

# A GUIDE TO ALZHEIMER'S CARE



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## Alzheimer's

The dark recess, closed forever  
Communication in the present  
Closed forever  
Mother, who are you  
Are you the little girl  
I never knew  
Hello, young man  
You look familiar  
You remind me of!!!!  
You wont be able to stay  
I have people for dinner  
Mother, there's no one here  
I have six places set for table  
They are in the other room  
There is no one here  
Only a television  
Have you seen your grandmother  
Mother, she died ten year's ago  
No, I saw her only this morning  
Oh, insidious life destroying  
Disease of the mind  
Thief of thought and conversation  
A chance to ask a mother  
The thing's I desire to know  
She in her little world  
I in mine  
Death was her only cure

**Allan James Saywell<sup>1</sup>**

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<sup>1</sup> Saywell, Allan James, *Alzheimer's*, (retrieved Oct. 30, 2007 from <http://www.poemhunter.com/poem/alzheimer-s/>).

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**\*\*\*Provided courtesy of The Estate Planning and Elder Law Center of Brevard\*\*\*  
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Founding members of The National Alliance of Attorneys for Alzheimer’s Planning  
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# Alzheimer's Disease

## WHAT IS ALZHEIMER'S DISEASE?

"Alzheimer's disease is an irreversible, progressive brain disorder that slowly destroys memory and thinking skills, and eventually the ability to carry out the simplest tasks. In most people with Alzheimer's, symptoms first appear in their mid-60s. Estimates vary, but experts suggest that more than 5 million Americans may have Alzheimer's."<sup>2</sup>

Although Alzheimer's disease is currently ranked as the sixth leading cause of death, studies over the last few years reveal that deaths that are linked to Alzheimer's disease are underreported. Findings show that in many instances, deaths are attributed to health conditions such as inhalation pneumonia that result from the effects of Alzheimer's as the body loses its ability to function effectively. The findings suggest that the deaths that result because of Alzheimer's disease can be attributed to many more people than have been reported. Researchers believe that if reported accurately, Alzheimer's disease would rank as the third leading cause of death, behind heart disease and cancer.<sup>3</sup>

A review of the Alzheimer's Association 2018 Alzheimer's Facts and Figures<sup>4</sup> reveals astonishingly high annual costs associated with the disease. Estimated at hundreds of billions of dollars, the cost of Alzheimer's disease is expected to increase exponentially, as are the numbers of people diagnosed with the disease. This report provides staggering details outlining the cost of care; including the fact that much of the cost of care is absorbed by the person with Alzheimer's and his or her family out of their own pockets, and the unimaginable number of hours people have donated to provide care for a loved one with the disease.

Caring for an individual with Alzheimer's disease is not only expensive but can be exhausting. The patient with Alzheimer's 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 a person living with Alzheimer's disease 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 moving into a nursing home. Yet a person who has Alzheimer's, and his or her family,

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<sup>2</sup> NATIONAL INSTITUTE ON AGING, *Alzheimer's Disease Fact Sheet*, available at <https://www.nia.nih.gov/health/alzheimers-disease-fact-sheet> (last visited Feb. 7, 2019).

<sup>3</sup> NATIONAL INSTITUTE ON AGING, *Number of Alzheimer's deaths found to be underreported*, at <https://www.nia.nih.gov/news/number-alzheimers-deaths-found-be-underreported> (last visited Feb. 7, 2019).

<sup>4</sup> ALZHEIMER'S ASSOCIATION, *2018 Alzheimer's Disease Facts and Figures*, available at <https://alz.org/facts/overview.asp> (last visited Feb. 7, 2019).

often view a nursing home as a dreaded choice 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 providing care for a person who has been diagnosed with Alzheimer's. 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 insurance will be billed, the services must be provided through a licensed home health agency. This license or certification is an indicator that an agency has met minimal standards set by the federal government.
2. Agencies make life for the patient's family easier. The agency is able to identify and hire workers, monitoring their work. The staffing process includes a responsibility for obtaining the needed clearances and background checks, lessening risk.
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 the paperwork involving social security and income tax withholding.
6. The agency provides coverage to replace a worker if someone calls off 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 private caregivers 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. Consider the exposure to potential liability. Who is responsible for costs if the worker is injured on the job, or is at fault to an injury or accident involving the patient?

3. A schedule will need to be completed and a contingency plan agreed to by all workers. What if someone needs a day off, calls off sick, or just does not report for work?
4. 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**



It is a common misconception that Medicare-funded home health services will meet all of the care needs for a person living with Alzheimer's. The circumstances under which a person would qualify for Medicare coverage of home health care are very limited. To qualify, a person would need to be 1) home bound (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 person 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 ended, the aide and social worker services would also be terminated.

### **Living Together in One Home**

If living alone is not feasible, an alternative plan is for the person with Alzheimer's disease and the caregiver to share living arrangements. Living under one roof with a person who has Alzheimer's disease will greatly impact the lifestyle of the entire household. The needs of the person who is diagnosed with Alzheimer's, as well as the needs of the caregiver (and family) should be carefully evaluated. Some things to consider are:

1. Is there a private and safe place for the person who is living with Alzheimer's?
2. Will every member of the household have adequate privacy?
3. Is there enough time and attention to devote to the person who has Alzheimer's disease?

- Caregivers and their families should be educated about Alzheimer's disease and the special needs of the patient.

### **Medical Alert Monitoring Services**

These are systems offered by various providers that can be used to summon help in an emergency. Typically, the person in distress presses a button on a necklace, wristband, or a wall mount, which signals to a central call center. Some devices allow voice communication. The call center will contact a list of responsible people that the patient has provided, or it can summons 911 for emergency services. These systems can be installed (or ordered online for self-setup) and charge a monthly monitoring fee. Some systems offer fall detection, can be GPS enabled, and can apply to landline or mobile devices. A helpful comparison of monitoring systems can be found at Consumer Reports.<sup>5</sup>

### **Adult Day Care Centers**

Adult day care can provide needed respite for caregivers. It can provide an option for keeping an individual who is living with Alzheimer's at home by providing day-based services in a community-based facility. Most adult day cares offer basic care, as well as social and recreational opportunities, with staff to assist and supervise participants. A few adult day care programs offer much more comprehensive care, including transportation to and from the facility, medical monitoring by a staff physician, and social service staff to address the psycho-social needs of the participant. There are more than 4,800 adult day care centers serving over 282,000 people. Ownership of adult day care facilities may be for profit or not for profit. In 2016, 44.4% of these were established for profit.<sup>6</sup> Care is typically provided Monday through Friday from 8:00 a.m. to 5:00 p.m. During non-program hours, the participant resides in a family home, with their caregiver. Adult day care facilities frequently provide care for patients with Alzheimer's disease and related dementias. The average cost for adult day care varies greatly from state to state, and even within states. This cost may be covered by the Medicaid program in some states.

### **Assistance in Living Facilities**

Assistance in living facilities (commonly referred to as assisted living or as personal care homes) are ideal for a resident with Alzheimer's who requires some assistance with the activities of daily living (bathing, toileting, dressing, transferring, and eating), but

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<sup>5</sup> CONSUMER REPORTS, *What to Look for in a Medical Alert System*, available at <https://www.consumerreports.org/cro/2014/06/what-to-look-for-in-a-medical-alert-system/index.htm> (last visited Feb. 11, 2019).

<sup>6</sup> CENTERS FOR DISEASE CONTROL AND PREVENTION, *Long-Term Care Providers and Services Users in the United States, Adult Day Services Center Component: National Study of Long-Term Care Providers, 2015–2016 2016*, available at <https://www.cdc.gov/nchs/fastats/adsc.htm> (last visited Feb. 11, 2019).

not constant supervision due to 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 additional care options to those living with 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 can range from \$3,000 to \$6,500 per month. The Veterans Administration can provide some assistance to eligible veterans and their spouses. The Supplemental Security Income (SSI) program may provide financial 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; be aware if the facility could potentially discharge the patient because they can no longer pay their way.

### **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 often at a rather hefty price. Once a resident is admitted, the appropriate level of care needed is provided for the duration of his or her life. These communities typically contain houses or apartments for those who are still relatively independent. Additionally, assisted living level of care is available when more care is needed, and, finally, skilled nursing facilities are available when an individual needs assistance with activities of daily living and increased medical care. 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 remains independent, or needs only an assisted living level of care, 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 tens of thousands of dollars to hundreds of thousands of 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.

Every person diagnosed with Alzheimer's 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 person with Alzheimer's 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 [www.medicare.gov](http://www.medicare.gov).<sup>7</sup>

### **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 a patient with Alzheimer's disease by attempting to keep the patient comfortable and free from pain the last days of life. Hospice care can be utilized wherever a person is living when the referral is made by their physician... in their community home, in assisted living, a skilled nursing facility, or in a hospital acute care setting.

Hospice involves a team of professionals, working together with the patient and their family, to make the end-of-life experience as meaningful for the patient as possible. The hospice team is comprised of doctors, nurses, social workers, therapists, dietitians, clergy, home health aides, and volunteers. Staff members are available 24 hours a day, 7 days a week to meet the needs of the person living with Alzheimer's and his or her family, to answer questions, and to make visits as needed.

As important as the physical end-of-life care is, the psychological care Hospice can provide to the patient and family of a person living with Alzheimer's disease is immense. Nurses, aides, social workers, and clergy discuss the dying process and other emotional issues and offer bereavement counseling.

Almost all Hospice services are covered by Medicare. To qualify, the person with Alzheimer's 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

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<sup>7</sup> MEDICARE.GOV, *Nursing Home Compare*, available at <https://www.medicare.gov/nursinghomecompare/search.html> (last visited Feb. 11, 2019).

solutions seem obvious, some are not so obvious to a novice caregiver. In addition, psychological denial of the reality of circumstances related to the disease, on the part of the person with Alzheimer's, as well as the caregiver, can become 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 person who has Alzheimer's disease does not realize, or will not accept, his or her own limitations. The assistance of a professional geriatric care manager could be extremely valuable.

### **Geriatric Care Manager**

A geriatric care manager is a professional who can assist in the management of all, or some, of the care decisions for a person who has Alzheimer's disease. 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 person living with Alzheimer's disease and his or her family to discuss the needs in their unique 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](http://www.caremanager.org)).

### **Area Agency on Aging**

The local Area Agency on Aging will assess the needs of a patient with Alzheimer's 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 person with Alzheimer's 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 a patient with Alzheimer's disease 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. Frequently, 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 person with Alzheimer's 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 person with Alzheimer's and his or her spouse. The cost is nominal, varying from just a few dollars to a donation of the patient's choosing.

Of note: Increasingly, private businesses unrelated to the Area Agency on Aging are entering the meal prep and delivery business in response to busy working households. If there is resistance to meals-on-wheels, or if there is a need to just streamline the family meal process because of caregiver demands, it may be worthwhile to check into local meal prep providers. In addition, more and more grocery stores are providing home delivery of groceries. A possible convenience and time saver.

**Senior Centers** - Senior centers provide group-focused activities designed to encourage socialization and recreation.

**Personal Care and Home Support Services** - Personal care services are provided when the primary need is for hands on personal care such as bathing and dressing. Home support cleaning services are provided when the need is for light housekeeping tasks such as laundry and shopping. There is often a cost associated with this service and is typically based upon a sliding fee schedule according to the person with Alzheimer's (and his or her spouse's) income.

**Nursing Home Waiver Program** - The trend in this country is toward home and community-based care. The Area Agency on Aging may offer a program to provide care at home for individuals who would otherwise need nursing home care. This program may mean the difference between enabling a patient with Alzheimer's disease to continue living at home, and his or her need to move to a skilled nursing facility. Often, a caregiver may need a little assistance with managing day-to-day Alzheimer's care. For example, the caregiver may just want to go out a few times a week and may need someone to stay with the

person with Alzheimer's. Or, the caregiver may want a nursing assistant to stay at night so he or she can get a full night's sleep. Services provided through this program can include: home-delivered meals, personal care, cleaning services, home modifications, medical supplies, caregiver respite services, day care, transportation, etc. This program is often Medicaid funded; therefore, in order to access services, the person with Alzheimer's disease may need to be eligible for, or receiving, state Medicaid benefits.

### **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 the person with Alzheimer's 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 Financial, Healthcare, and Mental Health Powers of Attorney, living wills/advance directives, and last will and testament). The elder law attorney can be instrumental in helping the client qualify for Medicaid 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](http://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 planning, this may not be his or her area of expertise. If possible, choose a Certified Elder Law Attorney, (CELA). This is an indicator that the attorney has been certified by the National Foundation of Elder Law Attorneys as experienced and proficient in the field and practice of elder law, including knowledge of the issues and legislation related to the aging population.



### **Alzheimer's Association**

After obtaining the services of both a geriatric care manager and an elder law attorney, a person who has been diagnosed with Alzheimer's 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."<sup>8</sup> They can be contacted at 1-800-272-3900 or on the web at [www.alz.org](http://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 MedicAlert® + Alzheimer's Association Safe Return® program.

MedicAlert® + Alzheimer's Association Safe Return® is a nationwide identification, support, and enrollment program that provides assistance

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<sup>8</sup> ALZHEIMER'S ASSOCIATION, *About Us*, available at [https://www.alz.org/about\\_us\\_about\\_us\\_.asp](https://www.alz.org/about_us_about_us_.asp) (last visited Oct. 9, 2017).

when a person with Alzheimer's disease, or a related dementia, wanders and becomes lost locally or far from home. There is an annually renewable fee for this program, and there may be a charge for the enrollment package.

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.

MedicAlert® + Alzheimer's Association 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 MedicAlert® + Alzheimer's Association Safe Return® notifies listed contacts. The nearest Alzheimer's Association office provides information and support during the search and rescue efforts.<sup>9</sup>

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

## **THE STAGES OF ALZHEIMER'S DISEASE**

Alzheimer's disease is a brain disorder that gradually destroys a person's memory and ability to learn, reason, make judgments, communicate and carry out daily activities. The disease is progressive and, at this point, incurable.

According to The National Institute on Aging, as well as the medical community at large, the progression of the disease can vary in persons.<sup>10</sup> Some first experience affected ability to reason or impaired judgement or may have difficulty finding appropriate words to express themselves verbally. They may have difficulty navigating within their visual field or making sense of the actual space they occupy. The disease has been organized into Three descriptive stages, Mild, Moderate, and Severe.<sup>11</sup> Some organizations describe levels of functioning within those three stages. Additionally, each person living with Alzheimer's disease will experience the stages in different ways and for different lengths of time. Each stage can be defined based upon exhibited

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<sup>9</sup> ALZHEIMER'S ASSOCIATION, *Safe Return*, available at <https://alz.org/care/dementia-medic-alert-safe-return.asp> (last visited Oct. 9, 2017).

<sup>10</sup> NATIONAL INSTITUTE ON AGING, *What are the Sign of Alzheimer's Disease*, available at <https://www.nia.nih.gov/health/what-are-signs-alzheimers-disease> (last visited Feb. 27, 2018).

<sup>11</sup> NATIONAL INSTITUTE ON AGING, *What are the Signs of Alzheimer's Disease*, available at <https://www.nia.nih.gov/health/what-are-signs-alzheimers-disease> (last visited Feb. 27, 2018).

patterns of behavior. The three stages of Alzheimer's disease printed verbatim from the website of the National Institute on Aging<sup>12</sup>, are described as follows:

### **Mild Alzheimer's disease (early stage)**

- Memory loss
- Poor judgment leading to bad decisions
- Loss of spontaneity and sense of initiative
- Taking longer to complete normal daily tasks
- Repeating questions
- Trouble handling money and paying bills
- Wandering and getting lost
- Losing things or misplacing them in odd places
- Mood and personality changes
- Increased anxiety and/or aggression

### **Moderate Alzheimer's disease (middle stage)**

- Increased memory loss and confusion
- Inability to learn new things
- Difficulty with language and problems with reading, writing, and working with numbers
- Difficulty organizing thoughts and thinking logically
- Shortened attention span
- Problems coping with new situations
- Difficulty carrying out multistep tasks, such as getting dressed
- Problems recognizing family and friends
- Hallucinations, delusions, and paranoia
- Impulsive behavior such as undressing at inappropriate times or places or using vulgar language
- Inappropriate outbursts of anger
- Restlessness, agitation, anxiety, tearfulness, wandering – especially in the late afternoon or evening
- Repetitive statements or movement, occasional muscle twitches

### **Severe Alzheimer's disease (late stage)**

- Inability to communicate
- Weight loss
- Seizures
- Skin infections

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<sup>12</sup> NATIONAL INSTITUTE ON AGING, *What are the Signs of Alzheimer's Disease*, available at <https://www.nia.nih.gov/health/what-are-signs-alzheimers-disease> (last visited Feb. 27, 2018).

- Difficulty swallowing
- Groaning, moaning, or grunting
- Increased sleeping
- Loss of bowel and bladder control

Knowledge of the stages of Alzheimer’s disease can serve to be very useful to a patient’s family and caregivers. This can better help families and care providers plan for the future.

## **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; however, memory loss can be caused by many different factors, including infection, organs that are not functioning properly, an injury to the head from a fall, alcohol use, medication effects, or vitamin deficiency<sup>13</sup>. Many people worry that they or someone they care about is developing dementia because they seem to be forgetting things more often, can’t seem to locate their keys or glasses, don’t remember the birthday of their grandchild, or forget where they parked in the grocery store lot. These unsettling experiences may only be a part of the normal process of aging. A helpful comparison<sup>14</sup> of natural aging and Alzheimer’s disease notes the following differences:

<b>Natural Aging</b>	<b>Alzheimer’s disease</b>
Occasional bad decisions	Frequent poor judgement and bad decisions
Missing a monthly payment	Unable to manage paying bills
Momentarily forgets what day it is but then remembers	Loses track of the date or season
Forgets a name or confuses a word on occasion	Trouble finding words to carry on a conversation
Misplaces an item now and then	Often loses items and has no idea where they are

<sup>13</sup> National Institute on Aging, *Do Memory Problem’s Always mean Alzheimer’s? Memory Loss Related to Medical Conditions*, available at <https://www.nia.nih.gov/health/do-memory-problems-always-mean-alzheimers-disease> (last visited Feb. 28, 2018).

<sup>14</sup> NATIONAL INSTITUTE ON AGING, *Do Memory Problem’s Always mean Alzheimer’s? Differences Between Normal Aging and Alzheimer’s Disease*, available at <https://www.nia.nih.gov/health/do-memory-problems-always-mean-alzheimers-disease> (last visited Feb. 28, 2018).

If unusual symptoms or behavioral patterns arise, a physician should be consulted. Behaviors that are of concern include the following list, taken verbatim from the National Institute on Aging website:<sup>15</sup>

- Asking the same questions over and over again
- Getting lost in places a person knows well
- Not being able to follow directions
- Becoming more confused about time, people, and places
- Not taking care of oneself – eating poorly, not bathing, or being unsafe

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 person with Alzheimer's, 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 to identify the resources available to help those affected by disease and their family members. Next, choose a health care professional that is right for you. The person diagnosed with Alzheimer's, or his or her caregiver, should contact not only a family physician, but also, a neurologist, psychiatrist, and/or psychologist. Medications that could help manage behavioral symptoms, and the appropriateness of medications that may slow the progression of Alzheimer's disease should be discussed early in the diagnosis. Although there is no drug that will cure the disease, advances in research have shown that some drugs and certain behavioral and dietary initiatives may slow down the disease process or make living with the disease less exhausting.

There is no single test that will prove an individual has Alzheimer's disease. After ruling out or addressing any treatable causes of symptoms, the medical professional will consider factors that could be a risk factor for Alzheimer's. Age, and a family history of the disease, dietary and heart health factors, and even environmental factors are considered.

The physician will not only discuss these risk factors and symptoms, but also will review medical records, diet, and medications. Information from these and the physical exam could help rule out other possible causes of the memory loss. Tests that could be used to arrive at a diagnosis include various types of brain scans, neuropsychological exams, blood tests, psychiatric evaluation and genetic testing<sup>16</sup>

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<sup>15</sup> NATIONAL INSTITUTE ON AGING, *Symptoms and Diagnosis of Alzheimer's Disease. Noticing Memory Problems? What to do Next*, available at <https://www.nia.nih.gov/health/noticing-memory-problems-what-do-next> (last visited Feb. 28, 2018).

<sup>16</sup> NATIONAL INSTITUTE ON AGING, *Symptoms and Diagnosis of Alzheimer's Disease, Diagnosing Dementia*, available at <https://www.nia.nih.gov/health/diagnosing-dementia> (last visited Feb.28, 2018).

Additionally, the physician may conduct a mini-mental state exam (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](http://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, church goers, 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 a person who has Alzheimer's 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 their loved one who is living with Alzheimer's. A caregiver should not ignore his or her own health. If the caregiver becomes unable to provide care, their family member who has Alzheimer's may need to be institutionalized sooner than he or she would have been, had the caregiver been able to provide care. Because 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 can provide training to novice caregivers. Education about the disease and how to care for someone at each stage can allow the person living with Alzheimer's to remain at home for an extended period.
7. Caregivers should begin to plan early for the present and future needs of any person diagnosed with Alzheimer's or dementia. It is most important to meet with 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 could be placed in the event care outside the home is needed.

Caregivers who are knowledgeable and supportive, 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 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 individual 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:

- The act of agitating, or the state of being agitated; the state of being moved with violence, or with irregular action; commotion<sup>17</sup>
- A stirring up or arousing; disturbance of tranquility; disturbance of mind that shows itself by physical excitement; perturbation.<sup>18</sup>

Agitation is a common emotion that every human experiences. To the person who is living with Alzheimer's, 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 person's feelings: "You seem upset, can you tell me what is wrong?" This simple question could help de-escalate a difficult situation.

The most common time when agitation is evident is during personal care. The person with dementia 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 person who has dementia that he or she is in a safe place.

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<sup>17</sup> "Agitation." *Wiktionary, the free dictionary*, 2018. <https://en.wiktionary.org/wiki/agitation> (May 7, 2018)

<sup>18</sup> "Agitation." *Wiktionary, the free dictionary*, 2018. <https://en.wiktionary.org/wiki/agitation> (May 7, 2018)

- Validate the 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 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 that you are upset
- ✓ 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
- ✓ Don't argue - you'll never win
- ✓ Laugh together
- ✓ If your talk becomes "heated," stop. Leave the room briefly and try again later
- ✓ Don't talk down
- ✓ Don't 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:

- He or she may be communicating pain, a possible urinary tract infection. Schedule an appointment with their physician.

Your loved one takes off their shirt in public:

- He or she 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:

- He or she 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:

- He or she 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...and so on.

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, Summary and Conclusion

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 adapt. 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. It is very important to talk to an Elder Law attorney while there is still the mental capacity to understand the powers that are being conveyed by a power of attorney. When there is suspicion that mental wellness is declining, do not wait to accomplish your legal planning. Because the disease may progress rapidly, it is important that documents are in place in the event the person who has a diagnosis of Alzheimer’s or dementia no longer has the mental capacity to understand the documents they need.

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, **financial** matters, and **mental health** issues.

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. At this writing, the language that is included in advance directives varies from state to state, and states are not required to accept advance directives that are from a different state. For example, in 2000 Florida enacted the Health Care Advance Directives Act, which contains some default presumptions you may not want, or agree with. 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, without a power of attorney document, 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 people do not have powers of attorney in place is not because they do not want someone to manage their affairs. Often, it is simply that they do 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.

**Mental health powers of attorney** are helpful in situations where mental health related treatment becomes necessary. This document is able to convey powers that address medication and mental health treatment issues. The **mental health power of attorney** may address your wishes concerning participation in clinical trials, experimental studies, or even your consent, or lack of consent, to the use of electroconvulsive therapy.

In our firm, we usually combine the **mental health power of attorney** with the **health care power of attorney** to ensure there is no confusion that the same person is making decisions in both areas. However, it is vitally important to address both general health decisions along with mental health decisions, since health care providers want explicit guidance on the scope of the agents' authority.

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, health care, and mental health powers of attorney is the critical first step. Because laws governing powers of attorney can change, it is important that an elder law attorney review and, if needed, update these documents routinely. Your existing power of attorney can be updated to include the required language that will be acceptable to healthcare and financial institutions.

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.

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 hydration. 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 begin by contacting 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, health care, mental health, 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 specific legal planning with an attorney experienced in dealing with dementia 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 of your 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 Veteran’s benefits. You may want to establish an irrevocable trust and transfer some of your assets to the trust to qualify for Veteran’s 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 qualification for Medicaid, you first need to know how Medicaid treats your assets. And you need to know that Medicaid rules are interpreted differently by the states and may vary from state to state. The examples used in this section are based on Florida interpretation of Medicaid rules.

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 consider at this time. Generally, the following assets are exempt:

- Home, if it is in Florida. 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.
- 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 \$2,500 may be exempt depending upon your situation
- Cash (for example, a small checking or savings account), not to exceed \$2,000
- Applicant's IRA or 401(k) plan(s), but it does count as income, to the extent of required minimum distributions.

In certain instances, some other assets, such as income-producing real estate, etc., may be either countable or exempt depending upon your unique 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 pension plans, second cars, recreational vehicles, second homes or cabins, 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 allowed to be transferred to the community (or at home) spouse and they are allowed to keep all the countable assets up to a maximum of approximately \$126,420. Any countable assets in excess of that must then be "spent down."

In other words, for a married couple who had \$200,000 in countable assets, the healthy spouse, or community spouse, would be able to keep \$126,420. The medically involved spouse would be allowed to keep his or her \$2,000. The excess would need to be spent down.

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 their assets before qualifying for Medicaid?

**Answer:** Not always. In fact, often couples have over \$126,420 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 may be able to help you determine if there are ways to protect additional assets in your situation.

**Question:** Will I 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 (exempt) asset. That means it is not considered 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. However, in Florida, there are constitutional protections for homestead that many states do not offer. In many states, creditors, including Medicaid, can force the sale of homestead property. This is not the case in Florida if the home is left to the surviving spouse or other family member. 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 \$15,000 is the most an individual can give away if he or she is going to apply for Medicaid?

**Answer:** No, the \$15,000 figure (2019) 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 Florida is currently \$9,171 (2018). Therefore, a gift will cause a penalty of one month for each \$9,171 given away.

**Question:** Is it possible to give money away and still qualify for Medicaid?

**Answer:** Generally, no. Any gifts to family members or anyone else (other than to a spouse) will trigger a lookback penalty. 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. This includes birthday or Christmas presents, even church donations. As discussed above, a gift will cause a penalty of one month for each \$9,171 given away.

**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 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:

### **1. Leave property titled solely in your name and 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. Probate is very expensive and takes a long time. 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 Florida'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.

Each state has its own intestate law and there are differences between the states regarding disposition of assets when there is no will. 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.

### **2. 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.

### **3. 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, receives an IRS tax lien, etc., 100% of that property may be subject to the lawsuit or tax lien, and the parent may be left without a home or assets. Also, that child, as legal owner, may withdraw the money for their own use and any joint owner of real estate must give their written permission before it can be sold. You basically lose control of your own assets. Joint tenancy “overrides” any last will and testament you may have executed.

### **4. Add beneficiary designations to your financial assets**

Adding a beneficiary designation (pay-on-death [POD] or transfer-on-death [TOD]) to your life insurance and financial accounts 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. For that reason, those beneficiary designations need to be periodically reviewed because of family changes; also, to ensure that the financial institution has not “lost” your beneficiary designations. This happens often, especially when banks or financial institutions are sold or otherwise merged.

### **5. 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 subject to probate. It is also very flexible in allowing distributions closely matched to your actual wishes.

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 or your kids 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 any minor children after your death, and it is critical to be sure that, where possible, the person who will be caring for these 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 to 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 elder law attorney who can examine your specific situation and advise you accordingly.

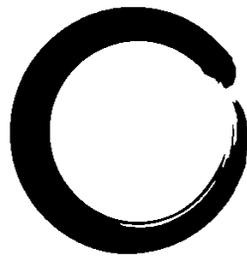


## WHAT STEPS SHOULD YOU TAKE NOW?

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 a law firm which has helped many families successfully deal with these issues, then contact our firm today!



Estate Planning  
Elder Law  
Center of Brevard

Robin M. Petersen, P.A.

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Phone: (321) 729-0087

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*[www.ElderLawCenterBrevard.com](http://www.ElderLawCenterBrevard.com)*

- ♦ Estate Planning ♦ Estate and Trust Administration ♦
  - ♦ In-Home Care Veterans Benefits Planning ♦
  - ♦ Elder Law ♦ Guardianship ♦ Medicaid Planning ♦
  - ♦ Veterans Aid & Attendance Benefits Planning ♦
  - ♦ Special Needs Planning ♦ Asset Protection ♦
- ♦ Long-Term Care Planning ♦ Business Succession Planning ♦

## *Cassidy V. Petersen, Esq., MBA*

Cassidy V. Petersen initially joined the firm in 2011 and has held various positions over the years – beginning as a receptionist, next as an estate planning paralegal, then as our firm administrator, and now as an attorney. Ms. Petersen focuses her practice in estate planning, business succession planning, probate, trust administration, Medicaid planning, VA planning, guardianship, and special needs planning.

Ms. Petersen welcomes the opportunity to discuss your estate planning, health care, and elder law concerns in order to help you develop a comprehensive and personalized plan. By planning for the future while you are healthy and able, you give yourself and your loved ones' security when illness or tragedy does strike. Advanced preparation of estate, health care, and elder law documents is an invaluable investment in your quality of life and peace of mind. Ms. Petersen works hard to earn the trust and respect of her clients by educating them on technical aspects of the law in an understandable manner. She assists clients in planning for the possibility of disability, incapacity, home health care, assisted living and/or nursing home placement, and enables them to avoid impoverishment caused by the escalating cost of long-term care.

Ms. Petersen, a Melbourne native, graduated from Melbourne High School in 2011. She earned her Bachelor of Science (B.S.) in Business Management, graduating *cum laude*, from Florida Gulf Coast University in 2014. Ms. Petersen received her Juris Doctor (J.D.), *cum laude*, from Stetson University College of Law in 2018, where she graduated among the top 10% of her class. Ms. Petersen chose to attend Stetson for its Elder Law Concentration Program. Additionally, Ms. Petersen obtained her Master of Business Administration (M.B.A.) from Stetson University in 2018.

While in law school, Ms. Petersen was a Teaching Assistant (TA) for Trusts & Estates, gained experience as a law clerk for Raymond James Trust Department, worked for a prominent elder law firm in Clearwater, FL, held a law clerk position at an international recruitment and consulting company, worked as a student associate for LexisNexis (one of the leading legal research companies), and she was an associate editor of the Journal of International Aging Law & Policy. She was also the recipient of the Melvyn Trute, P.A. Trust Award, which is provided to one law student each year who has shown excellence in the area of trusts and estates both inside and outside of the classroom.

She is a founding member of the National Alliance of Attorneys for Alzheimer's Planning (N3AP), a member of the Vassar B. Carlton American Inn of Court, and a member of the Brevard County Bar Association.

## *Robin M. Petersen, Esq., LL.M.*

Robin Petersen is the Founder and Managing Partner of the Estate Planning & Elder Law Center of Brevard, which has been serving Brevard County since 1991. The practice focuses exclusively in the areas of Estate Planning and Elder Law, Wills and Trusts, Probate and Trust Administration (representing the executor or trustee, as well as serving as the executor or trustee of the estate), Guardianship, planning for long term care costs through asset protection, the use of VA Aid & Attendance, and Medicaid benefit options. Because he has dedicated over 25 years of practice to these types of law, Robin understands that effective plans and solutions can only be achieved by taking the time to listen and gain a thorough understanding of every clients' needs, concerns, family situations, and overall goals.

After graduating with his Juris Doctor from Florida State University's College of Law in 1981, Robin obtained his license to practice law in Florida and before the U.S. Court of Military Appeals. Greatly influenced by his parents' service in World War II, and as a self-certified military brat, he joined the Air Force, where he proudly served as a legal officer (JAG).

After leaving the Air Force, Robin worked as an Assistant Public Defender. However, the memory of watching his father's family fall apart as they feuded endlessly over his grandparent's estate because of an unclear Will ultimately led him to open his own practice, the Estate Planning & Elder Law Center of Brevard.

To ensure that he could provide sage counsel to those who sought his services, Robin obtained his certification as an Elder Law Attorney through the National Elder Law Foundation, an American Bar Association accredited foundation. He is also a U.S. Veterans Administration Accredited Attorney, believing "We have a responsibility to make sure our veterans and their families receive the advice and long term care assistance they've earned and that they deserve." The desire to continually learn and grow in the field has been the catalyst for him to return to the classroom. In May of 2018 Robin earned his LL.M (Master of Laws, a post doctorate advanced degree) in Trial Advocacy at Stetson University of Law.

Because of his reputation and continual desire expand his horizons, Robin has achieved a rating of 10, the highest rating a lawyer can receive, from AVVO, one of the top websites for finding a lawyer. In addition, he is listed in Who's Who in American Law, Florida Super Lawyers, has instructed at the college level, hosts monthly seminars on topics related to Estate Planning and Elder Law, and most recently has co-authored the book, *Elder Law Strategies in Florida*.

# A GUIDE TO ALZHEIMER'S CARE



*Cassidy V. Petersen, Esq.*



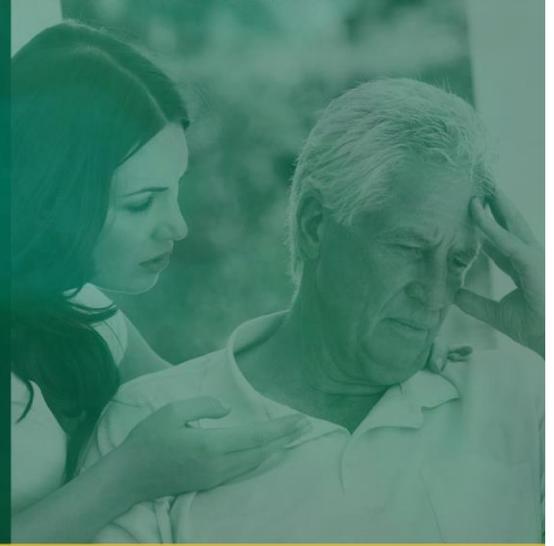
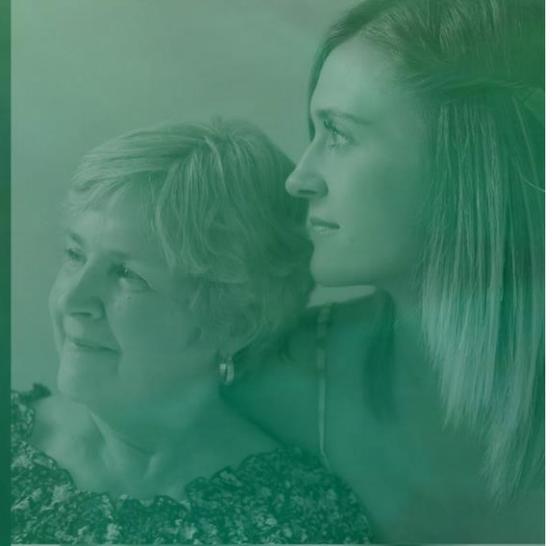
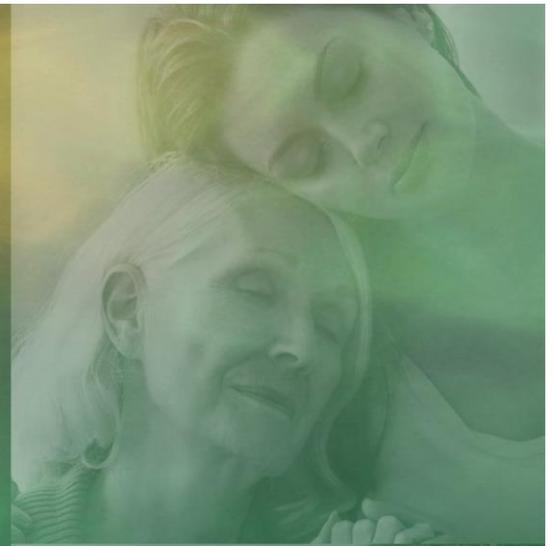
*Robin M. Petersen, Esq.*

## *Estate Planning & Elder Law Center of Brevard*

*SERVING YOUR NEEDS SINCE 1991*

### **Areas of Practice**

- Dementia/ Alzheimer's Planning
- Estate Planning
- Trust Administration
- Probate
- Elder Law
- Guardianship
- Medicaid Planning
- Veterans Benefits
- Special Needs
- Asset Protection
- Business Succession Planning



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