ELDER CARE

A Guide to Elder Care Options
# Table of Contents

**Introduction** ................................................................................................................. 4  
  Common Changes .......................................................................................................... 4  
  Aging Gracefully ........................................................................................................... 4  
**Planning for the Future** .............................................................................................. 5  
**Managing the Physical Changes of Aging** .............................................................. 8  
  Vision and Hearing ........................................................................................................ 8  
  Falls ........................................................................................................................................ 8  
  Incontinence .................................................................................................................... 9  
  Constipation .................................................................................................................. 9  
  Medication Management ............................................................................................... 10  
**Managing the Mental Changes of Aging** ................................................................. 10  
  Memory Loss: Prevention ............................................................................................. 10  
  Memory Loss: Treatment ............................................................................................. 11  
  Maintaining Brain Health ............................................................................................ 11  
**Aging in Place** ............................................................................................................ 11  
**Warning Signs That an Elder Needs Help** ................................................................. 13  
**Options for Care** ....................................................................................................... 14  
  Cost of Care .................................................................................................................. 15  
**What You Need to Know** ......................................................................................... 16  
  Medicare ......................................................................................................................... 16  
  Medicaid ......................................................................................................................... 16  
  Veteran’s Benefits ....................................................................................................... 17  
  Long-Term Care Insurance ......................................................................................... 17  
  Questions to Ask When Touring a Skilled Nursing Facility ...................................... 18  
  How to Find Ratings for a Skilled Nursing Facility .................................................... 19  
  Hospice Eligibility Guidelines ..................................................................................... 19  
  Using the Services of a Geriatric Care Manager ......................................................... 19  
  What to Take to Medical Appointments ..................................................................... 19  
  Finding Low-Cost Medications .................................................................................. 20  
  Understanding the Health Care Information Privacy and Protection Act (HIPPA) ....... 21  
  How to Get a Handicapped Permit ............................................................................ 21  
**Caregiving Issues** ..................................................................................................... 22  
  Caregiver Stress .......................................................................................................... 23  
**Resources** .................................................................................................................. 25
Introduction

The population of adults age 65 or older in the United States increased 21% in the last decade and is expected to double by 2030.\(^1\) A basic understanding of the aging process and issues related to it can help in planning for the future and in assisting an older family member. This handbook will provide information and resources to guide that process.

Aging is an ongoing process that is divided into two categories: *normal aging* and *usual aging*. Normal aging involves inevitable differences that occur due to physical changes in the body. Usual aging refers to typical age-related diseases that occur in older adults, such as high blood pressure and heart disease.\(^2\)

### COMMON CHANGES

During the aging process every system in the body undergoes changes. Height decreases 5 centimeters per year, and after 70 years of age a shift in body mass occurs, with a 30% decrease by age 80. Looking at each of the body systems, there are minor changes that occur:

- **Skin and hair**—Skin becomes thin and prone to bruising and tearing; wrinkles develop; mild hair loss (50-100 strands per day) and graying of hair occur.
- **Eyes, ears and mouth**—Fewer tears are produced; eye floaters (flashing lights and spots) increase; ear wax increases; taste buds lose their ability to discern bitter and sour.
- **Muscles and bones**—Strength decreases in hands and legs; joints become stiffer; gait becomes slower; there is difficulty maintaining balance when standing.
- **GI tract**—Movement of waste products through the intestines slows down.
- **Heart and lungs**—Left ventricle enlarges; large vessels lose their integrity; lungs get stiffer.
- **Kidneys**—Function decreases; frequency of urination decreases overall but may increase at night.\(^2\)

### AGING GRACEFULLY

Since the normal aging process cannot be controlled, it is the usual aging process that must be prevented. A healthy lifestyle including diet, activity, and sleep play a part in keeping one active into the 7th decade and beyond. The Mayo Clinic recommends the following for healthy aging: Include routine daily physical activity, eat a healthy diet and maintain an appropriate weight, stay socially and mentally active, stop smoking, and manage stress.\(^3\)

---

Maintaining physical activity is an important part of aging gracefully. The current recommendation is walking and moderate exercise, such as bike riding, weight lifting, or stretching workouts, plus muscle strengthening, for 2 hours and 30 minutes per week; or muscle strengthening with high-intensity aerobic exercise, such as a spin class, using an elliptical or stair climber; or a step class, for 1 hour and 30 minutes per week.4

Eating nutritious foods helps to maintain an appropriate weight and lifestyle. The U.S. National Institute on Aging guidelines suggest eating more fruits, vegetables, whole grains, and lean sources of protein while limiting salt intake, added sugars, and solid fats.5

Sleep protects mental and physical health. A lack of sleep can contribute to heart and kidney disease, diabetes, high blood pressure, and stroke. Although the amount of sleep needed varies from person to person, adults should get between 7 and 8 hours of restful sleep per night. One can assure quality sleep time by keeping the same sleep schedule every day, keeping the bedroom quiet, and avoiding stimulating activity or a large meal several hours before bedtime.6

Adopting these habits will go a long way in helping to prevent age-related problems concerning physical health. However, this is just one piece of successful aging. One also needs to consider planning for the future.

Planning for the Future

Contingency planning is an important part of everyday life and especially as it relates to aging. One must be prepared for both the inevitable and the unexpected issues that occur with growing older. The first step is to have an emergency readiness plan in case of a natural disaster or crisis. Emergency management professionals suggest answering the following questions to determine preparedness for an emergency:

• What is the evacuation route?
• Where is the closest emergency shelter?
• Where are the shut-off valves for gas, water, and electric utilities?
• Who is the out-of-area emergency contact?
• Are the following supplies on hand: water, non-perishable food, flashlight and batteries, portable radio, first aid kit, spare hearing aid batteries, waterproof matches, can opener, supply of medications, and cash?
• Is there a cell phone available and charged?
• If there is a need for medical equipment that requires electrical power, is there a generator, and has the power company been notified?
• If anyone requires special medical attention, is there a shelter that provides medical supervision?

If an older family member lives alone, a plan should also be put in place for him or her. If that individual lives in a retirement community or nursing facility, it is important to be familiar with the management’s emergency plan.

One of the best ways to address multiple concerns is to develop a Planning for Aging kit. This can be done as a series of files, paper or electronic, that are stored in a safe, easily accessible location such as a fireproof home safe or a safe-deposit box. It is also recommended to provide a copy to a close family member or emergency contact. The kit should include a listing of phone numbers and contact information for doctors, dentists, lawyers, financial providers, banks, and insurance agents; the location of bank accounts with numbers and listing of credit or debit cards; a copy of the person’s will, advance directives, durable power of attorney, prepaid funeral plans, and insurance policies; copies of Social Security, insurance, Medicare, and Medicaid cards; lists of routine household bills and taxes; a complete list of assets and debts; and the location of hidden valuables. It may also be beneficial to include a health profile that includes general health problems and a list of prescription medications, family history, and allergies. Having prepared a kit in advance makes management and decision making during an emergency much easier for everyone.

The next step is to make decisions about health care, including naming a surrogate decision-maker; stating which treatment results are desirable, discussing what to do in emergencies, and noting preferences regarding treatments and whether or not a time-limited trial would be acceptable—for instance, staying on a ventilator for 5 days to recover some strength or having a feeding tube for several weeks to treat dehydration or sudden weight loss.

There are essential documents that allow an individual to outline choices about health care, end-of-life care, and the appointment of a surrogate decision-maker. An advance directive tells doctors and health care providers what kind of treatment a person wants and does not want. It is comprised of a living will and a durable power of attorney. A durable power of attorney designates a person to speak on an individual’s behalf when he or she cannot do so. The living will is a document that spells out what a person would want done in regard to resuscitation, such as CPR; the use of a respirator or breathing machine; a feeding


tube; dialysis; artificial hydration; and any other specific requests concerning treatment or surgery. An attorney is not necessary for completing these forms, and they are readily available online and in large office supply stores. Each state has different regulations about registering the documents, but at a minimum, a copy should be given to the designated power of attorney, one’s health care provider, and a family member.⁸

It’s not uncommon for older people to shy away from discussions about their future, especially in regard to their health, finances, and other personal issues, so don’t be surprised if a loved one is reluctant to start a conversation. Here are a few tips to make the discussion easier:

- Limit the time for the discussion to 20 to 30 minutes initially.
- Express concerns and why it is time to have the discussion.
- Let the individual know that this is planning ahead for health problems, and how it will help to decrease stress if a problem should occur.
- Introduce the topics that are of greatest importance first.
- Allow the individual to absorb information before moving on.
- Ask the individual’s thoughts and opinions throughout the discussion.
- Reassure the individual that no decisions will be made without his or her input and approval.⁸

Financial planning is an essential part of growing older. Most Americans will enroll in some type of retirement plan offered by an employer but seldom think about what is needed if a major illness occurs or an individual is no longer able to remain at home. Setting up an annuity designated for future health care or living arrangements is an option. If an older person has not planned and is in need of additional funds to provide appropriate care, a home equity loan or reverse mortgage may provide the needed cash.⁹

A popular option is a living trust, a legal arrangement that appoints a specific individual to hold legal title to property for another. Living trusts can be a useful tool for estate planning, because they help to avoid probate, reduce estate taxes, or establish long-term property management. Three parties are generally involved in the creation of the trust: the person who establishes the trust, called the grantor; the person named by the trust as the controller of the property, called the trustee; and the person who receives the property when the grantor passes away, called the beneficiary. An individual may benefit from a living trust if the estate is in excess of $100,000 or may be subject to estate taxes. The services of an estate planner or attorney are helpful in drafting the trust and assuring it is line with state laws and regulations.⁹

Lastly, prepaid funeral plans are a good way to spread the cost of final expenses over a period of time and relieve the burden of loved ones having to make decisions during a time of grief and mourning. Most funeral homes allow customers to choose a package that includes type of burial, choice of coffin or urn, headstone or memorial plaque, and any incidental costs related to the services of the funeral home staff. Once the plan is completed, the only additional expense incurred is related to the cost of the vault for a burial, which increases over time. It pays to shop around, as all plans may not offer an overall cost saving. If an individual is spending down for Medicaid, the cost of a prepaid funeral plan is an accepted expense.10

Managing the Physical Changes of Aging

VISION AND HEARING
Loss of vision and hearing can lead to safety issues for older persons. Falls, accidents, and significant injuries are often a result of vision or hearing problems. Regular checkups and the use of prescription eyeglasses and hearing aids can go a long way in preventing serious injuries. For vision problems, large-print items, magnifying glasses, and adequate lighting are the simplest ways to maintain safety. Magnifiers come in all sizes, from handheld to full size for computer monitors to freestanding machines that magnify books, magazines, and newspapers. Other assistive aids are large-face and talking watches and clocks, large-print keyboard stickers for computer keyboards, large-button phones, color-coded medication boxes, and talking scales, thermometers, blood pressure monitors, and glucose monitoring machines.11

For the hearing impaired, many devices are available to amplify hearing and enhance existing household items. In most states, the local office of services for the deaf can provide specially equipped phones, signing services via the Internet, and blinkers on phones and other devices to take the place of buzzers and alarms. For emergency notifications, a vibrating device that is placed in the chair or bed where an individual can feel it activated warns individuals any time there is a message from the Emergency Alert System. Pressure-activated alarm clocks and television and answer machine amplifiers are also available commercially.12

FALLS
Falls can be related to the physical changes that occur with aging or to safety issues in the home. Falls lead to broken bones and serious injuries and account for a large number of emergency room visits each year. The best way to prevent falls is to maximize the safety of the home and accommodate for any problems walking or maintaining one’s balance.

There are simple measures to improve the safety of areas around the house where falls are more likely to occur: The flaps or curled

---


edges of carpet should be tacked down, loose floorboards should be repaired, and loose throw rugs should be removed. Stairs should have handrails on both sides and either have nonskid strips on the edge of each step or be painted with nonskid paint. The height of chairs and the bed should be measured to make sure they are easy to get in and out of without assistance. Emergency flashlights should be placed near the bed and doorways. Electrical and phone cords should be tucked away. Doorways need to be cleared of clutter. Lastly, an older person should always wear shoes that fit properly and are nonskid.

INCONTINENCE

The inability to hold one’s urine is not a normal part of aging. It is caused by a physical condition of the bladder and the muscles around it or another medical condition such as diabetes, and is common among individuals with dementia. It can also result as the side effect of medications commonly prescribed for conditions in older persons. The most common medications are diuretics (water pills), narcotic analgesics (pain pills), ACE inhibitors (blood pressure pills), and antiseizure medications. The cause and type of incontinence require an evaluation by a urologist, who will recommend the appropriate treatment. The three types of incontinence are stress, urge, and overflow. Stress incontinence is involuntary loss of urine when coughing, laughing, or exercising. Urge incontinence is the inability to delay urination after feeling the sensation that the bladder is full. Overflow incontinence is leakage of urine resulting from bladder spasms from an overdistended bladder. Treatment can be a prescription medication, minor surgery, or Kegel exercises (tightening and releasing of the muscles around the bladder).

Other interventions that may be helpful are establishing a routine schedule for urinating, limiting fluids after dinnertime, and wearing adult briefs. Incontinence can lead to rashes and skin breakdown from urine burning the sensitive skin, so briefs should be changed as soon as they become moist, and the use of a skin barrier cream can help to prevent this problem. Overactive bladder syndrome is not the same as urinary incontinence. With this condition there is no leakage of urine but instead a feeling of extreme urgency with frequent urination, and treatment is the use of prescription medication to decrease bladder spasms and urgency.

CONSTIPATION

Constipation is caused by irregular bowel habits, a diet low in fiber, and being inactive for periods of time. The easiest way to prevent constipation is to reverse the scenarios by exercising regularly and consuming more fiber and water. Fiber can be taken as a supplement or by eating whole grains, nuts, and 2 cups of fruits and vegetables per day. The total amount of fiber per day should be 21 to 25 grams for women and 30 to 38 grams for men. Six to eight 8-ounce glasses of water per day is needed for adequate hydration. If this fails, a stool softener can be used to lubricate the intestines. Laxatives can be used occasionally for severe constipation, but relying on laxatives for normal bowel function causes the intestines to become lazy and depend on the medication for bowel movements.


15 Kane et al. (pp. 257–259).
MEDICATION MANAGEMENT
Staying informed about the medication one is taking can prevent complications and help one to recognize side effects. This is especially true for older persons who may be on multiple medications for chronic medical conditions. Some of the points one needs to know are what the medication is intended to do and whether it is prescribed to treat the cause of the illness or the symptoms, how long it takes to be effective, how one knows it is working, and possible side effects. In addition, whether certain foods should be avoided, how the medication interacts with others one is taking, whether it is habit forming, and how long one needs to take it are good questions to ask.16

For individuals taking multiple medications and especially if remembering to take medications is a problem, there are many devices that can assist. A simple multiday pill container can be filled at the beginning of each week. If an individual needs a reminder, there are pillboxes that come with a built-in alarm that sounds when the medication is due. Individuals who are not able to prefill pillboxes and need a reminder can use a multidrawer tabletop box that is prefilled by family or a home health nurse once a month. An alarm sounds when medication is due, and the drawer containing the medication opens automatically. If the individual does not take the medication in a specified period of time, the drawer closes, and the family member or home care agency is notified. There are also agencies in some states that provide reminder services by phone for medications.16

Managing the Mental Changes of Aging

MEMORY LOSS: PREVENTION
Occasional forgetfulness of such things as dates, names, and information is a normal part of aging. These are sometimes referred to as senior moments, and these brain glitches occur more frequently as age increases. There are two types of memory: short-term and long-term. Short-term memory is new information, recent occurrences, and what is happening in the here and now. Long-term memory is the distant and recent past, and includes occurrences and education. As one ages, long-term memory stays intact, but short-term memory may take more time and effort to store information.17

The adage “You can’t teach an old dog new tricks” is absolutely untrue. The aging brain can store and remember new information. Its ability is enhanced by the use of all the body senses to take in the information. In other words, hearing a new piece of information while seeing it, reading it, or writing it can dramatically increase the chances of retention. Therefore, working puzzles, playing brain games, and reading or taking classes all help to keep the brain sharp.17


Research has shown that diet and medical conditions play a big role in maintaining brain function. A diet that is high in trans fat and cholesterol causes narrowing of the blood vessels and can decrease blood flow to the brain. Untreated or poorly controlled diabetes, high blood pressure, and heart disease can cause strokes and vascular dementia. Maintaining a healthy weight, following a low-fat diet, and getting yearly checkups all play a part in maintaining memory.\textsuperscript{18}

**MEMORY LOSS: TREATMENT**

It is not uncommon to worry that the normal lapses in memory may be a sign of dementia. The key to recognizing the warning signs of dementia is to be aware of the pattern, consistency, and type of forgetfulness. To put it simply, if the senior moments are increasing in frequency and affecting one’s ability to carry out day-to-day functions, there is cause for concern. The doctor can make a presumptive diagnosis of dementia based on a physical exam, lab tests, an MRI of the brain, and a mini-mental state exam (a set of questions and simple tests for cognitive function). The following are the most common types of dementia:

- **Alzheimer’s disease**—This is the most widely recognized form of dementia. It is characterized by the formation of plaques and tangles of nerve fibers in the brain. The decline that occurs as the condition progresses follows a distinct pattern of stages. Each stage marks a specific decline in memory and brain function.

- **Vascular or multi-infarct**—This form is caused by mini-strokes, which disrupt the blood flow to specific parts of the brain, rendering them useless. This condition may present more subtly and does not follow prescribed stages.

- **Lewy body**—This disease is characterized by signs of dementia and Parkinson’s disease. In addition to cognitive and memory problems, Lewy body patients often have trouble maintaining balance and experience a shuffling gait, tremors, and stiffness in the arms and legs. This condition is also associated with mood and personality changes.

Unfortunately, there is no cure for dementia. Treatment is focused on slowing the progression of the disease and treating symptoms.\textsuperscript{17}

**MAINTAINING BRAIN HEALTH**

There are some simple strategies for maintaining brain health. The Alzheimer’s Association recommends doing paper and pencil tasks, such as crossword puzzles, word searches, and word scrambles. Also, the use of software programs such as Brain University and Luminosity have been found to be helpful. Learning a new skill through education or social activities can stimulate brain health. It is also important to know one’s baseline cognitive function. A complete physical exam including a cognitive screening with the mini-mental state exam or Montreal Cognitive Assessment will set the baseline and address any issues that might be revealed. The exam should be repeated any time there is a change in memory, thinking, reasoning, or performing any daily or work activities.\textsuperscript{17}

**Aging in Place**

When asked, most older persons prefer to remain in their own homes. If this is the appropriate choice for an older loved one,
a general inspection of the house for safety hazards and needed repairs should be done. Emphasis should be placed on working smoke detectors, the accessibility of a small fire extinguisher, the temperature setting of the water heater (120 degrees), adequate lighting in all rooms, especially hallways and staircases, placement of night lights where necessary, an easily accessible shower, and removal of loose rugs.\textsuperscript{19}

The two areas of greatest concern are the kitchen and bathroom. Modifications may need to be made for an older person. In the kitchen, food, dishes, and pots and pans need to be at accessible levels to prevent bending over or the need for extended reaching. Power sources should be checked to avoid overloading circuits and the use of extension cords. If a gas stove is being used, the location of the shutoff valve should be readily accessible. In the bathroom, modifications may need to be made to the toilet and shower: Installing grab bars next to the toilet and in the shower can prevent falls. The toilet height can be raised by purchasing a bedside commode chair, which can be placed over the existing toilet to raise the level of the seat and provide extra support when sitting and standing. It is also useful for the person who has difficulty getting to and from the bathroom in a timely manner. Another way to prevent falls in the shower is to use a portable shower bench or chair and install a handheld showerhead. Nonskid strips can be placed on the shower floor and nonskid mats on the bathroom floor.\textsuperscript{19}

Other renovations to consider are installing handrails on all staircases and steps, inside and outside. For those who have difficulty walking down stairs or use a wheelchair; installing a ramp at the main door can prevent injury. Many local senior resource centers have a handyman who will do this at low cost or for free if the individual meets the income qualifications.\textsuperscript{19}

An alarm system can provide an extra layer of protection, especially for those who live alone. If the person is prone to falls, a personal alarm system may be invaluable. Personal alarms have improved in the last several years, with one of the most popular models being a wristwatch that sends a signal and a location via GPS when the wearer falls. Unlike previous models that required the person to push a button, the newer models are hands free.\textsuperscript{19}

Thanks to advances in technology, there are now apps and devices to assist with aging in place and safety concerns. The Family Caregiver Alliance has recommended the following:

- An app that allows a loved one to monitor the live video feeds if video cameras have been placed in strategic places throughout the house
- A GPS locator app that acts as a monitoring system for those with memory loss

• Tiny sensors that can be attached to key chains, cabinets, refrigerator doors, and pillboxes to alert a family member when an individual has left the house or taken food or medications—The system also provides a watch with a one-touch button for emergencies.

• A ready-made computer that requires no experience to use, as it has touch-screen buttons that link to video chat and e-mail, as well as a large display screen

• For the individual who cannot speak, an app that has preloaded statements and questions that the person can choose, and the phone or device speaks the selected statement

• An app that enhances available light to make reading easier, such as for pill bottles and small-print items.

Warning Signs That an Elder Needs Help

Despite one’s best efforts, there may be times when an older person may need additional help or may no longer be able to remain at home. There are some typical warning signs to look for: The first is unexpected weight loss. Older persons are prone to losing weight for many reasons, including chronic illness, difficulty eating, mouth pain due to broken and missing teeth or loosely fitting dentures, inability to afford food, taking multiple medications, and the need for assistance in eating. Any weight loss should be evaluated to rule out an underlying medical cause. If the reason is inability to prepare food, Meals on Wheels or online companies that provide bulk frozen prepared dinners may be an option. If the reason is that the individual can longer go grocery shopping, many local grocery stores now offer delivery services.

Second, falls or unexplained injuries may be a sign of decline in function or a medical problem. As an older person loses mobility and becomes less active, the muscles begin to weaken, increasing the risk for falls. The individual may not be able to support his or her weight when standing, walking, or getting up from bed or a chair.

On an even more serious note, if an older person starts to have significant memory problems, he or she may get lost in familiar surroundings, leave home without a destination, or become confused while driving. The ability to drive a car is often seen as proof that a person is still independent. Many older persons go out of the way to hide their declining ability to drive. A frank, open discussion is necessary to address safety concerns. Getting the doctor involved to discuss the physical reasons why driving is no longer safe may be helpful. Some rehabilitation clinics and the U.S. Department of Veterans Affairs offer driving safety evaluations.

Health problems do not always mean that driving needs to stop, but the decision may require awareness of things such as the effects of medications, eyesight and hearing problems, and problems with reflexes and range of motion. If the elder continues to drive against advice, taking away the keys or disabling the

---


vehicle may be another option, but this is only temporary. The best way to assure that the individual cannot drive is to remove the car.\textsuperscript{22}

Physical symptoms can also be a clue to more serious health problems that could lead to an older adult needing assistance. For example, fainting or dizziness could be a sign of one’s blood pressure lowering rapidly when standing up. Unexplained bruises, open areas on the skin, and redness of the skin over the hips, elbows, and shoulder blades need to be assessed by a health care provider for the underlying cause. Missing teeth or ill-fitting dentures make it difficult to eat and lead to weight loss. Swelling in the lower legs or feet is usually a sign of heart problems. Normal treatment for these symptoms can prevent falls, injuries, and illness.\textsuperscript{23}

\textsuperscript{23} Kane et al. (pp. 51–55).

Options for Care

If an older person can no longer safely live alone, then alternative arrangements may need to be made. Open and honest discussion is the first step in deciding when and where to move. Take into consideration whether the individual will need constant supervision or assistance throughout the day. A thorough assessment of which activities the individual needs assistance in performing is also necessary. An evaluation of the family members’ comfort and capability in caring for the individual is key to decision making. Once these determinations are made, the appropriate choice can be selected.\textsuperscript{24}

One of the first options is to move the older adult in with the family. Physical living arrangements must be adequate for this option to work. Evaluate the amount of space, the physical layout, any major modifications that would need to be made, and the need for privacy in deciding if this is the best option. Also take into consideration the amount of time that will be needed to care for the individual and the impact it will have on family members, work time, finances, and private time.\textsuperscript{24}

The second option is to hire in-home help. Caregivers can be found through ads in the newspaper, the Area Agency on Aging, home care agencies, and Web sites for services that screen and recommend caregivers. Before choosing a caregiver, one should interview several and in addition to references should ask the following:

• What are the person’s credentials?

• How much experience does the person have with elders?
• Is the person licensed and bonded?
• What is the backup plan for illness and vacation?
• What are the person’s fees and desired method of payment?25

If the family chooses to work through a home care agency, it is important to know if the agency does background checks on its employees, the minimum number of hours required per week, whether there will be consistency in staff, who the staff supervisor is, and how to contact that individual. The type of service will depend on the individual’s needs. A sitter provides companionship only; a housekeeper does light housecleaning and chores, prepares meals, and may run errands; and a nursing assistant provides personal care such as bathing, grooming, and assistance with dressing.25

The remaining option is to move the individual into a specialized community or facility. The type once again depends on the person’s needs:
• Independent living facilities offer apartments that provide amenities such as in-home dining, on-site medical care, housekeeping, planned activities, and transportation.
• Assisted living facilities offer individual rooms or apartments in a licensed facility that provide the same amenities as independent living in addition to assistance with bathing, dressing, and medication administration. Some facilities offer dementia care for those who need a supervised environment.

• Skilled nursing facilities are licensed to provide medical management and skilled nursing care for those who cannot perform activities of daily living or need short-term treatment to return home.
• Continuing care retirement communities are multilevel complexes that offer all levels of care, including independent living, assisted living, and a skilled facility. Typically, a person purchases an apartment or villa and has access to all levels of care.24

For those with dementia who are living with family, a great option to provide respite for caregivers is an adult day care program. These programs are run by local agencies and provide meals and structured activities during regular working hours. Fees are often based on a sliding scale. The individual must be able to move about and toilet with minimal supervision, and a tuberculin skin test and a recent physician’s note are also required.26

COST OF CARE
The cost of caring for an individual outside of the home varies by level of care and location. The majority of these options are not covered by Medicare, and additional costs may be added to room and board. Typical extra expenses can include prescription medications, physician visits, laundry services, medication management, and personal care. If one looks at the base rate for room and board, a 2014 survey by Genworth showed the following averages nationwide:
• Homemaker services: $19 per hour
• Home health aide: $20 per hour

• Adult day care: $65 per day
• Assisted living facility: $3,500 per month
• Long-term care facility (skilled nursing): $212 per day for a semi-private room and $220 per day for a private room
• Memory care: $3,000 to $7,000 per month27

What You Need to Know

MEDICARE
The federal government established the Medicare program for persons over the age of 65, those on Social Security Disability for 2 years, those on kidney dialysis, and retired railroad workers. Medicare has specific components (A, B, and D) that cover different types of medical services. Medicare A covers inpatient hospital care, nursing home care following a stay of at least 3 days (100% of the cost of the first 20 days and 80% thereafter; with a maximum of 100 days), medical home health services, hospice services, and 80% of the cost of medical equipment. It does not pay for private-duty nurses, a private room in a hospital or skilled nursing facility unless it is medically necessary, and cable and phone charges in the hospital or skilled nursing facility. Medicare B covers doctor’s visits, services of psychologists, chiropractors, podiatrists and optometrists, outpatient therapy services, dental work resulting from an accident or disease, medical supplies, ambulance services, vaccines, preventive health care, 50% of outpatient psychiatric services, and one pair of eyeglasses if needed after cataract surgery. Medicare D pays

for prescription medications. There are multiple Medicare D plans available, and they differ in cost per prescription and medications that are covered.28

MEDICAID
This federal program varies from state to state but is based on a person’s assets. There are two types of Medicaid: one for persons living at home and one for those residing in skilled nursing facilities. Long-term care Medicaid for those living in skilled nursing facilities allows the spouse to keep his or her home, one car, and half the assets equal to approximately $76,000 or a monthly income of approximately $2,000 (this can vary by state). The application process can take up to 90 days, and if an individual is going to spend down (transfer assets to meet eligibility requirements), it must be done 5 years before applying. An application requires proof of all assets such as property, bank accounts, annuities, and IRAs, and all monthly bills and expenses.28

Applying for Medicaid can be a time-consuming process. Required information includes proof of age, citizenship, identity, and marital status. Acceptable documents are:

• Birth certificate
• Marriage certificate
• U.S. passport
• Driver’s license with photo
• Separation or divorce papers
• Naturalization papers
• School ID
• Baptismal certificate
• Alien registration card

• U.S. military ID
• Adoption decree certificate

In addition, one needs to provide proof of income and financial resources. These include but are not limited to:
• Recent pay stubs
• Checking account statements
• Savings account statements
• Social Security statement or letter of eligibility
• Stocks and bonds
• Certificates of deposit
• Railroad retirement checks
• Amount of cash on hand
• List of valuables
• IRA, 401(k), 403(b), Keogh plans, or other financial pension checks
• Unemployment check stubs
• Money market accounts
• Annuities
• Property deeds
• Mortgages

Spending down may include the cost of care in a facility or at home, purchase of a prepaid funeral plan, purchase of a new vehicle, or making necessary home repairs and modifications.²⁸

VETERAN’S BENEFITS
The U.S. Department of Veterans Affairs (VA) provides some assistance for financing and providing care. Every state has multiple VA hospitals and outpatient clinics that provide acute and emergency care in addition to primary and specialty care. Community services include adult day care, home health care, respite care, hospice care, and community residential care. Skilled nursing facilities are available at VA centers, state homes, and contract facilities in the community. State veterans’ homes are a combination of assisted living and skilled nursing care that are designed for low-income individuals. The eligibility for admission varies, but all require a formal application. The application and review process can take a few weeks to months to complete, and there can be a waiting list.²⁹

Eligibility for VA services follows a protocol with priority to those veterans who are at least 70% service-connected, then those who are 60% service-connected with a permanent disability, followed by those with a combined disability of at least 70%, and then non-service connected veterans who meet income or asset criteria for services.²⁹

LONG-TERM CARE INSURANCE
More than 100 insurance companies offer some type of long-term care insurance, which usually falls into two categories: indemnity

policies, or what is known as expense incurred policies, and integrated policies with combined benefits. Indemnity policies pay a fixed amount that is determined by the policy owner and pays for services per day, week, or month to cover the expenses incurred. An integrated policy provides a total dollar amount for long-term care services.30

Long-term care insurance can be expensive, as premiums are typically between $200 and $400 per month, and inflation adjustments can add between 40% and 100% to the premium. Choosing the right policy requires careful shopping, and one may need the assistance of a long-term care insurance agent or a financial planner. It is also important to remember that no policy covers all expenses fully.30

QUESTIONS TO ASK WHEN TOURING A SKILLED NURSING FACILITY

When visiting a skilled nursing facility, have a prepared list of questions. Ask about the facility’s philosophy of care, the number and type of staff, meals, activities, special services, rates and fees, and issues that are important in the care of the elder. Specific questions could be

• Is there a resident council?
• How are birthdays and holidays celebrated?
• What arrangements are made for religious services?
• Is there a family council?
• How long has the facility been operational?

• How long have the administrator and director of nursing worked in the facility?
• What hospital does the facility use in case of emergencies?
• What physicians are available for medical care?
• What is the billing procedure?
• How are families contacted about care plan meetings?
• Who should be contacted if there are problems?
• What is the phone number for unresolved complaints?
• What is included in the basic costs, and what is not?
• Can a copy of the admission agreement be available for review?
• How is transportation provided, and is there a fee?
• How is personal laundry handled?
• What are the provisions for dental, podiatric, and eye care?
• Which pharmacy is used, and how does it bill?
• Is there a system to protect residents who wander?

Ask for a tour to get a feeling for the place and how the residents are treated. When asking for a tour, be wary if the staff says to make an appointment or come back at another time. A facility that requires an appointment usually has something to hide. Tours should be available anytime, and the best time to take a tour is mid-morning.31

**HOW TO FIND RATINGS FOR A SKILLED NURSING FACILITY**
The federal government via the Centers for Medicare and Medicaid Services has established rules and regulations for skilled nursing facilities. Each facility is inspected yearly and whenever there is a complaint. The facility receives a report of the inspection and any deficiencies that were noted. This report must be posted in a prominent place in the facility. It is also available through the Medicare Web site in the Nursing Home Compare section. To find a skilled nursing facility, go to that section and select a state, then choose a city or a specific facility, and the last three to four inspections will display. The report will have overall ratings for each category and list the type and severity of deficiencies. These records are also kept on file at most local libraries.31

**HOSPICE ELIGIBILITY GUIDELINES**
Hospice services provide care to individuals and their families at the end of life. These services include nursing care, social services, chaplain services, music therapy, and post-death support groups. There are eligibility guidelines that one must meet to qualify for services: being dependent in two or more activities of daily living (bathing, dressing, eating), scoring less than 70% on the Palliative Performance Scale (ability to walk, activity level, evidence of disease, ability to care for oneself, amount of oral intake, and consciousness level), and meeting specific guidelines for one’s diagnosis. Diseases that are covered by Medicare and insurance are cancer, amyotrophic lateral sclerosis (Lou Gehrig’s disease), Alzheimer’s disease, heart disease, HIV, liver disease, lung disease, acute renal failure and chronic kidney disease without dialysis, stroke, and coma.32

**USING THE SERVICES OF A GERIATRIC CARE MANAGER**
Geriatric care managers (GCMs) make sure the needs and wants of an elder requiring assistance are met, especially for those whose family are a long distance away or need extra help in managing care of a family member. GCMs are certified by the National Association of Professional Geriatric Care Managers in 47 states. A standard fee for services is charged and may be partially covered by insurance. A sampling of services provided by care managers includes phoning regularly to provide reports and address concerns, arranging for in-home services, scheduling medical appointments and transportation, arranging for home repairs or modifications, assessing the need for and ordering specialized medical equipment, arranging for bill paying services, and linking to community resources.33

**WHAT TO TAKE TO MEDICAL APPOINTMENTS**
Primary care providers have become busier and have less time to spend with patients due to recent changes in health care. This has

---


made it even more important to have a list of information commonly requested to bring when seeing a new health care provider. This list includes all past illnesses, injuries, hospitalizations, surgeries, and significant test results; current symptoms and health issues; known allergies; family history; degree of alcohol and tobacco use, if any; exposure to heavy metals or toxins (for example if one worked in farming, in factories, or with asbestos); vaccination records; and names and phone numbers of previous health care providers. Once one is established with the provider, then at least once a year he or she should bring all medications, prescription and over-the-counter, to the office for review. It is also important that if an individual is receiving care from more than one provider, this be done with each one to avoid duplication of prescriptions or potential harmful side effects.

FINDING LOW-COST MEDICATIONS

The cost of prescription drugs can add up, depending on one’s insurance coverage and the number of prescriptions needed. It is important to discuss with one’s health care provider any financial difficulty that might impede one’s ability to obtain a prescription medication or continue its use. The Family Doctor Organization makes the following suggestions about paying less for medications. Sometimes older medications work just as well as newer ones and are cheaper or covered at a better rate by insurance. Medical information Web sites can suggest alternatives that one can then discuss with the health care provider. There are coupons available for some prescription medications, and there are apps and Web sites that compile a list of coupons available from manufacturers and pharmacies. The manufacturer’s Web site may also provide discount cards. Discount cards allow one to pay less for a medication not covered by insurance. Cards can also be found through the AARP and the American Automobile Association (AAA). It is not uncommon to find medications that are lower in cost than what insurance pays. For example, big-box stores offer some prescription medications for $4.00 for a 30-day supply.

A word of caution about Web sites that offer discounted medications, which are usually shipped from other countries, is necessary. The National Association of Boards of Pharmacy found that only 3% of these pharmacies are legitimate, and it is illegal to purchase drugs from another country for personal use. To make sure the pharmacy is legitimate, look for the Verified Internet Pharmacy Practice Sites seal, or go to the Web site (https://vipps.nabp.net/) to see if the pharmacy is listed.

Other options may include considering a higher deductible insurance plan, looking at whether individual insurance policies compared to spouse and family plans might lower costs, using flexible spending accounts to put aside money for medications, and exploring whether one’s employer offers wellness incentives to participate in health programs.

---


UNDERSTANDING THE HEALTH CARE INFORMATION PRIVACY AND PROTECTION ACT (HIPPA)

Most individuals believe that medical and other health information is private and should be protected, and want to know who has this information. The Privacy Rule, a federal law, gives rights over one’s health information and sets rules and limits on who can look at and receive that health information. The Privacy Rule applies to all forms of individuals’ protected health information, whether electronic, written, or oral. The Security Rule is a federal law that requires security for health information in electronic form. Covered entities include:

- Health care plans—health insurance companies, health maintenance organizations, company health plans, and certain government programs that pay for health care, such as Medicare and Medicaid
- Health care providers—those that conduct certain business electronically, such as electronically billing your health insurance—including most doctors, clinics, hospitals, psychologists, chiropractors, nursing homes, pharmacies, and dentists
- Health care billing services that are not associated with a specific health care provider but conduct business electronically with multiple providers and health care agencies

The following is information that must be protected:

- Information one’s doctors, nurses, and other health care providers put in the medical record
- Conversations the doctor has about an individual’s care or treatment with nurses and others
- Information in an individual’s health insurer’s computer system
- Billing information from the provider
- Most other health information about an individual held by those who must follow these laws

HOW TO GET A HANDICAPPED PERMIT

There may come a time when an individual has difficulty walking long distances or has another disability that impairs his or her function. Parking closer to buildings can accommodate for the effects of disabilities, and this can be achieved by obtaining a handicapped parking permit. The first step to getting a permit is to make sure one meets the eligibility criteria, which are lack of full use of an arm or both arms; inability to walk a certain number of feet without stopping to rest; inability to walk

without the assistance of a cane, crutch, brace, prosthetic device, wheelchair, or another person; having a cardiac condition that is listed as Class III or Class IV in severity according to the American Heart Association; inability to walk without the aid of portable oxygen; or meeting certain requirements for limited vision. Next pick up an application at the local Department of Motor Vehicles office or online. The form must then be completed by a medical professional such as a physician, nurse practitioner, physician assistant, podiatrist, optometrist, or chiropractor. Once the form is complete, it should be delivered in person or via mail for processing. Some states charge a fee for permanent placards, but most are free. Upon receiving the handicapped placard, it should be displayed hanging from the rearview mirror.

Caregiving Issues

Caregiving is a full-time job and may involve caring for a spouse, elder loved one, or adult child with a disability. There are steps one can take to prepare for caregiving. Start by learning as much as possible about the individual’s illness, current treatments, and the likely course. If one chooses to use the Internet for obtaining this information, it is important to get quality and reliable information. As one reviews medical Web sites, the following questions should be kept in mind:

• Who is responsible for the content?
• What are the author’s credentials?
• Is the purpose and goal of the sponsoring organization clearly stated?
• Is there a way to contact the sponsor for more information?
• Is the Web site supported by public funds or donations?
• Is advertising separate from content?

One should accompany the individual to all medical appointments. A helpful resource from the National Institute on Aging is *Talking With Your Doctor: A Guide for Older Adults*, a free booklet on how to communicate with a health care provider. It is also important to know the details of insurance plans to avoid costly mistakes. If an individual has Medicare, Medicaid, or Medigap, the State Health Insurance Assistance Program (SHIP) provides counseling and assistance. To find a state program, visit [http://www.shipusa.org/](http://www.shipusa.org/).

Effective caregiving requires keeping up with a great deal of information. In addition to health care records and insurance information, one also needs to have financial records, legal records, monthly bills, information from outside health care services, and household records in a safe and easily accessible location. In a time of crisis, or when applying for services, having all of the records in one place will save time and frustration in completing applications.

The final step is determining what needs to be done for the individual, who will assume

---


the main caregiver role, and how others can help. The National Institute on Aging suggests having a frank and open discussion with family members, the individual needing a caregiver (if he or she is able to participate), and others who may be involved in the care. Although planning for the future is important, the initial planning should focus on what commitments are needed in the here and now. If a caregiver has made a promise to an individual, the promise will need to be explored and may have to be modified or forgotten. As hard as that conversation may be, it may be better than risking the guilt of a promise not kept.39

Today many family members live long distances from each other, with elder parents geographically separated from their adult children. For an adult trying to juggle the role of a caregiver, living a significant distance from parents can increase the strain he or she already feels. An individual may need to rely on others, such as professionals or significant others in the elder’s hometown. When one finds that an elder needs caregiving, find friends, church members, and neighbors who might run errands or look in on the elder. Another option is to enroll the elder in a friendly visitor or telephone assurance program offered by local senior services organizations.40

The long-distance caregiver can call often and at a different time of the day to assure all is well. An employer may offer family leave time for caregiving duties, and this can be utilized if one needs to travel to the elder’s location for more than a week. Caregiving is often a long-term task, so being prepared can make the process more manageable.40

The AARP has recommended that caregivers look into mobile phone applications (apps) that offer these features:

• An app that provides references about the disease, caregiving advice, ideas for medication management, and a checklist for doctor’s office visits.

• An app that contains logs for essential information, a calendar for events and appointments, ideas for medication management, and a place to store health information, insurance information, and emergency contacts.

Other apps are available that coordinate help from friends and family, match an individual with a caregiver or agency, and offer video appointments with a physician.41

**CAREGIVER STRESS**

Caring for a loved one produces a wide range of emotions: anger, resentment, guilt, impatience, loneliness, fear, and shame, to name a few. Caregivers donate a great deal of time and energy to meeting the needs of someone else. Many times caregivers neglect to care for themselves and only recognize this when the difficult emotions surface. Therefore, it is important that caregivers take a break each day to read a magazine, listen to music, or meditate.40

By developing coping strategies, you may be able to avoid reaching the point of exhaustion.


First, remember that you are never alone. It is important to seek out resources that can assist, such as organizations, support groups, places of worship, and charitable organizations. Without taking the time to find help, you risk burnout. Caregiver burnout is defined as becoming numb to the loved one’s needs and feelings, or no longer caring what happens. No caregiver should ever let it get that far, as it may be difficult to recover. Finding the balance can be difficult, so the Administration on Aging suggests:

- Prioritizing your time by keeping a calendar of activities
- Learning to delegate
- If still employed, helping your employer recognize the situation and keeping lines of communication open with the Human Resources department
- Using vacation time provided by an employer, and asking a family member to take over caregiving duties to allow time to get away
- Making time for yourself: spending time with friends, spending time alone, planting a small garden, going for walks, reading a book, getting a massage, or spending time on a favorite hobby

Most caregivers report feeling guilty about not doing enough, not making the right choices, or taking time away. This is a normal reaction to caregiving and should not hinder the caregiver in providing for the loved one. Following these simple tips can relieve the burden of caregiving.41

DEALING WITH CONFLICT

The role reversal that occurs when an adult child must care for an elder parent or loved one can cause conflict within the family unit. Areas of concern usually involve health care decisions, financial decisions, living arrangements, family relationship issues, general decision making, household care and maintenance, needs of the family members, and support for the main caregivers. Here are some tips to overcoming these conflicts:

- Plan a time to talk things over, and set an agenda. Focus the agenda on the main issues, and don’t discuss too much in one meeting.
- Practice good communication skills by clearly saying what is important and why, focusing on the future and not the past, and trying to respond in a way that is not defensive.
- Practice active listening skills by letting everyone speak without interruption, and repeat back what was said to assure understanding.
- Try role reversal by having family members pretend they are another family member who has the opposite view.
- Involve the care receiver in the discussion, and try to respect that person’s wishes.
- Gather needed information, and decide how tasks are going to be divided.42

These simple strategies can go a long way in avoiding unnecessary conflict and emotional confrontation when making decisions.

Resources

The following is a list of agencies and organizations that can help in planning for aging or in the care of an elder:

- AARP Consumer Protection: http://www.aarp.org/consumerprotect/
- AARP: http://www.aarp.org/
- Alzheimer’s Association: http://www.alz.org/
- Alzheimer’s Disease Education and Referral Center: http://www.nia.nih.gov/alzheimers/
- American Cancer Society: http://www.cancer.org/
- American Chronic Pain Association: http://www.theacpa.org/
- American Heart Association: http://www.americanheart.org/
- American Medical Association: http://www.ama-assn.org/
- American Stroke Association: http://www.strokeassociation.org/
- Arthritis Foundation: http://www.arthritis.org/
- CareGuide Inc.: http://www.careguide.com/
- Caregiver Action Network: http://www.caregiveraction.org/
- U.S. Centers for Disease Control and Prevention—Healthy Aging: http://www.cdc.gov/aging/index.htm/
- U.S. Centers for Medicare and Medicaid Services: http://www.cms.gov/
- Certified Financial Planners Board of Standards: http://www.cfp.net/
- U.S. Department of Veteran Affairs: http://www.va.gov/
- ElderWeb: http://www.elderweb.com/
- Family Caregiver Alliance: http://www.caregiver.org/
- Healthy Aging: http://www.healthyaging.net/
- Hearing Loss Association of America: http://www.hearingloss.org/
- Low Income Home Energy Assistance Program: http://www.acf.hhs.gov/programs/liheap/
- Meals on Wheels Association of America: http://www.mowaa.org/
- Medicare Rights Center: http://www.medicarerights.org/
- National Adult Day Services Association: http://www.nadsa.org/
- National Alliance for Caregiving: http://www.caregiving.org/
- National Association for Continence: http://www.nafc.org/
- National Association of Area Agencies on Aging: http://www.n4a.org/
- National Association of Professional Geriatric Care Managers: http://www.caremanager.org/
• National Association on Deafness and Other Communication Disorders: http://www.nidcd.nih.gov/
• National Center on Elder Abuse: http://www.ncea.aoa.gov/
• National Council on Aging: http://www.ncoa.org/
• National Eye Institute: http://www.nei.nih.gov/
• National Hospice and Palliative Care Organization: http://www.nhpco.org/
• U.S. National Institute on Aging: http://www.nia.nih.gov/
• National Resource Center on Nutrition, Physical Activity and Aging: http://nutritionandaging.fiu.edu/
• National Respite Locator Service: http://archrespite.org/
• Nursing Home Compare: http://www.medicare.gov/nhcompare/home.asp/
• Social Security Administration: http://www.ssa.gov/
• Today’s Caregiver: http://www.caregiver.com/
• U.S. Administration on Aging: http://www.aoa.gov/
• USDA Food and Nutrition Information Center: http://www.nal.usda.gov/fnic/
• Well Spouse Association: http://www.wellspouse.org/