# **Memory Care Resources for Veterans**

Receiving an Alzheimer's diagnosis can be devastating for both seniors and their loved ones. And while the news itself can be overwhelming, getting the right diagnosis is also the first step in receiving the right care. From therapies to medications, new and innovative treatments are being developed all the time to improve the quality of life of those living with memory impairment.

Understanding the disease and getting the right treatment as soon as possible is the best way to ensure that patients lead the best lives possible.

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# **Stages of Dementia**

Dementia is the general term used to describe memory loss and the deterioration of cognitive abilities, and Alzheimer's disease is the most common cause of dementia among older adults. In America, 1 in 9 adults over the age of 64 has the disease and that number rises to 1 in 3 once adults reach age 85. Alzheimer's is a progressive disease where the symptoms develop slowly and gradually get worse over time, eventually becoming severe enough to interfere with common everyday tasks.

Medical professionals often discuss dementia in stages. These stages refer to how far dementia has progressed and which symptoms one can expect to experience. Having these clearly defined stages helps caregivers understand where their loved one stands with the disease and allows them to better determine the right course of treatment.

Generally, dementia is defined in three stages – early, middle, and late.

## **Early Stages**

Patients in the early stages of dementia have difficulty concentrating, trouble remembering recent events or recently learned information, may have trouble managing their finances, and find it hard to travel alone to new places. Patients will also begin having a hard time socializing and may become withdrawn or refrain from doing activities they once enjoyed. Despite some of the symptoms still being mild, a physician will be able to diagnose dementia in the early stages.

## **Middle Stages**

Patients in the middle stages of dementia will start having major memory lapses. In addition to forgetting recent events, people in this stage will often begin to forget vital pieces of information like their home address, their phones number, and even the names of close friends and family. At this point, many patients will need some help completing daily living activities such as preparing meals, dressing, and bathing. As patients reach the late-middle stages their ability to speak declines and incontinence often becomes a problem. Noticeable personality changes and emotional problems are also common as many patients become anxious and agitated and may even experience delusions.

## Late Stages

As patients enter the late stages of dementia, they often lose the ability to speak and communicate. These patients will require help with even the most basic activities like eating and using the bathroom. They also often lose their psychomotor skills like the ability to walk.

Depending on the stage of dementia, the course of treatment for each patient will vary.

# **Managing Dementia**

The amount of care that a person with dementia requires will vary by the stage of the disease. Unfortunately, there is no cure for dementia, but there are some treatments available that have been shown to improve brain function and slow the disease.

## Medications

Depending on the patient and stage of the disease, doctors may prescribe one of several medications to improve brain function and slow symptoms. Medications are generally most effective in the early and middle stages of dementia and can help reduce symptoms, improve a patient's overall quality of life. Medications commonly used to treat dementia include:

- Cholinesterase inhibitors
- Memantine
- CBD

In other cases, medication might be prescribed to treat other conditions that are common with dementia. Many patients will struggle with insomnia, depression, anxiety, and psychosis over the course of the disease and medications that eliminate or minimize those symptoms can help patients live a more fulfilling and comfortable life. Some of these medications include:

- Anxiolytics used to relieve anxiety and agitation
- Antidepressants help improve both mood and function
- Antipsychotics used to treat psychosis and minimize hallucinations
- Hypnotics help patients fall asleep and stay asleep throughout the night

## **Therapies and Alternative Medicine**

Along with prescriptions, many patients find that natural medicines and various therapies are able to ease the symptoms of dementia and slow the progression of the disease.

#### Diet

A diet rich with leafy green vegetables, cruciferous vegetables, and fish has been shown to have a positive impact on dementia symptoms. Foods like these are high in antioxidants and can help to protect cells from damage.

#### Exercise

Even light physical activity like regular walks and gardening have been shown to promote brain health. While there isn't yet evidence that proves exercise slows the progression of dementia, it has been shown to help ease symptoms like anxiety, depression, and insomnia.

#### **Brain Exercises**

Studies have suggested that puzzles and brain training games like crossword puzzles and Sudoku may help slow the progression of dementia. Regularly reading books, playing board games, using a brain training app, and playing card games are other enjoyable brain exercises.

#### Therapy

Different forms of therapy have been shown to ease the symptoms of dementia patients and help improve their quality of life. For example, art and music therapy allow patients to experience something they enjoy and stimulate their mind while also serving as valuable social interaction.

#### **Alternative Medicine**

Many doctors now suggest alternative medicines such as acupuncture and massage therapy in addition to medication and traditional treatment. Massage therapy stimulates blood flow and acupuncture can help improve energy. Therapies like this can help ease symptoms and help release physical pain and tension.

# **Memory Care for Veterans**

When we think of the sacrifices that veterans make, we often think of time, life, or obvious physical injuries. Sometimes the sacrifices are more subtle, however. Veterans who served in combat zones experience both Traumatic Brain Injuries (TBIs) and Post Traumatic Stress Disorder (PTSD) at higher rates than the general population because of their exposure to hazards like explosions as well as other forms of violence and trauma. Recent research is finding that veterans who experience TBIs and PTSD are at risk for cognitive problems later in life. In one 2010 study, for example, researchers found that veterans with PTSD were twice as likely as their veteran peers without PTSD to develop dementia. A different study conducted in 2019 by some of the same researchers found that veterans with even "mild" TBIs were at a twofold increased risk of developing dementia.

As veterans who served in conflicts from World War II to the Gulf War and beyond reach mature ages, many of them are experiencing Alzheimer's or other forms of dementia. Some may be able to trace their illness to TBIs or PTSD that they experienced as a result of combat. Many veterans who served during peacetime have to deal with dementia diagnoses as well simply due to genetic predisposition or other factors. Whatever the cause of the disease, these veterans and their families are faced with the task of paying for the increasing costs of care associated with dementia. Veterans Affairs (VA) provides a variety of programs that can help with veteran memory care needs, but the options can be overwhelming for those unfamiliar with the VA system.

To help veterans and their families, we've created a guide to walk you through the basics of dementia and memory care. In this guide, you'll explore several ways that the VA can help you afford memory care services, and you'll find answers to some of the most frequently asked questions about memory care.

# The Basics of Dementia and Alzheimer's Disease

Dementia is a general term referring to cognitive decline that interferes with a person's ability to reason, remember, make choices, and complete normal daily activities. If you are a caregiver of a veteran, having some basic knowledge of dementia can help you understand the challenges the person you care for may be facing and can help you communicate more effectively with doctors.

## **Types of Dementia**

Alzheimer's is the most common kind of dementia for veterans and for the general public, but it's not the only one. Below you'll find quick explanations of the different kinds of dementia and their causes, symptoms, and progressions.

## **Alzheimer's Disease**

Between 60% and 80% of dementia cases are caused by Alzheimer's disease, according to the CDC. It typically affects those 65 and older, though there is a rarer, early-onset version of the disease that can affect those as young as 30. The hallmark of Alzheimer's is abnormal plaques and tangles that build up in brain tissue, as well as a loss of neurons. Small instances of memory loss, confusion, and mood changes are often the first signs, and symptoms become progressively worse over time.

#### Lewy Body Dementia

This type of dementia is caused by abnormal deposits of the protein alpha-synuclein in the brain. These deposits are referred to as "Lewy bodies," and they are separate from but can occur alongside the tangles and plaques associated with Alzheimer's. Lewy bodies also occur in Parkinson's disease, and there are Parkinson's and non-Parkinson's versions of this dementia. Muscle tremors and stiffness, along with hallucinations and fluctuations in recall, attention, and energy are common in Lewy Body dementia.

#### Vascular Dementia

Vascular dementia occurs when blood flow to the brain has been hindered by a condition or event, such as narrowed blood vessels, a stroke, or a brain hemorrhage. In the case of vascular dementia caused by a stroke, dementia can worsen dramatically if other strokes occur. This is in contrast to the gradual decline typically experienced by those with Alzheimer's disease. Symptoms can vary depending on the exact region of the brain affected. Uncontrolled diabetes and poor cardiovascular health are both risk factors for vascular dementia.

#### **Frontotemporal Dementia**

This term refers to <u>a wide range of disorders</u> of the brain in which tissue damage occurs in the regions behind the forehead or by the ears. Amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease, is just one well-known example of this kind of dementia. Diagnosis of one of the frontotemporal dementias tends to occur when a patient is between 40 and 60, which is significantly earlier than the average Alzheimer's diagnosis. The earliest signs are usually related to muscle function, and memory problems may show much later than in other forms of dementia.

#### **Mixed Dementia**

Often times, a patient can suffer from multiple forms of dementia. Because one form of dementia's symptoms may be more pronounced at first, medical professionals and family members alike can initially miss the fact that the patient has mixed dementia. An example of this could be a patient in the early stages of Alzheimer's who has suffered a ministroke that went undetected. Because the patient was already having trouble recalling things and was experiencing mild depression, this sudden increase in confusion and his trouble with making decisions may at first seem like the natural next step in Alzheimer's rather than evidence of a new condition.

#### "Reversible" Dementia

Sometimes what at first appears to be Alzheimer's or another form of dementia may actually be a temporary and treatable deficiency, a problem with medication interactions, an addiction to illicit drugs or alcohol, or a hormonal imbalance, especially of the thyroid. It could also be a brain tumor that is treatable but is interfering with brain function. These conditions are very different than the above dementias because they can be reversed with a prescription, procedure, or even a lifestyle change in some cases. Problems like these are often referred to as reversible dementias. The questions doctors ask and the tests they run are often designed to rule out some of these conditions during the diagnostic process.

## **Signs of Dementia**

Not every dementia presents with the same symptoms, and the list of possible symptoms associated with dementia is quite long. Below you'll find the most common symptoms, though the list is by no means exhaustive.

#### **Common symptoms:**

- Trouble recalling recent events
- Confusion and trouble making decisions
- Hallucinations and delusions
- Getting lost in familiar settings, including while driving
- Changes in sleep habits
- Reduced attention to personal care and grooming
- Trouble finding the right word or name, or general trouble with communication
- Fear, anxiety, or depression
- Aggression and anger
- Inappropriate speech or actions that indicate a loss of inhibitions
- Loss of independence in daily tasks
- Shuffling or difficulty with walking
- Staring spells

Many of these symptoms can occur on their own from time to time in perfectly healthy people, and the veteran in your life being occasionally forgetful or moody doesn't necessarily indicate that they have dementia. However, a doctor is the most qualified person to evaluate what changes in mood, memory, communication, or behavior mean in a senior. It's a good idea to schedule regular health checkups with a VA or community doctor and to discuss any symptoms even if they seem mild.

## **Stages of Dementia**

Stages of dementia vary dramatically depending on the kind of dementia. However, most forms of dementia have an **early, middle, and late-stage,** with only a few mild symptoms appearing in the early stage, more in the middle stage, and many and severe symptoms in the late stage that lead to a total loss of independence until the end of life.

Since Alzheimer's Disease is the most common form of dementia, we've provided a more detailed explanation of its stages below. This progression varies by patient and often occurs over a four-to-eight-year time period, though it can last longer.

## **Early Stage**

In the mild early stage, a person can often still drive, work, and care for her or himself reasonably well. It may become apparent that the person is losing things, forgetting new names, or having difficulty with planning ahead or with work and social activities. It may be difficult for family members to tell if some of the forgetfulness is normal or a symptom of brain changes, and a doctor should be consulted. The person experiencing the symptoms will probably be aware of them and troubled by them. A doctor may prescribe various forms of therapy or medication.

#### Middle Stage

In this stage, symptoms become more obvious but are still considered moderate. This stage can last for years. The patient will need support or frequent reminders for many daily activities such as personal grooming, selecting clothes, and using the restroom. Confusion, wandering, changes

in sleep, and forgetfulness about personal history is likely, and mood swings or delusions and hallucinations are also common.

#### Late Stage

In the late stage of Alzheimer's, symptoms are so severe that the patient is reliant on caregivers for virtually every facet of daily life, even including walking. Muscle control will decline, the patient will be less active or even immobile and will be prone to secondary health problems like pneumonia and other infections. The patient may appear totally unaware of his or her surroundings and will rarely attempt to communicate. Late-stage care will always include around the clock assistance, which is often referred to as memory care.

#### **Overlapping Stages**

The stages of Alzheimer's and other forms of dementia aren't clear cut. It might be difficult to say precisely which stage a patient is in. However, the main point of the stages is that the disease becomes progressively worse, affecting more and more daily functions as time passes. For more information on the stages of Alzheimer's, you may want to explore this <u>helpful article</u> from the Alzheimer's Association.

# **Alzheimer's and Dementia Treatment and Memory Care**

## **Benefits of Alzheimers and Dementia Treatment**

Most forms of dementia are currently considered progressive and incurable, although advances in medicine may change that in the future. Just because we don't have a cure now doesn't mean that a veteran experiencing dementia doesn't benefit from treatment, however. On the contrary, doctors and therapists have developed an array of treatment techniques that can make a dementia patient's life better. Patients can benefit from medications, therapies, activities, and assistance that range from in-home help to full-time memory care in a medical facility.

#### Proper treatment, including memory care, can:

- Slow the worsening of symptoms
- Improve the happiness and health of the patient
- Reduce the risk of injury for patients and caregivers
- Alleviate caregiver stress

## **Elements of Dementia Treatment**

Below we've outlined some key elements of dementia treatment so that you can know what to expect as you and your loved one learn more about their condition.

#### Diagnosis

A medical evaluation for the purpose of diagnosis can take many different forms, but will probably include all of the following:

- A general physical exam and inquiry into overall health and habits
- Conversation with the patient and oral, written, or physical tests to gauge cognitive function and reflexes
- A conversation with the patient's caregiver or spouse about their observations

In many cases, a doctor may order one or more of the following:

- Blood or other lab tests to rule out deficiencies or hormonal imbalances that are reversible
- CT or MRI scans to check for evidence of strokes, internal bleeding, or tumors
- PET scans to confirm the presence of Alzheimer's-related protein deposits or to evaluate brain activity

Be aware that problems with memory and moods aren't always evidence of incurable dementia. Poor nutrition, lack of sleep, depression, anxiety, thyroid problems, or tumors, and a variety of other conditions occasionally interfere with memory and manifest similar symptoms to those of other dementias. Early diagnosis is important in part because a professional will be able to distinguish between dementia and other conditions.

#### Medication

Once a senior has been diagnosed with Alzheimer's or with another form of dementia, a doctor may prescribe medication to manage symptoms. Not every patient will take the same medication for the same symptoms, and doctors may decide that medication is not helpful in some cases.

#### Commonly prescribed medications for dementia patients include:

- **Cholinesterase inhibitors:** These drugs alter brain chemistry in order to boost the levels of key chemicals involved in memory. Cholinesterase inhibitors are commonly prescribed to patients suffering from Alzheimer's, Lewy Body dementia, or Parkinson's disease.
- Memantine: This drug improves memory and daily function in some Alzheimer's patients. It works by blocking certain chemical receptors and altering the way the brain handles glutamate.
- Selective serotonin reuptake inhibitors (SSRIs): Dementia patients often experience depression and anxiety in addition to memory problems. These mood disorders can be a response to the diagnosis of dementia and fear for the future, and they can also be a symptom of changes within the brain caused by dementia. Selective serotonin reuptake inhibitors (SSRIs) can be used effectively to improve a patient's quality of life and to ease mood swings.

• Antipsychotics: With some forms of dementia, including Alzheimer's, hallucinations are common. Doctors sometimes prescribe antipsychotic drugs to reduce or eliminate hallucinations that are distressing to the patient. This kind of medication poses some risks to elderly patients and is generally used with caution and increased supervision.

Some of these medications can trigger serious or unpleasant side effects or interact with other medications that a senior takes. It's crucial that caregivers pay attention to how medication is affecting their loved ones. It's also important to return to follow up visits on whatever schedule the doctor suggests for monitoring the effect medications are having on the patient's dementia.

#### **Therapy and Activities**

Physical therapy, occupational therapy, and even music and art therapy can all be tools for improving the safety and happiness of patients with Alzheimer's or other dementias. Activities that include social elements that are stimulating without being overwhelming are often recommended because they can improve the patient's sense of well being and level of activity. Patients that don't participate in stimulating activities may decline more quickly than those that do.

Therapy can be useful for family caregivers, too. Therapy of various kinds can teach caregivers important coping skills and communication techniques so they don't become burnt out. Support groups for Alzheimer's caregivers are also often available in local communities.

#### **Assistance and Memory Care**

Patients in the middle and late stages of Alzheimer's or other forms of dementia need full-time assistance either from a family member, a nurse, or other trained professionals. The level of assistance needed varies quite a bit, but it generally starts as the need for someone to mind the patient and help them with activities of daily living such as cooking and taking medication, and then progresses to more medical and labor-intensive needs as the condition worsens. The provision of assistance for dementia patients, especially around the clock assistance in a secure medical facility, is often referred to as "memory care."

## **Memory Care Settings**

There are multiple types of locations where veterans can receive memory care: including at home and in a residential facility. More specifics are provided below.

- **In-home care:** Many families opt for in-home memory care, especially in the middle stage of Alzheimer's disease. Family members often serve as paid or unpaid caregivers, but they may also rely on non-medical trained aides from a community aide program during certain hours, especially to help with bathing and other difficult tasks. Many families also utilize "respite care" in which a paid caregiver takes over for a period of hours, days, or even weeks so that a family caregiver can go out of town or take a much-needed break.
- **Blended adult daycare and in-home care:** Adult daycares exist to provide secure medical or non-medical memory care and assistance while caregivers work. Adult daycare can be cost-effective and enable the adult child of a veteran with dementia to

make a living while looking after and providing a home for the parent at night and on days off. This is an ideal setup for those who can't be full-time caregivers but who still want to be very involved in the dementia patient's daily life. Adult daycares typically provide transportation and meals.

- Assisted Living: Privately owned assisted living facilities often have a memory care wing within the building. These wings will have private or semi-private rooms for the patients. A memory care unit within an assisted living facility will offer all of the meals and other services typically offered within the assisted living facility, with the addition of 24/7 supervision provided by trained staff. Many locations include alarmed doors to prevent dangerous wandering. The cost of care in these units will always be higher than the cost of living within regular areas of the same assisted living community.
- Nursing Homes: Nursing homes frequently provide memory care in special units or separate floors. Patients can receive 24/7 care from staff who are specially trained to handle dementia needs. Staff-to-resident ratios in nursing homes are regulated by state laws and could be even lower than one-to-ten, depending on location. Memory care units have secure perimeters so forgetful patients cannot wander off and put themselves in danger. These units are ideal for patients who need constant supervision along with skilled nursing care.
- Medical Foster Homes: Medical foster homes are local households that contract with the VA to provide full-time care equivalent to that provided in nursing homes .These homes are licensed and inspected regularly, and they may house veterans alongside non-veterans. Medical foster homes are staffed 24/7, and they typically have about six adults in them at a time. Caregivers live within the home. These homes typically receive funds from families rather than directly from government sources like the VA.

# VA Programs for Memory Care

#### **Overview of VA Memory Care Options**

	<u>Homemaker and</u> <u>Home Health</u> <u>Aide Care</u>	Veteran Directed Home Based Care (VD-HCBS)	<u>Aid and Attendance</u> <u>Allowance</u>	<u>Community Nursing</u> <u>Homes</u>	VA Community Living Centers	State Veterans Nursing Homes
Type of Benefit	In-home caregiving.	Funding for in-home caregiving, adult daycare, supplies, or other needs.	Additional pension funds for caregiving needs.	24/7 residential care with skilled nursing/ memory care.	Home-like 24/7 residential care skilled nursing/ memory care.	24/7 care with skilled nursing, domiciliary care, and often adult daycare and memory care.
Care Provider	Trained non- medical personnel.	Any home-based caregiver the family chooses.	In-home caregivers, medical foster homes, assisted living, or other providers the veteran chooses.	Private-sector providers that employ skilled nursing professionals.	Skilled nursing providers employed by the VA.	Skilled nursing in state-run, VA-approved centers.
Eligibility	Veterans who need help with ADL.	Veterans who need help with three or more ADL (in most cases)	Eligibility for the regular VA pension plus clinical need for help with ADL.	Determined by service- connected disability status, level of disability, and income.	Determined by service- connected disability status, level of disability, and income.	Determined by each state, spouses sometimes eligible for admission.
Cost to Patient	Possible copays.	Possible copays.	No cost unless needs exceed pension amount.	Possible copays.	Possible copays.	Varies by state and sometimes partially covered the VA.
Availability	Available in most communities.	Not available in all communities.	Available to anyone who meets eligibility requirements.	Available in many communities.	Approximately 100 locations throughout the United States.	Over 50 locations, with at least one in each state and one in Puerto Rico.

\*ADL stands for Activities of Daily Living, which include bathing, eating, cooking, and many other tasks necessary for normal daily life.

#### **Program Eligibility**

Veterans who qualify for VA Healthcare have access to a wide variety of help with the treatment of dementia. Whether the veteran in your life needs to see a doctor, to get an in-home aide, or to move to a 24-hour memory care unit, the VA should be able to provide some funding or support that is based on the veteran's income and priority level within the VA Healthcare system. Often times, the VA allows a veteran to use multiple programs at once.

Funding and care options may be especially plentiful for veterans whose dementia can be linked to their service record since that will put them in a higher priority category. If the veteran in your life has dementia and also has a record of TBI or PTSD that is connected to his or her service, their dementia could be considered a service-connected disability by the VA. If they were exposed to Agent Orange during the Vietnam War and are experiencing Lewy Body Dementia, which is linked to Parkinson's Disease, their condition may also be considered at least partially service-connected. It's always best to enquire if you're not sure, as rules surrounding dementia care have changed in the last few years.

Even if there's no obvious connection between dementia and the veteran's time in service, he or she may still be eligible for some VA Healthcare or pension benefits. Below you'll find some quick explanations of the VA programs covered in the above table, as well as explanations of some other programs you may find helpful although they don't meet extensive memory care needs. If you want to learn more about priority groups and VA Healthcare and pension eligibility, we'll cover that in more detail in Steps to Obtaining Memory Care through the VA.

#### Waitlists

If you're considering placing the veteran you care for in a residential setting such as a nursing home, assisted living facility, or medical foster care, be aware that some locations have waitlists. If you find that the veteran will not able to transfer right away due to a waitlist, you may still be able to get help from the VA with finding temporary in-home care solutions in the meantime.

## VA Programs That Are Most Helpful for Memory Care Needs

#### Homemaker and Home Health Aide Care

In many cases, if the VA assesses that a veteran suffering from dementia needs help with three or more activities of daily living (ADL), they may pay for a community aid agency to send a trained aide to your home. This aide will be trained to help with activities of daily living but will not be able to provide skilled nursing.

#### Typical tasks an aide helps with:

- Moving around within the home
- Going to appointments
- Eating
- Using the bathroom
- Bathing
- Getting dressed
- Personal grooming

Aides from the Homemaker and Home Health Aide Care program will be supervised by a registered nurse who will initially make a plan for the veteran's daily living needs but will not visit on a regular basis. Aides can visit multiple times a week or just once a week, depending on need. Those without service-related disabilities will usually pay a copay for these services, but all enrolled veterans are eligible as long as they meet clinical need requirements.

Availability for this program is fairly wide, but there still may be some areas without it.

#### Veteran Directed Home Based Care (VD-HCBS)

Veteran Directed Home Based Care (also called VD-HCBS or just Veteran Directed Care) is an alternative approach to memory care and other healthcare needs that give the veteran and/or caregiver control. In this program, those in need of care sit down with a VA social worker or case manager to set a care budget based on actual needs. Supplies and the need for assistance, including aides, respite care, or even adult daycare, are all part of the budget. The patient has the freedom to select a capable family member to be their paid caregiver, if desired.

Once a budget is approved, any care provider who's been included in the budget will be paid directly by the VA. Caregivers who purchase supplies included in the budget will be reimbursed from the budget.

This program gives incredible freedom to vets and their loved ones who are dealing with a dementia diagnosis. Receiving these funds gives families the power to make choices that truly suit their needs. This program is not available in all communities, so you will need to check someone from your nearest VA facility to determine if Veteran Directed Care is available to your family.

#### Aid and Attendance Benefit

Rather than a direct medical program, this benefit includes payments of extra pension funds based on need. If a healthcare team confirms that the veteran's dementia makes it necessary for

them to have aid and attendance to complete activities of daily living such as dressing, bathing, and cooking, then the monthly Aid and Attendance benefit (A&A) may be awarded.

Funds provided by this pension benefit can be used for a range of services. They might be used to pay for rent in an assisted living facility with a memory care unit, for care in a nursing home, medical foster home, or adult daycare, or for an aid who will come to the veteran's own home. Restrictions may apply, and those who receive this benefit should always consult a VA social worker to make sure you are using funding appropriately.

<u>Pension rates</u> are determined using complex math that involves service history, income, dependents, spouses, medical expenses, and disabilities. Some veterans with a regular VA pension plus the A&A or housebound benefit can receive over \$22,000 each year from the VA. Rates are highly specific to the individual, however, and not everyone can qualify.

Another benefit that is separate from but often brought up alongside the A&A benefit is the Housebound Allowance. You will see this benefit mentioned in the link we've provided for the A&A benefit. The Housebound Allowance is also additional pension funding that those who already receive the general pension may qualify for. If a medical care team can document that a veteran is unable to leave their home, the housebound benefit can be awarded as well as the A&A benefit.

#### **Community Nursing Homes**

Community nursing homes are residential medical facilities that include, at a minimum, 24-hour skilled nursing care for minor things like wound care or help with IV medication, occupational and physical therapy for those who need it, and access to social services. Many nursing homes also include their own memory care services, often in distinct units of the facility. Nursing homes may also offer hospice and palliative care, forms of care for the terminally ill that focus on comfort and pain relief rather than on improvement of the underlying condition.

The VA covers the cost of some community nursing home care at facilities that it approves, for those with a clinical need. VA officials routinely visit community nursing locations to verify that facilities are meeting VA care standards. Not all community nursing homes have room for new patients, and a patient may experience a wait time even if they are technically approved for admission.

#### VA Community Living Centers

VA Community Living Centers used to be called VA Nursing Homes. These community centers provide residential care to veterans at a similar level to that provided by community nursing homes, but they provide it in a more home-like atmosphere. These homes often allow residents to decorate their rooms and keep pets, and they host a variety of stimulating activities for veterans to enjoy.

There are approximately 100 VA Community Living Centers across the nation. Usually, to qualify for long term care at one of these facilities, a veteran needs to have a disability that is deemed to be 60% or 70% caused by a service-related injury. Although scientific evidence suggests that Traumatic Brain Injury (TBI) and Post Traumatic Stress Disorder (PTSD) make dementia more likely in service members, such a high service-related rating for dementia may be

difficult to obtain unless there is significant documentation. You'll need to consult with a VA caseworker about your options. These homes may be most likely to accept veterans who have other major service-related physical disability or condition along with dementia.

#### **State Veterans Nursing Homes**

After the Civil War, individual states set up nursing homes to meet the enormous need for rehabilitation and long-term care that disabled or homeless veterans from that conflict faced. Many of these state nursing homes are still operating today, now serving veterans of modern conflicts, and they are now called State Veterans Nursing Homes.

In terms of care provided, these facilities are similar to community nursing homes. They offer nursing home care, adult daycare, and domiciliary care. Domiciliary care is simply providing a place to stay for homeless veterans on a temporary or long-term basis. State veterans nursing homes are operated by the states they are located in, but VA officials visit and certify them yearly. It's possible for a facility to lose its status as a state veteran's nursing home if it stops meeting VA care standards.

There are state veterans nursing homes in all 50 states, and some states have multiple locations. There's also a state veteran's nursing home in Puerto Rico, but not in other U.S. territories.

## Other VA Assistance That Can Benefit Veterans with Dementia

In addition to the above resources that are very directly tied to memory care, there are several VA programs that can help veterans with dementia although they do not directly meet memory care needs.

#### Home Improvements and Structural Alterations (HISA)

This grant can provide significant funding to cover home accessibility improvement costs for disabled veterans. With this grant, a veteran who struggles with mobility issues may be able to install a ramp, a roll-in shower, alter a driveway, lower kitchen or bathroom counters for accessibility, and more. Further eligibility details, videos, and forms related to HISA grants are available in the above link.

If the veteran you care for is in a wheelchair or otherwise has significant disabilities, she or he can be granted up to \$6,800. The upper limit of \$6,800 is only available to those with conditions that VA considers at least 50% service-connected. Those with disabilities that are not service-connected may still be able to receive up to \$2,000 for some home accessibility alterations.

#### Home-Based Primary Care

In some cases, the veteran's VA healthcare team decides that the veteran's doctors, pharmacists, therapists, psychologists, and nurses should visit the veteran in his or her own home. Homebased primary care is usually used in cases where leaving the home simply results in more mental or physical risks and challenges than benefits. Eligibility is determined by caseworkers based on service-connected disability and financial factors, and copays for those eligible may apply. Home-based primary care is not a source of 24/7 aide or help with ADL, but it can be used in coordination with other VA memory care programs to give a veteran the care they need.

#### **Skilled Home Health Care**

Skilled home health care is available to veterans who live far from VA centers and have a clinical need to receive case management, occupational therapy, physical therapy, speech therapy, skilled nursing, wound care, or IV antibiotics at home. Skilled home health care is provided through local community companies that contract with the VA. It isn't available in all locations, and the veteran can be charged a copay. Skilled home health care services are most likely to be provided by a nurse as opposed to a doctor.

#### <u>Telehealth</u>

Telehealth, also known as remote monitoring care, refers to a broad range of services that utilize technology to connect a patient at home to a healthcare team. With telehealth, the veteran regularly uses home medical equipment to measure blood pressure, blood sugar, pulse, weight, blood oxygen levels, and more. Using cell phones, cellular modems, and phone lines, the veteran securely sends that information to a VA hospital, and a care coordinator passes the information to a physician or nurse if anything seems unusual.

Telehealth can help those receiving care at home to catch health risks early when they are most treatable. Telehealth can help caregivers provide the best care possible to veterans, enabling them to receive care at home as long as possible. This service is available to all enrolled VA healthcare members who have a clinical need for it, though services can vary by location. Most services provided through telehealth do not include copays.

#### Palliative Care Teams and Hospice

Palliative care is any care focused on comfort and relief of suffering and symptoms. Hospice care is palliative care that's provided in the last six months of life. Neither of these is, strictly speaking, memory care services, but they are often used when dementia has progressed to such a degree that the patient is immobile. Palliative care and hospice include services aimed at meeting medical, social, spiritual, and psychological needs.

These services are already included in many programs provided to veterans both at home and in residential settings. For example, if a veteran is in a memory care unit of a VA state nursing home, a family member of the veteran may just need to meet with a social worker at the nursing home in order for the veteran to begin receiving hospice or palliative care. Each situation will be a little different, and when it's time family can always contact the veteran's social worker with questions about palliative care or hospice. Copays are never charged for hospice, but they may be charged for palliative care.

#### **Respite Care**

Because it's not long-term care, we haven't included respite care in our memory care table. However, respite care can be extremely helpful to families that are providing memory care at home for a veteran. Respite care is when a temporary caregiver steps in to give family members a break. Through its respite care program, VA Healthcare can pay for the following services:

- Six hour time periods in which a person comes to the veterans home to temporarily care for the veteran
- Six hour time periods in which a veteran visits an adult daycare
- A nursing home respite care stay in which a veteran stays at a nursing home for up to 30 days per year while if family is out of town

Respite care can be a regular part of a care plan, or it can be a rarely-used service that comes in handy during stressful times.

# **Obtaining Memory Care through the VA**

## Step 1: Determine the Veteran's General Eligibility for VA Benefits

If you are caring for a veteran and want to help them take advantage of VA assistance for their memory care needs, then your first step should be to inquire about their eligibility and enrollment status for both VA healthcare and VA pensions. Chances are good that most elderly veterans are already signed up for the benefits they qualify for, but sometimes veterans may not realize they are eligible.

## Healthcare eligibility

If the veteran you care for is not already enrolled in VA Healthcare, you can check her or his eligibility for enrollment in this <u>VA healthcare eligibility</u> article. This article includes helpful explanations of <u>VA Priority Groups</u>. All veterans receive a priority designation of 1 to 8 based on wartime or combat service dates, service-related disability ratings, and income, among other factors.

The lower the number of priority group veterans receive, the higher their priority for enrollment and care. Those with higher priority numbers may be denied coverage or charged a copay for some services. The VA's budget for care changes year to year based on congressional approval. Priority groups allow the VA to serve those in the most need or with the most service-connected disabilities when congressional funding is low.

If you determine that the veteran you care for is probably eligible for care but is not signed up for it, you can <u>visit the VA website</u> to see a detailed list of documents needed and steps to take. VA Healthcare applications are usually processed within a week.

#### **Pension eligibility**

Many veterans who qualify for VA healthcare don't qualify for a VA pension. To qualify for a pension, a veteran must meet several requirements, including having served at least one day during a wartime period. Official wartime period dates can be viewed <u>here</u>. For more information on pension eligibility, you can explore the <u>VA Pension website</u>. If the veteran has never applied for a pension or has applied and been denied in the past, applying late in life may still be worth it.

For veterans who just don't have the financial means to pay for full-time memory care, pensions can provide the funds needed to dramatically improve their quality of life. Veterans who already receive a regular pension may also be eligible for additional pension allowances because of their need for help with activities of daily living like cooking and bathing, or because they are housebound.

## Step 2: Utilize Diagnostic Services from the VA

Once you're established general eligibility for VA Healthcare, you'll need to have your loved one's suspected or diagnosed dementia evaluated by a VA doctor. This <u>locator tool</u> can help you find the phone number for the nearest VA location and ask to set up an appointment.

#### Important things to know about visiting a VA doctor for dementia concerns:

- The VA selects a <u>care team</u> and doctor for the veteran
- Veterans in some priority groups pay copays
- The VA can help with <u>transportation</u> to an appointment in some cases
- The VA may bill <u>private insurance</u> to cover some of the care they provide, and this billing method could eliminate some of the copays
- If appointment wait times or distance are prohibitive, you may seek approval to receive <u>community care</u> for the veteran
- A first visit may include tests or a general physical as well as discussion of dementia

Keep in mind that receiving an official diagnosis of Alzheimer's or other forms of dementia may be an emotional experience for both you as the caregivers and for the veteran you care for. Ask your VA or community care provider about resources for coping, and plan to reread any provided pamphlets later to go over information you may have missed during the appointment.

## **Step 3: Utilize Medical Shared Decision Making Resources**

After diagnosis, medical shared decision making can help you decide your next steps for treatment. Medical shared decision making refers to the process in which patients, their loved ones, and their care team all come together to make healthcare decisions. With many options for memory care both at home, in the community, and in VA centers, it's important that everyone involved has a chance to voice their concerns and preferences with the medical team.

#### **Shared Decision Making for Veterans**

The Shared Decision Making Worksheet for Veterans might be useful for veterans in the early stages of dementia. You can read this worksheet with the veteran and write down their answers for them if they prefer that. However, sometimes a veteran experiencing dementia will be unaware of their own lapses in memory or will be emotionally unable to cope with facing changes brought on by dementia. In such a case, this worksheet may not be as helpful. Its utility will depend largely on the veteran's current state of mind, health, and desire to communicate.

#### **Self-Assessment for Caregivers**

Regardless of whether the veteran is able to complete the above worksheet, you as a caregiver can still use the <u>Caregiver Self Assessment</u> PDF, also provided by the VA. After completing this worksheet, you can use the included contact information to reach out to a VA social worker. Discussing your results with a social worker can help you to decide if you need more support or resources to prevent you getting burnt out in you important caregiver role.

After completing one or both of the above PDF worksheets, you may want to bring them to the next appointment the veteran has with his or her VA doctor.

## Step 4: Apply for Appropriate VA Assistance

Looking into VA resources that can help with long term memory care needs can be a confusing experience. There are many paths to memory care, and your best option depends on a combination of personal preferences, caregiver abilities, financial position, and clinical need. Your care team will probably suggest a program or service they think is suitable for the veteran, but you can also ask about the services listed below.

Keep in mind that eligibility or admission for most of the programs below is heavily tied to the veteran's priority group. You may not be able to determine eligibility for a program until you speak directly with a VA caseworker.

#### The following three options provide funding or help for at-home care options:

- Homemaker and Home Health Aide Care
- Aid and Attendance and Housebound Allowance
- Veteran Directed Home Based Care (VD-HCBS)

# These three options provide care in residential settings for those who cannot receive proper memory care at home:

- <u>Community Nursing Homes</u>
- VA Community Living Centers
- <u>State Veterans Nursing Homes</u>

#### Other VA resources to look into:

The following options don't provide full-time memory care, but they can all be a piece of the full care puzzle for patients with dementia.

- Skilled Home Healthcare or Home-Based Primary Care: Visits from doctors, therapists, pharmacists, and nurses to meet medical and nursing needs for those who have a clinical need not leave their homes for care.
- **Respite Care:** Access to temporary caregivers at home, in an adult daycare, or in a nursing home so that primary caregivers can run errands, take breaks, or even take much-needed vacations.

- **Telehealth:** Remote health monitoring through at-home medical devices that can be transmitted to VA medical staff. Care coordinators can review health data and determine if it needs to be passed along to a doctor for immediate attention.
- **Palliative Care and Hospice:** Palliative care and hospice care boh focus on managing pain and symptoms, but hospice is for the last six months of life. Both kinds of care are frequently available through various VA programs.
- **HISA Grants:** HISA Grants aren't for healthcare at all, but they provide funding for home alterations that are necessary to accommodate a disability. This may be helpful in cases where a veteran with dementia is also struggling with other physical disabilities.

Full explanations of all of the above options are included directly below our "Overview of VA Memory Care Options" table. If you haven't already viewed that table and the material below, you may want to do so now. You'll find information on eligibility and the services that are available.

## Step 5: Plan to Be Flexible About Care

One of the most important qualities a caregiver can have is flexibility. This is especially true for families who decide to provide care in-home with the help of support programs from the VA. It's important to be willing to change a care plan if it's no longer working.

#### Developments that may require you to change a home memory care plan:

- The caregiver's cognitive or physical health declines, limiting their strength or mobility
- The veteran develops secondary mobility or health problems that make home care more difficult or impossible
- The veteran develops a habit of wandering and cannot be confined in the home
- The caregiver no longer gets enough sleep because of the veteran's dementia-related altered sleep habits
- The veteran becomes too aggressive and hostile for the caregiver to safely interact with when alone
- The caregiver begins to feel overworked, isolated, unsafe, depressed, or anxious

Even with help from the Aid and Attendance pension, the Homemaker and Home Health Aide Program, or VD-HCBS, the conditions listed above could make providing care at home unrealistic, depending on the exact circumstances.

To truly provide the best care possible, plan to check in with yourself periodically, looking at your needs and the veteran's needs. Discuss any new difficulties and concerns with other family members or the veteran's social worker, actively seeking out objective opinions on how the home memory care you're providing is working.

Ultimately, one of the most loving things you can do for a veteran with dementia is to connect them to the care that's best for them. If at some point that means moving them to a quality residential facility funded by the VA, you can feel good about that choice.

# Paying for Memory Care and Alzheimer's Care

## The Cost of Memory Care

Many seniors want to know what memory care would cost them if they were to pay out of pocket. It's a difficult question to answer because memory care can take so many different forms, from paid and unpaid in-home caregivers, to adult daycare, to secure memory care wings in assisted living or nursing home settings.

National surveys can give us an idea of the true cost of memory care, though each situation will be different. A 2015 study funded by the <u>National Institutes of Health (NIH)</u> found that caregiver's yearly out-of-pocket spending to care for patients with dementia in the last five years of life was \$61,522. This yearly out of pocket cost is almost twice the cost of out of pocket spending for patients who had cancer or heart disease. For the most part, the out of pocket costs in this survey reflect what caregivers paid after insurances such as Medicare had paid for some services. Out of pocket costs are even higher for those with no health coverage.

Another comprehensive national survey, in this case conducted by <u>Genworth</u> in 2019, provides insight into the costs of various kinds of memory care. The figures below are the median national costs presented in annual figures:

Homemaker services: \$51,480 Home health aides: \$52,624 Adult medical daycare: \$19,500 Assisted living memory care: \$48,612 Nursing home memory care: \$90,155-\$102,200

Additionally, the cost of having a skilled nurse come to your home to care for a dementia patient costs \$87.50 per visit, according to the 2019 national median.

The above figures give only a snapshot of possible costs. Actual costs can vary tremendously depending on factors like location and the severity of dementia symptoms. Nevertheless, even this brief snapshot shows that dementia is an incredibly expensive condition to treat.

## How to Get Financial Assistance Outside of the VA

If you find that the veteran you care for does not qualify for VA Healthcare or pensions, or if VA resources are not plentiful in your area, you do still have other options for help with expenses. You may be surprised to learn that <u>Medicare</u> does **not** cover long term care, so you'll need to look beyond at some of the options below.

## **TRICARE**

Many veterans who don't qualify for VA Healthcare do qualify for and use TRICARE, insurance that's made for veterans and their families. TRICARE does **not** cover long-term care costs at all, but it can still help you with the costs of doctor visits, medications, and skilled nursing. It won't provide all the funding needed, but it can be part of the solution. TRICARE may work in combination with Medicare.

## **PACE**

State Medicaid Programs called Programs of All-Inclusive Care for the Elderly (PACE) can provide dementia care through a network of contractors within your community. The point of PACE programs is to enable seniors to stay at home instead of going into a nursing home or other institutions.

PACE covers therapy, prescription drugs, adult daycare, and many other medical and caregiving services that dementia patients typically need. Those with Medicaid have no premiums for the long-term care portion of PACE, and those with Medicare but not Medicaid will need to pay some monthly premiums.

#### Federal Long Term Care Insurance Program (FLTCIP)

Long term care insurance is designed to cover the extensive, long term costs of care associated with conditions like Alzheimer's Disease. This kind of insurance is available through private companies, but the Federally provided version is available to Federal and U.S. Postal Service employees and active and retired members of the uniformed services. It's also available to close family members like spouses, unlike VA Healthcare.

This program is administered by Long Term Care Partners, LLC in partnership with the US government. You can explore the program in full through the <u>FLTCIP</u> website.

# **Frequently Asked Questions**

## 1. How do I know if I or a loved one might have Alzheimer's?

Diagnosing Alzheimer's isn't something that you can do on your own, but you can look out for symptoms.

The list of possible Alzheimer's symptoms is quite long, but some to look out for include:

- Forgetfulness
- Confusion
- Changes in moods
- Changes in sleep patterns
- Getting lost in familiar places
- Hallucinations
- Aggressiveness
- Uncharacteristic inappropriate behavior

If you see some of these signs, it may be time to consult a doctor. Many of these behaviors occur sometimes in healthy people who are just tired or having a bad day, but if you're seeing multiple symptoms or consistent and worsening symptoms, don't wait to see how much worse they get. A doctor will be able to evaluate the patient's symptoms while also ruling out other possible causes such as hormonal imbalances or nutritional deficiencies that are causing cognitive problems.

#### 2. How much does Alzheimer's care cost?

Alzheimer's care costs vary widely depending on what kind of setting the family chooses to provide care to the patient in. Estimates for the cost of in-home care often are cited as \$43,000 per year, while the cost of memory care in a nursing home setting can cost over \$100,000 a year in many cases. The good news for veterans is that with VA Healthcare, many veterans pay just modest copays for services, rather than bearing the full cost of care.

#### 3. Who should I contact for more information about benefits?

If you have any questions about whether or not you qualify for VA Healthcare, you can call 877-222-8387, Monday through Friday, 8:00 a.m. to 8:00 p.m. If you're already enrolled in VA Healthcare but have a question about eligibility for a specific health service, however, you'll want to contact a local <u>a local VA location</u> and get connected with a VA social worker.

If you need to find out about your eligibility for a VA pension, you can visit a VA regional office, or you can call an office using the provided regional contact information in the <u>VA</u> <u>Regional Office Locator Tool</u>. If you find you are eligible for a general pension, you also may be eligible for the Aid & Attendance (A&A) or Housebound pension allowances.

#### 4. How do I apply for benefits?

To apply for VA Healthcare benefits, you'll need to visit <u>the VA's website</u>. The application process will require you to have on hand some personal information, including:

- A recent tax return
- The veteran's social security (SS) number, as well as the SS numbers of any of the veteran's dependents
- Account numbers for Medicare, Medicaid, TRICARE, or any other form of insurance the veteran already has

Once you have the information you need, you can apply online, over the phone 877-222-8387, Monday through Friday, 8:00 a.m. to 8:00 p.m. or even by mail at Health Eligibility Center, 2957 Clairmont Rd., Suite 200, Atlanta, GA 30329.

To apply for pension benefits, you should follow this link.

You'll need to have on hand the following for your pension application:

- SS number
- Military history
- Financial information for the veteran and dependents
- Work history
- Bank account information for direct deposit
- Medical information

#### 5. How long does it take to get approved for benefits?

Approval for VA benefits depends on what exactly you're applying for. To discover your general eligibility for VA Healthcare, you'll need to wait about a week after you've submitted all required paperwork. If you're trying to get approval for a pension or a grant, your wait time could be significantly longer, but the VA does not provide an exact time frame.

After you are enrolled in VA Healthcare, you may need to fill out additional applications for various services you want to use. With some services, you'll need to sit down with social workers and draw up a budget in which you are asking the VA to provide funding for specific purposes. This is true of the Veteran Directed Care program. The application process can be lengthy, and you'll want to ask your VA social worker for an estimated wait time at the time that you apply.

#### 6. What support is available for family and caregivers?

Caregivers and family members of veterans with dementia often experience financial strain and mental or health struggles because they are investing so much time, energy, and money in helping their loved ones. To recognize the often overlooked role that caregivers play, VA services include a helpline for caregivers: 1-855-260-3274. Those who call can receive advice and information on available services, and they can also talk about their frustrations if they need a sympathetic ear.

Local VA offices also have professionals called Caregiver Support Coordinators that caregivers can consult with. If you want to get in touch with a local caregiver support coordinator, start by using this <u>locator tool</u>.

If you're looking for caregiver resources specifically related to health, the VA provides a page that has links to many different caregiver resources <u>here</u>. As a family member of a veteran, it's possible that you'll qualify for TRICARE insurance or CHAMPVA cost-sharing so that you can get quality care for your own health needs.

## **More Memory Care Resources for Veterans**

If you still want to learn more about Alzheimer's and dementia, or if you're looking for more resources to support you as a caregiver, you'll find the following government and nonprofit websites helpful.

	Website	Contact Information Phone:	Important Features
VA Caregiver Support	<u>caregiver.va.gov/</u>	(855) 260-3274 Monday – Friday 8 a.m.– 8 p.m. (EST)	Helpful articles and videos for caregivers, a toll-free helpline, and a caregiver coordinator locator tool.
VA Beneficiary Travel	va.gov/HEALTHBENEFITS/vtp	Points of contact for different regions <u>provided in this link</u> .	Detailed information on how to access free transportation services from the VA, including forms and cost information.
Caregivers Video Series	ruralhealth.va.gov/vets/resources.asp	<b>Phone</b> : 801-582-1565 ext. 2770 <b>Email</b> : <u>ORH-</u> <u>WR@va.gov</u>	Links to informational videos for caregivers of veterans with dementia. Visitors to the website are encouraged to use the provided contact information to ask questions, give feedback, or request a DVD copy of videos.
Alzheimer's and related Dementias Education and Referral Center (ADEAR)	alzheimers.gov/	<b>Phone</b> : (800) 438-4380, Mon-Fri, 8:30 a.m5:00 p.m. (EST) Eastern <b>Email</b> : adear@nia.nih.gov	Informational articles, up-to-date dementia research, resources for memory care professionals, and links to clinical trials for Alzheimer's treatments.
Alzheimer's Association	<u>alz.org/</u>	Phone: (800) 272-3900 for a 24/7 helpline Email: access an email contact form here Address: 225 N. Michigan Ave. Floor 17 Chicago, IL 60601	General information on Alzheimer's, numerous caregiver resources, financial information, links to support groups for caregivers, opportunities to volunteer, advocate, and fundraise for the cause, and r
The National Alliance for Caregiving	<u>caregiving.org/</u>	Phone: (202) 918-1013 Email: info@caregiving.org Address: 1730 Rhode Island Ave. NW, Suite #812 Washington, D.C., 20036	Guidebooks, links to research on caregiving, advocacy information, and links to many government and nonprofit websites that can provide caregiver help in the "Resources" tab.