodations where the couple initially resided. Religious and other not-for-profit organizations sponsor CCRCs. Large corporations also develop them.

The financial arrangements under which the CCRC obligates itself to house and care for residents for life vary widely and are discussed in chapter 4 because they constitute a use of personal assets to meet long-term care needs.

### **Hospice Care**

**hospice care**

*Hospice care* is a system of treatment designed to relieve the discomfort of a terminally ill individual and to maintain quality of life to the extent possible throughout the phases of dying. When hospice care is available, the cost of treating terminally ill patients is usually much less than the cost of traditional hospitalization. It is not designed to produce a cure. Hospice care,

only recently considered a long-term care component, has a number of unique patient care features.

First, as the definition suggests, the care emphasizes comfort and palliative treatments to manage pain rather than the performance of heroic medical treatment and surgical procedures.

Second, in addition to the formal caregivers and care coordinators described previously, the hospice care team includes psychologists, spiritual advisers, and bereavement counselors. Counseling for the patient and family members from these professionals is a standard component of hospice care.

Third, hospice care can be provided in multiple settings, depending on the needs and circumstances of the care recipient. The home is the typical setting because of familiar surroundings and the likely presence of family members who are often caregivers. Individuals without family caregivers may enter a freestanding hospice facility, which provides a home-like setting, professional staff, and continuous access by family members. Nursing homes and hospitals may also serve as hospice care settings.

Finally, because hospice care is provided at the very end of an individual's continuum of care, its duration is usually measured in weeks or months, not years.

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## NOTES

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1. *PCA Aging Advocacy*, Philadelphia Corporation for Aging (PCA), from its Web site at [www.pcaphl.org/advocacy.html](http://www.pcaphl.org/advocacy.html), accessed on January 19, 2005.
2. *A Profile of Older Americans: 2003*, The Administration on Aging, available at [www.aoa.gov/prof/statistics/profile/2003/6.asp](http://www.aoa.gov/prof/statistics/profile/2003/6.asp), accessed on January 19, 2005.
3. *Area Agencies on Aging: A Link to Services of Older Adults and their Caregivers*, National Association of Area Agencies on Aging, from its Web site at [www.n4a.org/aboutaaas.cfm](http://www.n4a.org/aboutaaas.cfm), accessed on January 19, 2005.
4. *The National Nursing Home Survey: 1999 Summary*, Centers for Disease Control and Prevention (CDC)/National Center for Health Statistics (NCHS), June 2002.