

Overview and Learning Objectives

As its title suggests, this module provides basic information about long-term care (LTC) and serves as the foundation for the subsequent modules. The module will help you answer the following questions:

- What is LTC?
- How do people receive LTC assistance?
- How likely is it that a person will need LTC?
- How much does LTC cost?
- Who pays for LTC services?

Self-Assessment

- What are Activities of Daily Living (ADLs)? Instrumental Activities of Daily Living (IADLs)?
- What reasons might someone have for using an informal, unpaid caregiver instead of a formal, professional caregiver?
- What are some of the different settings for receiving formal LTC services?
- What are some of the contributing factors for the current shortage of LTC workers?
- How likely is someone to need LTC? Nursing home care?
- What are some of the risk factors for needing LTC?
- How much does nursing home care cost? Assisted living care? Home care?
- In 2003 in Texas, what was the range of nursing home costs? In 2003 in Texas, what was the range of daily nursing home care costs?
- How do most people pay for their LTC services?
- What is the largest payer of LTC services? Nursing home care services?
- In Texas, what is the largest payer of LTC services?

Definition of Long-Term Care

Activity: Write down the words and phrases that come to mind when you think of “Long-Term Care.”

Definition of Long-Term Care (cont.)

Long-term care can be defined as the medical and non-medical support services needed by an individual with a prolonged illness or disability to perform activities of daily living (ADLs) or instrumental activities of daily living (IADLs). ADLs are personal care and mobility activities that are necessary for everyday living. IADLs are additional activities for independent living. The six ADLs and several examples of IADLs are listed in the table below.

Activities of Daily Living (ADLs)	Instrumental Activities of Daily Living (IADLs)
<ul style="list-style-type: none"> ▪ Bathing ▪ Dressing ▪ Eating ▪ Using the toilet ▪ Transferring (e.g., getting out of bed) ▪ Continence (bladder/bowel control) 	<ul style="list-style-type: none"> ▪ Grocery shopping ▪ Laundry ▪ Preparing meals ▪ Housework ▪ Managing Medication ▪ Transportation

Individuals with cognitive impairments may also require LTC.

Cognitive Impairment: A deterioration or loss in intellectual capacity that results in impairments related to short- and long-term memory, orientation to people, place, and time, deductive or abstract reasoning (including judgment), and ability to perform ADLs.

Long-term care differs from acute care in that LTC services are intended primarily to maintain health status, while acute care aims to improve or correct a medical problem.

Levels of Long-Term Care

Long-term care encompasses many different types of services, which are sometimes grouped into the following levels:

- **Skilled care** is medical or nursing care (such as help with medications, caring for bandages and wounds) and therapies (such as occupational, speech, respiratory, and physical therapy). Skilled care is usually delivered by a nurse, therapist, or other trained professional.

Most people think of skilled services when they think of LTC but the reality is that less than 15 percent of all persons who need LTC require skilled care.

- **Personal care or custodial care** is help with the ADLs, such as bathing and dressing. The goal of personal care is to provide help with activities that individuals are unable to perform on their own. Most people who need LTC need personal care.
- **Supervisory care** provides monitoring and supervision, a safe or controlled environment, and stand-by help with ADLs to ensure that individuals do not harm themselves or others. Supervisory care is often needed because of a severe cognitive impairment.

Long-Term Care Settings

Long-term care services can be provided in a variety of settings: in the home by family, friends, volunteer groups, or social services agencies; at senior centers, adult day care programs, and adult care homes; or in nursing homes or continuing care retirement communities. This section describes some of the many different types of settings, caregivers, and services for LTC.

Informal Care

Much LTC assistance is provided by informal, unpaid caregivers. In 1998, nearly one out of four American adults reported providing some form of informal LTC services.¹ These caregivers are usually family members or friends who may provide a variety of services to assist their relatives or neighbors, from paying bills and preparing meals to helping them bathe or dress.

Caregivers may provide assistance for a variety of reasons, including²:

- The person being cared for does not require skilled, professional services;
- The person being cared for cannot afford skilled, professional services; or
- The person being cared for does not want to be cared for by strangers.

Providing this informal care, however, can take a significant toll on the caregiver. Many caregivers juggle their caregiving responsibilities with other family or work responsibilities: over 60 percent of informal caregivers are between the ages of 18 and 49 and more than two-thirds are married, indicating that many caregivers are probably raising their own children. In addition, more than half are employed full-time and another 12 percent are employed part-time.³ These competing responsibilities can add to the emotional strain and financial burden of providing informal LTC services.

To ease the burdens of caregiving, the federal government through the Older Americans Act and many states have created caregiver support programs. These programs typically provide counseling, information, and respite care to informal caregivers.

¹ Kaiser Family Foundation, *Survey of Long Term Care from the Caregiver's Perspective*. 1998.

² Ibid.

³ National Alliance for Caregiving & AARP, *Family Caregiving in the US, Findings from a National Survey*, 1997.

Formal Care

Individuals requiring skilled, professional LTC services can receive them in a variety of settings. In many cases, individuals will use a combination of different services in order to meet their LTC needs. For example, individuals may receive both formal home health care services and informal care from a family member or they may attend an adult day care program in addition to receiving home health care services.

Home Care Services

Home care services may be provided by licensed nurses, home health aides, or social services agencies, depending on the type of services required by the individual. Typical home health services include:

- Skilled care, such as nursing services, physical, occupational, or speech therapy, or wound care.
- Personal care or assistance with ADLs, such as eating, dressing, or bathing.
- Homemaker or IADL assistance, such as preparing meals.

Community-Based Services

Community-based services such as Adult Day Care Programs provide part-time care in a group setting for frail and isolated individuals. Services may include health monitoring, therapy, meals, social services, and personal care.

Residential Care

Residential care services are available in a variety of forms:

- Nursing Homes are residences offering a comprehensive array of services including skilled nursing care, physical, occupational, and speech therapy, personal care (assistance with ADLs), and meals.
- Assisted Living is a type of living arrangement in which personal care services such as meals, housekeeping, transportation, and assistance with activities of daily living are available as needed to people who still live on their own in a residential facility. In most cases, the “assisted living” residents pay a regular monthly rent and additional fees for the services they receive.

- Continuing Care Retirement Communities (CCRCs) are housing communities that provide different levels of care based on what each resident needs over time. This is sometimes called “life care” and can range from independent living in an apartment to assisted living to full-time care in a nursing home. Residents move from one setting to another based on their needs but continue to live as part of the community. Care in CCRCs is usually expensive. Generally, CCRCs require a large payment before an individual moves in and then charge monthly fees.
- Board and Care Homes are a type of group living arrangement designed to meet the needs of people who cannot live on their own. These homes offer help with some personal care services.

Workforce Issues

The United States is facing a critical shortage of LTC workers that will only intensify in the coming decades. Some of the factors that are currently contributing or will contribute to the shortage are listed below.

- **High staff turnover rates:** Turnover rates for nursing assistants, which have been estimated to be as high as 100 percent annually in nursing homes,⁴ are caused by low wages, stressful working environments, and little respect.
- **Fewer informal caregivers available:** The responsibility of carrying for an elderly individual traditionally fell to the person's adult children (typically to their adult daughters). Today, however, adult children often do not live near their parents, making such informal caregiving arrangements difficult or impossible. In addition, women are increasingly working outside of the home, giving them little time to care for an elderly parent. Because fewer families can rely on informal caregivers, demand for home health aides and other professional care providers is increasing.
- **Aging population:** As the baby boomer generation ages and life expectancy increases, demand for LTC services will increase significantly. Unfortunately, the population growth for people between the ages of 20 and 64, who typically provide LTC services, will not match the growth rate of people needing the services.⁵

While the shortage in LTC workers is a problem throughout the country, it can be especially severe in rural and other underserved areas. In addition to the factors listed above, these areas must contend with additional issues such as:

- Wages in rural areas are often significantly lower than wages available in urban areas.
- Fewer young nurses and LTC workers are willing to stay in rural areas, making it difficult for facilities and agencies to replace their retiring workers.
- The distance between clients in rural areas makes service delivery difficult.

⁴ Stone, Robin, and Joshua Weiner. *Who Will Care For Us? Addressing the Long-Term Care Workforce Crisis*. October 2001.

⁵ Ibid.

Risks of Needing Long-Term Care

Approximately 60 percent of individuals age 65 and older will require LTC at some point in their lives.⁶ About 43 percent will require nursing home care. There are many factors that increase a person's risk,⁷ including those listed below.

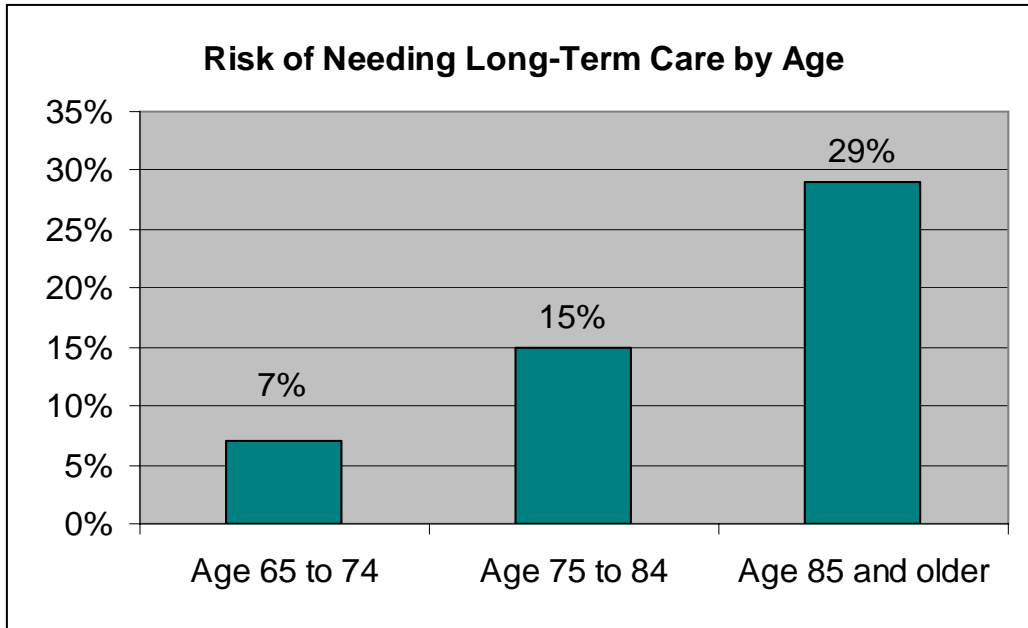
- **Age** – Age is the single most important risk factor for needing LTC services. However, younger people can also need LTC. It is estimated that nearly 40 percent of all persons currently receiving LTC services are working-age adults between 18 and 64 years old.⁸
- **Marital Status** – Single individuals are more likely to need LTC services. This is due mostly to the fact that a single or widowed individual is less likely to be living with someone who can provide informal care.
- **Gender** – Women are more likely to require LTC services. This is due partly to the fact that women often outlive their husbands and therefore are more likely to be older and single.
- **Lifestyle** – Smoking, poor diet, stress, and/or a sedentary lifestyle may lead to chronic health conditions requiring LTC.
- **Health** – Chronic conditions including emphysema, diabetes, or arthritis increase the risk of needing LTC.
- **Family History** – Individuals with a family health history of physical or mental illness have an increased risk of needing LTC.

⁶ *Long-Term Care Insurance, Baby Boom or Bust?* Conning & Company, 1999.

⁷ B.C. Spillman and J. Lubitz. "New Estimates of Lifetime Nursing Home Use: Have Patterns of Use Changed?" *Medical Care*. Volume 40, Number 10, 2002.

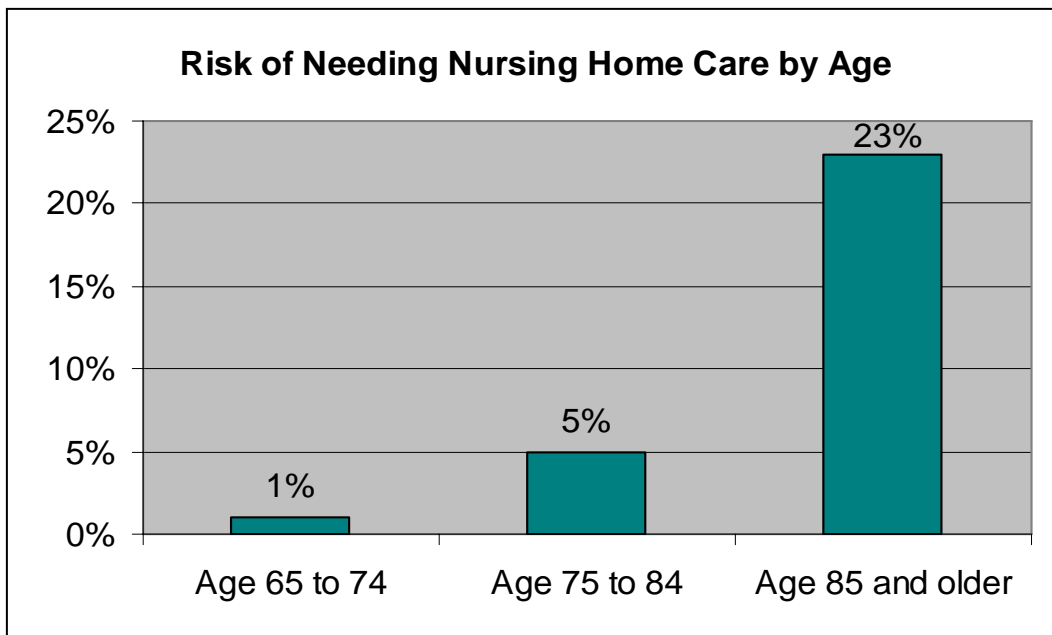
⁸ General Accounting Office. "Long-Term Care: Current Issues and Future Directions," April 1995.

As mentioned above, age is the most important risk factor for needing LTC. The chart below shows the percentage of individuals in each age group using LTC services during a 12-month period.



Source: Urban Institute, *Long-Term Care: Consumers, Providers, and Financing*. March 2001

The chart below illustrates the percentage of individuals in each age group who needed nursing home care during a 12-month period.



Source: Urban Institute, *Long-Term Care: Consumers, Providers, and Financing*. March 2001

Costs of Long-Term Care

Long-term care is expensive. In 2001, the average national cost of . . .

- Nursing home care was \$56,000 per year;⁹
- Assisted living care was approximately \$22,500 per year;¹⁰ and
- Part-time home care was between \$12,000 and \$16,000 per year.¹¹

By comparison, in 2000, the median household income for persons age 65 and over was \$23,048,¹² which barely covers the cost of one year at an assisted living facility and covers less than half the cost of one year in a nursing home.

Since the average nursing home stay is approximately 2.5 years and the average cost of nursing home care is \$56,000 per year, the average cost of a nursing home stay is about \$140,000.¹³ The expense, therefore, can quickly exhaust an individual's personal savings.

The costs of LTC can vary significantly depending on geographic location. For example, while the average cost of one year in a nursing home was about \$56,000 in 2001, the costs can exceed \$80,000 per year in areas of the country with a high cost of living.

Texas

In Texas, in 2003, the cost of a nursing home stay could range from \$30,000 to more than \$50,000 per year. Depending on the services needed and the costs of care in your area, average daily rates could range from \$90 to more than \$150 per day.

Source: Texas Department of Insurance, *Long-Term Care Insurance (July 2004)*

⁹ U.S. Department of Labor, *Report of the Working Group on Long-Term Care*.

¹⁰ National Center for Assisted Living, *Facts and Trends: The Assisted Living Sourcebook 2001*.

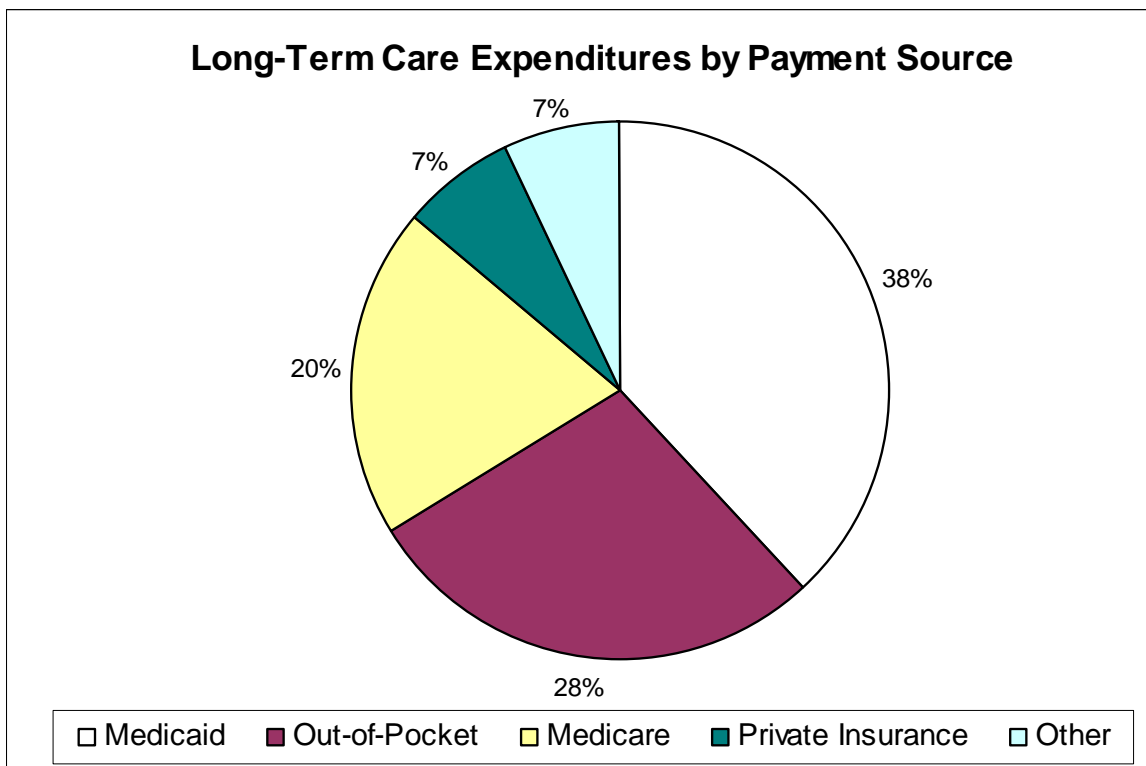
¹¹ U.S. Department of Labor, *Report of the Working Group on Long-Term Care*.

¹² U.S. Census Bureau.

¹³ U.S. Department of Labor, *Report of the Working Group on Long-Term Care* and Kemper, P. and Murtaugh, C.M. (1991). Lifetime Use of Nursing Home Care. *New England Journal of Medicine* (324):595-600.

Long-Term Care Payment Systems

Long-term care services are paid for by many different sources including Medicaid, personal savings, Medicare, and private LTC insurance. Most people who need LTC pay out of their own income and savings. However, on an aggregate basis, Medicaid is the largest single payer for both LTC services in general and nursing home services specifically. That’s because, once a person uses up his or her financial resources paying for care, Medicaid becomes responsible for paying for the care. The charts below illustrate the payment sources for all types of LTC services and for nursing home care specifically. It should be noted that these figures show payments by source on an aggregate basis (that is, they show percentages of the total cost of LTC or nursing home care, not the percentage of individuals using each payment source). In addition, these figures do not include the cost of LTC services provided by informal caregivers.



Source: CMS, National Health Accounts, 1999.

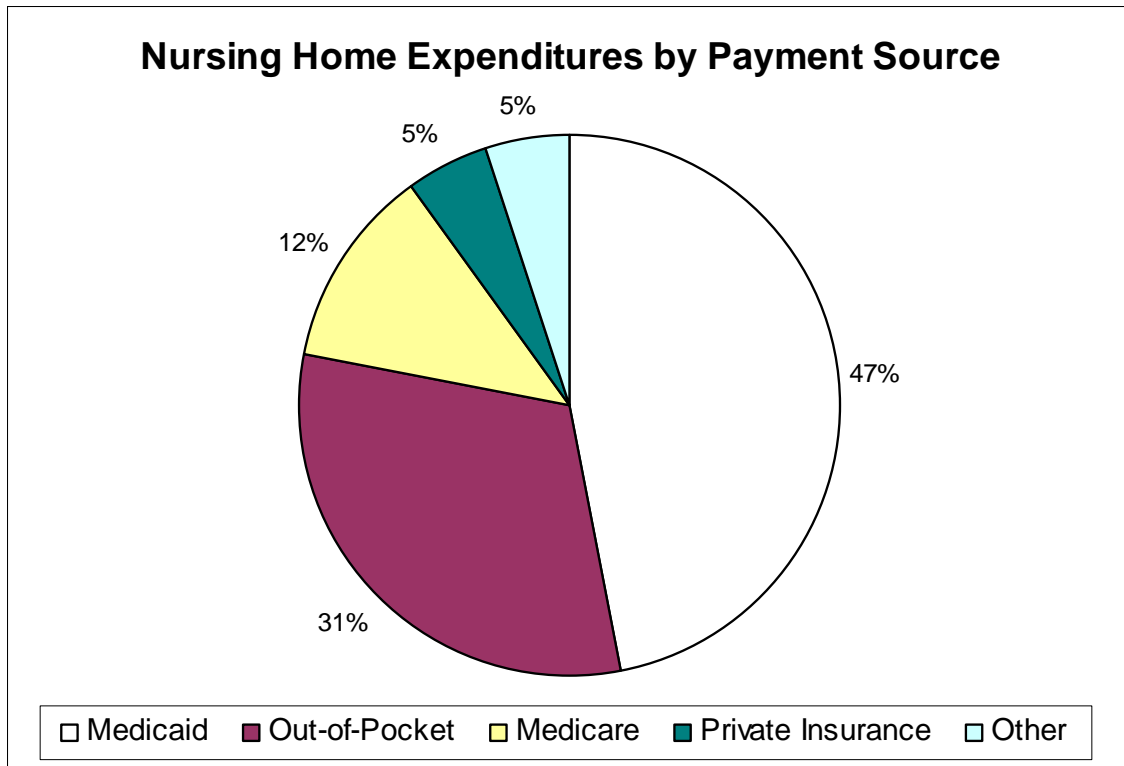
“Other” can include the Veterans Administration (the VA), and religious communities.

Texas

In Texas, most long-term care expenses are paid by Medicaid, a state and federal assistance program for eligible individuals with low incomes. The rest are paid out-of-pocket by individuals or through Medicare or long-term care insurance.

Source: Texas Department of Insurance, *Long-Term Care Insurance (July 2004)*.

The chart below illustrates the payment sources for nursing home care.



Source: CMS, National Health Accounts, 1999.

Payment for an individual's LTC services is usually more complicated than it may appear from these charts. For example, since individuals requiring LTC usually need an array of services, a person may have some of his services paid by one source and other services paid by another. In addition, the payment source for certain services may change over time as the person's needs change or as they exhaust their health care benefits or personal resources. For example, many individuals begin by paying for their care. When they deplete their financial resources, Medicaid will take over. Or Medicare may pay at the outset but once an individual no longer needs skilled care or his or her care extends beyond a certain number of days, Medicare payment ends. The person may then rely on other payment sources such as their own financial resources or Medicaid.

The case studies on the following pages illustrate the complexity of paying for LTC services.

Case Study 1: Sam

Sam is an 82 year-old widower with an income of \$2,000 per month and savings of \$14,500. He suffered a stroke and was hospitalized for several weeks. Following his hospital stay, he is discharged to a skilled nursing facility, where he will stay indefinitely. The nursing home charges \$150 per day or \$4,500 per month.

His nursing home stay is paid for as follows:

First 20 days: Medicare covers all costs.

Days 21 to 34: Medicare and Personal Income.

Sam pays \$105 per day (\$1,470 for 14 days) and Medicare pays the rest. He uses his regular monthly income to cover his portion of the costs.

Days 35 to 184: Personal Income/Savings

On Day 35, Sam's doctor decides he no longer needs skilled care (only personal care) so his care is no longer covered by Medicare. Sam will be responsible for the cost of his nursing home care. His monthly nursing home bill is \$4,500 and his monthly income is \$2,000, so he must pay \$2,500 per month from his savings. With \$14,500 in savings, Sam must spend \$12,500 before he is eligible for Medicaid. He can pay for five more months (150 days) of his stay (\$12,500/\$2,500).

Days 185 and beyond: Personal Income/Medicaid.

Sam has exhausted his savings. He can now "spend-down" his income (more about that later) to qualify for Medicaid. His nursing home costs are now covered by a combination of his income and Medicaid.

The case study illustrates how Sam's nursing home care was paid for by several different sources as he first exhausted the benefits available to him under Medicare and then his personal savings. At the end, his nursing home costs are being paid by two sources: Medicaid and his personal income. If Sam stays 2.5 years (the average nursing home stay), his LTC payment sources would be: 52% paid by his own income and savings, 3% by Medicare, and 45% by Medicaid.

Case Study 2: Margaret

Margaret is an 85 year-old woman who lives alone but within a short drive of her adult daughter, Allison. She has a LTC insurance policy. Margaret has begun to experience difficulty in performing some activities of daily living, including bathing and dressing herself, and some instrumental activities of daily living, including grocery shopping, paying her bills, and preparing meals. Margaret, with the help of her daughter, makes the following arrangements to address her LTC needs:

Bathing and Dressing

Because Margaret does not need skilled nursing care or therapy services, she does not qualify for home health care coverage under Medicare. However, her LTC insurance policy will cover up to \$50 per day for home care, allowing Margaret to have a home health aide come to her home each day to help her bathe and dress.

Grocery Shopping

Margaret's daughter, Allison, will help her do most of her grocery shopping. But because Allison sometimes travels for business, they contact Margaret's church to find a volunteer who will take Margaret shopping and look in on her when Allison is out of town.

Paying Bills

Allison will now pay Margaret's bills and keep her financial, legal, and medical records in order.

Preparing Meals

Margaret and Allison have dinner together twice per week and Margaret has lunch twice per week at her senior center. To supplement this, they make arrangements with the local Meals on Wheels program to have lunch delivered to Margaret's home three times per week. For her other meals, Allison will help Margaret prepare meals on the weekend that she can reheat for herself during the week.

The case study illustrates how Margaret has used a combination of formal care (provided by her home health aide) and informal care (provided by her daughter, a church volunteer, and local social service agencies) to meet her current LTC needs.

Module Exercise

1. People need long-term care (LTC) when they are unable to perform their Activities of Daily Living (ADLs) without the help of another person. Which of the following correctly lists the ADLs?
 - a. Bathing, Dressing, Toileting, Taking Medication, Eating and Transferring
 - b. Bathing, Dressing, Toileting, Transferring, Continence and Eating
 - c. Bathing, Dressing, Toileting, Ambulating, Taking Medication and Eating
 - d. Bathing, Dressing, Toileting, Continence, Eating and Taking Medication

2. There are different types of LTC. Which of the following terms correctly describes the type of care you receive when you need help with bathing, dressing or other Activities of Daily Living (ADLs)?
 - a. Personal care
 - b. Skilled care
 - c. Supervisory care
 - d. Intermediate care

3. When people need LTC, which type of care are they least likely to need?
 - a. Skilled care
 - b. Personal care
 - c. Supervisory care
 - d. Intermediate care

4. Which term refers to care that is provided by family or friends?
 - a. Formal care
 - b. Custodial care
 - c. Supervisory care
 - d. Informal care

5. Which of the following terms does not refer to a type of residential care setting for LTC?
 - a. Continuing Care Retirement Community
 - b. Adult Day Care Facility

- c. Assisted Living Facility
 - d. Board and Care Home
6. What is the probability that someone age 65 or older might need some type of LTC at some point in his or her lifetime?
- a. 13 percent
 - b. 25 percent
 - c. 45 percent
 - d. 60 percent
7. Nursing home costs vary from one state to another. What is the average annual cost of nursing home care in the U.S. today?
- a. \$36,000
 - b. \$56,000
 - c. \$66,000
 - d. \$76,000
8. Some people who need nursing home care are not there for long, while others may have a very lengthy stay. How long is the average stay in a nursing home?
- a. 180 days
 - b. 1.5 years
 - c. 2.5 years
 - d. 3.0 years
9. On an aggregate basis, which of the following sources pays the largest portion of LTC costs?
- a. Medicare
 - b. Private health insurance
 - c. Medicaid
 - d. Out-of-pocket from a person's income and assets
10. On an individual basis, which of the following sources pays the largest portion of LTC costs?
- a. Medicare
 - b. Private health insurance

- c. Medicaid
 - d. Out-of-pocket from a person's income and assets
11. Overall, in Texas, which of the following sources pays most long-term care expenses?
- a. Medicare
 - b. Medicaid
 - c. Long-term care insurance
 - d. Out-of-pocket from a person's income and assets