



The Comprehensive Guide to Alzheimer's Care

INCLUDING:

- **What is Alzheimer's disease?**
- **How do I care for a loved one with Alzheimer's?**
- **What legal steps should I take right now to protect myself and my loved ones?**

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What Is Alzheimer's Disease?

Alzheimer's disease is a progressive and fatal brain disease. Alzheimer's destroys brain cells, causing problems with memory, thinking and behavior severe enough to affect work, lifelong hobbies or a social life. Alzheimer's gets worse over time, and it is fatal. Today it is the seventh leading cause of death in the United States.

There are now more than 5 million people in the United States with Alzheimer's disease. Every 72 seconds, someone develops this disease. The number of people surviving into their 80s and 90s is growing due to changes in demographics as well as advances in medicine; therefore, the number of those affected by Alzheimer's disease will grow as a portion of this population.

Direct and indirect costs of Alzheimer's disease and other dementias, including Medicare and Medicaid costs and the indirect cost to business of employees who are caregivers of persons with Alzheimer's, amount to more than \$148 billion annually. Much of the cost of care is absorbed by the Alzheimer's patient and his or her family out of their own pockets.

Caring for an individual with Alzheimer's disease is not only expensive, but also challenging. Alzheimer's patients will experience the disease process in different ways at various stages of the disease. Caregiver responsibilities can range from paying bills and balancing the checkbook to bathing and dressing. This chapter explores the care options available to Alzheimer's patients and their families who make great sacrifices to care for them.

Many care options exist in the spectrum between living in a private residence and going to a nursing home. Yet an Alzheimer's patient and his or her family often dread a nursing home as the only resort without learning about all of the care options that exist.

Care Options for An Individual With Alzheimer's Disease

Many care options are available to a family caring for an Alzheimer's patient. These include such services, programs, and facilities as:

✪ Private In-Home Care

In-home care workers can be hired privately or through a home health agency. There are many advantages to hiring home health aides or companions through an agency:

1. If Medicare, Medicaid, or another third party will be footing the bills, the services must be provided through a licensed home health agency. This license or certification also means an agency has met minimal standards set by the federal government.
2. Agencies make life for the patient's family easier. The agency finds the workers, screens them, and monitors the work.
3. If an agency offers a full range of services, the care tends to be coordinated and more comprehensive.
4. Agencies have insurance in the event an accident occurs or a worker is injured while on the job.
5. The agency handles all of the paperwork involving Social Security and income tax withholding.
6. The agency replaces a worker if someone calls in sick, needs a vacation or personal day, or does not report for work.

There are many things to consider when hiring private caregivers:

1. Someone will need to obtain references and monitor the work closely. Many of these workers are first rate and provide excellent care; however, be sure that the workers being hired are trustworthy. Criminal background checks can be obtained through the state police.
2. A schedule will need to be completed and a contingency plan agreed to by all workers. What if someone needs a day off, calls out sick, or just does not report for work?
3. Who is responsible for the tax withholding? Generally, if the people hired to work are in the patient's home and directed by the patient (or the

patient's family member/caregiver) about the workers' duties and work hours, the workers are employees and not independent contractors. The family member/caregiver should talk with the patient's accountant regarding the income tax issues.

❖ **Medicare Funded Home Health Services**

A common misconception is that Medicare funded home health services will meet all of an Alzheimer's patient's care needs. The circumstances under which an Alzheimer's patient would qualify for Medicare coverage of home health care are very limited. The Alzheimer's patient would have to be 1) homebound (have a medical condition which makes it difficult to obtain services outside of the home); 2) in need of skilled nursing or rehabilitation services, rather than simply requiring personal care; and 3) approved to receive these services by the attending physician.

Medicare does not cover a nursing assistant to stay with the Alzheimer's patient all day while the caregiver goes out or to work. Aide services are usually for only a short period of time (maximum of two hours) and for only one to three days per week. Home health aides and social workers may be covered if their services are an integral part of the skilled care package; however, once the skilled need has stopped, the aide and social worker services would be terminated.

❖ **Living Together in One Home**

If living alone is not feasible, another alternative is for the Alzheimer's patient and the caregiver to share living arrangements. Living with an Alzheimer's patient will greatly impact the lifestyle of the entire household. The Alzheimer's patient's needs as well as the caregiver's (and his or her family's) needs should be carefully evaluated. Some things to consider are:

1. Is there a private and safe place for the Alzheimer's patient?
2. Will every member of the household have adequate privacy?
3. Is there enough time and attention to devote to the Alzheimer's patient?
4. Caregivers and their families should be educated about Alzheimer's disease and the special needs of the patient.

⊗ Medical Alert Services

These are systems that can be used to summon help in an emergency. Typically, the patient in distress presses a button on a necklace or watch which signals to a central call center. The center then either calls a list of emergency contacts that the patient has provided or summons 911. These systems can be installed for approximately \$50 to \$100 and charge a monthly monitoring fee that ranges from \$25 to \$40.

⊗ Adult Day Care Centers

Adult day care can provide needed respite for caregivers. It can provide an option for keeping an Alzheimer's patient at home by providing needed respite care. There are more than 3,400 adult day care centers. They typically provide care Monday through Friday from 8:00 a.m. to 5:00 p.m. Adult day cares primarily provide care for patients with Alzheimer's disease and related dementias. The average cost for adult day care is \$95 daily. This cost may be covered by the Medicaid program in some states.

⊗ Assisted Living Facilities

Assisted living facilities (or personal care homes as they are also known) are ideal for Alzheimer's patients requiring some assistance with the activities of daily living (bathing, toileting, dressing, transferring, and eating), but not constant supervision of more acute medical needs. Residents are encouraged to be as active and as independent as possible. Assisted living facilities offer three meals per day, recreation and socialization, transportation, assistance with the activities of daily living and medication, and laundry/housekeeping. Some facilities offer private rooms and residents can often bring their own furniture and personal belongings to create a more homelike environment.

Assisted living facilities have been progressively changing. They are able to offer more varying levels of care than in the past. Many facilities offer care to those suffering from Alzheimer's disease and other cognitive impairments. There are facilities that even have units dedicated to providing more specialized care.

Payment for care in an assisted living facility is almost exclusively private pay. The cost of care typically can range from \$120 to \$230 daily. The Department of Veterans Affairs can provide some assistance to eligible veterans and their spouses. The Medicaid program can provide assistance for

patients residing in facilities that will accept this type of payment. When looking at assisted living facilities, be sure to ask the admissions director what will happen to the patient when and if his or her funds are exhausted because the assisted living facility could potentially discharge the patient.

✪ **Continuing Care Retirement Communities**

Continuing Care Retirement Communities (CCRCs) are also sometimes known as “life care centers.” They offer it all from independent living to skilled nursing facility care, but usually at a rather hefty price. Once a resident is admitted, he or she can receive the level of care needed for the duration of his or her life. These communities typically contain houses or apartments for those who are still relatively independent. Additionally, there is assisted living available when more care is needed, and, finally, skilled nursing facilities are available when an individual needs assistance with all of his or her activities of daily living. Residents can move within the CCRC as care needs change. This helps keep a family together. If one spouse needs nursing home care, but the other needs only care in an assisted living facility, both can continue to reside on the same campus.

While CCRCs are generally quite costly, they offer enormous peace of mind. Entrance fees vary greatly from \$20,000 to more than a few hundred thousand dollars depending upon the type of contract that is signed. (Sometimes, the entrance fees are refundable. Again, this would depend on the contract signed.) There are usually monthly maintenance fees as well.

Each Alzheimer’s patient will experience symptoms at different times and work through the stages of the disease at various rates; therefore, it is impossible to predict when and if the Alzheimer’s patient will need care in a skilled nursing facility, although, it is quite likely that a time will come when care can no longer be provided in the community. Planning for an admission to a skilled nursing facility should begin well in advance of the need for nursing home care. This advance planning allows the family to be well informed of what facilities are available, what services are provided, and what the care will cost. Skilled nursing facilities can be found (according to city, county, or state) and then compared at the official government website for Medicare at www.medicare.gov.

⊗ **Hospice Services**

Hospice is the philosophy and practice of caring for the dying. It is based on the belief that death is a natural and inevitable part of life and that at some point all efforts should be focused on enhancing whatever life remains. Hospice can assist an Alzheimer's patient in his or her home by attempting to keep the patient comfortable and free from pain the last days of life.

Hospices provide doctors, nurses, social workers, therapists, dieticians, clergy, home health aides, and volunteers. Staff members are available 24 hours a day, 7 days a week to meet the needs of the Alzheimer's patient and his or her family, to answer questions, and to make visits as needed. Hospice services can be provided both at home and in health care facilities.

As important as the physical care is, the psychological care Hospice can provide to the family of an Alzheimer's patient is equally important. Nurses, aides, social workers, and clergy discuss the dying process and other emotional issues and offer bereavement counseling.

Almost all Hospices are covered by Medicare. To qualify, the Alzheimer's patient must elect the Hospice benefit. If at any point the patient decides to return to the original Medicare benefit, he or she can do so by signing a statement of revocation.

Professionals to Contact For Help

There is no place like home. Often, planning and adjustments within the home make the difference between the ability or inability to manage at home. Although some solutions seem obvious, some are not so obvious to a novice caregiver. In addition to this, denial on the part of the Alzheimer's patient as well as the caregiver becomes a factor. This often makes it difficult for the caregiver to recognize the degree of decline in someone who has always been so independent. This difficulty can become even worse when the Alzheimer's patient does not realize, or will not accept, his or her own limitations. If possible, the assistance of a professional geriatric care manager should be obtained.

✿ Geriatric Care Manager

A geriatric care manager is a professional who can assist in the management of all or some of an Alzheimer's patient's care. A geriatric care manager, who is often a nurse or a social worker, can assess the situation, connect the caregiver with appropriate services, and then oversee every aspect of care on an ongoing basis.

Typically a geriatric care manager will first meet with the Alzheimer's patient and his or her family to discuss the needs of the situation. The care manager will assess the daily living needs of the patient, then will draft a plan of care outlining what services will be provided when, by whom, and at what cost. Once these services are in place, the care manager is able to monitor them on a regular basis. A care manager can sometimes be found through the local Area Agency on Aging or through the National Association of Geriatric Care Managers (www.caremanager.org).

✿ Area Agency on Aging

The local Area Agency on Aging will assess the needs of an Alzheimer's patient and counsel the family regarding the benefits and services available. Many Area Agencies on Aging offer the following services; however, these services may vary among agencies:

Friendly Visitors/Telephone Reassurance – This is a program where volunteers call once a day or every few days to check on an individual. Some programs will send visitors to the home to provide

companionship and check on the individual. The volunteer could remind the Alzheimer's patient to complete a task (such as taking a medication) or could even report back to a designated person about any potential problems.

Family Caregiver Support Program – Depending upon annual income, family caregivers may be reimbursed for out-of-pocket expenses (such as nutritional supplements, disposable briefs, or medical equipment/supplies). In addition, some agencies offer grants for special home modifications and devices that ease caregiving tasks. Examples include wheelchair ramps, bathroom modifications, stair glides, and lifts, just to name a few.

Transportation Services – If an Alzheimer's patient needs a ride to a doctor's appointment, day care, or elsewhere, a number of public or private groups provide door-to-door transportation. Often this transportation is provided through the Area Agency on Aging. Most often, these agencies are equipped with full-sized vans and wheelchair accessible vans. Generally, this transportation is provided free of charge or at a minimal cost for the Alzheimer's patient and his or her caregiver.

Home Delivered Meals – These are more popularly known as meals-on-wheels. This program delivers a complete home meal to the Alzheimer's patient and his or her spouse. The cost is nominal, varying from just a few dollars to a donation of the patient's choosing.

✪ **Elder Law Attorney**

When an individual is diagnosed with Alzheimer's disease or another related dementia, his or her family should contact an elder law attorney as soon as possible. The elder law attorney can help an Alzheimer's patient and his or her family find their way through the myriad of available services. The elder law attorney can assist the patient with preparing legal documents (such as powers of attorney and last will and testaments), qualifying for Medicaid and VA benefits to pay for care, and protecting assets from long-term care costs. An elder law attorney can be found through the National Academy of Elder Law Attorneys at www.naela.org or by talking with area professionals such as a representative of the Alzheimer's Association. Be cautious when choosing an elder law attorney. Just because an attorney advertises that he or

she does Medicaid or long-term care planning, this may not be his or her area of expertise.

🌟 **Alzheimer's Association**

After obtaining the services of both a geriatric care manager and an elder law attorney, an Alzheimer's patient and his or her family should contact the Alzheimer's Association. "The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support, and research. They can be contacted at 1-800-272-3900 or on the web at www.alz.org. The phone line is open 24 hours a day, 7 days a week. The Alzheimer's Association offers a wide array of services including Alzheimer's Association Safe Return program.

Alzheimer's Association Safe Return ® – a nationwide identification, support and enrollment program that provides assistance when a person with Alzheimer's or a related dementia wanders and becomes lost locally or far from home.

Assistance is available 24 hours a day, 365 days a year. If an enrollee is missing, one call immediately activates a community support network to help reunite the lost person with his or her caregiver.

Safe Return faxes the enrolled person's information and photo (if provided) to local law enforcement. When the person is found, a citizen or law official calls the 800-number on the identification products and Safe Return notifies listed contacts. The nearest Alzheimer's Association office provides information and support during the search and rescue efforts.

Local chapters of the Alzheimer's Association provide many services to the family of an Alzheimer's patient. They provide information and referral, care consultation, support groups, and education. A local chapter can be found by contacting the Alzheimer's Association.

The Seven Stages of Alzheimer's Disease

There are typically 7 stages of the disease; however, all experts do not agree that there are 7 distinct stages. All Alzheimer's patients will experience the stages in different ways and for different lengths of time. Each stage can be defined based upon exhibited patterns of behavior. Knowledge of these stages can serve to be very useful to a patient's family and caregivers.

The Alzheimer's Association defines the 7 stages as follows:

1. No impairment – This stage may last for several years. There are usually no visible signs of the disease. Often times, neither the family physician nor family members notice any changes.
2. Very mild decline – Slight memory loss begins to occur. An individual may start to forget some names and dates and begin to lose things such as car keys. An individual in this stage may be able to easily “hide” or compensate for any problems.
3. Mild cognitive decline – Memory loss is more prevalent. This loss begins to affect everyday activities. An individual in this stage is often unable to accomplish even the simplest of tasks (such as balancing the checkbook). Friends and extended family begin to notice the memory loss.
4. Moderate cognitive decline – Memory loss becomes even more prevalent in this stage. Individuals may experience episodes of wandering, paranoia, depression, and sleeplessness.
5. Moderately severe cognitive decline – The individual needs some assistance with the activities of daily living (such as bathing, dressing, and preparing meals). There are major gaps in memory.
6. Severe cognitive decline – Significant personality changes may emerge. Individuals lose most awareness of events and surroundings. Individuals generally can remember their own name; however, may forget the name of their spouse. They have increased episodes of incontinence and require even more assistance with the activities of daily living.
7. Very severe cognitive decline – Individuals in this stage are often residing in nursing facilities. In this stage, individuals lose the ability to walk, then the ability to sit. They are usually bedridden and need complete assistance with all aspects of daily living. They are incontinent, not able to feed themselves, and incapable of expressing their needs. Swallowing becomes impaired.

Detection and Proper Diagnosis of Alzheimer's Disease

Many people find it difficult to take the first steps necessary in diagnosing Alzheimer's disease. Often, an individual and his or her family members do not want to admit there is a problem. This denial can delay the process of dealing with the disease and obtaining the necessary help and support services. Identifying signs and symptoms of Alzheimer's disease is the first step in early detection of the disease. Alzheimer's is not a normal part of the aging process. Memory loss can be caused by many different factors such as infection or vitamin deficiencies. Any time memory loss is detected it is important to contact the family physician who can do testing and make a more formal diagnosis.

According to WebMD, mild symptoms of Alzheimer's disease can include:

- 1) Memory loss and changes in expressive speech
- 2) Inability to learn new information
- 3) Taking longer to finish routine daily tasks
- 4) Mood and personality changes such as depression or increased anxiety
- 5) Difficulty planning meals or taking medications on schedule
- 6) Trouble performing simple math problems, handling money, balancing a checkbook, or paying bills
- 7) Confusion about the location of familiar places
- 8) Poor judgment leading to faulty decisions

Moderate symptoms of Alzheimer's disease can include:

- 1) Increased memory loss – forgetfulness extends to forgetting old facts, such as past career and name of friends
- 2) Shortened attention span
- 3) Difficulty organizing thoughts
- 4) Deficits in intellect and reasoning
- 5) Problems with language, including speech, reading, comprehension, and writing
- 6) Inability to learn new things or cope with unexpected situations
- 7) Repetitive statements, movements, or questions

- 8) Difficulty recognizing family and friends
- 9) Restlessness, agitation, anxiety, tearfulness and wandering, especially in the late afternoon or evening (called “sundowning”)
- 10) Hallucinations, delusions, suspiciousness, or paranoia
- 11) Lack of concern for appearance and hygiene
- 12) Loss of impulse control
- 13) Difficulty performing tasks such as using the shower and toilet

Severe symptoms of Alzheimer’s disease may include:

- 1) Complete loss of language and memory
- 2) Weight loss
- 3) Skin infections and difficulty swallowing
- 4) Groaning, moaning, grunting, or speaking gibberish
- 5) Increased sleeping
- 6) Refusal to eat
- 7) Loss of physical coordination
- 8) Lack of bladder and bowel control
- 9) Difficulty with essential activities of daily living

There is not a current cure for Alzheimer’s disease; however, there are treatments and services that will make life easier for not only the Alzheimer’s patient, but also his or her family and caregiver.

Timely diagnosis will allow caregivers and family members to plan for the disease process. Knowledge is power. First, it is important to learn about the disease and the resources available to help those afflicted with disease and their family members. Next, choose a health care professional that is right for you. The Alzheimer’s patient or his or her caregiver should contact not only a family physician, but also, a neurologist, psychiatrist, and/or psychologist. The available medications should be discussed early in the diagnosis. The drugs will not cure the disease, but, hopefully, they will slow down the disease process.

Additionally, the physician may conduct a Mini-Mental State Examination (MMSE). This test is most commonly used by health care providers to test an individual's mental capacity. The individual will be asked a series of questions to screen for cognitive impairment over a number of areas. The maximum possible score is 30. Scores of 26 or less generally show some sign of cognitive decline. The forms and/or software for this test can be obtained at www.minimental.com.

In addition to the MMSE, another widely used mental test is the Mini-Cog. This test is composed of a three-word recall and a clock drawing test.

Caring for The Caregiver

A diagnosis of Alzheimer's disease affects not only the individual but also the caregiver. Caring for someone with Alzheimer's disease is challenging. The task of caregiving often falls primarily on the shoulders of one person. The stress of this 24 hour care in addition to the feelings of despair and sadness can take a toll on the caregiver's own health. The caregiver needs to recognize:

1. He or she cannot do it alone. There are resources available through the Area Agency on Aging and the Alzheimer's Association – just to name a few.
2. If someone offers help, take it. Accepting help is not a sign of weakness. Caregivers need to be realistic. If family members, friends, churchgoers, and others offer help, caregivers should not feel guilty. It is important for the caregiver to get away – even if it is just for a few short hours. Or, if the caregiver is not comfortable leaving the house, he or she could just take a nap.
3. Caregivers should find a support group. Learning that others have had similar experiences can be an enormous relief. There is comfort in knowing that a caregiver is not alone. A lot of good ideas and tips for dealing with the disease process come out of those support group meetings. A local support group can be found by contacting the national Alzheimer's Association.
4. Caregivers should take some respite time. Many nursing homes and assisted living facilities are equipped to take Alzheimer's patients on a respite basis. This allows the caregiver to go away and become "recharged." Caregivers experiencing stress, anger, and frustration do not always provide the best care.
5. Maintaining the caregiver's own health is just as important as caring for the Alzheimer's patient. A caregiver should not ignore his or her own health. If the caregiver becomes unable to provide care, the Alzheimer's patient may need to be institutionalized sooner than he or she would have been had the caregiver been able to provide care. As a result of the overwhelming task of caring for someone with Alzheimer's disease, caregivers often suffer from depression. Caregivers should take advantage of resources available (such as counseling) and talk to their own medical providers.

6. The Alzheimer's Association is able to provide training to novice caregivers. Education about the disease and how to care for someone at each stage can allow the Alzheimer's patient to remain at home for an extended period of time.
7. Caregivers should plan ahead by finding an elder law attorney experienced in planning for those with Alzheimer's (and other related dementias). They should also visit assisted living facilities and nursing homes to obtain a good idea of where their loved ones should be placed in the event care outside the home is needed.

Caregivers who are knowledgeable and supported and who care for themselves can ultimately provide the best care to their loved one.

Common Concerns When Caring For A Loved One with Alzheimer's Disease

☼ What is sundowning and how do I deal with it?

Sundowning is a term that describes increased confusion as the day progresses. The cause of sundowning is unknown, but there are factors that may contribute to the symptoms, such as fatigue, low lighting, and increased shadows. As the day progresses, the person with Alzheimer's disease becomes more confused. Sundowning is predictable, beginning at about the same time each day. Due to the predictability, there are ways to help combat this difficult behavior.

- Keep a consistent routine.
- Provide a scheduled quiet time. This should be no more than one hour. If the Alzheimer's person is unable to rest, try soft music, low lighting, and hand/back massages.
- After quiet time has ended, make sure there is adequate lighting throughout the house.
- As sundowning begins, keep the Alzheimer's person busy as a means of distracting from the lowering of the sun.

Remember that as the care provider, you are at risk of fatigue and burn out. Be sure to use whatever help is available to you so that you can continue to provide the level of care you desire to give your loved one.

☼ How do I deal effectively with agitation?

Agitation is defined as:

- Extreme emotional disturbance.
- A stirring up or arousing; disturbance of tranquility; disturbance of mind that shows itself by physical excitement.
- A mental state of extreme emotional disturbances, the feeling of being agitated; not calm.

Agitation is a common emotion every human experiences. To the Alzheimer's person, agitation is often the result of unmet needs or frustrations they are unable to express. This section deals with five areas that

contribute to agitation and provides suggestions on how to best assess what is going on and how to cope with the agitation in a positive manner.

✪ **The person**

Many professionals working with individuals with dementia believe that behind every behavior exhibited, there is a cause or reason. Malcolm Goldsmith of the *UK Journal of Dementia Care* said, “If we spent as much time trying to understand behavior as we spend trying to manage and control it, we might discover what lies behind it is a genuine attempt to communicate.”

When agitation is displayed, stop and validate the dementia person’s feelings: “You seem upset, can you tell me what is wrong?” This simple question could help defeat the escalation of a difficult situation.

The most common time when agitation is evident is during personal care. The dementia person may feel as if he or she has lost his or her sense of dignity. When providing personal care, start by briefly explaining what will happen: “I am going to help you wash your hair, doesn’t it feel good to have clean hair?” Be sure to give explanation in a gentle tone each step and do not rush. Rushing will almost always lead to agitation and make the day more difficult for both of you.

Be sure to offer affirmation throughout the day, such as: “Thank you for helping me pick out those clothes. You look beautiful today.” “You did a great job at setting the table.”

Often fear will spark agitation. Use a gentle touch and soft spoken and positive words throughout all tasks, reminding the dementia person that he or she is in a safe place.

- Validate the dementia person’s feelings.
- Offer care with dignity.
- Do not rush.
- Offer affirming statements.

✪ Communication

Good communication is an important part of any relationship. When caring for a person with dementia, the ability to communicate becomes more and more difficult. Both expressing and processing information becomes impaired. This inability to express and process can be frustrating and manifest itself as agitation. Agitation can include anything from pacing to actually lashing out. As caregivers, we want to prevent this reaction as much as possible by communicating effectively and allowing the person time to process and respond.

The following tips will improve communication:

- ✓ Approach from the front to prevent startling.
- ✓ Maintain eye contact.
- ✓ Lower the tone of your voice. A high pitch may indicate anger.
- ✓ Smile and be pleasant.
- ✓ Talk with a calm presence.
- ✓ Speak slowly, clearly, and directly.
- ✓ Identify yourself.
- ✓ Use short, simple sentences.
- ✓ Ask one question at a time.
- ✓ Eliminate background noise.
- ✓ Give plenty of time to respond.
- ✓ If he or she cannot find words, gently finish the sentence.
- ✓ Repeat information when needed – repetition is good.
- ✓ Frequently affirm/praise him or her, even for the smallest things.
- ✓ Allow choices when possible, for example, “Coffee or milk?” “Blue or yellow shirt?”
- ✓ Validate feelings.
- ✓ Use gentle touch.
- ✓ Give hugs many times a day and laugh together.
- ✓ Don’t argue – you’ll never win.

- ✓ If your talk becomes “heated,” stop. Leave the room briefly and try again later.
- ✓ Don’t talk down to or correct him or her.
- ✓ Don’t demand. Ask nicely.
- ✓ Don’t take adverse behavior personally.
- ✓ Slow down! Hurrying increases frustration.

⊗ **Non-Verbal Communication**

Non-verbal communication is important to be aware of, both what we are communicating to our loved ones, and what they are communicating to us. Non-verbal communication can be processed and expressed by persons with dementia through body language, facial expressions, and tone of voice. They are sensitive to how you communicate with them and able to determine if you are being sincere or not.

⊗ **Interpreting non-verbal communication:**

Your loved one gets up and goes to the bathroom several times per hour.

- *They may be communicating pain, a possible urinary tract infection. Schedule an appointment with their physician.*

Your loved one takes off their shirt in public.

- *They may be expressing that they are too warm. Try putting lighter clothing on and something difficult to take off independently.*

Your loved one has a grimaced look on their face.

- *They may be experiencing pain somewhere. Look at their position and ask if they hurt anywhere.*

Your loved one firmly holds her mouth closed when you’re feeding them.

- *They may not be hungry. Try feeding later.*

Your loved one cries when you walk out of the room.

- *They may be expressing fear of the being alone. Try giving them an object to hold, such as a stuffed animal when you leave the room and assure them you will be back.*

❖ Pain Management

Pain occurs in a cycle:

Pain → Anxiety → Fatigue → Depression → Pain → Anxiety → Fatigue → Depression. → back to Pain

If a person with dementia is in this cycle, and unable to communicate it, you may have to step in and figure out what the problem is. There are many causes to the pain, including infection, arthritis, joint and muscle problems, inflammation, headaches, etc. If your loved one has a history of any of these conditions, continue with treatment as ordered by a physician. Continue to have your loved one's overall health assessed by routine exams to determine any condition that could cause pain or discomfort. Prior to the appointment, inform the physician about your observations. Dementia typically does not progress that rapidly. If your loved one takes medication, be aware of the possibility that some medications can cause agitation. Always consult your physician if you have questions or concerns. For the caregiver, the issue of overall care management is a constant guessing game of assessing and responding to needs of their loved one as well as possible.

❖ Environment

Environment includes the circumstances and conditions that surround us. It plays a large role in human behavior. It is important to create a safe and comfortable environment for the person with dementia. The following areas need to be assessed for optimal comfort:

- Temperature: too hot or too cold
- Lighting: too bright or too dim
- Walkways/hallways: too cluttered
- Noise: too loud, too much
- People: comfort with those who are around

Look for patterns associated with agitation such as the time of day, activity or event, children visiting, bathing. When you notice the pattern, readjust your schedule to meet the dementia person's needs.

⊛ Agitation

Use “Behavior Acceptance” when dealing with the dementia person. This term means looking beyond the behavior to the core of the problem causing the behavior. Look to correct the problem, which typically will adjust the behavior. Always remember that as individuals, we all need to be loved. The person with dementia needs to feel loved, safe, secure, needed, useful, and a part of the environment. We must provide this for them by showing them love, including them whenever possible, and allowing them to help in whatever way they can.

The person with dementia is not able to change, so you as the caregiver must. Constantly assess how you can better respond to a situation or behavior in a positive manner.

Legal Steps You Should Consider

You will need to make decisions for your loved one when he or she no longer has mental capacity. Power of attorney documents give you the legal right to do this.

A **power of attorney** is a document that gives someone the legal authority to make decisions for you if you cannot make decisions for yourself. There are powers of attorney for **health care** issues and **financial** matters.

The **health care power of attorney** allows someone to make decisions for you concerning doctors, hospitals, medication, etc. People often wonder . . . “My husband and I have been married for 40 years, can’t I just make decisions for him?” Unfortunately, the law presumes that no matter how long you have been married, or no matter how close you are to your loved one, if you have not given your loved one the authority to act for you under a proper power of attorney, then you must have meant *not* to give him or her permission to act for you.

Parents are the legal guardians of their minor children, and decisions which need to be made while the child is under 18 years of age can legally be made by the parent. Once that child is no longer a minor (after age 18), however, the parent loses the legal authority to make those decisions. In addition, if your parent or spouse or child over age 18 has not given you specific authority to make decisions for him or her, then the law presumes that he or she must have meant not to give you such authority. And that means you will not be able to make decisions for that person.

If your loved one loses the ability to give you authority under a power of attorney (that is, if he or she can no longer understand the documents) and decisions need to be made, you may have to go to court and begin a costly and sometimes time-consuming legal process to be appointed his or her guardian.

In my experience as an elder law attorney who has helped thousands of families, the reason why people do not have powers of attorney in place is not because they did not want someone to manage their affairs. Often, it is simply that they did not know they needed these documents. It comes as a shock when I tell them that, since this was never put in writing, they have no legal authority to make decisions for their spouse, parents, or children.

The other type of power of attorney is a **financial power of attorney**. This document covers a wide range of financial situations, from handling real estate, to dealing with bank accounts and paying taxes, to almost anything you can think of from a financial standpoint. It is crucial that you have the appropriate financial power of attorney in place.

Having the appropriate financial and health care powers of attorney is the critical first step. Next, depending upon the specific situation, other legal issues related to end-of-life planning may arise.

A **living will** is an expression of your wishes regarding end-of-life decisions. If you do not want to be kept alive artificially should you be terminally ill with no chance of recovery (as decided by a doctor) and unable to communicate your wishes, you should sign a living will making your wishes clear. For a doctor to withhold or withdraw artificial, life-sustaining treatment, there must be clear and convincing evidence that those are the patient's wishes. The best way to accomplish this, of course, is to put your wishes in writing by signing a living will. As we know, Terri Schiavo did not do this. Her husband said before Terri became ill, they had discussed these issues, and Terri had made it clear she would not have wanted to be kept alive in her condition. Her parents disagreed. Terri was kept alive for 15 years and an extensive and expensive court case resulted.

It is important to realize that a living will can be tailored to suit your wishes. For example, some may not want their lives prolonged in any way should they be terminally ill and unconscious, while others may want all means possible used to keep them alive. Still others may wish to decline all life-prolonging treatment with the exception of food and water.

Regardless of your decision, it is critical that you discuss your wishes with your family members and loved ones. While a living will is clear and convincing evidence of a person's wishes, it is possible from a practical standpoint that in a true end-of-life situation, the document's strength might be diminished if parents, children, or spouses claim the living will does not reflect their loved one's wishes. This could also happen if close family members simply do not agree with each other on whether the living will reflects their loved one's wishes. You can imagine the concerns a doctor is going to have when a patient's living will says she doesn't want to be kept alive artificially but the patient's daughter is pleading with the doctor to

keep her mother alive - saying that she knows her mother would have wanted to live. You must discuss your wishes with your loved ones.

The key is to act now. You may want to contact an elder law attorney to discuss questions you have about living wills. Once you have been educated about your options, you can make the decision that is right for you. And once your decision is made and you have acted on it, you can take the next step of discussing your wishes with your family. Good elder law attorneys who take a holistic approach to serving their clients can help you with this part of the process as well.

After executing powers of attorney for finances and health care and an advance directive for health care (a living will), you and your family may need to consider other legal planning.

Revising last will and testaments and trusts: Whenever a “major life event” occurs, attorneys recommend that you review your will and trusts. Your current legal documents may no longer be appropriate. You may want to make changes that reflect your new circumstances. Being diagnosed with an illness such as Alzheimer’s disease is a “major life event” worthy of review. The plans that were put into place when you were healthy may no longer be appropriate.

For instance, many clients set up what are referred to as “sweetheart wills” in which each spouse leaves everything to the other spouse, and then at the death of the second spouse, to the children. This may be the wrong way to set things up now, given one spouse’s illness. It may be that things can be arranged in a better fashion so that if the “healthy spouse” passes away first, the assets can be put into a trust to benefit the spouse who is suffering from dementia or be passed down to the children to protect those assets from Medicaid. This is where legal planning with an attorney experienced in dealing with these patients is critical.

After consulting with an elder law attorney experienced in Medicaid planning, you may wish to protect your assets from your possible nursing home care costs by establishing an irrevocable trust and transferring some assets to the trust.

If you are a wartime veteran (or a surviving spouse) suffering from Alzheimer’s disease, you may want to consider consulting with an elder care

attorney knowledgeable in the area of Veterans benefits. You may want to establish an irrevocable trust and transfer some of your assets to the trust to qualify for Veterans benefits to pay for your long-term care costs.

Changing Property Titles – Reviewing property titles is an important part of planning. That way, you can be sure your family members are protected if your illness requires long-term care in a nursing home.

Entering Into Caregiver Contracts – A caregiver contract, also referred to as a “care agreement,” “family care agreement,” or a “personal service contract,” is an agreement between an individual who suffers from dementia and his or her caregiver wherein the caregiver agrees to provide care and/or housing to the individual and the individual agrees to compensate the caregiver for his or her services and/or living accommodations. A properly drafted caregiver contract is a way for an individual to transfer money to a caregiver and not create a Medicaid ineligibility period.

Strategies For Financial Gifts – Consulting a knowledgeable attorney is especially important before you transfer any property or make any gifts. The attorney can help you review your financial situation to determine whether a gifting plan or other financial strategy is appropriate. Making gifts can protect your family and help save your estate, but acting improperly can have severe legal consequences, and can even make you ineligible for government benefits. Thus, it is crucial that you have sound advice from an attorney experienced in dealing with long-term care.

Long-Term Care Strategies – In addition, you may want to consider the benefits programs that are available. For instance, Medicaid, a federally funded program administered by the states, may pay some health care costs (assistance with bathing, light housekeeping, cooking, laundry, etc.) while an eligible patient remains at home. But there are strict rules about how you can qualify for this and what benefits are available. With that in mind, let’s review the basics of Medicaid and how to qualify.

The Basics of Medicaid

In order to understand Medicaid qualification, you first need to know how Medicaid treats your assets.

Basically, Medicaid breaks your assets down into two separate categories. The first are those assets which are exempt, and the second are those assets which are non-exempt, or countable.

Exempt assets are those which Medicaid will not take into account at this time. Generally, the following assets are exempt:

- Home, if it is in New Jersey. The home must be the principal place of residence and the resident may be required to show some intent to “return home” even if this never actually takes place. For a single person, this exemption is limited to \$906,000 (in 2021) of home equity.
- Household and personal belongings such as clothing, furniture, and jewelry
- One vehicle (a car or truck or van)
- Pre-paid funeral plans and burial plots
- Cash value of life insurance policies with an aggregate face value of no more than \$1,500 may be exempt depending upon your situation
- Cash (for example, a small checking or savings account), not to exceed \$2,000.

In certain instances, some other assets, such as income producing real estate, etc., may be either countable or exempt depending upon your particular situation.

The assets which are not exempt are considered countable. This typically includes checking accounts, savings accounts, certificates of deposit, money market accounts, stocks, mutual funds, bonds, most IRAs, most pension plans, second cars, etc.

While the Medicaid rules themselves are complicated and somewhat tricky, for a single person, it’s safe to say that you will qualify for Medicaid so long

as you have only exempt assets, plus a small amount of cash (no more than \$2,000).

What are Spousal Protection Provisions?

Married couples can benefit from the Spousal Impoverishment provision of the Medicare Catastrophic Act of 1988. The intent of the law was to change the eligibility requirements for Medicaid in situations where one spouse needs nursing home care, while the other spouse remains in the community (for example, at home or in an assisted living facility).

Basically, under the Spousal Protection Act, a couple gathers all of their nonexempt (countable) assets together in a review. The exempt assets are the ones described earlier, such as the home, one vehicle, etc. The non-exempt assets are then divided in half, with the community (or at home) spouse being allowed to keep one-half of all of the countable assets up to a maximum of \$137,400 and a minimum of \$27,480 (in 2022). The other one-half of the assets must then be “spent down.”

In other words, for a married couple who had \$100,000 in countable assets, the healthy spouse, or community spouse, would be able to keep one-half of those assets (\$50,000 in this example) and the ill spouse would be allowed to keep his or her \$2,000.

The laws are very tricky as to exactly how the spend down is completed. Suffice it to say that someone who is pursuing Medicaid eligibility should consider the following types of spend-down items. These are listed in no particular order:

- Purchase pre-paid funeral plans
- Purchase a new car
- Payment of health care costs (including nursing home if needed)
- Purchase of a new home
- Make home improvements
- Buy household goods or personal effects
- Repay debt

These are not the *only* appropriate items for a spend down. There are other expenses which would also qualify. The main rule to keep in mind is that whatever goods or services are purchased must be purchased at fair market value and must be for the benefit of the patient and/or the patient’s spouse.

Some Frequently Asked Medicaid Questions

As complicated as Medicaid is, there are certain questions that come up over and over again. While no book will be a substitute for the advice of an attorney experienced in counseling individuals with Alzheimer's disease and their families, let's at least review some of the questions that frequently arise.

Question: Is a married couple always required to spend down one-half of their assets before qualifying for Medicaid?

Answer: Not always. In fact, often, couples have over \$137,400 (\$137,400-community spouse and \$2,000 Medicaid recipient 2022) and qualify for Medicaid benefits without spending down. Although there are income and asset criteria a couple must meet before one of them qualifies for benefits, federal and state laws were written to protect individuals from becoming impoverished if their spouse needs care. Medicaid planning is like tax planning in that the laws provide certain "safe harbors" that, with expert advice from a knowledgeable attorney, can save Medicaid applicants and their families thousands of dollars. An experienced elder law attorney can help you determine if there are ways to protect additional assets in your particular situation.

Question: Will this cause me to lose my home?

Answer: Many people who apply for Medicaid ask this question. For many people, the home constitutes much or most of their life savings. Often, it's the only asset that a person has to pass on to his or her children. Under the Medicaid regulations, the home is generally an unavailable asset. That means it is not taken into account when calculating eligibility for Medicaid.

However, in 1993, Congress passed a law which requires the states to try to recover the value of Medicaid payments made to recipients. This process is called estate recovery. Estate recovery does not take place until the recipient of the benefits dies. In the case of a married couple, it occurs after the death of both spouses under the current laws. At that point, the law requires states to attempt to recover the benefits paid from the recipient's estate. In recent years, as state budgets have gotten tighter, many states have become more aggressive about their estate recovery programs. For instance, New Jersey will place a lien on a Medicaid recipient's home under certain conditions.

For that reason, you will need assistance from someone knowledgeable about the rules and regulations to determine whether there will be estate recovery, and whether it can be avoided in your particular situation.

Question: Is it true that under current Medicaid laws, parents cannot make gifts to their children once they are contemplating Medicaid or have entered a nursing home?

Answer: No. In fact, a proper gifting program can be a great Medicaid planning technique. At the time an applicant applies for Medicaid, the state will “look back” five years to see if any gifts have been made. Any financial gifts or transfers for less than fair market value during the five year look-back period may cause a delay in an applicant’s eligibility. Also, just because the state may ask about gifts made during the prior five years, does not mean that all of those gifts will be considered. You do need to be aware of a new law which became effective February 8, 2006. Under the terms of that new law, the gifting rules have become far more complicated. An elder law attorney can help determine if gifting would be appropriate under your circumstances.

Question: Is it true that \$16,000 (2022) is the most an individual can give away if he or she is going to apply for Medicaid?

Answer: No, the \$16,000 figure is a federal gift tax figure, and not relevant with respect to Medicaid’s specific asset transfer rules. The maximum monetary figure Medicaid applicants need to concern themselves with is the “penalty divisor.” The penalty divisor is the state-assessed average cost for nursing home care by which the state assesses Medicaid penalties. The penalty divisor for New Jersey is currently approximately \$10,986.50 (\$361.20 a day). Therefore, a gift will cause a penalty of one month for each approximately \$10,986.50 given away (in 2022).

Question: A Medicaid applicant’s home is considered “exempt” under current Medicaid laws. Can an applicant give away his or her house without incurring penalties?

Answer: No. Any assets which are given away are considered transfers for less than fair market value. If an applicant gives his or her house away, the state will assess a penalty based on the fair market value of the house at the time the property was transferred.

Suffice it to say that the Medicaid laws are complicated. There are a number of steps which families can take to preserve their assets and qualify for benefits. These range from gifting strategies to personal care contracts to annuities to increasing the amount of money the at home spouse is allowed to protect. It is important to keep in mind that these laws are constantly changing, and that the advice which was given to a friend or neighbor last year may no longer be relevant, or even appropriate. It's also important to understand, however, that with expert advice you may be able to protect yourself and your loved ones while qualifying for all of the benefits the law allows.

What Is Probate and Do You Need To Avoid It?

One concern many people have is how to be sure that their property will pass to their loved ones in the event of their death. There are basically five ways people can transfer property to their loved ones upon their death. Depending upon the age of those who will be receiving property or the dynamics among family members who are receiving the property, it is important to choose your method of transfer very carefully. The following are some examples:

Leave property titled solely in your name, do not establish a last will and testament

If your property is titled only in your name at the time of your death, then your property will go through a process known as probate. If you do not have a last will and testament, a court will order your property to be divided among your surviving relatives according to New Jersey's intestate law. Basically, the courts, via the state statute, provide who will receive your property if you have done no planning. In essence, the state has written a will for you. It typically says that if you do not have a will, at your death, a certain amount will pass to your spouse, if you have one, and a certain amount to your children. If you have no spouse or children, then more distant relatives will receive your assets. Obviously, most people want to have a greater say regarding who will receive their property. That is why they take other estate planning measures, such as those described below.

Establish a last will and testament

Establishing a last will and testament allows you to provide written instructions about how your property is to be divided upon your death. In your will, you designate an "executor" or "personal representative" of your estate who administers the probate estate. With the supervision of the court, your representative will then distribute your property as you have outlined in your will. A will can sometimes be advantageous since a court will become involved in the distribution of your assets. That way you will be assured your belongings go to whom you want them to go, and that family dynamics will not affect your wishes. Also, if you have one or more minor children, it is critical to have a last will and testament so you can designate whom you would like to be the guardian of your children.

Add a joint owner with a right of survivorship to your property

Adding a joint owner with a right of survivorship to your property (a joint tenant) will pass 100% of that property to the joint owner upon your death. Probate is not necessary. This is often the way spouses choose to title their property. Joint tenancy can, however, be a problem. For instance, if a child is added to your property, and that child is later sued due to a divorce, car accident, etc., 100% of that property may be subject to the lawsuit, and the parent may be left without a home or assets. Joint tenancy “overrides” any last will and testament you may have executed.

Add beneficiary designations to your property

Adding a beneficiary designation (payable-on-death [POD] or transfer-on-death [TOD]) to your personal property is another way to avoid probate. Again, 100% of your property passes to the person(s) you have designated as the beneficiary. Unlike a joint owner, however, the beneficiary has no access to your property until you have passed away, thus avoiding any problems with attachment of your assets by the beneficiary’s creditors. Like joint tenancy, however, the beneficiary designations “override” any last will and testament you have executed.

Establish a revocable or irrevocable trust during your life

A trust is an estate planning document which allows an individual to direct another person (the trustee) to manage property during the individual’s life and to distribute property upon the individual’s death, according to the individual’s specific wishes. Unlike a will, a trust is not probated. A trust may also be established to limit or, in some cases, avoid New Jersey estate and inheritance tax.

Proper estate planning is a must if you want to be sure your property will pass upon your death to your loved ones according to your wishes. For instance, if you have young children, it is crucial for you to have a will and a trust in place because minor children cannot take title to property in their own names. Additionally, it is important to arrange for the care of your minor children after your death, and it is critical to be sure that, where possible, the person who will be caring for your children will have access to the funds to properly care for them. In addition, some people are not emotionally equipped to handle sums of money they receive outright, and it

is common to see individuals who have received an inheritance quickly spend that inheritance in the matter of a few short weeks or months. Proper, thoughtful estate planning can avoid this and insure that everyone is protected and your life's savings, no matter how large or small, are not squandered. Before taking any action to avoid probate or establish a trust, you should consult an estate planning attorney who can examine your specific situation and advise you accordingly.

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What Steps Should You Take Now?

As you can tell from reading these materials, planning for someone who has Alzheimer's disease can be complicated. Proper planning in advance can help alleviate many frustrations as the disease progresses. It is my desire as an elder law attorney to make this difficult process as easy as possible for you so that you can concentrate on giving your loved one the care he or she needs.

The time to act is now. With proper planning, you will insure that things are handled according to your wishes and that you've taken the best steps possible to protect your loved ones and to protect your family's financial security.

If you would like the guidance of an elder and disability law firm which has helped many New Jersey families successfully deal with these issues, then please call Hauptman & Hauptman at 973-994-2287 or visit our website at www.HauptmanLaw.com.

Imagine the peace of mind you will have when you stop reacting to your situation and start putting into place a positive action plan which will allow you to protect yourself and your loved ones.

My best wishes to you,

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