



Understanding Long-Term Care

PATTI C. WOOTEN SWANSON, Nutrition, Family, and Consumer Sciences Advisor, University of California Cooperative Extension, San Diego County; **NANCILYNNE SCHINDLER**, Staff Research Associate, University of California Cooperative Extension, San Diego County; and **THOM T. TRAN**, Staff Research Associate, University of California Cooperative Extension, San Diego County

OVERVIEW OF THE FINANCIAL CAREGIVING SERIES

The publications in this series are based on research conducted with adult child caregivers and caregiving professionals. The series provides practical insights and strategies for adult children (and other family members or friends) who are concerned about or caring for their aging, ill, or disabled loved ones. Financial caregiving tasks are organized and prioritized for caregivers according to three possible scenarios: when there is time to plan, when you observe that some assistance may be needed, and when there is a crisis. Caregiver resources include step-by-step implementation plans, consumer checklists, worksheets, and locations for finding more information. The series contains seven publications:

1. *Introduction to Financial Caregiving and Glossary* (Publication 8379)
2. *Communicating with Your Parents about Finances* (Publication 8380)
3. *Getting Organized: Bill Paying and Record Keeping* (Publication 8381)
4. *Understanding Long-Term Care* (Publication 8382)
5. *Planning and Paying for Long-Term Care* (Publication 8383)
6. *Estate Planning* (Publication 8384)
7. *Financial Fraud and Abuse* (Publication 8385)

The information presented in the Financial Caregiving Series is for general educational purposes only and is not intended to substitute for professional advice regarding legal, tax, or financial-planning matters.

OVERVIEW OF LONG-TERM CARE

Long-term care (LTC) refers to a variety of medical and nonmedical (personal) services for people who have chronic illnesses, disabilities, or mental impairment, such as Alzheimer's disease. While a person may need long-term care at any age, older adults are the most common users. Long-term care can be provided at home, in the community, in assisted-living facilities, or in nursing homes. Almost 80 percent of those who need care continue living at home in the community and depend on informal (unpaid) care from family and friends as their only source of care. Another 14 percent receive a combination of informal and formal care (paid care). Only 8 percent rely totally on formal (paid) care (Family Caregiver Alliance 2005).

Case Study: Who Can Benefit from Adult Day Care?

Paul is 69 years old and recently suffered a stroke. He needs some care and supervision, so he has been living with his son and daughter-in-law, John and Cindy. However, John and Cindy both work, so they needed help caring for Paul during the day. They solved the problem by enrolling Paul in an adult day care program near their home. Cindy drops Paul off at the center in the morning, and John picks him up after work. The center monitors Paul's medications, provides some physical therapy, serves him lunch, and gives him an opportunity to socialize with other seniors.

Most long-term care is nonmedical or personal care that assists people with support services such as activities of daily living like dressing, bathing, and using the bathroom. Medical care includes assistance with the health-care tasks most people do for themselves, such as monitoring blood glucose levels (for diabetics) or changing dressings on wounds, as well as skilled nursing care. Long-term care services are available for a variety of everyday activities, including the following:

- eating
- bathing or showering
- dressing
- walking
- getting in or out of a chair
- using the toilet
- preparing meals
- housework
- shopping
- managing money
- transportation
- using the telephone
- taking medication

Some people equate *long-term care* with *nursing homes* (also called *skilled nursing facilities* and commonly referred to as *rest homes*). However, elders and their families can choose from a number of other long-term care alternatives, including

- community-based services
- home health care
- assisted living (AL)
- continuing care retirement communities (CCRCs)

This publication includes descriptions of the various types of long-term services and facilities, the people they are designed to serve, the average costs, and consumer considerations when shopping for and selecting services. [Table 1](#) contains a summary of long-term care services.

Community-Based Services

The U.S. Administration on Aging (AoA) funds local Area Agencies on Aging (AAAs) to coordinate community-based, long-term care services for seniors. Services typically include adult day care, nutrition programs like Meals-on-Wheels, transportation services, personal care, assistance with household chores, and activities and meals offered by senior centers. Services are usually free or low-cost for qualifying individuals.

Table 1. Description of long-term care services by type of care

| Type of long-term care | Description | Eligibility criteria | How to pay* | Discharge decisions |
|---|---|---|--|---|
| community-based care in the home | The elderly person lives in his or her own home and receives services at home or at an Adult Day Care center. | self-referral and doctor referral for home health rehabilitation services | self-insure; LTCI; health insurance for doctor referrals | decided by the elderly person |
| live-in caregiver | The elderly person lives in his or her own home with a caregiver. | self-referral | self-insure; LTCI | decided by the elderly person |
| independent living | The elderly person lives in a senior retirement community without medical services. | self-referral | self-insure | decided by the elderly person |
| assisted living | The elderly person lives in a community or complex with varying levels of custodial and medical care. | self-referral | self-insure; LTCI; Medicaid | decided by the elderly person |
| continuing care retirement community (CCRC) | The elderly person lives in a community with a variety of living arrangements where they can move around based on the level of care that is required. | self-referral when healthy; doctor referral when nursing care required | self-insure, LTCI, Medicaid (if approved for nursing care) | decided by the elderly when healthy; doctor discharges from nursing care if the patient improves or moves to hospice care |
| skilled nursing care | The elderly person stays in a nursing home due to the high need for medical and custodial care. | doctor referral based on medical needs | Medicaid; self-insure; LTCI; Medicare for brief stays | doctor discharges if the patient improves or changes to hospice care |
| hospice | The elderly person receives end-of-life care at home or in a hospital or hospice facility. | doctor referral and self-referral for nonlife-sustaining care | self-insure; LTCI; health insurance; Medicaid | decided by the elderly person |

Sources: U.S. Department of Health and Human Services (Medicare.gov Web site, www.Medicare.gov).
 Note: *LTCI=long-term care insurance.

Adult Day Services

If your parents need someone to check in on them or care for them during the day (when family caregivers are not available), or they feel isolated and alone during the day, you might consider Adult Day Services (ADS), also called adult day care. ADS offer care and companionship for seniors who need some assistance or supervision during the day, but don't need 24-hour care. In some cases, ADS enables families to continue caring for their loved ones at home and delay or prevent the need for moving to an assisted-living facility or a nursing home (O'Keeffe and Siebenaler 2006).

Adult day programs differ in emphasis. Some offer health and therapeutic services, such as nursing care; physical, occupational, and speech therapy; counseling; social services; medical monitoring for health markers such as blood glucose levels; and administering medications. Other programs emphasize social activities, such as exercise programs, recreational activities, and field trips. Some ADS offer both health services and social activities. Most provide nourishing meals, and some offer free or low-cost transportation to and from the adult day facility. Seniors can enroll to attend daily or several times a week on a scheduled basis. Some ADS offer drop-in care.

In the United States, more than 3,500 adult day centers provide care for 150,000 older Americans.

Nonprofit organizations and public agencies operate about 75 percent of adult day service programs, and most are affiliated with larger organizations such as home health-care agencies, skilled nursing facilities, medical centers, or organizations for seniors (National Adult Day Services Association 2006).

Cost. Generally, adult day services (ADS) cost less than other types of long-term care. Adult day services are usually less expensive than home health care, and typically cost about half the daily fee in a skilled nursing facility.

Nationally, adult day care averages \$59 per day, with fees ranging from \$5 to \$175 per day (Genworth Financial and National Eldercare Referral Systems 2008). Some centers charge fees on a sliding fee scale, meaning that families pay fees based on their income. Generally, Medicare and private health insurance *do*

not cover adult day care, but in some cases Medicaid and Veterans benefits may provide coverage.

Choosing an adult day care facility. Use the checklist for evaluating an adult day care center in appendix A to compare costs, services, and quality of care among ADS. Before making a decision, take your parents to visit centers you are considering so they can meet the staff, get a feel for the atmosphere, and observe the functional level of other participants. Choose a facility where your parents are comfortable with the staff and environment.

Nutrition Services

Meals-on-Wheels. Many communities offer home-delivered meals to seniors who cannot plan and cook meals for themselves. *Meals-on-wheels* is a worldwide concept with organizations in many places. Typically, programs deliver nutritionally balanced, hot meals for lunch, and a cold sandwich, milk, and varying side dishes for the dinner meal. Eligibility requirements vary, and programs may charge a small fee based on ability to pay. The Meals-on-Wheels Web site at www.mowaa.org has a searchable database that you can use to find a home-delivered meal program in the area where your parents live.

Congregate meal programs. In many communities, nonprofit agencies such as the YMCA and faith-based organizations offer free or inexpensive group meals. To learn about programs where your parents live, contact the local Area Agency on Aging or a senior center in their community.

Transportation

Communities often have transportation programs for elders who don't drive and can't use public transportation. These programs offer free or inexpensive rides for essential trips, such as medical appointments and business errands, as well as for shopping and senior activities. You can find these services listed in the city or county government pages of the telephone book. Private transportation services may also be available (for hire).

Friendly Visitor and Telephone Reassurance Programs

Friendly visitor programs (which have different titles in different communities), provide regular personal or telephone contact (usually by volunteers) for older persons who are homebound or live alone. Besides developing friendships, volunteers can help caregivers identify problems when they occur and notify someone who can help.

"I've even had someone come to the home and interview me as part of a plan for what I can do with my mother. And they're willing to go to Mom's house with me to talk about... someone coming into the house once a week, getting someone to clean the house..."

—Caregiver, describing how a local agency helped her develop a plan of care

Case Management

If your parents' care is complex—involving a number of home and community-based services—or if you don't live near your parents, you might consider hiring a geriatric care manager or caseworker to organize and coordinate their care.

Geriatric care managers are health and human service professionals, such as nurses, social workers, and psychologists with a specialized focus on issues related to aging and eldercare. Both public and private case management agencies are available.

Assessment. There are a variety of public and private resources to help assess an elder's needs. If you are unsure what long-term care services are appropriate for your parents, a case manager can meet with them, assess their needs, and develop a plan of care. Some recommended services may be covered under Medicare or Medicaid, and others are paid for privately. Contact the state or local Area Agency on Aging to find out what assessment services are available where your parents live. Once services are initiated, a case manager can follow up to assure that appropriate services are being provided.

Service Coordination. Case managers draw on a variety of services to help you find the needed care. They can give you information about qualified health and personal care providers in the local community. A privately hired case manager may contract for care on your behalf, hire and supervise your parents' caregivers, schedule appointments for visiting nurses or therapists, enroll your parents in adult day care, arrange transportation to and from day care, and arrange for placement in an assisted-living facility or nursing home.

For information about long-term care assessments and a list of case management agencies, contact the local Area Agency on Aging which is listed in the government pages of the telephone book. Look under "Aging," "Elder Services," or "Senior Services."

Home Modification and Repair Services

In some communities, home repair and renovation program volunteers help older people keep their homes in good repair to prevent health or safety hazards, and so that small problems don't become major ones. For example, volunteers might patch a leaky roof, repair faulty plumbing, or insulate drafty walls. They may also help secure the homes of seniors who are temporarily living in long-term care facilities but expect to return home.

Senior Centers

Senior Centers offer classes, meals, and social activities for qualifying elders. They also provide seniors and their families with information and referrals to community-based, long-term care services.

Home Health Care

Most elders prefer to stay in their own homes as they get older. Those who do this usually rely on a volunteer network of family and friends who assist with everyday activities such as paying bills, grocery shopping, housecleaning, and taking trips to the doctor's office. However, when volunteer caregivers are not available or don't have the necessary skills, families also use home- and community-based services to supplement what they can provide. Home health services help many elders avoid or at least delay hospitalization or institutional care toward the end of life.

Homemakers and chore workers. If your parents need assistance with household duties, they can hire a *homemaker* or *chore worker* to help them. Homemakers perform light duties such as laundry, meal preparation, general housekeeping, and shopping. Chore workers do household tasks, such as heavy cleaning, minor repairs, and yard work (National Association for Health Care and Hospice 2007).

Home health aides. These caregivers, sometimes called *home care aides*, assist with activities of daily living (ADLs). These include getting in and out of bed, walking, bathing, using the toilet, dressing, and eating. Some aides have special training and are qualified to provide more complex services under the supervision of a nursing professional.

Skilled nursing care. Sometimes an elder needs nursing care for the treatment of an illness or injury. Skilled nurses perform duties that can only be performed safely and correctly by trained and licensed health-care workers. Medicare pays for home care only if the patient meets certain conditions.

Respite care. This is temporary care provided by some type of long-term care program so that the usual caregiver can rest or take some time off. Respite care services range from a few hours or days to several weeks.

Medical equipment. Sometimes doctors or other health-care providers order *durable* medical

equipment (reusable equipment) for home use. Medical equipment and supply dealers provide home care patients with products ranging from respirators, wheelchairs, and walkers, to catheters and wound care supplies. Dealers deliver and install the equipment (if necessary), and teach patients and caregivers how to use it properly (National Association for Health Care and Hospice 2007).

Hiring Home Health-Care Providers

There are two choices when hiring home health caregivers. You can contract with a home health-care organization that will supply the caregivers, or hire an independent provider (direct hiring) found through referrals or classified ads.

Hiring caregivers through an agency is typically easier than direct hiring because the agency manages all aspects of personnel recruitment, hiring, supervision, and compensation. Direct hiring is sometimes less expensive, but it takes more time and energy than going through an agency. In some states, publicly funded home care programs allow you to hire a family member to provide home care (Family Caregiver Alliance 2001).

Home health-care organizations include home health agencies, homemaker and home care aide (HCA) agencies, staffing and private-duty agencies, hospice organizations, and companies specializing in medical equipment and supplies. Most agencies recruit, train, and supervise their own staff. Others are essentially referral networks for self-employed caregivers who work as independent contractors. Some states require

Writing a Job Description

In addition to any specific caregiving tasks, be sure to include the following items in a home health-care job description (when and if appropriate):

- health-care training (level and type: CNA, LVN, RN)
- driving (car needed or only valid driver's license)
- ability to lift care recipient
- Ability to operate special equipment
- experience with people with memory impairments and/or other disabilities
- language skills (English or other)
- any other special skills needed

(Family Caregiver Alliance 2001)

Research suggests that 33 to 50 percent of home accidents, such as falls, could be prevented by home repairs and modifications

(Administration on Aging 2007a)

agencies to be licensed and meet minimum standards (National Association for Health Care and Hospice 2007). Appendix B contains a checklist for evaluating a home health agency.

If you and your parents decide to hire directly rather than through an agency, you need to organize a list of duties and expectations for the position, obtain referrals or advertise the position, interview applicants, and check references. You will also need to obtain the applicant's Social Security number, and copy the documents used to demonstrate eligibility to work in the United States. It's also a good idea to furnish an employment contract specifying work hours, salary, payment details, and reasons for termination. Refer to appendix C for more information about hiring a home care employee. Appendix D contains a checklist for caregiver interviews. Refer to appendix E for a sample list of items to include in a caregiver contract.

Cost of Home Health Care

Your parents' home health care costs may include substantial expenses beyond what is spent to hire a caregiver. Appendix F contains a worksheet for identifying and estimating onetime expenses involved with home care, such as purchasing assistive devices and making home modifications to improve your parents' comfort and safety at home. Use the monthly expenses worksheet in appendix G to estimate regular, recurring costs associated with home care, including medical supplies that need to be replenished on a regular basis.

From a financial perspective, if you are trying to decide between home care and some form of residential care, realistic cost comparisons must include the *total* cost of home care: personnel and employment, one-time expenses (see appendix F) and other living expenses (Senior Resource 2007). Listed below are some items that might appear on your parents' list of expenses:

- mortgage and association fees
- property taxes
- maintenance and gardening

- home repairs
- fire, theft, and liability insurance
- electricity and gas
- water, sewer, and trash pickup
- telephone and cable
- meals
- transportation
- car ownership (payments, maintenance, repairs, and insurance)
- housekeeping (laundry, linen service, and cleaning)
- Supplemental Medicare Insurance

Home health care may be more or less expensive than institutional care for your parent. However, actual costs may be very different when considering Medicare and Medicaid reimbursements (if relevant) and private long-term care insurance coverage, if available. (This topic is discussed in Part 5 of the Financial Caregiving Series, *Paying for Long-Term Care*.)

Home Modification and Repair

Do your parents want to stay in their own home as they get older (rather than moving to some type of assisted-living facility)? If so, is their home safe and comfortable for them? For example, can they manage the steps to the front door or the stairs to a second-floor bedroom? Are they finding it difficult to open kitchen cabinets, especially if they have to reach above their heads, as with cabinets mounted above the refrigerator? Is it difficult for them to read the controls on the washer and dryer or oven?

Most homes are built for healthy people and may not accommodate age-related physical changes such as diminished strength, limited mobility, reduced range of motion, or changes in balance and coordination. However, instead of relocating, your parents may be able to continue living at home if some relatively simple and inexpensive changes are made to their home, as in the following examples (Price 2001a). If your parents have limited flexibility or ability to lift, you might

- install lever faucet handles or single-control faucets that are easy to use
- add lever handles on doors, and loop or U-shaped handles on cupboards and drawers
- replace standard light switches with paddle switches placed at a comfortable height (placing them where they could be reached by someone in a wheel chair)

- install grab bars in the shower or by the toilet and tub

If your parents have limited mobility, you could

- install a bath/shower seat and transfer bench to make it easier to get in and out of the bath
- install handrails for support (use handrails on *both* sides of stairways)
- minimize thresholds on interior and exterior doorways for easy maneuvering
- add a textured surface to sidewalks and driveways to increase traction and stability

For parents whose vision is impaired, minor changes might increase their comfort and safety at home, such as

- purchasing appliances with large print controls
- installing under-the-cabinet lights or task lighting over kitchen counters
- adding digital displays on thermostats
- installing lighting near outside sidewalks, stairs, and doors
- using nightlights where appropriate

In some situations, more extensive (but relatively minor) home modifications might allow your parents to remain at home either independently or while receiving home care. These include

- improving general and task lighting in and around the home
- installing ramps, elevators, or stair lifts
- widening doorways to accommodate a walker, wheelchair, or crutches
- installing insulation, storm windows, and air conditioning
- adding a downstairs bedroom
- adding living space for a caretaker

Professional Assistance with Home Modification

If you are uncertain how to make your parents' home barrier-free, contact a geriatric care manager or a local home-modification program to conduct a *livability* assessment of the home and determine what modifications are needed. Contact the Area Agency on Aging or a local Senior Center to find a home-modification program. The National Resource Center on Supportive Housing and Home Modification Web site (www.homemods.org) has a virtual library with assessment tools, "how to" guides for home modification, and links to resources and suppliers.

Hospice Care

Hospice is essentially a *philosophy* of care for the terminally ill and their families. Generally, hospice care is based primarily in the home (rather than an institution) so patients can stay in familiar surroundings with their family during the later stages of their illness.

Hospice agencies employ an interdisciplinary team of skilled professionals and volunteers who give comprehensive medical, psychological, and spiritual care to the patient and their loved ones. They provide medications, medical supplies, and equipment necessary for the patient to stay at home.

Once a person enrolls in hospice care, trained professionals are available 24 hours a day to assist the family with care, ensure the patient's wishes are honored, and keep the patient comfortable and pain-free. Most hospice organizations are Medicare-certified and licensed according to state requirements. Use the checklist for evaluating a hospice agency in appendix H to compare costs, services, and quality of care among hospice agencies.

Paying for Home Modification and Repair

While Medicare doesn't pay for home adaptations, Medicaid may cover some costs for qualified elders. Also check to see if the state or local governments where your parents live have grant or loan programs to help pay for home modifications. Some community agencies offer volunteer programs that provide free labor for minor repairs and changes that make a senior's home more livable.

Assisted Living

If your parents are willing to relocate or plan to move as their needs change, they have a number of options for long-term care and supportive housing. These include *board and care homes*, *rental senior housing*, and *continuing care retirement communities*. Each of these terms refers to a type of *assisted-living* or service-oriented housing

(Administration on Aging 2007b).

Assisted-living facilities (ALFs) are designed for individuals who can't function in an independent living environment, but don't need daily nursing care. Accommodations vary from a single room in a board and care home, to a full-size apartment in a multi-unit complex. Assisted-living facilities usually offer more health-related services than do independent-living retirement communities. ALFs typically offer the following services (Assisted Living Federation of America 2005):

- meals
- housekeeping
- transportation
- 24-hour security
- help with eating, bathing, walking, etc.
- medication management
- health and medical care

- emergency call systems
- organized social activities
- laundry service

Types of Assisted-Living Facilities

Assisted-living (AL) communities offer residents the services that an in-home caregiver would provide, such as help with bathing, dressing, meals, and housekeeping. The amount of help provided depends on individual needs. Most AL communities have on-site medical centers and a nurse on duty 24 hours a day for emergency home visits. Often the monthly fees are all-inclusive.

Rental retirement communities charge an entrance fee and monthly rent. Usually there is a nursing unit on-site or nearby, and residents pay an extra daily fee if they are admitted to the nursing care unit.

Board and care homes provide assisted-living services in smaller, home-like settings. These homes provide shelter, supervision, meals, and personal care to a small number of residents. Some homes specialize in caring for individuals with certain conditions, such as mild mental impairment, early-stage Alzheimer's, or late-stage Alzheimer's. Residents may have a private room or share their room with another resident. All residents share the rest of the living space. Board and care homes are sometimes called personal care homes, adult foster care homes, adult care or residential facilities, domiciliary or sheltered care, or independent-living homes.

Cost of Assisted Living

Assisted-living facilities may be less expensive than either home health-care services (especially 24-hour care), or nursing home care. Costs vary widely depending on the size of the living areas, services provided, the geographic region where the facility is located, the type of care a resident needs, and whether or not the facility is licensed.

Nationally, the average monthly cost for a one-bedroom unit in an assisted-living facility is \$2,714 per month, or \$32,572 annually. About a third of assisted-living facilities charge a one-time entrance fee (also called a community fee), ranging from \$25 to \$120,000, with the average at \$1,622 (Genworth Financial 2007). Board and care is usually less expensive than other assisted-living arrangements. Continuing care retirement communities (CCRCs) are generally the most expensive. Upscale facilities

and those located in urban areas are typically more expensive than the average.

Paying for Assisted Living

Most private long-term care insurance (LTCI) policies cover assisted-living expenses. Without LTCI, residents and their families generally pay for some or all of their care from their own financial resources (National Clearinghouse on Long-Term Care 2008; Assisted Living Federation of America 2005). Some states use Medicaid waiver programs to help very low-income elders pay for assisted living. The percentage of licensed facilities participating in Medicaid varies from state to state.

Selecting an Assisted-Living Facility

If you are not familiar with the assisted-living facilities where your parents live, you can find out what is available by using the online “Eldercare Locator” at www.eldercare.gov (a service of the U.S. Administration on Aging) or request a list of facilities from the local Area Agency on Aging.

Gather information. To get firsthand information and referrals, talk with your parents’ health-care professionals, as well as with family and friends. Obtain brochures and other information from facilities you might consider to learn about the amenities and services they offer. Get a list of all the services included in the base rate, and optional services available for extra fees. Carefully review resident agreement policies that describe costs, services, and conditions for rate changes.

Visit facilities that you are considering.

Before making a decision, you and your parents should visit any assisted-living facility you are seriously considering to get a feel for the general atmosphere and to observe attitudes of the staff. This is important even under the tightest time constraints, since a poor choice will be difficult to correct. Appendix H contains a checklist for evaluating an assisted-living facility.

Other considerations. Besides quality of care and costs, two additional issues should be considered before making your decision and signing the assisted-living contract: discharge policies and licensing.

- *Review the discharge policy.* Review the facility’s disclosure statement to find out if there are any physical or medical circumstances that would lead to your parent being (involuntarily) discharged

from the facility. Some ALFs discharge patients who cannot attend meals in the community dining area (due to health or mobility problems), or who have been diagnosed with dementia.

- *Find out if the facility is licensed.* Thoroughly check out a facility that you and your parents are seriously considering. There are no federal quality standards for assisted-living facilities. Licensing requirements and monitoring activities vary among the states. With little or no outside supervision, an unlicensed facility may not provide acceptable standards of care. The Assisted Living Federation Association’s Web site (www.ALFA.org) contains links to state agencies that regulate and license assisted-living facilities, and to a model consumer disclosure statement.

Continuing Care Retirement Communities

Elders who want to plan ahead for all possible changes in their health, and who can afford the cost, might consider moving to a continuing care retirement community (CCRC). CCRCs give residents access to all the care they might need in one location: individual homes or apartments for independent living, assisted living for those needing help with daily care, and a nursing home for those requiring around-the-clock nursing care. CCRC residents can get the care they need without having to move and leave their friends. In general, residents are only admitted to a CCRC while they are still independent and able to take care of themselves.

CCRC Contracts

Most CCRCs offer a “life care contract” that guarantees to provide all necessary health and personal care for the remainder of a resident’s life. Residents are assured placement in the community’s assisted-living facility or skilled nursing facility if needed. CCRCs offer three types of contracts (AARP 2007b):

- *Extensive contracts* include unlimited long-term nursing care at little or no increase in the monthly fee.
- *Modified contracts* cover long-term nursing care for a specified length of time. After the contract expires, there are additional charges for continued nursing care.
- *Fee-for-service contracts* charge full daily rates for long-term nursing care, if it is required.

Before signing a CCRC contract, check the record of its nursing home, since contracts usually require residents to use the CCRCs facility for skilled nursing care. See “Nursing Home Compare” on the Medicare.gov Web site (www.medicare.gov) for detailed information about the past performance of every Medicare- and Medicaid-certified nursing home in the country.

Costs of CCRCs

Continuing care retirement communities generally charge large initial payments or buy-in fees (also called entry fees) to move into the community. Entrance fees range from \$38,000 to \$400,000. In addition to the buy-in fee, residents also pay monthly fees ranging from \$650 to \$3,500 per month (Centers for Medicare and Medicaid Services 2007b). Geographic location and amenities influence the costs. CCRCs can increase monthly fees from year to year as inflation dictates. Some CCRCs charge monthly rent but no entrance fee.

Finding a CCRC for Your Parents

To find an accredited continuing care retirement community, use the online search tool offered by the Commission on Accreditation of Rehabilitation Facilities Web site (www.carf.org). You can search by geographic location in the United States and Canada to get company names, contact information, and links to company Web sites (if available).

CCRCs differ in the quality of care offered, so it is worthwhile spending time to find the best, most appropriate community for your parents. The process is similar to the process described for selecting an assisted-living facility, and many of the questions that you might want to ask about these communities are the same as those to consider when choosing a nursing home. Appendix I contains a checklist for evaluating a continuing care retirement community.

Nursing Homes

Nursing homes offer care for individuals who are not in the hospital but need skilled nursing care. Facilities are regulated by state boards of health. Doctors supervise the medical care, and nurses are available whenever a resident calls for them. Nursing homes provide meals, laundry, and housekeeping services. Some also offer activities such as art classes, religious services, and organized parties.

A nursing home is appropriate for people who meet one or more of the following criteria (Rose et al. 2007):

- Cannot take care of themselves because of physical, emotional, or mental problems.
- Can no longer take care of their personal needs, such as eating, bathing, using the toilet, moving around, or taking medications (custodial care).
- Cannot live alone, and require more care than their caregiver can provide.
- Might wander away if unsupervised.
- Have extensive medical needs, requiring daily attention or monitoring by a registered nurse under the supervision of a medical doctor.
- Are going to be discharged from the hospital and require temporary skilled nursing care before returning home or to a residential facility.
- Have been recommended for a nursing home by a physician.

Costs of Nursing Homes

Nursing home care is expensive and costs are increasing. The average cost of a private room is \$209 per day or \$76,460 annually (Genworth Financial and National Eldercare Referral Systems 2008). As with other types of long-term care, nursing home costs vary according to geographic location and services offered.

Paying for Nursing Home Care

Medicare pays for some skilled nursing expenses, but not custodial care. Generally, eligibility begins after a patient has been in the hospital for at least 3 days. Once eligibility requirements are met, Medicare pays for the first 20 days of skilled nursing care. After that, it reduces the coverage and the patient pays a large co-payment. After 100 days of nursing home care, coverage ends and the patient assumes the full cost of any further care.

Medicaid covers nursing home care for certain groups with low incomes and limited resources. If your parents do not presently qualify for Medicaid but they anticipate qualifying in the near future, choose a nursing home that accepts Medicaid so your parents will not have to move again when Medicaid starts paying for their care.

Private health insurance policies vary as to the number of days of nursing home coverage. Private long-term care insurance pays according to the rates specified in the policy.

Evaluating Nursing Homes

Use the checklist for evaluating a nursing home in appendix J to help you and your parents decide if a

particular nursing home meets their needs. The checklist includes important questions to ask the nursing home administrator and items to look for when touring a facility.

The Medicare Web site (www.Medicare.gov) has an interactive database called “Nursing Home Compare” where you can find out how well a Medicare- or Medicaid-certified nursing home has performed on 19 measures of quality. These reports include nursing home characteristics and staffing information, as well as the number of health or safety deficiencies identified during the three most recent state inspections, and reports of recent complaint investigations. If a nursing home has no deficiencies, it means that it met the minimum standards at the time of the inspection. While this information cannot be used to identify nursing homes that provide outstanding care, it can identify those with problems that may or may not have been corrected.

It is important to recognize that the quality of a nursing home may improve or deteriorate significantly in a short period of time due to changes in management or ownership. To learn whether a facility you are

considering has documented complaints or violations on file, check the public records office in the local Department of Health Services or ask the State Ombudsman’s office.

A 2006 study compared the care provided by for-profit and not-for-profit nursing homes. Results indicated that not-for-profit nursing homes regularly provide more hours of daily care for their patients, invest more resources in patient care, and have fewer deficiencies in the continuum of care than their for-profit counterparts (American Association of Homes and Services for the Aging 2006).

An analysis of nursing home inspection reports for more than 16,000 nursing homes concluded that independently owned, not-for-profit nursing homes are more likely to provide good care than chain-owned nursing homes, since they typically have more staff and are more likely to use registered nurses (Consumers Union 2006).

“And I really think it’s best for adult children to select a skilled nursing facility [or any type of supportive housing] that’s convenient for them to visit.”

—Administrator of a skilled nursing facility, advising families on criteria for choosing a facility

WHERE TO BEGIN

When There Is Time to Plan

It is never too early to start planning for long-term care. Although talking with your parents about their preferences can be very sensitive, the best time to start the conversation is *before* there is a crisis, and when your parents can be involved as much as possible in the choices to be made. Waiting until there is a crisis is stressful and may limit your parents’ LTC options. The following steps are recommended:

- Talk with your parents about where they would like to live if/when their needs change.
- Encourage them to identify assets they could use to pay for their long-term care needs, including pensions, Social Security income, and investments.
- Help them review their finances and consider what choices they will have for living arrangements. (Some types of care may be unavailable due to financial limitations and lack of insurance coverage.)
- Visit a few long-term care facilities and start a list of those with good reputations and excellent service where your parents would feel comfortable living.
- If appropriate, place your parents’ names on the waiting list for the facility that is the best fit. (Some CCRCs may have waiting lists of a year or more).

When You See Signs That Your Parents May Need Assistance

One day you may notice that your parents are not able to take care of themselves, their home, or their finances. If this happens, consider getting a geriatric assessment of their condition (rather than relying on your own subjective observations). Your parents’ doctor(s) or the Area Agency on Aging can refer you for a free or low-cost assessment to evaluate all aspects of your parents’ condition, including their medical needs, their ability to take care of themselves, and whether or not they can live independently at home. Use assessment results to determine the support services your parents need or may need in the future. Other appropriate actions include the following:

- Explore the range of services available to seniors in your parents’ community.
- Assess your parents’ financial resources and ability to pay for long-term care services if needed.
- If they have not already done so, encourage and/or help your parents to find and organize their financial and legal documents.

- Help them evaluate the livability of their home and identify ways to make their home safer and more comfortable.
- Assist them in arranging for repairs or modifications to make their home safer, more accessible, and more comfortable.
- If your parents anticipate relocating in the future, help them investigate alternatives.
- If appropriate, encourage them to put their names on a waiting list for senior housing.
- Encourage them to stay as independent as possible for as long as possible.
- Make any financial decisions with your parents (rather than for them).

When There Is a Crisis

After a crisis, the top priorities are arranging for care at home or in the community, and determining how to pay for it. If your parents are able, encourage them to prepare wills and designate durable powers of attorney for health care and finances as soon as possible. If necessary, find an attorney who will meet with them at the hospital or their long-term care facility.

RESOURCES FOR UNDERSTANDING LONG-TERM CARE

Comprehensive Information about Long-Term Care

U.S. Administration on Aging (AoA). The AoA Web site is designed to help older persons and their caregivers quickly obtain information about services available to them through the Older Americans Act and other federal, state, and local programs. See “Elders and Families” on the AoA Web site, www.aoa.gov.

Medicare.gov. The official government Web site for people with Medicare provides a clear and concise overview of long-term care: what it is, steps to choosing long-term care, types of care, and ways of paying for long-term care. See “Long-Term Care” on the Medicare.gov Web site, www.medicare.gov.

National Clearinghouse for Long-Term Care Information. This Web site was developed by the U.S. Department of Health and Human Services to provide information and resources to help families plan for their future long-term

Before arranging for care, obtain a professional evaluation of your parents’ condition, and ask health-care providers for their recommendations about the type and level of care needed. (For example, the type of care needed after a fall that results in a broken hip may be very different from what is required after a stroke.) This will give you an idea of where to start.

The hospital social worker or discharge planner (care coordinator) can help facilitate your parents’ transition back home with appropriate care or, if necessary, help place them in an assisted-living facility or nursing home. These professionals often have connections with various facilities and are experienced in working with them for placements.

Hospital discharge policies are dictated by insurance reimbursements, and may require quick decisions. However, if at all possible, don’t choose an assisted-living facility or nursing home without visiting it at least once. If there are no satisfactory facilities, or there is a waiting list for the facility your parents want, ask the discharge planner to make short-term arrangements while you and your parents search for an appropriate solution.

care (LTC) needs. It is primarily intended as an information and planning resource for individuals who don’t yet require long-term care, but it includes information on services and financing options that can be helpful to all individuals. National Clearinghouse for Long-Term Care Information Web site, <http://www.longtermcare.gov>.

Needs Assessments

Family Care America. A number of caregiver Web sites have checklists that will help you determine the type of care your parents need. Family Care America is one example, with its comprehensive “Needs Assessment Worksheet” that you can download from their Web site at www.familycareamerica.com. (The site also has useful checklists for evaluating various types of senior services and facilities, and one for home modifications.)

Cost of Care Information

Genworth Financial Cost of Care Survey. Genworth Financial commissions an annual “Cost of Care Survey” that collects data used to calculate

the average cost of care charged for home care, assisted living, and nursing homes across the United States. The most recent survey report is available at http://www.genworth.com/content/genworth/www_genworth_com/web/us/en/products_we_offer/long_term_care_insurance/long_term_care_overview/what_is_the_cost_of_long_term_care.html. (See “How Much Does Long-Term Care Cost?”)

MetLife Mature Market Institute. The Institute conducts annual market surveys of home care, assisted living, and nursing home care costs in the United States. Review the reports to find cost-of-care information in the area where your parents live or expect to receive long-term care. Reports include detailed information about the hourly rates for various types of home care providers, and average daily rates for private and semiprivate rooms in various types of long-term care facilities. Find the current report at www.metlife.com/. Search for “MetLife Market Institute Studies” or call the Institute at (203) 221-6580 for a copy of the report.

Facilities and Services (and databases for identifying specific ones)

Eldercare Locator. Use the online “Eldercare Locator,” a public service of the U.S. Administration on Aging, to find state and local Area Agencies on Aging and community-based organizations that provide senior services. Visit <http://www.eldercare.gov> or call 1-800-677-1116 to speak to an information specialist.

Home Health Compare. The Medicare Web site has a searchable database of all Medicare-certified home health agencies in the United States. In addition to giving the name and contact information, the database also provides information on how well each home health agency cares for their patients and thus can be used to compare agencies. Search for agencies by name or geographic location at www.medicare.gov. (See “Steps to Choosing Long-Term Care.”)

Nursing Home Compare. The Medicare Web site has a database of every Medicare- and Medicaid-certified nursing home in the country. In addition to helping elders and their families identify nursing homes near where they live, this tool provides detailed information about the past performance of every facility,

including nursing home characteristics, quality measures, inspection results, and nursing staff information. Medicare.gov Web site, <http://www.medicare.gov/NHCompare>.

Not-for-Profit Services. The American Association of Homes and Services for the Aging (AAHSA) has a searchable online database of 5,700 not-for-profit aging services providers including nursing care, assisted-living units, independent-living units, home- and community-based services, and adult day services. See “Consumer Tips and Advice” to find the “Homes and Services Directory” on the AAHSA Web site, <http://www2.aahsa.org>.

Industry and Trade Associations. Various eldercare trade associations also have searchable online databases that can be used to find local services or facilities that meet industry standards. The following are examples:

- Adult Day Services: <http://www.nadsa.org>.
- Assisted Living: www.alfa.org.
- Continuing Care Retirement Communities: www.carf.com.
- Home Care and Hospice: <http://www.nahc.org>.

Fact Sheet: Hiring In-Home Help. The Family Caregiver Alliance (FCA) has helpful information for families that want to hire care providers directly, rather than through an agency. The FCA Web site includes information and tools to help you assess the type of care needed, understand the pros and cons of hiring through an agency, write a job description, and develop a job contract. It also discusses the employer’s responsibilities, legal issues to consider, and practical suggestions to make your home care situation work. FCA Web site, <http://www.caregiver.org/caregiver/jsp/home.jsp>. (See “Fact Sheets, Caregiving Issues and Strategies.”)

How to Tour a Nursing Home. The American Association of Homes and Services for the Aging, a membership organization of not-for-profit aging services providers, offers a narrative guide aimed at helping families make informed visits to nursing homes. It includes information about characteristics that indicate quality of care in a nursing home and tells how to look for the indicators. See “Consumer Information” on the AAHSA Web site, <http://www2.aahsa.org>.

Since You Care® Guides. These user-friendly guides provide practical suggestions and tools for finding and selecting various types of long-term care services and facilities, and hiring an independent caregiver. The guides were prepared by the MetLife Mature Market Institute in cooperation with the National Alliance for Caregiving and MetLife's Nurse Care Managers. Search for "Since You Care Guides" on the MetLife Web site, www.metlife.com.

Home Modifications

AARP. The AARP Web site has extensive information about home modifications to facilitate aging in place. It includes an overview of principles for making a home safer and more comfortable for elders, and checklists for evaluating a home to identify specific problem areas. There are suggestions for modifying kitchens, bathrooms, doors, floors, walkways, and lighting. AARP Web site, www.aarp.org. (Go to "Topics in Family, Home, and Legal" and see "Home Design.")

National Resource Center on Supportive Housing and Home Modification. This center helps families and individuals plan for their housing,

health, and supportive service needs. The Web site has tools you can use to assess your parents' home for safety and comfort, practical strategies for modifications, and links to home-modification products and services. Homemods.org Web site, <http://www.homemods.org>.

National Association of Home Builders' Research Center (NAHBRC). The NAHBRC offers a free "Directory of Accessible Building Products" that contains descriptions of nearly 200 commercial products for people with age-related limitations and disabilities. Access the directory at the NAHBRC Web site (www.nahbrc.org/bookstore) or by calling (800) 638-8556.

The Do-Able Renewable Home: Making Your Home Fit Your Needs. This how-to book, published by the American Association of Retired Persons (now AARP), was designed to help individuals overcome problems they might encounter in their homes as they grow older. It provides information about making a home safer and more comfortable for someone with limited range of movement, strength, dexterity, eyesight, or hearing. It has examples and illustrations. The full text is available online at the Homemods.org Web site, <http://www.homemods.org/resources/library.shtml>.

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APPENDICES

APPENDIX A. CHECKLIST FOR EVALUATING AN ADULT DAY CARE CENTER

Center's name: _____

Address: _____

Phone number: _____

E-mail: _____ Web site: _____

Contact: _____

Instructions:

- Visit each center more than once.
- Make an appointment with the administrator and ask for references.
- Use the checklist below to evaluate the center.
- Visit other centers and compare your notes.

Hours:

Half-day program? Open from _____ to _____ Full-day program? Open from _____ to _____

| Features to consider | Yes | No | Does not apply | Comments |
|---|-----|----|----------------|----------|
| Eligibility requirements | | | | |
| age requirements | | | | |
| medical conditions that the center will not accept | | | | |
| shared facilities with other onsite elder care residence | | | | |
| Cost | | | | |
| What is the cost per day? | | | | |
| Is there a sliding fee scale? What is it? | | | | |
| Are discounts provided for weekly or monthly use? | | | | |
| Is there an additional cost for certain medical conditions? How much? | | | | |
| Does the center accept Medicaid or other types of reimbursement? | | | | |
| Is financial assistance available? | | | | |
| If transportation is provided, is there an extra fee to use this service? | | | | |



| Features to consider | Yes | No | Does not apply | Comments |
|---|-----|----|----------------|----------|
| other fees | | | | |
| Physical environment | | | | |
| Is the center clean, comfortable, and free of odors? | | | | |
| Is it wheelchair accessible or amenable for other disabilities? | | | | |
| Are exits clearly marked, unobstructed, and easily opened from inside? | | | | |
| Is the equipment and furniture comfortable and in good shape? | | | | |
| Is there security for participants that wander? | | | | |
| Is there a place to isolate sick persons from the rest of the participants? | | | | |
| Are the building codes up to date? | | | | |
| Does the center meet state-determined standards of day care? | | | | |
| Services, activities, and meals | | | | |
| transportation to and from the center provided | | | | |
| transportation to other places for appointments, shopping, etc., provided | | | | |
| posted schedule of activities | | | | |
| choice of activities for the participant | | | | |
| social services | | | | |
| medical assessment and/or treatment | | | | |
| nursing services | | | | |
| physical therapy | | | | |
| recreational therapy | | | | |
| speech therapy | | | | |
| exercise or activity available | | | | |
| bathing | | | | |
| assistance with dressing/grooming/using the restroom | | | | |
| dietary counseling | | | | |
| menu planned by dietician | | | | |
| meals balanced and appealing | | | | |
| Staff credentials/certification and behavior | | | | |
| What type of staff is on duty (social workers, nurses, aides, recreational therapists)? | | | | |
| Is the staff credentialed? | | | | |
| Is there enough staff to meet needs of participants? | | | | |
| Do the staff members treat participants with care and sensitivity? | | | | |
| How long has center been in operation? | | | | |
| Is center licensed by the state (if licensing is required)? | | | | |
| Any complaints filed against this facility to the state health department? | | | | |
| If so, what has the facility done to alleviate the problem? | | | | |
| Did someone spend time finding out what you wanted or needed during your visit? | | | | |

Sources: Adapted from Centers for Medicare and Medicaid Services 2007a; Professional Educators Benefits Company 2008; National Adult Day Services Association 2008; and Whirrett 2002.

APPENDIX B. CHECKLIST FOR EVALUATING A HOME HEALTH AGENCY

Agency name: _____

Address: _____

Phone number: _____

E-mail: _____ Web site: _____

Contact: _____

| Agency criteria | Yes | No | Does not apply | Comments |
|---|-----|----|----------------|----------|
| Medicare-certified | | | | |
| Medicaid-certified | | | | |
| Offers the specific health-care services my parents need (like nursing or physical therapy)? | | | | |
| Meets my parents' special needs (like language or cultural preference)? | | | | |
| Offers the personal care services my parents' need (like help bathing, dressing, and using the bathroom)? | | | | |
| Offers the support services my parents need (like help with laundry, cooking, shopping, or housekeeping), or can help them arrange for additional services that they may need, such as Meals on Wheels? | | | | |
| Has staff available to provide the type and hours of care my parents' doctor ordered? | | | | |
| Can start when needed? | | | | |
| Recommended by my parents' hospital discharge planner, doctor, or social worker? | | | | |
| Has staff available at night and on weekends for emergencies? | | | | |
| Explained what my parents' insurance will cover, and what they must pay out of pocket? | | | | |
| Does background checks on all staff? | | | | |
| Has letters from satisfied patients, family members, and doctors that testify to the home health agency staff providing good care? | | | | |

Sources: Adapted from AARP 2007a; and Centers for Medicare and Medicaid Services 2007a.

APPENDIX C. HIRING A HOME CARE EMPLOYEE

When hiring a caregiver for your loved one, it is important to screen potential employees carefully to be sure they have the necessary qualifications, training, and temperament for the job. Have applicants fill out an employment form that includes their full name, address, telephone number, date of birth, Social Security number, educational background, work history, and references. Provide applicants with a written copy of the job description.

Interviews

When interviewing a prospective home care employee, include a full discussion of your parents' needs and limitations, the home care worker's experience in caregiving, and his or her expectations. When hiring a home care aide, it is a good idea to list the job tasks and ask applicants to check those that they are willing and able to perform. If the older person needs to be transferred from a wheelchair, make sure that the aide knows how to do this safely. If the aide does not know how to bathe a person in bed or transfer, but is otherwise qualified, it may be possible to provide the necessary training, but make sure the person can do it before being hired.

Factors to Consider When Hiring

Don't try to hire someone on a 7-day-a-week basis. No employee can remain a good employee for long, if no time is allowed for personal needs and interests. Additionally, aides who live in or sleep over cannot be expected to be on call 24 hours a day. If your parents need frequent help or supervision during the night, you should hire a second home health aide, or have a family member fill in.

If your parents need a considerable amount of help, live-in help may be available, which can be less expensive than paying employees by the hour or the day. However, keep in mind that you will be providing food and lodging and that it may be more difficult to dismiss live-in aides, especially if they do not have alternative housing available. It is also important to ensure that the aide has his or her own living quarters, and that he or she has some free time during the day, sufficient time to sleep, and days off.

References

Ask to see the applicant's licenses, certificates (if applicable), and personal identification, including Social Security card, driver's license, and photo ID.

Thoroughly check the applicant's references. Ask for the names, addresses, phone numbers, and dates of employment for previous employers, and be certain to contact them.

If there are substantial time gaps in their employer references, it could indicate that they have worked for people who were not satisfied with their performance. Try to talk directly to former employers rather than accepting letters of recommendation. With the applicant's permission, it is also possible to conduct a criminal background check.

Job Expectations

Be clear about the employee's salary, when he or she will be paid, and reimbursement for money the aide may spend out of pocket. Discuss work hours, vacations, holidays, and benefits. Clarify policies pertaining to absences, lateness, unacceptable behaviors (such as smoking or drinking on the job), reasons for termination, and the amount of notification time each of you should give if the employment is terminated. Furnish a written copy of this information so both of you can refer back to it if a question or problem arises.

If you work and are heavily dependent on the home care assistant, emphasize the importance of being informed as soon as possible if he or she is going to be late or absent so that you can make alternative arrangements. Keep a list of home care agencies, other home care workers, neighbors, or family members who can provide temporary (substitute) care, if needed.

Transportation

If free or low-cost community transportation is not available, try to hire someone who drives. This will save you substantial amounts of money in taxi or commercial van ride fares. If the home care employee is going to drive your family car, you must inform your insurance company, and provide a copy of the aide's driver's license to your insurance agent. Your insurance company will check to see if the license has been revoked, suspended, or if the aide has an unsatisfactory driving history. If the home care assistant has a car, discuss use of his or her car on the job and insurance coverage.

Insurance and Payroll

Check with your insurance company about coverage for a home care employee, and contact the



appropriate state and federal agencies concerning Social Security taxes, state and federal withholding taxes, unemployment insurance, and workers' compensation. If you do not personally want to deal with these somewhat complicated withholdings from the employee's salary, you can hire a payroll preparation service to issue the employee's check with the necessary withholdings.

Some home care aides work as independent contractors. However, even in these cases, you must report their earnings to the Internal Revenue Service. Before employing an aide on a contract basis, consult a financial advisor or tax preparer to make certain that you are following the IRS rules governing contract workers, since there can be a fine line between who is considered to be an employee versus a contractor.

Ensuring Security

Regardless of who cares for your parents, protect their private papers and valuables by putting them in a locked file cabinet, safe deposit box, or safe. To ensure security, take the following precautions:

- Make arrangements to have someone you trust pick up the mail, or have it sent to a post office box where you can pick it up.
- Check the phone bill for unauthorized calls and, if necessary, have a block placed on 900 numbers, collect calls, and long-distance calls. Your parents can always use a prepaid calling card for long distance calls.
- Protect checkbooks and credit cards. Never make them available to anyone you do not thoroughly trust.
- Review bank and credit card statements, along with other bills, at least once a month. Periodically

request credit reports from a credit report company.

- If you do leave valuable possessions in the house, it is best to put locks on cabinets and closets and to have an inventory with photographs.

Supervising a Home Care Worker

Once you have hired a home care worker, make sure the lines of communication are fully open and that both you and the worker have a clear understanding of the job responsibilities to your parents and to each other. Explain what you want done and how you would like it done, keeping in mind that the home care employee is there to care for your parents and not the rest of the family. If the home care worker lives in, try to ensure that he or she has living quarters that provide your parents and the assistant the maximum amount of privacy possible.

Once the home care aide is on the job, meet periodically or on an as-needed basis to discuss any problems the home care assistant or your parents may have with the arrangement and to find ways to resolve them. If, after repeated attempts, you find that major problems are not resolved satisfactorily, it may be best to terminate the relationship and seek another home care employee. During this time, it may be necessary for your parents to reside temporarily in a long-term care facility or for you to hire an aide through an agency. It is best to have reserve funds on hand should such an emergency arise.

Sources: AARP 2003; FamilyCare America, Inc. 2009; Family Caregiver Alliance 2001; and Family Caregiver Alliance and Southern Caregiver Resource Center 2002.

APPENDIX D. CHECKLIST FOR CAREGIVER INTERVIEW

Caregiver's name: _____

Address: _____

Phone number: _____

E-mail: _____ Web site: _____

Contact: _____

Instructions:

- Write a job description.
- Make an appointment with prospective caregiver and ask for references.
- Use the checklist below to ask about caregiver experience and discuss caregiving duties.
- Interview other potential caregivers and check references.

| Interview questions for applicant | Yes | No | Does not apply | Comments |
|--|-----|----|----------------|----------|
| Caregiver experience | | | | |
| Previous experience as a caregiver? | | | | |
| References available? | | | | |
| License to drive? | | | | |
| Physically able to lift care recipient? | | | | |
| Language skills (English or other)? | | | | |
| Special training? | | | | |
| Caregiver availability | | | | |
| Available to work the required hours? | | | | |
| Able to work the estimated duration of times that care is necessary? | | | | |
| Caregiver salary | | | | |
| applicant's expectation of daily/weekly salary: | | | | |
| hourly rate offered: | | | | |
| Discussion of care recipient's needs and special issues (sample list) | | | | |
| dentures | | | | |
| eyeglasses | | | | |
| canes/walkers | | | | |
| medical equipment | | | | |
| behavior problems | | | | |
| emergency situations | | | | |
| paperwork: medication log, expense log, receipts, etc. | | | | |
| other: | | | | |
| Discussion of location and use of health and safety precautions (sample list) | | | | |
| smoke detector | | | | |
| fuse box | | | | |
| fire extinguisher | | | | |
| standard first-aid kit | | | | |
| emergency telephone numbers | | | | |

Sources: AARP 2003; FamilyCare America, Inc. 2009; Family Caregiver Alliance 2001; and Family Caregiver Alliance and Southern Caregiver Resource Center 2002.



APPENDIX E. DEVELOPING A CAREGIVER JOB CONTRACT

The caregiver job contract is based on the type of care your parents need. It represents a formal agreement between the employer and the household employee. If questions or problems occur during employment, either party can refer to the written contract to resolve issues. The contract should include the following information:

- name of employer and household employee
- wages and tax withholdings
- benefits, such as mileage, meals, vacation, holidays
- timing and method of payment of wages
- work hours
- employee's Social Security number
- job description: duties
- unacceptable behavior: smoking, drinking, bad language
- rules for termination: reasons, how much notice
- dated signatures on the contract for employee and employer

Sources: Family Caregiver Alliance 2001; and Family Caregiver Alliance and Southern Caregiver Resource Center 2002.

APPENDIX F. HOME CARE: INITIAL (ONE-TIME) EXPENSES

Enter the expenses for the following assistive devices. In Column A, enter the cost of the device. In Column B, enter how much another party (such as Medicaid or long-term care insurance) will pay toward that expense. Subtract Column B from Column A and enter the result in Column C. That is the amount your parents have to pay.

| Type of device | (A) Cost of device | (B) Amount paid by another party | (C) Amount paid by parents |
|---|-----------------------|--|----------------------------------|
| Assistive devices | | | |
| hospital bed or adjustable bed | | | |
| shower chair or bench | | | |
| nonslip mats | | | |
| nonslip mats for rugs | | | |
| lift chair | | | |
| walker, cane, or crutches | | | |
| wheelchair | | | |
| scooter | | | |
| assistance call system | | | |
| nonslip footwear | | | |
| adaptive clothing with easy closures, fasteners, dressing aids (zipper pull, long shoehorn, leg lift strap, etc.) | | | |
| bedside commode | | | |
| bedpan | | | |
| urinal | | | |
| other | | | |
| Subtotal: assistive devices | | | |
| Home-modification devices | | | |
| brighter lighting | | | |
| elevator or stair lift | | | |
| grab bars | | | |
| handrails | | | |
| wheelchair ramps | | | |
| thresholds | | | |
| raised toilet seat | | | |
| wheel chair lift | | | |
| adjustable or hand-held shower head | | | |
| wider doorways | | | |
| Subtotal: home-modification devices | | | |
| Totals: | | | |

Source: Adapted from Clinical Tools, Inc. 2001a.

APPENDIX H. CHECKLIST FOR EVALUATING AN ASSISTED-LIVING FACILITY

Facility's name: _____

Address: _____

Phone number: _____

E-mail: _____ Web site: _____

Contact: _____

| Features to consider | Yes | No | Does not apply | Comments |
|---|-----|----|----------------|----------|
| Facility operations and eligibility | | | | |
| accepting new residents | | | | |
| waiting list | | | | |
| location easy to visit for family and friends | | | | |
| location near health-care providers, shopping, and entertainment | | | | |
| appropriate security and evacuation plans | | | | |
| Cost of care | | | | |
| cost per day/month: | | | | |
| list of services included in cost | | | | |
| additional costs | | | | |
| adequate notice if fees increase | | | | |
| conditions that would lead to a rate increase | | | | |
| types of reimbursement accepted: | | | | |
| security deposit required | | | | |
| clear explanation of refund policy, contract amendment/termination policies, and billing schedule | | | | |
| Physical environment | | | | |
| facility clean and free of odors | | | | |
| building codes up to date | | | | |
| friendly and approachable staff | | | | |
| residents appear friendly, sociable, and content | | | | |
| wheelchair accessible or amenable for other disabilities | | | | |
| flooring and carpets safe for walking | | | | |
| adequate storage space for residents | | | | |
| restrooms have handicap accommodations | | | | |
| appropriate natural and artificial lighting | | | | |
| comfortable temperature | | | | |
| well maintained grounds | | | | |
| resident garden | | | | |
| designated resident smoking area | | | | |
| Activities | | | | |
| posted schedule of activities | | | | |
| activities scheduled outside the facility: | | | | |
| <ul style="list-style-type: none"> • limitations on the number of residents allowed to attend activities scheduled outside the facility • transportation provided | | | | |





| Features to consider | Yes | No | Does not apply | Comments |
|--|-----|----|----------------|----------|
| pets allowed | | | | |
| exercise accommodations | | | | |
| library | | | | |
| beauty salon | | | | |
| religious services | | | | |
| Dining and meals | | | | |
| dietician-approved menu | | | | |
| enjoyable and appealing meals | | | | |
| special diets accommodated | | | | |
| meal schedule acceptable | | | | |
| snacks available between meals | | | | |
| common dining area | | | | |
| meal delivery to resident's room | | | | |
| private dining area available for guests/special occasions | | | | |
| Staff and facility credentials/certification | | | | |
| type of staff on duty (social workers, aides, recreational therapists) | | | | |
| same staff available on a daily basis | | | | |
| adequate staff available to accommodate residents | | | | |
| number of years in operation: | | | | |
| facility licensed (if required by state) | | | | |
| administrator is licensed | | | | |
| Medicare/Medicaid-certified | | | | |
| Any complaints filed against this facility to the state health department? | | | | |
| If so, what has the facility done to alleviate the problem? | | | | |
| Medical and personal care services | | | | |
| list of all medical services and personal care available | | | | |
| appropriate medical services provided | | | | |
| 24-hour assistance | | | | |
| Written plan of care for each resident? | | | | |
| If so, how and when is it updated? | | | | |
| Facility uses hospital where my parents' physician practices? | | | | |
| If so, is transportation provided? | | | | |
| Self-administration of medications permitted? | | | | |
| Staff available and trained in administering medications? | | | | |
| Pharmacy services on-site? | | | | |
| Physical, speech, and occupational therapy available in the facility? | | | | |
| medical conditions not accepted by the facility: | | | | |

Sources: Adapted from ElderWeb 2007; CarePathways 2007; AARP 2008a; and American Health Care Association 2003.

APPENDIX I. CHECKLIST FOR EVALUATING A CONTINUING CARE RETIREMENT COMMUNITY (CCRC)

CCRC's name: _____
 Address: _____
 Phone number: _____
 E-mail: _____ Web site: _____
 Contact: _____

Instructions:

| Features of the CCRC | Yes | No | Does not apply | Comments |
|--|-----|----|----------------|----------|
| Operations and eligibility | | | | |
| accepting new residents | | | | |
| waiting list | | | | |
| location easy to visit for family and friends | | | | |
| appropriate security and evacuation plans | | | | |
| uses the hospitals where my parents' physician practices | | | | |
| provides services needed | | | | |
| someone listened to my concerns during the visit | | | | |
| provided a guide during my visit | | | | |
| Physical environment | | | | |
| facility clean and free of odors | | | | |
| building codes up to date | | | | |
| friendly and approachable staff | | | | |
| clean and well-groomed residents | | | | |
| private area available to meet with staff | | | | |
| equipment and furniture in good shape | | | | |
| wheelchair accessible or amenable to other disabilities | | | | |
| appropriate natural and artificial lighting | | | | |
| comfortable temperature | | | | |
| restrooms equipped with handicap accommodations | | | | |
| flooring and carpets safe for walking | | | | |
| well-maintained grounds | | | | |
| resident garden | | | | |
| designated resident smoking areas | | | | |
| pets allowed | | | | |
| Activities | | | | |
| posted schedule of activities | | | | |
| variety of activity options available to residents | | | | |
| residents involved in activity/event planning | | | | |
| exercise accommodations | | | | |
| religious services | | | | |
| Dining and meals | | | | |
| dietician-approved menu | | | | |
| special diets accommodated | | | | |





| Features of the CCRC | Yes | No | Does not apply | Comments |
|---|-----|----|----------------|----------|
| residents involved in meal planning/preparation | | | | |
| enjoyable, appealing, balanced meals provided | | | | |
| common dining area | | | | |
| snacks available between meals | | | | |
| meal delivery to condos/apartments | | | | |
| private dining area available for guests/special occasions | | | | |
| Staff and facility credentials/certification | | | | |
| type of staff on duty (social workers, nurses, aides, recreational therapists): | | | | |
| same staff available on a daily basis | | | | |
| adequate staff available to accommodate residents | | | | |
| security provided for residents who wander | | | | |
| staff trained in emergency procedures | | | | |
| number of years in operation: | | | | |
| licensed facility | | | | |
| licensed administrator | | | | |
| Medicare/Medicaid-certified | | | | |
| accredited by CARF-CCAC | | | | |
| Any complaints filed against this facility to the state health department? | | | | |
| If so, what has the facility done to alleviate the problem? | | | | |
| Any quality-of-care deficiencies in the facility's State Inspection Report? | | | | |
| If so, how have they been corrected? | | | | |
| Cost of care | | | | |
| cost per day/month: | | | | |
| list of services included in monthly or yearly cost | | | | |
| additional costs for certain services | | | | |
| adequate notice if fees increase | | | | |
| under what conditions the daily/monthly rate would be increased | | | | |
| Residents | | | | |
| rent their living space | | | | |
| own their living space | | | | |
| types of reimbursement accepted: | | | | |
| security deposit required | | | | |
| clear explanation of refund policy, contract amendment/termination policies, and billing schedule | | | | |
| renter's or homeowner's insurance required | | | | |
| Services provided | | | | |
| brochure listing all services and personal care available | | | | |



| Features of the CCRC | Yes | No | Does not apply | Comments |
|--|-----|----|----------------|----------|
| acceptable health-care and personal care services included in contracts | | | | |
| 24-hour assistance | | | | |
| Written plan of care for each resident? | | | | |
| If so, how and when is it updated? | | | | |
| medical conditions not accepted by the facility: | | | | |
| transportation within the community | | | | |
| housekeeping | | | | |
| activities-of-daily-living services available if needed by resident | | | | |
| appropriate contact with family/ physician if resident's care needs increase | | | | |

Sources: Adapted from Assisted Living Federation of America 2009; Assisted Living On-Line.com 2007; and Getcare.com 2007.

APPENDIX J. CHECKLIST FOR EVALUATING A NURSING HOME

Nursing home's name: _____

Address: _____

Phone number: _____

E-mail: _____ Web site: _____

Contact: _____

| Features of the nursing home | Yes | No | Does not apply | Comments |
|--|-----|----|----------------|----------|
| Basic information | | | | |
| Medicare-certified | | | | |
| Medicaid-certified | | | | |
| has the level of care needed (e.g. skilled, custodial) | | | | |
| has a bed currently available at the level of care needed | | | | |
| has special services in a separate unit if needed (e.g. dementia, ventilator, or rehabilitation) | | | | |
| has a bed currently available in special services unit | | | | |
| located close enough for family and friends to visit | | | | |
| Appearance of residents | | | | |
| clean, appropriately dressed for the season or time of day, and well groomed | | | | |
| Physical environment | | | | |
| free from overwhelming, unpleasant odors | | | | |
| clean and well kept | | | | |
| comfortable temperature | | | | |
| good lighting | | | | |
| comfortable noise levels in dining room and other common areas | | | | |
| Smoking allowed? | | | | |
| If allowed, is smoking restricted to certain areas? | | | | |



| Features of the nursing home | Yes | No | Does not apply | Comments |
|--|-----|----|----------------|----------|
| furnishings are sturdy, yet comfortable and attractive | | | | |
| Residents' rooms | | | | |
| personal belongings and/or furniture allowed | | | | |
| storage space (closet and drawers) provided | | | | |
| window in each room | | | | |
| access provided to personal telephone and television | | | | |
| choice of roommates allowed | | | | |
| water pitchers placed where residents can reach them | | | | |
| policies and procedures established to protect residents' possessions | | | | |
| Hallways, stairs, lounges, and bathrooms | | | | |
| exits clearly marked | | | | |
| quiet areas available where residents can visit with family and friends | | | | |
| equipped with smoke detectors and sprinklers | | | | |
| all common areas, resident rooms, and doorways designed for wheelchair use | | | | |
| hallways have handrails | | | | |
| bathrooms have grab bars | | | | |
| Menus and food | | | | |
| choice of food items available at each meal (Ask if your parents' favorite foods are served.) | | | | |
| nutritious snacks available upon request | | | | |
| staff helps residents eat and drink at mealtimes if help is needed | | | | |
| Activities | | | | |
| a variety of activities available for all residents, including those who are unable to leave their rooms | | | | |
| outdoor areas available for resident use | | | | |
| if so, staff helps residents go outside | | | | |
| active volunteer program | | | | |
| Staff | | | | |
| relationship between staff and residents appears warm, polite, and respectful | | | | |
| all staff wear name tags | | | | |
| staff knocks on door before entering residents' rooms | | | | |
| staff refers to residents by name | | | | |
| training and continuing education program offered for all staff | | | | |
| background checks done on all staff | | | | |
| tour guide knows residents by name and is recognized by them | | | | |
| full-time registered nurse (RN) available at all times | | | | |
| same team of nurses and certified nursing assistants (CNAs) work with the same resident 4 to 5 days per week | | | | |
| CNAs work with a reasonable number of residents | | | | |
| CNAs are involved in care planning meetings | | | | |
| full-time social worker on staff | | | | |



| Features of the nursing home | Yes | No | Does not apply | Comments |
|---|-----|----|----------------|----------|
| Licensed doctor on staff? | | | | |
| Doctor present at nursing home daily? | | | | |
| Can doctor be reached at all times? | | | | |
| number of years management team has worked together: | | | | |
| Safety and care | | | | |
| emergency evacuation plan | | | | |
| fire drills | | | | |
| preventive care provided (like yearly flu shot) to help keep residents healthy | | | | |
| residents allowed to see their personal doctors | | | | |
| arrangement with nearby hospital for emergencies | | | | |
| care plan meetings held at convenient times so residents and family members can attend | | | | |
| If nursing home has failed to meet one or more federal or state requirements, have all deficiencies been corrected on last state inspection report? | | | | |

Source: Centers for Medicare and Medicaid Services 2008.

APPENDIX K. HOME MODIFICATIONS TO FACILITATE “AGING IN PLACE”

Adjustments and modifications can be applied to your parents’ home or property to make it more functional for their changing needs. Some of these modifications include concepts such as *universal design* and *accessory units*.

Universal Design

Universal design incorporates home modifications that make it accessible to anyone with a disability. Universal design has several principles that guide modifications in the home (AARP 2007c; AARP 2007d; Hartmann 2003; Perkins 2003; Price 2001b):

1. Modifications should compensate for a reduced range of motion. Installing railings in bathrooms, moving light switches to a lower position, and power outlets to a higher position are examples of this principle.
2. Modifications should compensate for reduced strength of an aging adult. Using easy gliding hardware for drawers and changing the pulls on cabinets so they can be opened with less strength and effort are examples.
3. Modifications to assist with mobility and agility is another key concept of universal design. Modifications that include the use of ramps, wider

doorways with lower thresholds, ground floor bed and bathrooms, and low-pile carpeting are all examples.

4. Modifications that help with balance and coordination can assist the elderly to remain in their own homes. Changes such as installing raised toilet seats and extended dual handrails, and securing the edges of area rugs, minimize problems with balance and coordination. Anyone in a wheelchair could reach most things easily in a home planned according to universal design.

Accessory Apartments

Accessory units are private housing arrangements that are in, or next to, a single family home. There are two types of accessory units: accessory apartments and elder cottage housing opportunity units (ECHO). Accessory apartments are created within a single-family home as a complete and separate unit with a kitchen and bathroom. ECHO units are complete and portable homes installed in the yard of a single-family home. Granny flats or guest homes are other names for ECHO units (AARP 2008b). Universal design elements can be incorporated into these structures.

Important Considerations

There may be legal restrictions for implementing home modifications. Zoning ordinances and covenants can restrict building and structural changes.

Tax issues. Consult a tax advisor or the IRS to determine what impact an accessory unit will have on your taxes. Renting an apartment affects the landlord and the tenant.

Costs. Modifying a home to incorporate an accessory apartment costs an average of \$20,000

or more. (See the Homemods.org Web site at www.homemods.org for details.) ECHO units cost an average of \$30,000 or more, depending on the type of materials used, the size, and the cost of permits and land preparation on the existing property.

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E-mail: danrcs@ucdavis.edu

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