

DEMENTIA: UNDERSTANDING THE FACTS AND PLANNING FOR THE FUTURE



BRATTON
ESTATE & ELDER CARE ATTORNEYS

Office locations:

18 Kings Highway W., Haddonfield, NJ 08033
505 S. Lenola Rd., Ste. 119, Moorestown, NJ 08057
120 Sanhican Dr., Trenton, NJ 08618
1201 New Road, Ste. 132, Linwood, NJ 08221
1650 Market St., Ste. 3600, Philadelphia, PA 19103

www.brattonlawgroup.com

ABOUT US

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The experienced attorneys and care coordinators at Bratton Estate & Elder Care focus exclusively in specialized practice areas – elder law, life care planning, estate planning, asset protection, special needs planning, and tax. By concentrating our knowledge and expertise in these niche areas, we are able to make and maintain important personal and professional connections necessary to advise our clients. For more information about Bratton Law, visit brattonlawgroup.com or call our Haddonfield office **856-857-6007**.

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“What the heart has once known, it shall never forget.” -

Anonymous

What is Dementia?

Dementia is a term used to describe a range of symptoms reflecting changes in memory, thinking, behavior, and social skills. These symptoms are severe enough to interfere with daily life and is most common in middle-aged or older individuals, but it can also affect younger people. Dementia is not a disease; instead, several diseases cause dementia. While some memory loss can occur as people age, dementia is progressive, and over time, the symptoms will increase in frequency and severity.

Understanding the Facts

Dementia is increasing. The World Health Organization reports that more than 50 million worldwide have dementia and expects this number to almost triple by 2050. In the United States, the Alzheimer’s Association reports, from 2000 to 2017, the incidence of deaths due to dementia increased 145% in the United States. 1 in 3 seniors die due to disease-causing dementia—this is higher than prostate and breast cancer combined. Diseases which cause dementia are not currently curable, but it is possible to treat the symptoms to help improve the lives of those who suffer from diseases leading to dementia.

Signs and Symptoms

The early symptoms of dementia vary with the specific disease according to the Alzheimer's Association but can include:

- Forgetting small details such as the names of things or people
- Increasing incidents of getting lost and becoming confused when driving or walking
- Unable to keep track of time and “losing” time.
- Difficulty completing familiar tasks
- Trouble understanding visual images and relationships

As the disease progresses, the symptoms become more severe and impact the daily lives of those suffering from a disease causing dementia. As the disease advances, a person may find:

- Inability to recall recent events
- Misplacing items and unable to retrace steps
- Feeling lost at home and becoming disoriented
- Requiring help with personal care such as tying shoes or buttoning clothes
- Acting differently, including wandering and asking the same questions over and over.
- Struggling with communicating and finding words
- Unable to reason or solve everyday problems
- Paranoia

In late-stage dementia, the symptoms are much worse. The individual may experience much more intense symptoms as the disease progresses, and the individual may experience:

- Difficulty recognizing friends and family
- Having trouble walking
- Needing more assistance with care
- Behavioral and personality changes which can include aggression.
- Incontinence
- Eating and weight loss

Seeing a loved one experience these symptoms can be alarming yet not everyone who has these symptoms is diagnosed with dementia. Harvard Health recommends finding the cause of symptoms as thyroid disorders, vitamin B12 deficiency, and 50 other treatable conditions can cause dementia.

Causes of Dementia

Certain conditions leading to dementia can be reversible meaning with prompt treatment, cognitive functioning can be improved or even restored. One might experience dementia with the following conditions:

- Delirium after surgery
- Depression
- Reactions to medication such as antidepressants, narcotics, corticosteroids, antihistamines, and sedatives
- Tumors

- Subdural hematomas

In many cases, dementia resulting from any of these causes is treatable and leads to improvement of symptoms. Irreversible dementia occurs when the cause is a degenerative disease, which means the underlying cause cannot be treated or stopped. While symptoms can be treated, the diseases which cause irreversible dementia are progressive and severely impact the quality of life. Someone diagnosed with any of the following disorders has a form of irreversible dementia:

- Alzheimer's disease
- Vascular dementia
- Frontotemporal lobar degeneration
- Parkinson's disease
- Huntington's disease

The causes of all of these diseases vary as the damage occurs in different parts of the brain in each disease. Since the diagnosis with any of these diseases means the damage is progressive, over time, there will be more loss of memory and cognition and the development of other symptoms.

Dementia-Associated Mortality

Researchers at the United States Center for Disease Control and Prevention found in a study of death certificate data that, "Overall, age-adjusted death rates for dementia increased from 30.5 deaths per 100,000 in 2000 to 66.7 in 2017." Age also plays a factor in the development of dementia. People are living longer, and as they age, they are more likely to develop

dementia. The Centers for Disease Control also note that dementia-related mortality is higher for women than men. Two-thirds of dementia patients are women. While it is believed more women have dementia because they live longer than men, more research is needed to determine other possible causes.

Overview of the Most Common Types of Dementia

Alzheimer's Disease

The Alzheimer's Association, which provides information on Alzheimer's disease, notes this disease is the most common cause of dementia with approximately 60 to 80 percent of all those with dementia being diagnosed with this disease. Those in the early stages of the disease experience:

- Memory loss
- Challenges in planning or solving problems
- Depression and apathy as symptoms increase
- Challenges in recalling conversations and some words
- Recurring errors in planning and problem-solving.

The Alzheimer's Association describes how as the disease progresses, patients begin to show more severe signs of dementia:

- Feelings of disorientation, confusion, and irritability
- Challenges in walking and swallowing

- Personality and mood changes including aggressive behavior
- Judging distance and differentiating between color or contrast
- Withdrawal from social activities

In the article, “What is Alzheimer’s?” the Alzheimer Association explores how Alzheimer’s disease develops when over time, protein fragment beta-amyloid, also known as plaques appear on the outside of neurons and then are found inside of neurons. Neurons cannot function with the development of this protein and are damaged, leading to the eventual death of the neuron. These changes happen over many years, and since Alzheimer’s is a slowly progressive disease, the changes in the brain which cause dementia are irreversible. Those who are diagnosed at age 65 or older will survive approximately 4-8 years with Alzheimer’s disease.

Vascular Dementia

Vascular dementia is caused by a decreased blood flow to the brain from strokes, smoking, diabetes, or high blood pressure. Vascular dementia can happen gradually or slowly and often occurs with Alzheimer’s disease. People most at risk of developing vascular dementia are those who have recently had a stroke, heart attack, or have high cholesterol. The Mayo Clinic also advises atrial fibrillation can lead to an increased risk for stroke and the development of vascular dementia.

Lewy Body

The National Institute on Aging, offers information on this form of dementia and explains the disease of Lewy body dementia is the second most common disease-causing dementia after Alzheimer's disease. This type of dementia is caused by the presence of protein deposits called Lewy bodies, in the neurons of brain cells. This disease affects motor control and movement with some of the same symptoms of Parkinson's disease. Lewy body dementia can also cause visual, auditory, olfactory, and tactile hallucinations. Lewy body dementia is progressive and patients usually live 5-7 years after the initial diagnosis.

Frontotemporal Dementia

The Mayo Clinic explains this type of dementia as disorders affecting the frontal and temporal lobes of the brain. The affected part of the brain shrinks, and this leads to dramatic changes in their interactions with others. For example, they may become inappropriate when in a group. This unusual behavior is due to becoming impulsive and losing the ability to use language. What makes this type of dementia different from others is that it occurs at a younger age, generally between 40 and 45. Unfortunately, this disease is often misdiagnosed as a psychiatric disorder, leading to a delay in proper treatment of the symptoms.

Mixed Dementia

Mixed dementia is common and means that someone has two or more types of dementia. The National Institute on

Aging refers to this type of dementia as caused by changes in the brain due to Alzheimer's disease and another neurodegenerative condition which destroys the neurons in the brain leading to a wide variety of symptoms. The progression of the disease depends upon the areas of the brain affected and often impacts each person differently. Since any combination of diseases can cause this type of dementia, the progression of the disease, as well as the symptoms, can vary. The most common type of mixed dementia is Alzheimer's disease and Lewy body disease. With both of these diseases, an individual will have a range of symptoms and changes in behaviors.

Resources to Pay for Care

Paying for the care of a dementia patient can be challenging and usually in the case of someone who is over the age of 65, Medicare or Medicaid will be the primary ways to pay for treatment. Private insurance may also be used to care for the dementia patient in certain circumstances. Some of the ways to pay for care are outlined below. Retirement plans, non-qualified assets, personal property, and other resources may also be used for medical care in a private pay scenario.

Medicare

In some cases, due to the age of onset of dementia, Medicare is used to provide care and is a federal health insurance plan for people 65 and older or those who have been receiving disability payments for two years. Medicare is beneficial as it covers inpatient care but not long-term care and some of the fees for treatment of dementia in those 65 or older. The

challenge with Medicare is understanding precisely what it will cover. This type of insurance will pay up to 100 days of skilled nursing care if certain requirements are met, but long-term care is not included. Toward the end of life, Medicare will pay for hospice. Once the 100 days of skilled care are used, another form of insurance or private pay is needed to continue long-term care. This period is when Medicaid can be used to help with rising healthcare costs for those with dementia.

Medicaid

Medicaid offers those who are low income with few assets the opportunity to have long-term treatment for dementia. This government plan is funded both by the federal government and the states. Each state has specific eligibility and benefits for Medicaid.

For dementia patients, Medicaid is used to pay for in-home care, adult day care, assisted living, foster care, and nursing homes. Dementia Care Central, an online resource developed with funding from the National Institutes of Health, offers resources for understanding how Medicaid can be used for the treatment of dementia patients. The first step is qualifying for Medicaid. In some cases, it is easy to determine whether or not someone is eligible for Medicaid:

- For single applicants, most states allow up to \$2,349 in monthly income in 2020 and up to \$2,000 in assets. Unless the individual is in a nursing home, or assisted living, he or she can keep the monthly income as long as it does not exceed this limit. Nursing home and assisted living patients must

surrender most of their income to pay for services. If the income is higher than this amount, some states allow the use of a Miller Trust.

- When an applicant is married, the spouse who is receiving care will be evaluated separately from the spouse remaining at home.
- When two married applicants apply for Medicaid, generally the joint assets must be less than \$3,000 in most states.

A qualified elder law attorney can help in planning for accessing Medicaid benefits as exceptions apply in some cases. An elder law attorney can also assist in protecting assets for a Medicaid applicant or the spouse and family.

Veterans Benefits

Veterans can receive care for dementia through a range of services offered at the United States Department of Veteran Affairs (VA). The VA reports more than 69% of veterans do not know the benefits available to them for treatment and care of dementia. One specific benefit, the Aid and Attendance Pension, can reduce costs associated with care and offer anywhere from about \$1209 to \$2230 per month to a veteran or the veteran's spouse. These funds can help in paying for services:

- In-home care
- Board and care
- Private pay nursing homes
- Assisted living

Those who qualify for this resource are those who meet at least one of the following requirements:

- Age 65 or older with limited income
- Totally and permanently disabled
- Receiving Social Security Supplemental Income (SSI)

After applying for Aid and Attendance, it can take several months to begin receiving benefits. It is important to note as well that only 1 in 7 veterans entitled to Aid and Attendance claim it.

Long Term Care Insurance

Long term care insurance helps to cover costs for extended care not covered by health insurance or Medicare. These services include bathing and help with other daily tasks. The AARP reports that by the time an individual reaches 65, there is a 50-50 chance he or she will require long term care at some point in life. The cost for long term care on the average is \$140,000. Choosing a policy to protect yourself from unexpected costs can be a wise decision if within your budget.

Long term care coverage can pay for:

- Nursing home care
- Assisted living facilities
- Adult day care services
- In-home care
- Home modification
- Care coordination

It is worth noting that long term care insurance is a good choice for families who have assets that exceed the Medicaid guidelines as it will enable them to avoid using savings to pay for care if they also have an asset protection plan in place.

Ramifications of Not Planning

Caregiver Burnout

Caring for someone with dementia is stressful, and it is common for caregivers to experience a wide variety of emotions. The Alzheimer's Association cautions that caregivers, also known as the invisible second patients of dementia commonly feel exhausted, irritable, and depressed, which can lead to burnout. Caregiver stress can also include anger, social withdrawal, and anxiety. Caring for a loved one with dementia can be draining and cause burnout often results in a decline in mental and physical health for the caregiver.

Poor Decisions on Placement

Finding the right long-term care facility for someone with dementia is challenging and becomes even more complicated if the family of the patient has not made plans for a loved one. Planning for long-term care for dementia patients is one of the most important decisions a family will have to make because care is so expensive. Families often know that Medicaid, if the dementia patient is approved for benefits, can be used to pay for long-term care, but what is less well known is the out of pocket costs for such care. If planning is not done, the family may have to put a dementia

patient in a less than desirable facility or may incur enormous costs for care. Understanding how to use resources effectively is essential to avoid having to make poor decisions.

Loss of Retirement Assets and Savings

Paying for long-term care is a challenge for dementia patients and their families. The Alzheimer's Association cautions that without planning, a dementia patient's family may have to use all retirement assets and savings first as Medicaid, a resource for paying for long-term care, has strict limitations on income and personal assets as it is expected someone with dementia will use all available resources before being approved for Medicaid. If a plan is not in place at the time when someone needs long-term care, the risk of losing valuable assets rises considerably.

Loss of Home

No one wants to lose a home to pay for nursing home costs. Without proper planning for long-term care, this can happen. In some cases, as noted by the Alzheimer's Association, Medicaid payments can be paused until the dementia patient's home is listed for sale, further placing stress on the family to pay for long-term care during this time. In some cases, with proper planning, the home may not have to be sold, and there won't be a pause in Medicaid benefits for the patient, which avoids the traumatic experience of losing everything in the process of seeking out the necessary care for a loved one.

Failure to Obtain Medicaid If Not Applied for Properly

At some point, most dementia patients will need Medicaid for long-term care. It is not uncommon for the patients who need Medicaid the most, to be denied for benefits. This denial often happens when a family does not know much about Medicaid and has not developed a plan with an attorney for long-term care of a senior. According to the American Council on Aging, families will discover the most likely reasons for being denied Medicaid are because of income or assets which exceed the guidelines for Medicaid. Another reason for denial of Medicaid is the look-back penalty which means that if a family disposed of assets to help a loved one qualify for Medicaid, there would be a delay in approval as all assets need to be used to pay for long-term care before Medicaid provides benefits. One might wonder how planning could help in this situation, and by meeting with an attorney to make a long term plan, the family will be able to avoid a gap in services, such as a period of denial of Medicaid while also keeping certain assets.

Legal Steps to Take Now

POA

In estate planning, a power of attorney, also known as a POA, can grant someone the ability to act on another's behalf when decisions in managing finances are necessary. When developing a plan to care for a dementia patient, considering a power of attorney is crucial as it will allow someone trusted by the patient to make decisions related to

the management of assets over time. A power of attorney grants another person the right to manage finances but not necessarily to make healthcare decisions. In the event healthcare decisions need to be made, another type of power of attorney is required, called the healthcare power of attorney.

As dementia progresses, some of the symptoms may leave the patient confused and unable to make decisions in his or her best interest. This is how a power of attorney can safeguard against poor choices and ensure that all assets are safely protected.

Healthcare POA

Planning for someone to make medical decision for a dementia patient is another step in estate planning. The New Jersey Department of Health, advocates for creating an advance directive to allow others to make medical decisions for dementia patients when needed. The advance directive includes an instruction directive and a proxy directive. A proxy directive is known as a healthcare power of attorney in New Jersey and allows someone to make medical decisions on behalf of a dementia patient. Without a proxy directive, healthcare decisions may be made by a court or guardian, which may not reflect the wishes of the patient. The choice to create an advance directive will also avoid the unfortunate occurrence of relatives trying to take over the patient's care. Sometimes, people think a durable power of attorney, which allows oversight of financial issues also permits someone to make medical decisions. Knowing the difference between the two is essential.

Living Will

In addition to power of attorney, dementia patients can choose to create a living will also called an instructive directive. This option will allow a dementia patient to clarify the treatment and care when he or she is incapacitated and unable to make decisions. A living will is often used as a guide in decision making for life-sustaining treatment. Planning for such situations is necessary to avoid the court or a guardian making decisions on the dementia patient's behalf.

Will

Planning for the care of a dementia patient also includes creating a will. If a dementia patient's symptoms are worsening, and he or she desires to make a will, this is still possible as long as the patient is not incompetent. Determining an individual's competence relies upon certain things in New Jersey--that the person can understand the meaning and purpose of the document, identify their intended beneficiaries and can understand what property is involved. Making a will as soon as possible after the diagnosis is the best option to make sure the patient is competent to make decisions and that the wishes of the patient are clearly defined.

Living Trust

A living trust provides information about what to do with property and assets, similar to a will. The Alzheimer's Association notes that the difference with a living trust is that

all financial assets can be put in one place, and appointing a trustee will ensure the trust will be managed should one become unable to do so. The way it works is that all assets such as titles of property, bank accounts, and other resources are transferred to the trust. In some situations, a living trust even allows an estate to avoid the process of probate. The trust maker, also known as the Grantor, usually creates a living trust to address the possibility of avoiding probate and planning for possible incapacity. At the time of death, the property in the living trust can be either distributed to beneficiaries or the trust can continue.

Irrevocable Trust

Creating an irrevocable trust creates some of the same benefits of revocable trusts. An irrevocable trust can determine precisely how much a beneficiary will receive and when he or she will receive the property. Also, it can help shield property from probate, avoid taxes, and protect assets from creditors, divorcing spouses, and long term care costs. An irrevocable trust is different from other types of trusts because it cannot be changed without the permission of the beneficiary or, possibly, a trust protector. The benefit of having an irrevocable trust is that once assets and property transfer into the trust, these resources no longer belong to the trust maker and are safe from creditors. One of the most significant benefits from creating an irrevocable trust is if the property in the trust increase in value, it is safe from future taxes on the estate.

Taxation

Trusts are taxed in one of three ways for income tax purposes:

1. Simple Trust – The trust language dictates that the income must be distributed to the beneficiary and therefore the income will be attributed to the beneficiary to be placed on his/her tax return.
2. Complex Trust – The trust language states that the income may be distributed to the beneficiary. In this case, the income will be attributed to the beneficiary if distributed to him/her, or, in the alternative, if not distributed to the beneficiary then the trust income will be taxed at compressed trust rates.
3. Grantor Trust – The trust income will be attributed to the Grantor to be placed on the Grantor's tax return.

It is essential to understand which type of trust you have for income tax purposes as each may have a significant tax consequence and you do not want to be caught unaware.

Guardianship

Guardianship allows others to make decisions for an incapacitated person. This responsibility includes managing care and overseeing finances. The New Jersey Department of Health and Human Services cautions that guardianship will only be granted by the court if a loved one is incapacitated and unable to make decisions on his or her own. The Superior and Surrogate's Court in New Jersey is responsible for granting and monitoring the guardianship of

the elderly and generally will grant the petition for the guardian to manage assets, take care of expenses, and oversee finances.

Care Options for an Individual with Dementia

Adult Day Cares

Adult day care is the opportunity for caregivers to get a respite from caring for an elderly individual, and to offer the elderly the chance to socialize, have supervised medical care or dementia care. The Administration of Community Living, the government agency developed to help seniors stay in their communities and avoid institution notes the following services are available at adult day cares:

- Counseling
- Education
- Evening care
- Exercise
- Health screening
- Meals
- Medical care
- Physical therapy
- Recreation
- Respite care
- Socialization
- Supervision
- Transportation
- Medication management

The most significant benefit of adult day care is allowing an individual to remain within the community while a caregiver works or takes a break from providing care. Adult day care can be costly, but options for paying for care include Medicaid, Medicare, or the Veterans Health Association. Area agencies on Aging (AAA) can also assist in finding the right adult day care and options for paying for services.

Home Health Care

Home health care refers to treatment given in the home for illness, injury or chronic conditions, and Medicare reports that home health care can include:

- Wound care for pressure sores or a surgical wound
- Patient and caregiver education
- Intravenous or nutrition therapy
- Injections
- Monitoring serious illness and unstable health status
- Skilled therapy services including physical, occupational, and speech

To start the process for home health care through Medicare, a doctor will need to order the care. Then a home healthcare agency will work with the doctor and the family to provide care right in the patient's home. One valuable reason for having home healthcare is that the agency providing the care will coordinate with doctors and others to make sure a senior receives medication and recommended treatment. This service is for those who have a home in the community and wish to remain in it while receiving medical care and

supervision. Private duty home care is also an option and does not require a doctor's order.

Assisted Living Facilities

Assisted living facilities describes a community of those needing less daily care and who are still somewhat independent. Those who are in assisted living facilities may need help with medication or require some medical care. The National Center for Assisted Living identifies the types of services an individual with dementia or another health issue may receive in such facilities:

- 24-hour supervision
- 3 meals a day in a group dining room
- Personal care services (help with bathing, dressing, toileting, etc.)
- Medication management, or assistance with self-administration of medicine
- Social services
- Supervision and support for persons with Alzheimer's or other dementias and disabilities
- Recreational and spiritual activities
- Exercise and wellness programs
- Laundry and linen service
- Housekeeping and maintenance
- Arrangements for transportation

On average, a senior may stay in an assisted living facility for 2-3 years before moving on to a nursing home if that becomes necessary. Most assisted living facilities are not

able to provide the intensive medical care of nursing homes, and those needing more care should explore nursing homes.

Nursing Homes

When a senior needs more intensive full-time care, a nursing home may be the best option. These facilities offer housing, 24-hour supervision, and rehabilitation services. The National Institute on Aging (NIA) provides information about nursing homes and how to select the best one for the senior's needs. Some of the specific services offered include:

- Nursing care,
- 24-hour supervision,
- Three meals a day
- Assistance with everyday activities.
- Rehabilitation services, such as physical, occupational, and speech therapy.

Although some elderly individuals may live in a nursing home for a short while after hospitalization, most residents stay for a longer time period. Choosing a nursing home is a crucial decision for seniors.

Hospice

Hospice is a service provided when a senior is diagnosed with a terminal illness. Hospice care provides support and ongoing medical supervision for the individual when treatment for the terminal illness stops. Usually, hospice becomes an option when a doctor determines a patient has

six months or less to live. These services can be provided at home, in a nursing home, in an assisted living, or even an inpatient hospice unit. The National Institute on Aging recommends exploring all the hospice services available such as:

- Teams of doctors, nurses, spiritual advisors, and trained volunteers
- Care including medical, emotional and spiritual support

The hospice team is available 24 hours a day and visits regularly. It is also worthwhile to note that while treatment for the terminal illness may end, other treatment may continue in hospice such as care for high blood pressure, infections or symptoms which are related to the terminal illness.

Caring for the Caregiver

Caregivers of dementia patients encounter many challenges, and to take care of others, they need to remember to take care of themselves. Knowing when to take a break or how to access resources in the community is essential to avoid burnout. Some options include:

- Respite services - provides short term care for an individual with dementia so a caregiver can go on vacation, shop, visit friends, or do other things to deal with the stress.
- Meal services - offers prepared meals to seniors

- Counseling and therapy - these services are in addition to adult day care, home health care, and hospice, which allow a caregiver to have time to recover from the intense demands of caring for someone with dementia.

Other resources include agencies and organizations which can help provide support to caregivers. The National Institute on Aging suggests that caregivers contact these agencies:

1. NIA Alzheimer's and related Dementias Education and Referral (ADEAR) Center
Email: adear@nia.nih.gov
Phone: 1-800-438-4380
www.nia.nih.gov/alzheimers
2. Alzheimer's Foundation of America
Phone: 1-866-232-8484
www.alzfdn.org

In addition to these resources, the team at Bratton Law can help with coordinating health and long term care, offering support and education to families and serving as the elder's advocate.

Conclusion

In order to make the best decisions for you and your family, consulting with an elder law attorney will enable you to consider all the options available to you and provide you with the knowledge, guidance and expertise to navigate the

often complicated legal procedures necessary to ensure your assets remain safe and are protected throughout your lifetime. Bratton Law has the experience and the knowledge to offer you the best in estate planning, elder law, and life care planning with compassion and a knowledgeable staff.

For elder law, life care planning, estate planning, asset protection, and probate administration, contact Bratton Law today.

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