



TIMELY RESOURCES
CARE GUIDE:
PLANNING FOR LONG TERM
CARE

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PLANNING FOR LONG-TERM CARE

This booklet is a rather long read. Relax. Get a cup of tea. Hopefully, you don't have to be in a rush. (If you are pressed for time, give us a call at Alzheimer Resource Services or contact your local Agency on Aging for more immediate assistance.)

There is a lot to consider when looking at long term needs and there are several services available. Take your time. Take notes. Write down your needs (or possible needs), your questions, and who might be able to answer them or direct you to someone who can.

This booklet will also give you resources.

- A The resources are not all-inclusive. There are many sources of information available to the consumer and you are encouraged to shop.**
- A Some areas will have more services and resources than others. Because media (TV, etc) covers such a broad geographic area, you may see ads for services / providers that aren't available in your market.**
- A Ask questions. Explore what is available.**

A word of caution:

Internet has made a huge impact on all aspects of our lives. We are in a position to be better informed consumers but we are also in a position to be misinformed consumers.

- A Is the website reliable?**
- A Is the website up-to-date?**
- A Does the website have links to non-existent sites or 404 Errors?**
- A Who sponsors the website?**
- A Who are the advertisers?**
- A Check out the domain suffix. (.com, .edu, .org, .net, and so on)**
- A If you are searching for caregivers online, make sure you check any prospective employees thoroughly. Don't rely solely on the information provided on the website. Check references. Meet in person. Use caution.**

On social media:

Social media can be helpful but be alert, be aware, and be cautious. There are groups that focus on many things such as disease specific or caregiver support which can offer encouragement and a sense of belonging. There are also people who troll these sites looking for vulnerable potential scammers.

Beware of possible scammers.

- A Those who want to take advantage of others can find a pool of possible scammers on social media.**
- A Artificial Intelligence can help scammers create any face or persona that may appeal to someone who is in a vulnerable position or who is looking for a relationship.**
- A If you are looking for caregiving assistance on social media, check references, insist on a face-to-face or in-person meeting.**
- A Ask questions.**
- A Don't take posts at face value.**
- A Guard your personal information.**
- A Guard the personal information of your care receiver.**

Learn what you can

We are often put in a position of obtaining support services as we try to manage a crisis. Perhaps we have an acute event that creates the need for an urgent response or perhaps we are put in the position of caregiver to manage an acute need. It may be due to a fall, an illness, or a deteriorating health condition.

Do your homework before a crisis presents. Find out who can offer information and learn about resources and types of services. A little preparation can save a lot of stress!

What is long-term care?

Long-term care (or LTSS - long term services and supports) refers to:

- A **A broad range of medical, personal and social services**
- A **Services that are developed and coordinated to meet physical, social, emotional and spiritual needs of those with chronic illnesses and disabilities.**

Services are provided across the care continuum.

- A **Long-term care services may be delivered in the home, in the community or in an institution**
 - **Long-term care is not limited to nursing home care**
- A **Long-term care may be needed for anyone from infancy to old age**
 - **This guide focuses on older adults**
- A **Long-term care entails a variety of services and programs for those whose needs range from “a little” to “a lot”**

Thought should be given to services that will meet needs over an extended period of time.

- A **An individual’s needs change**
 - **Health needs**
 - **The illness or disabling condition may change**
 - **Other health concerns may arise**
 - **Care needs**
 - **The care receiver’s abilities may change (physical and cognitive)**
 - **Environmental needs**
 - **Does the environment meet the care receiver’s needs**
 - **Is the home accessible?**
 - **Is the home aging friendly?**
 - **Can the home be modified? Are there funds to do this? Is it practical approach?**
 - **Does alternative housing need to be considered?**
 - **Service needs**
- A **The service delivery systems change**
 - **They go out of business or are bought by other companies (which often entails a name change and maybe staff changes)**
 - **Funding changes especially with state agencies**
 - **Services change**
 - **Service costs change**
 - **Terminology changes with services and programs**
- A **The caregiver may experience life changes**
 - **Health**
 - **Injury**
 - **Family**
 - **Work**
 - **Financial**

As social, physical and life circumstances change, the individual or the person managing the care has to adapt to those changes. Planning for long-term care prepares you with information to help you navigate the changes that aging, illness, or injury brings.

Should people plan for long-term care?

In a word - Yes!

Planning for *retirement* is emphasized from the time we enter the work force and people plan in a number of ways. Financial planning may involve contributions into IRAs, savings or annuities. Consumers may purchase long-term care insurance coverage. Moving forward, we look at smaller and more convenient housing or we may plan a move to a warmer climate or a move closer to family. Many people spend time thinking about what to do when they retire. Go back to school? Plan a second career or a post-retirement job? Do I need to supplement my income?

We think of retirement, being financially secure, and what we will do. But – we seldom think of planning for incapacity.

People seldom think about planning for *disability or their inability to do everyday activities* such as grocery shopping, personal care, housekeeping and laundry. What can we do to prepare for our possible dependence on others? We can't anticipate every twist and turn that life offers but we can be pro-active.

We need to know what financial resources are available to pay for services, what services are available, and who to call to get the information.

Be aware of changes with insurances. Companies change and benefits change. Medicare benefits change to provide preventive services and other wellness incentives. Prescription drug plans change formularies.

People need to work longer to collect full Social Security benefits. Federal laws pass that take years to enact. The changes that are occurring on the Federal level will impact how we plan for our individual retirements and long term care needs – and this is an ever-changing field.

How will this information help?

This information will explain long-term care services and supports. (Think of this as a Cliff notes version.) Although services differ, this booklet will give you information that will enable you to ask questions so you can learn what is available in your area.

Think about:

- A **Availability** of services
 - What services are available to consumers in your area?
- A **Accessibility** of services
 - Services may be available in your area but are they accessible? Can you get to them or can they get to you?
- A **Affordability** of services
 - Can you afford the service? Are there programs or benefits that can help pay for services? (Federal programs, State programs, Veterans benefits, United Mine Workers benefits, long term care insurance, etc.) Costs vary in different markets. Services tend to be more expensive in larger urban areas but there are more services. **Please check with your local providers** for a range of prices in your area as costs differ from region to region. Ask the provider if they anticipate any cost changes or ask when cost changes usually occur.
- A **Appropriateness** of services
 - Is the service appropriate to the care receiver's / care partner's needs?

Alternatives may need to be explored. Be creative!

DEFINING LONG-TERM CARE or LTSS (LONG TERM SERVICES & SUPPORTS)

Long-term care may be divided into three categories:

- **IN-HOME SERVICES**
These services are provided to care receivers in their homes. Home may be the house that your family has lived in for years; or, it may be a new home. It may be an apartment in the neighborhood, in a high rise or in a senior community.

- **COMMUNITY-BASED SERVICES**
These services are offered in the community setting. They may be through senior centers, churches, alternative housing, agency or office settings.

- **INSTITUTIONAL CARE**
These services are offered in a facility setting: assisted living, nursing home or rehabilitation settings.

IN HOME CARE SERVICES

What are in-home services?

In-home services include home support services or in-home (non-medical) services, environmental services, supportive assistance and may include health services and end-of-life care. These services are provided in the client's home.

Home support services (or non-medical in-home services) offer companion services, housekeeping services and personal care services.

- A **Companion services offer socialization and supervision.**
- A **Housekeeping services include dusting, vacuuming, laundry, meal preparation, damp mopping – the environmental services that allow an individual to remain in a safe and clean living area.**
- A **Personal care services include bathing, dressing and grooming assistance.**
- A **Costs vary from agency to agency.**
- A **Most agencies require a minimum block of time of service.**
- A **There may be up-charges for personal care assistance.**

Home support agencies

- A **May be a division of home health agency; a freestanding agency; or, the service may be a component of another delivery system such as senior centers or other senior service providers.**
- A **Workers' training and certification may vary.**
- A **Reference checks, background checks, drug checks, and/or finger-printing MAY be used in screening in-home service providers. Ask how employees are screened.**

Payment sources vary.

- A **Medicare does not cover this level of care.**
- A **Many long-term care insurance policies offer coverage for in-home assistance as long as policy criteria and documentation requirements are met.**
- A **Some specially designated insurance policies will help with costs but policy restrictions apply. (Check with your insurance carrier for coverage under your specific policies: cancer, auto, and any others.)**
- A **Paying out-of-pocket is a method of payment.**
 - o **Income, savings, annuities, sale of property, reverse mortgages, and other assets are often used to pay for care.**

Is there assistance to pay for home care?

There may be assistance through other sources if the care receiver qualifies.

- A **Some state-managed programs (Aged & Disabled Waiver Programs, Traumatic Brain Injury Waiver Programs, or ID/D Waiver Programs) offer home support as a component of the program, and, individuals must meet eligibility requirements and be approved for the program.**
- A **The Veteran's Administration may be a resource for financial assistance with home support services through the Aid & Attendance Program for Veterans and Widows of Veterans or the Homemaker program. Applicants must meet eligibility requirements.**
- A **States may have a program or grant related to a specific diagnosis such as in home assistance for families dealing with Alzheimer's or related dementias. There may also be programs funded through the specific state's aging office. Check on these programs through your local senior services provider or area agency on aging office.**

Some agencies may hire a family member or friend to provide care. Ask agencies about this option if you know someone who is interested.

Caregiver contracts can be developed for family members providing care. Read more about caregiver contracts in the article “[Personal Care Agreements](https://www.caregiver.org/resource/personal-care-agreements/)” from the Family Caregiver Alliance (or go to <https://www.caregiver.org/resource/personal-care-agreements/>) to see if this may be a consideration for your situation. Consult an attorney for laws governing personal care agreements in your state.

Hiring an individual privately may be an option but it is important to check all references thoroughly, define a work contract and wage, develop an emergency plan and make arrangements for Social Security, Worker’s Compensation, taxes and other legalities.

Social service agencies, hospitals and nursing homes may be sources for “private pay lists” of those who are seeking work. When a list is provided, ask friends, family, minister / priest / rabbi to review the list. Highlight names that are possibilities; cross off ones that are not. There are also on-line registries for private duty workers. (Be cautious.) Check prospective employees thoroughly and to your satisfaction. Prices vary for privately contracted workers. Skill levels vary in the private-pay resource pool.

Whether seeking assistance from an agency or hiring someone privately, make a list of tasks that need completed.

Home-delivered meal services help maintain nutritional integrity. Perhaps the person has trouble cooking. Does their diet consist mainly of sweets, salty snacks, or other foods that aren’t very nutritious?

- A Home delivered meals through senior centers or other social service agencies are usually delivered once a day, five days a week (most often Monday through Friday) and may include meals for weekends and / or holidays.
- A Some programs deliver on holidays; others do not.
- A The meals generally include a hot meal and beverage.
- A Shelf-stable boxes may also be delivered for those who are eligible.
- A Individuals must qualify as home bound.
- A Costs vary from donation-based to for-fee basis.
- A Programs may be free-standing or through volunteer organizations, senior centers and/or church organizations.
- A Delivery areas are often limited especially in rural areas and organizations may use delivery services such as Mom’s Meals for those outside the delivery are.
- A Some organizations deliver several frozen meals for microwave preparation or will prepare a meal for someone else to pick up and take to the care receiver.

There are other options for meals. Grocery stores or convenience markets often have hot meals or easy-to-prepare meals, and restaurants offer items from their menu and many deliver. There are also many delivery options through on-line services, and meals can be tailored to dietary needs, preferences, and/or frequency. Search your browser for home delivered meal options.

Transportation may be available from your area senior center, Mobility Management company, volunteer organization, hospital or clinic, public transportation company, or non-emergent medical transportation company contracted through state agencies. In-home service agencies may offer transportation to their clients as part of the care plan. Paratransit options for those with mobility challenges may be available from your transit authority. Non-emergent transportation may be available from a local fire department or ambulance service. Some housing communities offer transportation for their residents. Costs vary depending on the source of the service.

Outreach services may be available through senior centers, veterans clinics, volunteer organizations, or mental health clinics, and entail visits by social service professionals. These visits may be to assess the individual’s service needs, assess their ability to continue to live alone or determine the need for protective intervention, and/or assist with billings or program applications. There is generally no charge for this type of activity.

Friendly visitor services offer individuals to stop by the home and visit, run errands and/or write letters. Typically there is no charge this service which is often provided by religious groups such as congregation members or interfaith groups, volunteer groups or through senior centers. Retired Senior and Volunteer Programs may also offer Friendly Visitor Services.

Telephone reassurance services, like the friendly visitor programs, are often provided by interfaith groups, volunteer groups or through senior centers. Generally, there is no charge for this service which offers telephone support to vulnerable adults who live alone.

Library outreach services offers books and audio books to those who are homebound. The service may be offered through local libraries.

Online reading services offer an opportunity for readers to get books and not leave their home. [Internet Archive](#) and [Book Bub](#) are two sources of books, documents, and other materials. There are other on-line reading services. There are also audio books form a number of sources. All genres of books are offered. Chirp© is one source of audio books.

Home Modification can include installing grab bars, walk-in tubs or showers, stair lifts (inside and/or outside), and ramps, and it can include bigger projects such as building an addition to an existing residence or modifying an existing residence (ie: moving laundry to a first floor or adding a bathroom to a first floor).

Home health care covers a range of services provided by healthcare professionals such as nurses, physical therapists, speech therapists and/or occupational therapists for the purpose of restoring or maintaining health. Personal care services such as assistance with bathing, grooming and dressing are provided by home health aides and are provided in conjunction with the skilled health service. Services are provided based on a ‘visit’ not a specific time period.

- A Medicare covers the skilled services if the patient meets Medicare home health guidelines.
 - The patient must be certified by the referring physician as needing the skilled service; must be homebound according to home health guidelines; must need intermittent care; and, the care plan must be arranged / approved by the physician/primary health care provider.
 - Care must be provided by a Medicare-certified agency.
 - Medicaid will generally pay for these costs, also, (as well as medical supplies, equipment and prescriptions) if the patient has met eligibility guidelines, been approved by the state and if the services are provided by an agency that is certified by that state’s Medicaid-approved provider.
 - Private insurance may cover these costs but be sure to check the plan for any restrictive eligibility criteria.
 - Paying privately (out of pocket) is an option but an expensive one. Costs vary from area to area. The cost is also most often based on a service “visit”. When obtaining home health services from a private-pay perspective, call and check on pricing from local providers. Also, consult with the physician/primary health care provider regarding the need for skilled services.

With hospital stays becoming shorter, home health care is valuable in rehabilitation, helping to identify and correct potential problems, and in supporting the care receiver’s progress, and in maintaining independence . The facility social worker or discharge planner may help facilitate home health referrals for a care receiver who is being discharged from a facility.

If your care receiver is homebound, talk to your physician about home health care. If your loved qualifies, they may benefit from physical, occupational, or speech therapy.

Hospice care is provided to the terminally ill for any end-stage / terminal illness who wish no curative measures.

- A The purpose of hospice is to help the terminal patient (with a prognosis of six months or less) and their family cope with the death process and handle the physical, spiritual, and emotional pain.
 - o Several services are available including nursing and medical assistance, personal care aides, spiritual support, and bereavement services.
- A The care may be provided at home or in a facility.
- A Hospice care is covered by most insurances
 - o Medicare will cover hospice care for those who select the hospice benefit of Medicare.
 - o Medicaid coverage is determined by individual states.
 - o Private insurance may also cover hospice care.
 - o Many hospice agencies will not turn a patient away regardless of ability to pay but do not assume that this is always the case.
- A Hospice guidelines may dictate a patient be discharged from hospice care if their lives extend beyond the coverage range of the specific hospice agency.
 - o Recertifications are done to assure continued eligibility or discharge.
- A Hospice may have an in-patient facility for symptom management or for those who are dying.
 - o The hospice company may work with another facility if they don't have an in-patient unit.

Palliative care is offered to those who need pain control and/or symptom management. This may be offered in the home or it may require in-patient care to regulate pain control measures.

- A Palliative care patients need not be in hospice care but they may be a hospice patient.
- A Palliative care may be offered by a hospice organization, a hospital, a pain management clinic, or other health care facilities.
- A Medicare and insurances usually cover at least part of palliative care but ask the agency's business office about your coverage.

COMMENTS:

****Generally, in-home services are not covered by Medicare, Medicaid or private insurance as they are not medical services. Some services are donation based; others have a set fee; some may be on a sliding-scale basis.**

There are programs that receive federal and state monies that will fund some in-home service such as Aged & Disabled Waiver, Traumatic Brain Injury Waiver, or ID/D Waiver programs for those with mental retardation or developmental challenges. Eligibility requirements differ from state to state. Medicaid slots for in-home assistance are also generally limited and subject to changes in the Medicaid programs.

Some Medicare Advantage plans offer added on benefits to their products such as dental and vision allowances, money for groceries, over-the-counter medications, and/or utility expenses. There may also be benefits for those who are recently discharged from the hospital such as meal programs. Check with your Medicare Advantage company regarding added on benefits.

NOTES:

COMMUNITY-BASED SERVICES

What are community based services?

This area of service includes a number of nutrition, social or health care services and also includes alternative housing arrangements.

Examples of community-based care include:

Congregate housing facilities are managed by government agencies, private interests or non-profit groups; and, offer independent living for the individual. Some housing offers units specifically for older adults; others may be designated as “aged and/or disabled” housing; still others have a mixed population.

Amenities vary although ‘personal care assistance’ is not provided. Some facilities offer transportation, limited housekeeping, access to meals, and social and recreational programs, and others offer only housing. Most have some sort of keyed entry for security. Costs vary with some facilities charging a flat rate and others basing the rent on a percentage of income/ assets. Some facilities charge fair-market rent for those who exceed income/asset limits while others will not accept those who exceed income/asset limits. Congregate housing may be high rise apartments; residential-style living; individual cottages; or, side-by-side single-family units.

Senior Centers which may offer services that can include in-home assistance, legal, financial, recreational, nutritional (meal programs – home delivered and congregate), and counseling services. These may include fuel assistance applications, insurance (Medicare supplements, Part D products) counseling and/or income tax assistance. Activities such as cards, crafts, ceramics, pool, etc may be conducted on a regular basis. Senior centers offer a place to meet and an opportunity to socialize with peers. Health screens, flu shot clinics and exercise programs may be available. Some senior centers also sponsor trips for seniors. The centers may be freestanding or may be housed in churches, housing projects or in multi-service centers. Many provide newsletters that include activity schedules and program information. Most counties have at least one senior center. Senior centers administer many programs that come from the state units on aging.

Congregate meal sites offer a place for seniors to have a hot meal in the company of others. The cost of the meal is often donation-based. These meal sites may be in the senior center (nutritional requirements followed), elderly housing, schools or churches. Transportation may be offered to the site.

Adult Day Programs provide a range of services for the individual with dementia, other cognitive impairment, and/or mental health needs who need supervision and socialization. Often health screens are available for participants. Transportation may be provided.

Some programs are designed for the chronically mentally ill and those participating in day treatment programs may need a mental health diagnosis. Some programs are those who have intellectual or developmental challenges. These programs teach and reinforce life skills.

The programs may be operated from a senior center, a hospital, a church, a school or nursing home, or they may be free-standing. Fees for Adult Day Services vary and may be based on a sliding-scale fee (based on income) or may have a fixed rate. Some programs have special funds set up for participants to offset costs and some are approved for VA coverage. Medicaid may cover Adult Day Services in some states. Some long-term care insurance policies offer adult day service coverage.

Some Day Service Programs are based on a social model; some are based on a medical model and provide more intensive medical services. Operational hours vary with some programs offering evenings and weekends and others, just day-time hours during the week. Adult day programs are not available in all areas.

Respite care offers a break for caregivers that ranges from a few hours to a few weeks. The care may be provided in the home or in a facility. Funding streams for respite care vary. This is traditionally an out-of-pocket expense, not covered by Medicare, Medicaid or other insurer. (The Medicare Hospice Respite benefit is an exception.) Consumers will want to review long-term care insurance policies and Veterans' benefits. There may also be respite programs through local senior centers; and, many senior centers are able to provide some respite care through special Federal funding which may offer free services or sliding-scale fee services. Contact your senior service provider for options. Also, when arranging respite in a facility, make sure you have a firm contracted commitment for a respite bed.

Some of these community-based programs are donation-based, some have set fees, some will work with sliding-scale fees based on income. VA may cover the cost of some day care programs or some in-home services. Long-term care insurance policies may cover some aspects of community-based care depending on the specific policy. Generally, however, these services are privately paid (out-of-pocket).

Other possible services could include:

Aging & Disability Resource Centers were developed to assist states in their efforts to create a single, coordinated system of information and access for all persons seeking long term support to minimize confusion, enhance individual choice, and support informed decision-making. Area Agencies on Aging may house the ADRC programs which focus on information for the aging and those with disabilities. "No Wrong Door" programs continue to be developed across the country.

Support Groups are available in many areas for caregivers, those suffering from a specific disease or for those who may be dealing with grief or loss. These may be held in churches, hospitals, nursing homes, senior centers or other locations or they may be virtual. Social media has support options. (Be cautious! This can be a platform for scammers.) These are generally free.

Counseling services may be provided in the home but are often limited to an office, hospital, agency or clinic. More agencies are providing services to nursing home residents, also. Fee structure varies, as does Medicare and insurance coverage. Agencies may offer this service in the home but the availability is limited.

Free standing clinics offer medical care, often for those who are under- or uninsured.

Other services you may want to explore:

Case or Care Management is becoming increasingly important in long-term care. Care management can assist with problem identification, problem solving, review of options, service delivery and monitoring. Care management may be a component of another service and be offered at no charge; it may be offered as a single service and have a fee associated; it may be a service that is incorporated into a state-funded program and have no extra charge such as Medicaid Waiver programs. Some attorneys are incorporating the services of geriatric care managers into their practices. Some Medicaid programs are exploring managed care in nursing facilities.

Adult Protective Services are available for those adults who are being abused, neglected and/or exploited, or who are suffering self-neglect. Adult Protective Service workers respond to reports of abused/neglected/ exploited individuals, determine the validity of the report and seek remedial action with the family, the court system and/or others. At times it is necessary to appoint a guardian ad litem to facilitate the best interests and/or protection of the individual. Most often the Departments of Health and Human Resources investigate Protective Service situations. The laws on Adult Protective Services vary from state to state.

INSTITUTIONAL CARE SERVICES

Acute care or hospitalization might be needed. Often a hospital admission is the first place that it becomes apparent that an individual needs more help than can be provided at home. The hospitalization may be result of a fall, a fracture, a traumatic brain injury, pneumonia, a car accident, or any other incident requiring medical care.

Acute care admissions have a short-term stay, often with a classification system (such as DRGs or Diagnostic Related Groups) governing the length of stay. Insurance coverage plays heavily into length of stay in a hospital. Discharge is made to the home (possibly with supportive services) or to a facility for either skilled (short term) or intermediate (longer stay or permanent) care. **NOTE: Check the ‘admission’ status!** There are instances in which a patient will be an ‘observation’ patient as opposed to an ‘admission’. They may also be downgraded to ‘observation’ from ‘full admission’. Observation status affects how Medicare / insurances pay and also affect the patient’s status if skilled care is needed. The patient should receive written notification of their status as well as information on how to file a grievance about the decision.

Specialized clinics are available for treatment, diagnoses and/or research. Sub-acute care / rehab services are also available for more complicated medical care or longer-term, more intense rehab services and care.

In-patient care may be needed in a behavioral health facility.

Medicare, Medicaid, private insurance and out-of-pocket are payment methods.

****DEPENDING ON THE CARE NEED:** Alternatives for ‘fast tracking’ may be considered with Urgent Care or MedExpress-type offices that most often offer diagnostic evaluations of urgent care needs, x ray, lab work, and prescriptions (as needed) with follow up directed to your primary care physician.

WHAT IF I NEED TO CONSIDER MOVING TO A FACILITY WHERE I CAN RECEIVE HELP?

Institutional care

There are various levels of assistance for the person who can no longer live at home.

Assisted living (referred to as residential board and care, adult group homes, adult care facilities, personal care homes, assisted living residences, and / or retirement homes) is an option for those who need extended care but not acute care (hospitalization). This may involve a chronic illness or recovery from an acute illness or injury.

Assisted living as defined by the Assisted Living Federation of America is a special combination of housing, supportive services, personalized assistance and health care designed to respond to the individual needs of those who need help with activities of daily living and instrumental activities of daily living. Support services are available 24 hours per day to meet the scheduled and unscheduled needs in a way that promotes maximum dignity and independence for each resident and involves the resident’s family, neighbors and friends. Assisted living standards are being refined continuously and specific states have specific standards. When talking about assisted living, be definitive in describing what services you and/or your loved one are seeking. Some facilities are licensed as “assisted” living and provide environmental assistance only – housekeeping, laundry, etc.

Residents of assisted living facilities generally receive room and board, meals, some level of personal care assistance, housekeeping assistance, medication assistance and supervision. Some assisted living facilities will offer ‘aging in place’ as long as state regulations can be met. Some facilities have access to physical therapy for their residents.

Costs of assisted living facilities vary. Some facilities charge a base rate and add charges based on services needed; some are priced at a flat fee. Some assisted living facilities are freestanding; some are part of a continuing care community

A category of Assisted Living: Residential Care Communities offer “any group of 17 or more residential apartments, which is part of a larger independent living community and which are advertised for the express purpose of providing residential accommodations, personal assistance, and supervision on a monthly basis to 17 or more persons who may be dependent upon the services of others by reason of physical or mental impairment or who may require limited and intermittent nursing care but who are capable of self preservation and are not bedfast.” Such residential care communities must offer apartment units with lockable doors, at least one bedroom, a kitchenette with a sink and refrigerator, and one full bathroom. There are size guidelines and no more than two individuals may occupy an apartment. (It may be that the resident cannot reside in residential care as long as he / she would be able to remain in an assisted living facility.

These terms may also be used for assisted living:

Board and care homes or personal care homes which may be unlicensed or unregulated although states most often require the homes’ registration with a central office. Check with your specific state for their regulations and standards of homes. (Your local Department of Health and Human Resources and/or your local long-term care ombudsperson can direct you to the regulatory agency for your state.) Prices vary greatly as do the quality of the home and the quality and intensity of the care. Care is usually paid for out-of-pocket although veterans assistance and long-term care insurance policies (check the terms of your coverage) may pay toward this care. You may also hear this level of care referred to as Residential Board and Care Homes, Adult Group Homes or Domiciliary Care.

Adult care homes are sponsored by the state’s Department of Health and Human Resources. The local Department of Human Services offices monitor these homes. Supplemental payment assistance may be available to those with low incomes. Home sponsors are generally non-skilled but provided with on-going training. Room and board, meals, general supervision and transportation is generally provided to residents. Availability may be limited.

The cost of these levels of care varies. Rates vary greatly and may be cited as a daily rate. Quality of the home and quality of care varies. The sizes of these homes vary. Some house up to five residents; others house more residents. Regulations dictate type of home and the number of residents permitted. Sponsorship or ownership varies. Some are non-profit; some are for-profit.

These types of care represent the lower levels of supervised care (as opposed to ‘nursing home care’) for those who are institutionalized. Some facilities offer “environmental services” and others offer personal care assistance as well. It is important that the home be visited and credentialing checked. There are regulatory bodies in each state that survey (evaluate) licensed facilities. Ask about licensure and any deficiencies noted on those surveys.

Financial assistance may be available through Medicaid (in some states), Veteran’s, other Health and Human Resource monies such as Residential Care Supplements or Assisted Living Waivers, or other insurers depending on state regulations and level of care. Care may also be a private pay or out-of-pocket expense which is generally the case with levels of care below the nursing home care level of intermediate/custodial care.

Nursing home residents may receive skilled nursing care (short term), intermediate care (long term), and some facilities have acute rehabilitation. Residents may receive room and board, meals, personal care assistance, nursing services, supervision, medication administration, and therapeutic and/or rehabilitative services. Facilities most often have social and recreational programming as well.

Financial assistance may be available through Medicare (skilled level of care), Medicaid, Veteran's, or other insurers depending on state regulations and level of care. Care may also be a private pay or out-of-pocket expense for those who do not qualify for Medicaid. Medicaid may be an option for the intermediate/custodial level of care if income and medical/care guidelines are met, the application for assistance is approved, and the facility accepts Medicaid.

Skilled care is generally covered by Medicare in decreasing increments, is time-limited and certification of a skilled care need is required. Veterans' facilities or facilities sponsored by fraternal organizations (such as the Masons) may also be an option for institutional care. It is important to be specific regarding care needs when looking into long term institutional care. Consult the primary health care provider for more insight into care, prognosis, and prospective needs.

Intermediate care also known as custodial care is for individuals who do not meet the criteria for skilled care but need 24-hour supervision and nursing assistance. Medicare does not cover the cost of intermediate/custodial care. Medicaid will cover this cost for those who meet program requirements for financial eligibility and medical eligibility and who are approved for the program; and, in a facility that accepts Medicaid for payment. Private insurance may cover part or all of this cost for those who meet policy requirements. Long-term care insurance may also cover this cost for those who meet policy requirements.

Skilled care is for those people who need intensive 24-hour care by a registered nurse or other skilled medical practitioner. Medicare will pay for this service in decreasing increments if the individual meets the criteria for skilled care (IE: admission to acute care facility, required length of stay prior to transfer to skilled care, skilled care need) and if the facility is Medicare-certified.

Medicare covers skilled care in a certified facility if all criteria are met but in decreasing increments over time. Medicaid may also cover parts of care but since this is a federal/state program, eligibility and services covered vary from state to state. There are various insurances that cover parts of nursing home care but each has its own criteria and limitations. VA may cover parts of care in a VA-approved facility or there may be more extensive coverage in a facility that is strictly for veterans. VA also offers Aid & Attendance Benefits for those who qualify. Nursing home costs have a broad range. Costs usually vary for a private room vs. a semi-private room. If a patient leaves a facility (for example: the need for hospitalization), their bed may not be "held" or reserved for their return – or there may be a limit to the number of days the bed is held. Make sure to consult the facility regarding bed hold regulations for your particular situation. Also, consumers will want to make sure that their care receiver can return to the facility. Sometimes the care needs are such that facilities will not accept a returning patient. Some facilities are not Medicare nor Medicaid approved for the resident who must enter the intermediate/custodial or skilled level of care. This can mean that the cost remains an out-of-pocket expense or the resident must move to a facility that accepts and is approved for Medicare and/or Medicaid.

Continuing Care Retirement Communities offer housing and a range of other types of services (health care, social services) and accommodate residents as they move along a continuum of care. Many of these communities have housing ranging from independent to assisted living to intermediate/custodial care to skilled nursing care. Fee structure is based on the individual's care needs and fees vary between the various levels of care. Most facilities accept Medicare and / or Medicaid for the skilled / intermediate levels of care. Some facilities require an entrance fee as well as a monthly fee. Residents may have the option of home health care as needed and most often have the opportunity of moving to a higher level of care on the premises when their health status changes; or, they may have access to personal care assistance within that "community". Costs vary with different facilities.

General note: Care receivers may be placed in facilities in states other than their state of residence. This is the case with assisted, intermediate and skilled care as well as rehabilitation hospitals. Medicaid (if needed) is applied for in the state **IN WHICH THE CARE RECEIVER IS PLACED**. It may be more challenging to place an individual in an out-of-state facility especially if Medicaid will be the payment source.

NOTE: HOSPICE CARE

Hospice care can be provided in a facility. If your care receiver is a patient in assisted living or a nursing facility, and they are eligible for hospice care, that service can be provided where they are.

A benefit of Hospice care is respite for the caregiver. If the care receiver has hospice care in the home, they can be transferred to a facility for the hospice respite benefit. Your hospice agency can explain the benefits of hospice care.

Palliative care is offered to those who need pain control and/or symptom management which may require in-patient care to regulate pain control measures.

- A Palliative care patients need not be in hospice care but they may be a hospice patient.
- A Palliative care may be offered by a hospice organization, a hospital, a pain management clinic, or other health care facilities.
- A Medicare and insurances usually cover at least part of palliative care but ask the agency's business office about your coverage.

The Long-Term Care Ombudsman program advocates for the rights care receivers of home health care (in some states) and long term care facilities (in other states). Your state unit on aging can advise you on the scope of the ombuds' program. (Some states do not offer ombuds services for patients of home care.) The Ombuds can assist with information on survey results for long-term care facilities as well. Contact your local Area Agency on Aging for information on your area ombudsman program.

NOTES:

OTHER SERVICE CONSIDERATIONS:

What else might help in considering long term care planning for a loved one? Here are a few areas to consider:

Assistive devices, durable medical equipment, home modification such as

- A Help in the home: kitchen devices (ie: large dials for stoves), large face clocks, “flashing light” door alarms, large handled devices, magnifiers, change door knobs for easier grip, etc
- A Grab bars, wheelchairs, walkers, power chairs
- A Ramps
- A Raised toilet access, bidet
- A Temperature control on water
- A Adding a bathroom or a separate living space

There are several resources for assistive devices and home modification information.

- A Departments of Rehabilitation Services, Assistive Technology offices, on-line companies, and retail outlets such as Wal-Mart may be sources for equipment and information.
- A Programs such as the [WV VISIONS](#) (Visually Impaired Seniors In Home Outreach Network program) offer assessment and information on adapting the environment for those seniors who are visually impaired.
- A There may also be low-vision clinics to assist those with visual impairments.
- A Several universities have Centers for Excellence in Disabilities which offer information and resources for those with a wide range of challenges. Some offer lending “libraries” of equipment for consumers to try.
- A YouTube videos have information on many home modifications and “hacks” (meaning making small changes in order to make the situation you're in easier and more efficient for everyone)

Personal emergency response systems are those devices that signal help in an emergency situation. These units may have a device worn around the neck or wrist and / or a base unit. When the device is activated, help is summoned through the telephone system with a call going out for help. Cell phones have emergency contact buttons and some have fall detection. Costs vary for the service. Hospitals and private companies offer the PERS.

Project Lifesaver or other tracking programs for people with cognitive impairment (Alzheimer’s disease or related dementia, autism, Down’s Syndrome) who may wander from their home or safe place. [Project Lifesaver](#) is an international program. Check for the agency in your area. This radio tracking system helps locate people who are wearing an arm or ankle band with a radio frequency.

Safe Return is a locator program offered through the Alzheimer’s Association in collaboration with Medic Alert. The person is registered with identifying information and a picture. They wear an identifying bracelet or accessory to identify them as a participant of the [Safe Return program](#) so if they are found, their information can be put into a data base to identify the person and return them to the designated caregiver.

State Health Insurance Information Programs or SHIP programs are available in all states. These programs have people to assist with questions about Medicare, Medigap, Part D (prescription only as well as Medicare Advantage programs) and other insurance questions. Assistance is available to Medicare beneficiaries of any age. Your local agency on aging or senior center may direct you to a SHIP counselor. Some SHIP counselors are volunteers. Find your SHIP office [here](#).

Medicare Savings Programs offer financial benefits for qualifying Medicare beneficiaries. Based on the income of the beneficiary, the Part B premium and/or deductibles and/or other program-associated costs are covered. Learn about the program [here](#).

Medicare Part D Low Income Subsidy is a financial subsidy for qualifying Medicare beneficiaries for their Part D premiums. Guidelines for the program can be found [here](#).

Limited Income Newly Eligible Transition Program or LI NET operates as a temporary PDP for low-income Medicare beneficiaries who are not enrolled in a prescription drug plan and who are entitled to either prospective and / or retroactive coverage. LI NET will cover all Part D drugs without prior authorization or other utilization management requirements, such as step therapy or quantity limits (other than FDA-required quantity limits). Because LI NET will serve LIS-eligible individuals, there will be no premium or deductible. There also will be no pharmacy network restrictions. In 2006 the Centers for Medicare & Medicaid Services (CMS) created the "Point-of-Sale Facilitated Enrollment" (POS) process, administered by WellPoint. The purpose of the POS is to assist people who are dually eligible for Medicare and Medicaid (dual eligibles) in filling their prescriptions at the pharmacy if they have not yet been assigned to a Part D prescription drug plan (PDP). Contact your state unit on aging or your state SHIP for additional information. Read about the program [here](#).

Prescription drug assistance may be available from the pharmaceutical manufacturer of the specific drug, a group of pharmaceutical companies, through a state assistance program such as Medicaid or other program, through a community health clinic and/or may be offered at slightly reduced rates through hospital pharmacies. Medicare now offers Prescription Drug Programs through Part D. [NOTE: Generally, Medicare beneficiaries who are eligible for a Part D product will NOT be eligible for pharmaceutical companies' prescription assistance programs. Free clinics such as Health Rights may also eliminate prescriptions for Medicare beneficiaries who are eligible for a Part D product.] There are also commercial prescription services available and state programs such as senior discount cards such as Golden Mountaineer or Golden Buckeye cards or programs like Pennsylvania's PACE program. The Medicare Modernization Act has caused changes with the implementation of a prescription drug benefit through Medicare. This will impact "dual eligibles" (those who receive Medicare and Medicaid). You can search [NeedyMeds.com](#) for prescription assistance programs.

Discount Drug Cards such as Good Rx or Visory Health offer discounts for many prescriptions. These cards can most often be used for those with prescription drug coverage. Search for 'discount drug cards' to explore your options. [Help Advisor](#) offers information on discount drug cards.

Specific health concern organizations such as the American Health Assistance Foundation, the American Diabetes Association, the American Cancer Society and others may provide information, hot lines, referral services, equipment, educational materials or other services. Many of these offer fact sheets, brochures, and materials on their Web sites.

Specialized legal counsel may be a consideration when making estate planning decisions. The services of a specialist may be needed in the following areas: elderlaw, financial planning, trust, property, oil and gas leases and royalties, wills and / or estates. Most states have Legal Aid / Senior Legal Aid / pro bono programs that provide basic information and referrals for more in-depth consultation and planning. Search for legal aid, senior legal aid, or your state's American Bar Association for legal resources. [The National Academy of Elder Law Attorneys](#) offers information on specialists in that field.

Home deliveries are usually offered by your local grocery store and / or pharmacy. Also, almost anything can be ordered for home delivery from several sources from Amazon to Wal Mart and from the 'big box' stores. Many sites offer a 'subscription' for repeat orders of frequently used products. Groceries, personal care products, pet items, and much more can be ordered for home delivery. Meal programs are also available.

United Mine Workers offers benefits to its retirees that may include durable medical equipment, briefs, transportation allowance and other services. If you or your care receiver is a retired miner with UMWA benefits, call their customer assistance (number on the back of your card) to see if there are services that can help. Get more information at the [website](#).

Veteran's Administration offers numerous services for veterans, widow(er)s of Veterans and other dependents that include the Aid & Attendance Program which may help with financial assistance for in home services, assisted living and nursing home care. The [website](#) offers information on benefits for burial, grave side services, flags and other Veteran needs. VA also offers a program for caregivers. The Support Services for Veterans and Families is offered in all states working veterans and families who are homeless or facing homelessness. Other support services are offered through the SSVF program. Transportation may be provided through the local VA office. The regional Veteran's office or your local Veterans Outreach office can help with information.

Volunteer services may available from different sources. Community organizations, religious organizations, civic clubs and schools may have volunteer services available free of charge. Local United Way organizations often observe a Day of Caring offering various assistance around the community. Faith in Action Caregivers Inc may have an office in your area. Some faith communities or religious organizations sponsor programs that provide housing repairs, housing weatherization or other chore assistance from volunteers (such as the Sower Program in Ohio). Consider local Kiwanis, Lions, Key Clubs, Circle K, Rotary clubs, etc. when seeking assistance. Schools may have programs for community service such as shopping for seniors or doing small chores.

Other considerations for assistance may include the Donated Dental Program, the National Eye Care Program, Knights of Templar or other specific health assistance organizations.

What do I do now?

Assess your concerns and the needs of your family.

What does the individual need vs. what do they want?

What are the care goals?

Do they want to remain in the community?

What services are available in the community?

What are the eligibility requirements for the specific programs being explored?

What are the costs of the services?

Will your family member/loved one be able to maintain their current residence?

Can they live alone or with supports safely?

Can they manage the upkeep? Does it currently need repair or modification?

Do they want to remain where they are?

Where is the home geographically? Is it easily accessible especially in bad weather?

Is the neighborhood safe?

Review the financial status.

What can be done now to provide for future needs?

Is supplemental insurance needed?

Is a pre-need burial trust needed?

What financial and estate planning needs to be done?

What requirements may need to be considered regarding transfers of assets? Are there penalties or laws governing transfers of assets? (There are regulations with Medicaid.)

Do you need to seek counsel from an elderlaw attorney?

Review your support system.

Will a spouse and/or children be able to help when assistance is needed?

Will the services in the community meet the needs?

Are the services accessible and/or affordable?

Who can help? Church? Friends? Civic organizations? Social service agencies?

Medical care?

Remember the A's of services:

Availability

Accessibility

Affordability

Appropriateness

You may benefit from professional guidance in planning for long-term care, such as social service assistance, estate planners and/or elderlaw attorneys. Help is available through Area Agencies on Aging, case management agencies, senior centers, hospital social workers, volunteer programs, adult day centers and resource and referral agencies. Information can be obtained on insurance programs – supplemental programs, Medicare, Medicaid, services, eligibility requirements, income tax preparation and program requirements, to name but a few.

NOTES:

Where can I get more information?

The Alzheimer Resource & Referral Services whose mission is to provide information, education and support to seniors and their caregivers. Alzheimer's Resource Services has no geographic limitations and assessment & consultation services are offered at no charge.

The local Area Agency on Aging can help with direct information or referrals to any agency that can provide guidance for long-term care decisions. The Area Agencies on Aging house the Aging & Disability Resource Centers.

The local senior center is a good place to learn about programs and options that are available for care as well as provide a place for activities, socialization and other services.

Many areas have general information and referral helplines to help guide the individual looking for resources. 211 is a "help" number for services.

The Social Security Administration and the local Department of Health and Human Resources or Department of Human Services have information on many programs and can assist with determining how to apply for specific programs.

Check under Social Services in the telephone book or look in the Service Directory section often found in the front of the telephone book.

Talk to your friends. Have they used long-term care services? What did they learn about long-term care? Who do they recommend? Who do they recommend you avoid?

Talk to your minister, priest or rabbi. Often the clergy person is the source of information for other members of the congregation when help is needed.

Your physician and/or nurse practitioner may be able to guide you to an appropriate information source. Your physician may also provide guidance when dealing with an acute or a chronic illness. What is the prognosis? What might be needed along the continuum of care?

Hospital social workers and/or social workers with home health agencies have experience with community services.

Be a wise consumer and find out all you can about services in your area.

Who can I call?

NO GEOGRAPHIC LIMITATIONS

Altenheim Resource Services 1387 National Road, Wheeling WV 26003

304 243-0996

Akoegler1995@gmail.com

www.altenheimcommunity.com

Empowering older adults, caregivers (family & professional), and their advocates through information, education and support.

Call for information on services, support groups and general information on caregiving. A video, print and periodical library is available as well as many brochures and pamphlets. Programs are scheduled through the year.

Eldercare Locator

Find services in your area

800 677-1116

<https://www.eldercare.acl.gov>

211

Find services in your area

OHIO

Ohio Department of Aging

800 266-4346

Area Agency on Aging, Region 9, Cambridge OH

800 945-4250

(Includes Belmont, Jefferson, Harrison, Carroll counties + 5 others) Nationwide:

Buckeye Hills Area Agency on Aging

800 331-2644

(Includes Monroe, Noble and 6 other counties)

Belmont County Department of Job and Family Services

740 695-1075

Senior Services of Belmont County

740 695-4142

Long-Term Care Ombudsman

800 282-1206

(Region 9 & 10)

PENNSYLVANIA

Pennsylvania Department of Aging

717 783-1550

Southwestern PA Area Agency on Aging

724 489-8080

(Washington, Greene, Fayette counties)

In state:

888 300-2704

Allegheny County Area Agency on Aging

412 350-5460

In state:

800 344-4319

Westmoreland County Area Agency on Aging

724 830-4444

Pennsylvania Adult Protective Services

800 490-8505

WEST VIRGINIA

West Virginia Bureau of Senior Services 877 987-3646

AREA AGENCIES ON AGING/WV

Region I Northwestern Area Agency on Aging 304 242-1800
(WV counties including Hancock, Brooke, Ohio & Marshall)

Region II WVSU Metro Area Agency on Aging 304 720-6858
(Covers 11 WV counties including Kanawha, Boone, Jackson, Lincoln + others)

Region III Upper Potomac Area Agency on Aging 304 257-1221
(Covers 15 counties including Berkeley, Jefferson, Lewis, Upshur + others) **In state: 800 296-1221**

Region IV Appalachian Area Agency on Aging 304 425-1147
(Covers 13 counties including Greenbrier, Raleigh, Fayette + others) **In state 800 473-1207**

WV Department of Human Services 304 232-4411
Wheeling WV office
State office **800 642-8589**

WV Department of Human Services State Adult Protective Services 800 352-6513

Long-Term Care Ombudsman 800 834-0598

NORTHERN PANHANDLE SENIOR CENTERS

Family Service-Upper Ohio Valley (Ohio County Senior Center) 304 233-2350

Marshall County Senior Center 304 845-8200

Brooke County Senior Center 304 527-3410

Hancock County Senior Center 304 564-3801

WV AGING & DISABLED RESOURCE CENTERS Statewide Toll Free line: 1 866-981-2372
<https://www.wvadrc.com>

BRIDGING WV – NO WRONG DOOR Statewide Toll Free line: 1 866 981-2372
<https://br.wv.org>

ALL STATES:

Aging and Disabled Resource Centers contact your Area Agency on Aging office

IMPORTANT NUMBERS I WANT TO REMEMBER:

QUESTIONS I NEED TO ASK ABOUT MY LONG TERM CARE NEEDS / THOSE OF MY FAMILY: