

Section 7

Supportive Housing



Making the Decision

When is the right time for facility care?

It is difficult to know when to begin looking for facility care for a loved one. However, if you are the primary care provider for someone with Alzheimer's disease (AD) or a related dementia, you may begin asking this question as the disease progresses. The most important thing to remember is that there is no "right" time for everyone. Each individual and family is different, and there are several factors to consider. To discuss these factors a family meeting is recommended including family, close friends & neighbors, and when appropriate, the person with Alzheimer's disease (AD) or related dementia. Use the checklist below to help you assess your caregiving situation.

Safety

- Does your loved one forget or refuse to use safety equipment such as wheelchairs, walkers, or grab bars?
- Is the home environment becoming more difficult for the person with AD or related dementia? (e.g., stairs, in accessible doors, dark hallways)
- Has your loved one had accidents with the stove, appliances, or other household items?
- Has the person with AD or a related dementia had trouble getting around the house without falling or needing assistance with walking?
- If your loved one smokes, has he had smoking accidents? (e.g. forgetting to extinguish cigarettes and burning holes in clothing)

Personal Hygiene

- Is it difficult for your loved one to get to the bathroom when needed?
- Is the person with AD or a related dementia unwilling or unable to bathe?
- Is the person with AD or a related dementia unwilling or unable to change clothing when needed?
- Is your loved one unable or unwilling to help with personal care task?
- Have care needs for your loved one become too difficult or too demanding for you?

Behavioral Concerns

- Has your loved one ever wandered away from home or been lost?
- Is your loved one combative, suspicious, angry, or refusing care?
- Has the person with AD physically harmed himself or you at any time in the past?

Nutrition

- Does this person with AD or a related dementia have trouble preparing meals or eating independently?
- Do you have difficulty encouraging your loved one to eat appropriate, nutritious foods?
- Is your loved one having health problems associated with poor nutrition? (e.g. vitamin deficiency, dehydration, weight loss, other illness)
- Have eating and/or swallowing become difficult for the person with AD or a related dementia?

Time and Energy

- Does your loved one need help with most Activities of Daily Living (ADLs)? (e.g. eating, bathing, dressing, personal hygiene)
- Do housekeeping duties need to be done so frequently that care becomes an excessive demand?
- Have you frequently lost sleep at night due to worrying about caregiving?

Financial Concerns

- Do you or would you have difficulty affording in-home help 24 hours a day?
- Have the financial strains of caregiving been difficult on your personal budget? (e.g. durable medical equipment cost, incontinence, food and prescription drug purchases)
- Do you miss work frequently due to your caregiver responsibilities?

Caregiver Issues

- At the end of the day, have you felt like you couldn't make it through another day? Is this a recurring thought?
- Is your health at risk or beginning to suffer because of your caregiving responsibilities?
- Have you lost your privacy or the ability to organize and run your household?
- Is there frequent conflict between household members related to caregiving issues?
- When you get a break from caregiving, do you still feel overwhelmed and exhausted?

In-home Care

- Have you tried and been unsuccessful with in-home services such as housekeeping, delivered meals, personal and companion care?
- Have you had difficulty getting your loved one to attend adult day programs?
- Has overnight respite care been used?
- Have you had difficulty enlisting the assistance of family and friends to give yourself a break?

If you answered “yes” to many of these questions, you may need to begin thinking about alternative care options. These are just some of the factors to consider when making this difficult decision. Individual personalities, family history, and outside support should always be part of your decision.

Adapted from the Alzheimer's Association, Oregon Trail Chapter

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Remember to...

- Plan ahead to prevent making decisions during a crisis.
- It is all right to ask for help – you need emotional and physical support.
- You are doing the best you can!



Supportive Housing for Older Adults

If you are considering supportive housing, there are a few different types of environments to choose from. The most appropriate type of housing will depend upon your needs or anticipated needs.

Retirement Apartments (Independent Living)

Meals, transportation, activities, security, housekeeping, emergency response system are provided to residents in individual apartments.

Cost: \$980–\$5000/mo. Meal plans vary. Additional services may be available for a fee.

Assisted Living Centers

Apartment setting with meals, transportation, activities, housekeeping, 24-hour supervision, administration of medications, assistance with personal care. More than 10 residents. Specialized dementia care may be available.

Cost: Prices vary depending upon care needs, room size and amenities. Average base monthly cost (exclusive of care needs) in Tucson in 2012 was \$3,443/month or \$41,316/year. Subsidies available if eligible: Arizona Long Term Care System in contracted centers, Veterans Administration. There are two sliding fee scale facilities in Tucson: St. Luke's Home (520) 628-1512 and Marshall Home For Men (520) 624-5193. Regulated by the Arizona Department of Health Services.

Assisted Living Homes (Adult Care Homes)

Private home caring for up to 10 older adults. Services include housekeeping, meals, 24-hour supervision, and assistance with personal care, medication administration and activities. Specialized dementia care is available in some homes.

Cost: Usually \$2,000–\$5,000/month and up depending upon care, room size and amenities. Subsidies available if eligible: Arizona Long Term Care System in contracted homes, Veterans Administration. Regulated by the Arizona Department of Health Services. Referral agencies can assist families in finding a home.

Skilled Nursing Facilities

Residential health care facility offering ongoing nursing care. Three levels of care may be offered: intermediate care, skilled care, dementia/secure.

Cost: Depends upon care needs, room size and amenities. Average cost in Tucson in 2012 was \$218/day for a private room (\$79,570/year); \$186/day for a shared room (\$67,890/year). Subsidies available: Arizona Long Term Care System, Veterans Administration. Medicare generally pays for rehabilitation only. Regulated by the Arizona Department of Health Services.

Continuing Care Retirement Community (CCRC)

CCRCs offer a full continuum of care, ranging from independent retirement apartments or villas, to assistance with personal care in assisted living apartments, to long-term care in a skilled nursing facility. Designed to allow residents to receive all their care needs on the same campus. Types of contracts available vary.

Selecting Residential Care for Older Adults

- Determine that the facility provides the level of care needed by you or your loved one now and in the near future. Be realistic about care needs.
- Make a scheduled visit first and unannounced follow up visits.
- Ask to see a copy of the most recent survey by the Department of Health Services. Have there been complaints filed/deficiencies noted against the institution? If so, what were they?
- Does the facility have a contract to provide care to residents in the Arizona Long Term Care System (ALTCS)?
- What is the monthly base fee and what services does it cover? What additional services are there and do they cost extra? Is there an itemized list of services? Is there a move-in fee?
- Under what conditions might fees increase? What are the conditions for terminating a contract? How much notice will be given? What is the refund policy?
- What if the older adult must be hospitalized or needs another level of care? What is the procedure if care needs increase above that which the facility can provide? How much notice will be provided?
- Do research on the ownership of the facility. Interview the executive director/owner/manager. How long has he or she been at that facility? What is his or her philosophy of care?
- Can they accommodate couples and are the fees specific to the individual care needs?
- Do physicians or registered nurses regularly visit the facility?
- Review the documentation of medication administration. What techniques are used if someone with dementia refuses his or her meds?
- What is the ratio of staff to residents, including on weekends and at night? Is there awake staff available 24 hours per day? How often are residents checked at night?
- How are caregivers screened? What background checks are done? What initial and continuing education is required? How are their skills evaluated and their credentials checked? How long has staff been at the facility?
- Have caregivers received specific training in dementia care? How do staff handle difficult behaviors?
- Are caregivers available with the physical strength and training necessary to perform safe transfers or whatever task is required?
- Are caregivers available with the cultural sensitivity and language skills you or your loved one need?
- Is this facility able to meet your or your loved one's specific requirements (e.g., non-smoking, fragrance free, etc.)?

- Does the agency have nondiscrimination policies and provide staff training on cultural competency issues including lesbian, gay, bisexual, and transgender (LGBT) concerns?
- How are complaints made and how are they handled?
- Is the environment attractive, both indoors and outdoors?
- Are sanitary conditions maintained throughout the facility?
- Are residents addressed by appropriate names?
- Are residents appropriately dressed and groomed for time of day?
- Do caregivers knock before entering a resident's room?
- Are residents cheerful and able to talk freely with you?
- Ask for a copy of the monthly activity calendar to see if the activities would interest you or your loved one.
- Is there meaningful stimulating activity available at the needed frequency and level?
- How far do residents have to walk to activities and to their dining room?
- Will the distance be a barrier to participation in activities or meals for you or your loved one?
- Can residents decorate their own rooms? How are roommates selected?
- Ask to see a menu. Can the facility accommodate special dietary needs?
- Do residents participate in menu planning if desired? Are snacks available between meals?
- Is there an emergency call system? Is it conveniently located? Who responds to the call?
- Is there private phone service in each room?
- Are visitors welcome at any time? Could pets live in or make visits?
- Are visitors monitored or screened in any way?

The following websites may be useful: www.medicare.gov for nursing home information, and www.azdhs.gov/als for information on assisted living homes and centers. For information about survey results or complaints you may contact the Tucson branch of the Department of Health Services Healthcare Licensure at (520) 628-6965.

Resident's Rights In Care Facilities

Residents of long-term care facilities have the right to:

- Be treated with respect and dignity
- Be free from chemical and physical restraints
- Manage their own finances
- Voice grievances without fear of retaliation
- Associate and communicate privately with any person of their choice
- Send and receive personal mail
- Have personal and medical records kept confidential
- Apply for State and Federal assistance without discrimination
- Be fully informed prior to admission of their rights, services available, and all charges
- Be given advance notice of transfer or discharge

For more information, go to the website www.azdes.gov/daas/lto/

*Source: Arizona Long Term Care Ombudsman Program
Division of Aging and Adult Services and the Area Agencies on Aging*

Advocacy for Individuals in Residential Settings

When a loved one moves to a long term care facility, concerns may arise about the care he or she is receiving. There are several agencies that can deal with complaints or concerns as well as those that regularly monitor and report on these facilities:

Pima Council on Aging (PCOA) Long Term Care Ombudsman Program

Website: www.pcoa.org

Help Line: (520) 790-7262

E-mail: ltco@pcoa.org

The Long Term Care Ombudsman Program at PCOA consists of trained volunteers and staff who regularly visit assisted living and nursing home residents in Pima County to monitor the facilities and advocate for residents' rights. Working with residents and their families along with the facilities, the ombudsmen investigate and resolve problems, provide information, referral and consultation and work with licensing, certification, and other enforcement agencies to improve the quality of care in long term care facilities. The ombudsmen also identify problem areas in facilities and advocate for change.

The ombudsmen can help with concerns and problems about:

- The quality of long term care provided
- Residents' rights
- Physical abuse and neglect
- Dietary needs
- Privacy and confidentiality
- Financial issues (e.g. billing, government benefits, financial exploitation)
- Physical or chemical restraints
- Facility transfer or discharge

Adult Protective Services (APS)

Online reporting: www.azdes.gov/reportadultabuse

Telephone reporting: (877) 767-2385

- Monday-Friday 7 a.m. - 7 p.m. / Sat-Sun 10 a.m. - 6 p.m.

APS is a state-wide program that receives and investigates reports of possible neglect, abuse and exploitation of vulnerable adults. APS workers conduct investigations in facilities as well as in private homes and apartments. A vulnerable adult is defined as an individual who is 18 years of age or older who is unable to protect him/herself from abuse, neglect or exploitation by others because of a physical or mental impairment. APS works in partnership with law enforcement, the courts and community-based service providers to facilitate services and supports that help protect vulnerable adults from abuse, neglect and exploitation, and help them live as independently as possible.

Arizona Department of Health Services (ADHS)

Website: www.azdhs.gov

General information: (602) 542-1025

Licensing Services: (602) 364-2536

The ADHS Division of Licensing Services licenses and monitors health and child care facilities and providers throughout Arizona. Licensing inspections, on-site surveys (usually done annually), and complaint investigations are conducted to promote quality care and safety and ensure that performance standards are met for facility operation and maintenance. The website includes AZ Care Check, where you can find information about deficiencies found in facilities. You can also submit complaints about nursing homes or assisted living facilities online. The Division of Licensing Services includes two separate offices, Long Term Care that inspects nursing homes and Assisted Living Facilities, Assisted Living Homes and Centers, and Adult Foster Care. You can also find the most recent federal inspection survey results at: www.medicare.gov/nursinghomecompare.

Factors to consider in evaluating a facility:

- Residents' lack of proper hygiene
- Bedsores (pressure sores)
- Inadequate number of staff
- Unsafe environment (e.g. tears in carpet, broken furniture)
- Urine or fecal odors
- Restrained residents
- Inadequate records
- Poor supervision of staff
- Unexplained injuries
- Alleged abuse
- Not enough food
- Inadequate clothing

Arizona Center for Disability Law (ACDL)

Website: www.acdl.com

Intake: 602-274-6287 (Voice/TTY) or (800) 927-2260 (Voice/TTY)

The ACDL is a federally-designated Protection and Advocacy System for the State of Arizona. Protection and Advocacy Systems (P&As) throughout the United States assure that the human and civil rights of persons with disabilities are protected. In creating P&As, Congress gave them unique authorities and responsibilities, including the power to investigate reports of abuse and neglect and violations of the rights of persons with disabilities. P&As are also authorized to pursue appropriate legal and administrative remedies on behalf of persons with disabilities to insure the enforcement of their constitutional and statutory rights.

Source: Pima Council on Aging

Glossary:

Frequently Used Terms in Long-Term Care

Adult Day Health Care Center

(ADHC) A structured program that is usually offered on weekdays and may offer activities, meals, and health and rehabilitative services for the elderly in a supervised setting. Transportation is sometimes included in the fee. ALTCS covers this benefit.

Activities of Daily Living (ADLs)

- Examples of ADLs are:
- Bathing
- Dressing
- Grooming
- Eating
- Bed mobility
- Transferring
- Toileting
- Walking

Advance Directives

These are documents that allow individuals to designate decisions they want to have made and who will be authorized to make those decisions for medical and related care. They take effect when patient becomes mentally or physically unable to make or communicate wishes. Living Wills, Durable Power of Attorney for Healthcare and Durable Mental Healthcare Power of Attorney are examples of advance directives.

Alzheimer's Disease

Alzheimer's disease ("AD") is the most common of the dementia disorders. It is a progressive, degenerative disease that attacks the brain and results in impaired memory, thinking and behavior. Symptoms include:

- Gradual memory loss
- Decline in ability to perform routine tasks
- Disorientation in time and space
- Impairment of judgment
- Personality change
- Difficulty in learning
- Loss of language and communication skills

As with all dementia, the rate of progression in Alzheimer's patients varies from case to case. Refer to your local chapter of the Alzheimer's Association or www.alz.org for more assistance.

Application Date

The date the ALTCS application is received by the eligibility agency.

Assisted Living (Non-Medical Senior Housing)

Assisted living is a general term for living arrangements in which some services are available to residents (meals, laundry, and medication reminders) but residents still live independently within the assisted living complex. In most cases, assisted living residents pay a regular monthly rent, and then pay additional fees for the services they require. ALTCS covers service in many situations. The facility should be asked if they have a contract with the ALTCS program.

Assisted Living Center – (ten or fewer residents)

These are group living arrangements (sometimes called group or domiciliary homes) that are designed to meet the needs of people who cannot live independently, but do not require nursing home services.

Assisted Living Homes - (four or fewer residents)

Private homes that take in four or fewer residents and care for them 24 hours a day. More of a family environment. ALTCS covers this benefit.

Attendant Care

A service benefit of the ALTCS program whereby a family member, friend, neighbor, or loved one can be paid to be the member's caregiver. The only person not eligible to be paid is the parent of a member who is under 18.

Case Manager (Care Manager)

A social worker or health care professional, who evaluates, plans, locates, coordinates and monitors services with an older person and the family. Once on the ALTCS program, a case manager is assigned to the member to coordinate service. These professionals have access to your loved one's needs and home situation and they coordinate and monitor the necessary care and services. They work closely with you and other family members, making it possible even for those who live far away to stay involved. ALTCS covers this service.

Conservator

Person appointed by the court in a legal proceeding to act as the legal and financial representative of a person who is mentally or physically incapable of managing his or her own financial affairs.

Co-Payment

This is the portion of a medical expense that is the member's financial responsibility. HMOs generally have fixed low co-payments, usually around \$5 - \$10.

Continuing Care Retirement Communities (CCRC's)

CCRC's are housing communities that provide different levels of care based on the needs of their residents from independent living apartments to skilled nursing in an affiliated nursing home. Residents move from one setting to another based on their needs, but continue to remain a part of their CCRC's community. Many CCRC's require a large payment prior to admission and charge monthly fees beyond that. For this reason, many CCRC's are too expensive for older people with modest incomes.

Deductible

A common cost-sharing arrangement of traditional indemnity insurers under which a policyholder must pay a set amount toward covered services before the insurer is required to pay claims.

Dementia

Dementia is characterized by the loss of intellectual functions such as thinking, remembering and reasoning to the extent that a person's daily functioning is affected. It is not a disease in itself, but rather a group of symptoms which may accompany certain diseases or physical conditions. The cause and rate of progression of dementia vary. Some of the well-known diseases that produce dementia include:

Alzheimer's Disease

Multi-infarct Dementia

Huntington's Disease

Pick's Disease

Creutzfeldt-Jakob Disease

Parkinson's Disease

Depression

Depression

Depression is a psychiatric disorder marked by sadness, inactivity, feelings of hopelessness, and sometimes suicidal tendencies. Many severely depressed individuals will have some mental deficits including poor concentration and attention. When dementia and depression are present together, intellectual deterioration may be exaggerated. Depression, whether present alone or in combination with dementia, can be reversed with proper treatment.

Durable Power of Attorney

A power of attorney is a document where one person (the principal) appoints another person (the agent) to act on behalf of the principal. A Durable Power of Attorney survives the incapacity of the principal.

Enrollment Date

The date AHCCCS enrolls the person in a health plan (Program Contractor).

Estate Planning

Steps you can take while living to determine what happens to your property when you die.

Gatekeeper

A term sometimes used to refer to HMO primary care physicians or nurse practitioners and Case Managers because of their responsibility for referring members to specialists or other services.

Gifting

Giving funds to charity, family or other entity.

Guardian

Person appointed by court to make personal, placement and medical decisions for someone who is incapacitated.

HMO (Health Maintenance Organization)

A health plan that both pays for and provides, or arranges to provide, access to comprehensive medical services. HMOs are reimbursed for services on a fixed monthly basis.

Incapacity

The inability to make or communicate personal decisions. Incapacity can be mental or physical, temporary or permanent.

Long-Term Care Facilities/Skilled Nursing Facilities/Nursing Home

A nursing home is a residence that provides room, meals, recreational activities, help with daily living and protective supervision to residents. Generally, nursing home residents have physical or mental impairments which keep them from living independently. Nursing homes are certified to provide different levels of care, from custodial to skilled nursing (services that can only be administered by a trained professional). Cost can be covered by the ALTCS program.

Health Care Power of Attorney

Allows a designated representative to make health care decisions for a person who is incapacitated.

Home and Community Care

Most people want to remain at home as long as possible. A person who is ill or disabled and needs help may be able to get a variety of home services that might prevent one from having to move into a nursing home. Home and community based services (HCBS) include:

Personal care

Respite care

Medical transportation

Nursing care

Home health aide

Home modification

Attendant care

Adult day care

Durable medical equipment

Home Health Agency

An organization that provides home care services, including skilled nursing care, physical therapy, occupational therapy, speech therapy and care by home health aides.

Home Health Aide

A home health aide does not have a nursing license. The aide provides services that support any services that the nurse provides. ALTCS covers this service.

Irrevocable

Unchangeable or irreversible.

Living Will

A document that makes known a person's wishes regarding medical treatments, usually for those at the end of life.

Long-Term Care Insurance

Private insurance designed to cover long-term care costs. These insurance plans vary greatly, and it is wise to do some research before purchasing any long-term care policy. Generally, only relatively healthy people may purchase long-term care insurance.

Managed Care

A method of delivering and paying for health care through a system of networks of providers. Managed care seeks to ensure the quality and contain the cost of comprehensive medical care. Managed care plans include HMOs, preferred provider organizations, point of service plans and similar coordinated care networks.

Medicaid/Medical Assistance

A joint federal and state program that helps with medical costs for some people with low incomes. Programs vary from state to state, but most health care costs are covered if one qualifies for both Medicare and Medicaid. ALTCS is Arizona's version of Medicaid for chronically ill elderly and the disabled.

Medicare

Federal program providing health care coverage/insurance for people over 65 years of age, certain younger people with disabilities, and people with End-Stage Renal Disease (ESRD) (permanent kidney failure that must be treated with dialysis or a transplant). Part A covers inpatient care, skilled nursing facility, hospice and short-term health care. Part B covers doctors' services, outpatient hospital care and durable medical equipment. It does not provide for long-term care of the elderly except under limited conditions.

Medical Social Services

Help with social and emotional concerns one may have related to one's illness. This might include counseling or help in finding community resources.

Medicare Supplemental Insurance

This is private insurance (often called Medigap) that pays Medicare's deductibles and coinsurances, and which may cover services not covered by Medicare. Most Medigap plans will help pay for skilled nursing care, but only when that care is covered by Medicare.

Medigap Policies

A Medigap policy is the most common way that a health insurance policy helps one pay for some nursing home costs. A Medigap policy pays for the 'gaps,' or co-insurance, left by Medicare such as the co-pay owed for days 21 through 100 of a Medicare Benefit period. Premium payments for new Medigap policies usually range from approximately \$50.00 to \$150.00 per month.

Out-of-Pocket Costs

Costs for medical services not covered by an insurer or an HMO. Unlike persons with conventional insurance, HMO members incur minimal out-of-pocket costs.

Parkinson's Disease

Parkinson's disease ("PD") is a progressive disorder of the central nervous system which affects more than one million Americans. Individuals with PD lack a substance called dopamine, which is important in the central nervous system's control of muscle activity. PD is often characterized by:

- Tremors
- Stiffness in limbs and joints
- Speech impediments
- Difficulty in initiating physical movement

Late in the course of the disease, some individuals develop dementia and eventually Alzheimer's disease. Medications such as levodopa, which prevents degeneration of dopamine, are used to improve diminished motor symptoms in PD patients but do not correct the mental changes that it causes. Contact www.bni.org or (602) 406-4931.

Revocable

Capable of being revoked or changed

Share of Cost

The amount the ALTCS member must pay out of their income towards the cost of their long term care services. In assisted living, this amount is called “room and board.”

SNF

SNF stands for “skilled nursing facility.”

Trust

A trust may be used for management of assets during a person’s lifetime.

Source: JacksonWhite Attorneys At Law

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