

Alzheimer's  New Jersey<sup>®</sup>

# 2020–2021 Reference Guide

# Alzheimer's New Jersey™

**F**or over 35 years, we have been here for our local communities, providing care and support for families impacted by Alzheimer's disease. Five years ago, we changed our name from Alzheimer's Association, Greater New Jersey Chapter to Alzheimer's New Jersey® to maintain our vital local focus as an independent New Jersey not for profit organization. Our Board made the difficult decision to disaffiliate from the Alzheimer's Association in response to the Association's decision to merge all independent Chapters into a single national corporation – ending local governance. We knew then what we know now – New Jersey's 600,000 people affected by Alzheimer's need an organization completely dedicated to them.

Our name – Alzheimer's New Jersey® – reflects this strong commitment. You can be assured that 100% of our donors' generosity and the time and energy of our volunteers and staff are dedicated to our New Jersey mission. If you need support and assistance, please call our Helpline at 888-280-6055.

## **Our Vision**

Improve the lives of people in New Jersey who are affected by Alzheimer's disease and other dementias; offering continuous hope and support.

## **Our Mission**

To respond to the needs of people in New Jersey who are affected by Alzheimer's disease and other dementias, by providing programs and community partnerships that increase awareness and access to services.



*Dear Friends,*

**C**OVID-19 has brought many changes to our lives. But, for New Jersey families impacted by Alzheimer's, Alzheimer's New Jersey is the first line of support for local families. Through our education and support programs, we help caregivers and family members get the help they need so they and their loved ones with Alzheimer's can live safely, with dignity, care, and hope.

The COVID-19 health crisis has increased the financial and emotional stress on families impacted by Alzheimer's disease. During this time of historic need, like at many non-profit organizations, our requests for support are high and our resources at Alzheimer's New Jersey® have been stretched to the limit.

Yet, our much-needed programs have continued without disruption as we effectively transitioned from face-to-face programming to webinars and teleconferences. We are proud of the way we have rapidly changed and continued to serve our New Jersey communities.

This online Alzheimer's Disease Reference Guide is another example of that change. Moving from our traditional print version to this online resource, we hope has created greater accessibility, more visibility for our advertisers and overall, a more useful resource for the community.

I thank everyone who has supported our focused mission of helping New Jersey families during these challenging times. This includes our Board of Directors, donors, corporate sponsors, community partners, volunteers and, of course, our advertisers in this Reference Guide. The need for help and support has never been greater – and this Reference Guide is just one more example of how we can help families be better prepared to manage the many challenges of Alzheimer's disease.

On behalf of the 600,000 New Jersey residents affected by Alzheimer's, thank you for helping us “take care of our own.”

When Alzheimer's touches your life – we are here. Stay connected with us!

Warmest regards,



Kenneth C. Zaentz, CFRE  
President and CEO

# Alzheimer's New Jersey™

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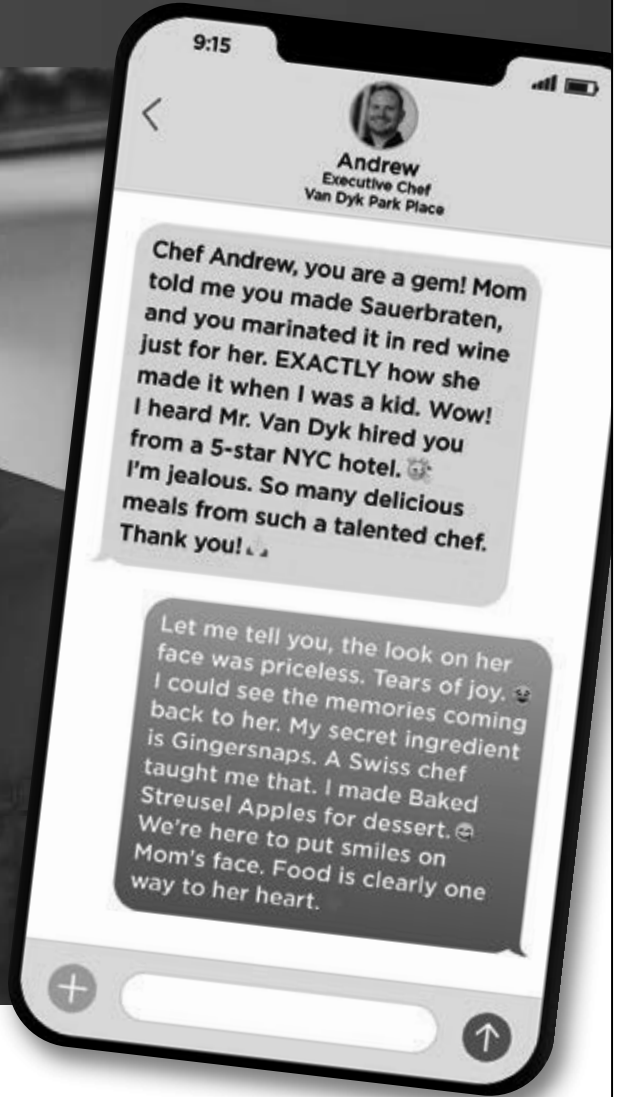
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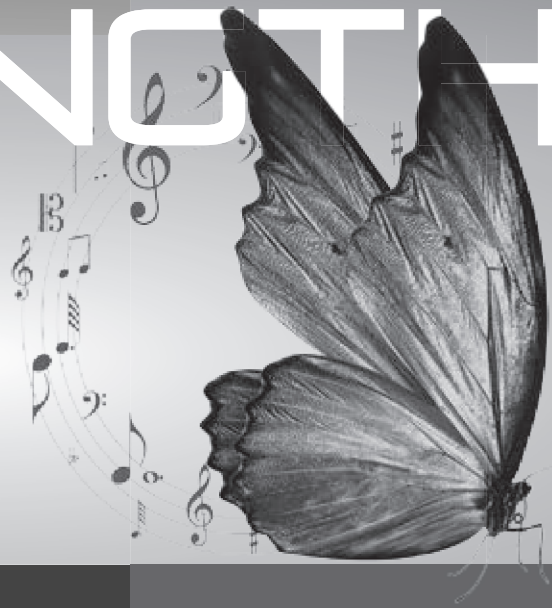
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# STRENGTH IN COMMUNITY

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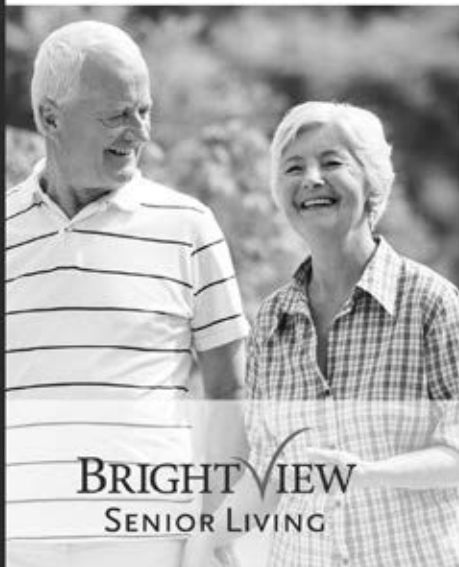
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# Proud to support *Alzheimer's New Jersey* in the fight for a cure!



## **Adept Legal Counsel for Families Dealing With Alzheimer's**

Our Elder Care and Special Needs group has helped many New Jersey families respond to the challenges of supporting a loved one suffering from Alzheimer's by focusing on long-term care planning and advocacy. This is why our Elder Care and Special Needs group includes a dedicated social worker to ensure these issues are managed holistically with our attorneys. We believe that estate planning is not just about what happens after you die, but how you live as you age. Long-term care planning addresses health care needs, family dynamics, personal values, and the resources available, and aims to resolve the financial burden of care by maximizing our clients' eligibility for public programs, including Medicaid, Medicare, and Veteran's benefits.

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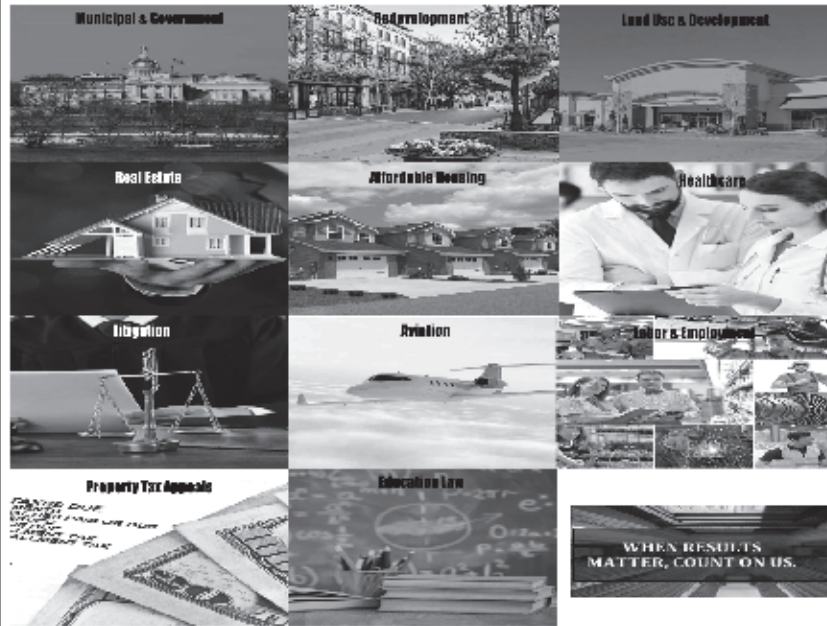
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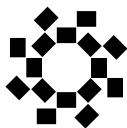
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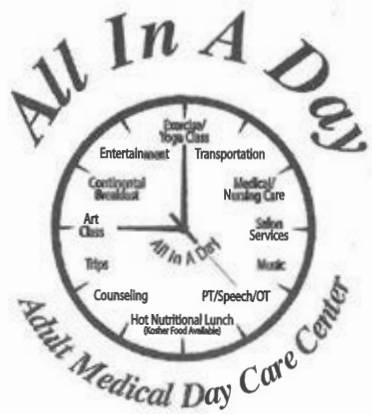
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Alzheimer's Disease Reference and Information Guide

Alzheimer's  New Jersey®

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# Alzheimer's Disease Reference and Information Guide

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## Programs and Services: Our response to COVID-19

In response to the challenges that COVID-19 is creating for our communities and most especially for New Jersey families impacted by Alzheimer's disease, we have made changes to the way we deliver our services. We continue to provide the essential support and education those caring for persons with dementia need, especially during these unpredictable times.

**Alzheimer's New Jersey is here for you** – creating new ways to bring you programs that provide resources, information and guidance.

**Helpline (1-888-280-6055)** Our professionally trained staff provide callers with personal and confidential assistance about Alzheimer's and other dementias and available community resources. Translation service is available in over 200 languages.

**Family Support Groups** are being held via telephone and Zoom to continue our goal of providing caregivers, families, and friends the emotional support and education they need to better understand and manage Alzheimer's disease and other dementias. These groups are a great way to connect with other people who are facing the challenges and issues that arise when a loved one has dementia. To learn more, please read our **Support Group Frequently Asked Questions** or complete the online **Support Group Inquiry Form**.

**Online Education Programs**, available by Webinar and phone, provide valuable information and guidance on various topics related to Alzheimer's and other dementias.

**Guest Speaker Programs** are regularly hosted by Alzheimer's New Jersey featuring presenters who share their expertise and refreshing perspectives on research as well as medical, legal and care issues that impact those with Alzheimer's disease and their caregivers. Many of our presenters are recognized throughout New Jersey and beyond as experts in their fields.

**The Respite Care and Wellness Program** is designed to provide family caregivers with information and education about the importance of regular time-off from caregiving, and help link them to available community-based respite care resources. We also provide financial reimbursement of \$1,000 to help support the cost of respite care services.

**Clinical Trial Connections**<sup>®</sup> program provides assistance to individuals and families who may be interested in participating in a clinical trial. The program helps individuals and families find available trial programs within their community and within nearby communities. Clinical research trials test new ways to detect, treat and prevent Alzheimer's disease and dementia. They offer the opportunity for individuals to participate in studies, while also helping others through the advancement of research.

**Always Safe**<sup>®</sup> provides individuals and families with educational information and resources about home and personal safety, and provides professional education and training about Alzheimer's and dementia to New Jersey law enforcement and emergency first responder.

## Common Warning Signs of Alzheimer’s Disease

Alzheimer’s disease is not a normal part of aging. Like all parts of the body, the brain works differently as a person ages. However, there is a difference between normal aging and Alzheimer’s disease. Every case of Alzheimer’s disease is different, but experts have identified common warning signs. Contact your doctor with concerns.

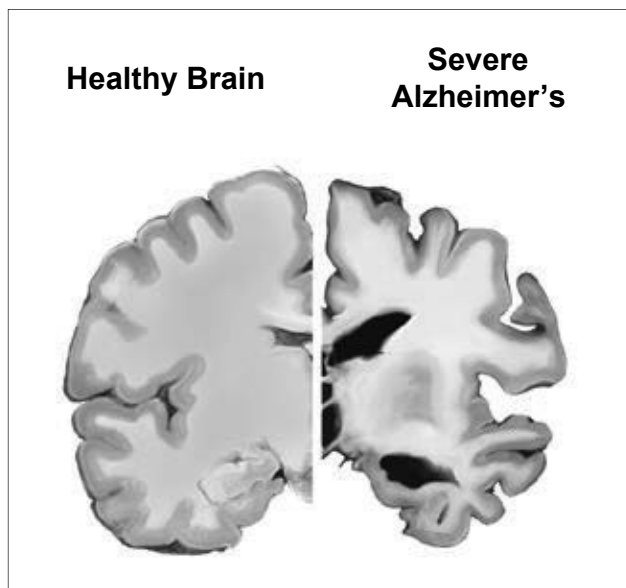
Area of Concern	Normal Aging	Possible Indicator of Alzheimer’s Disease or Other Dementia
Memory Loss	Temporarily forget names or where you left your keys	Difficulty remembering familiar names, places or recent or important events.
Disorientation	Forget the day of the week or why you entered a room.	Unsure of how to get to a room in your home or how to remember the day of the week.
Challenged by familiar mental tasks	Make a mistake when balancing a checkbook.	Your bank account is often overdrawn because your checkbook is not balanced.
Difficulty completing activities of daily living	May forget to rinse your toothbrush or run the dishwasher	Unsure how to brush your teeth. Place inappropriate items in the dishwasher (e.g. remote control)
Trouble using words appropriately	Occasionally struggle to find the right word.	Difficulty completing sentences and following directions or conversations.
Poor judgement	May be more vulnerable to scams.	Give money to solicitors excessively and beyond what is affordable. Dress inappropriately for weather (ex. wearing a winter coat in the summer).
Changes in mood and personality	Fatigued by obligations or irritable when routine is disrupted.	Extremely overwhelmed by disruption in a routine. Increased suspicion, withdrawal and disinterest.

# Alzheimer's Disease: An Overview

Alzheimer's disease is a progressive brain disease that destroys memory and thinking skills and eventually, the ability to carry out the simplest tasks of daily living. It is the most common cause of dementia.

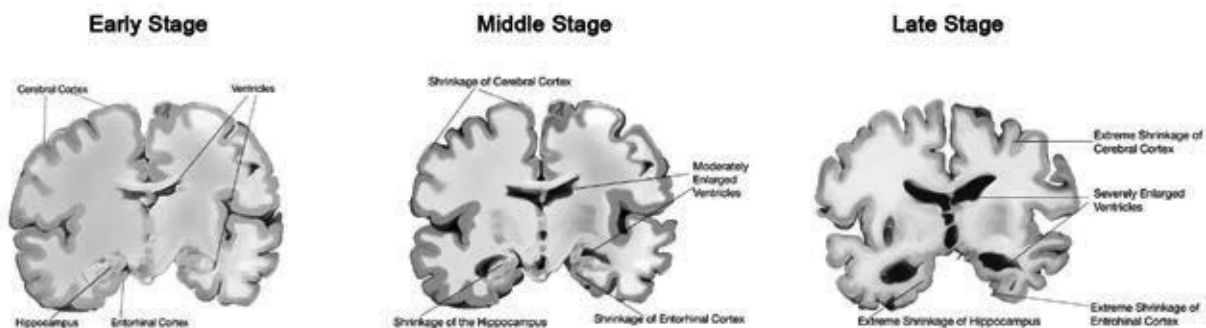
Alzheimer's disease is named after Dr. Alois Alzheimer, a German physician. In 1906, Dr. Alzheimer described changes in the brain tissue of a woman who had died of an unusual illness that robbed her of her memories and caused personality changes. After her death, he found in her brain abnormal clumps (now called amyloid plaques) and tangled bundles of fibers (now called neurofibrillary tangles). These plaques and tangles are now considered the hallmarks of Alzheimer's disease. The images below show how the progression of Alzheimer's disease affects the brain.

Alzheimer's usually starts in a region of the brain that affects recent memory, then gradually spreads to other parts of the brain. While current treatments may temporarily delay the appearance of symptoms in some people with Alzheimer's, there is currently no medication that cures this devastating disease. A good support system is important for the individuals with Alzheimer's disease and their caregivers.



**Above:** The image of a healthy brain compared to that of a brain severely affected by Alzheimer's.

**Below:** The physical changes in the brain throughout the stages of Alzheimer's disease.





# Mild Cognitive Impairment, Alzheimer's Disease, & Other Dementias

---

## What is Mild Cognitive Impairment (MCI)?

Mild cognitive impairment (MCI) is the stage between the expected cognitive decline of normal aging and the more serious decline of dementia. It's characterized by problems with memory, language, thinking or judgment.

If a person has mild cognitive impairment, he or she may be aware that memory or mental function has "slipped." Family and close friends also may notice a change. But these changes aren't severe enough to significantly interfere with the person's daily life and usual activities. Mild cognitive impairment may increase one's risk of later developing dementia caused by Alzheimer's disease or other neurological conditions. But some people with mild cognitive impairment never get worse, and a few eventually get better.

The brain, like the rest of the body, changes as people grow older. Many people notice gradually increasing forgetfulness as they age. It may take longer to think of a word or to recall a person's name. But consistent or increasing concern about mental performance may suggest mild cognitive impairment (MCI).

There is no specific test to confirm a diagnosis of mild cognitive impairment (MCI). Your doctor will decide whether MCI is the most likely cause of your symptoms based on the information you provide and results of various tests that can help clarify the diagnosis.

## What Is Dementia?

Dementia is the loss of cognitive functioning—thinking, remembering, and reasoning—and behavioral abilities to such an extent that it interferes with a person's daily life and activities. These functions include memory, language skills, visual perception, problem solving, self-management, and the ability to focus and pay attention. Some people with dementia cannot control their emotions, and their personalities may change. Dementia ranges in severity from the mildest stage, when it is just beginning to affect a person's functioning, to the most severe stage, when the person must depend completely on others for basic activities of living.

Signs and symptoms of dementia result when once-healthy neurons (nerve cells) in the brain stop working, lose connections with other brain cells, and die. While everyone loses some neurons as they age, people with dementia experience far greater loss.

While dementia is more common as people grow older (up to half of all people age 85 or older may have some form of dementia), it is **not** a normal part of aging. Many people live into their 90s and beyond without any signs of dementia. One type of dementia, frontotemporal disorders, is more common in middle-aged than older adults.

The causes of dementia can vary, depending on the types of brain changes that may be taking place. Alzheimer's disease is the most common cause of dementia in older adults. Other dementias include Lewy body dementia, frontotemporal disorders, and vascular dementia. It is common for people to have mixed dementia—a combination of two or more types of dementia. For example, some people have both Alzheimer's disease and vascular dementia.

## Alzheimer's Disease

The first symptoms of Alzheimer's vary from person to person. Memory problems are typically one of the first signs of cognitive impairment related to Alzheimer's disease. Decline in non-memory aspects of cognition, such as word-finding, vision/spatial issues, and impaired reasoning or judgment, may also signal the very early stages of Alzheimer's disease. And some people may be diagnosed with mild cognitive impairment. As the disease progresses, people experience greater memory loss and other cognitive difficulties.

Alzheimer's disease progresses in several stages: preclinical, mild (sometimes called early-stage), moderate, and severe (sometimes called late-stage).

# Mild Cognitive Impairment, Alzheimer's Disease, & Other Dementias

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## Signs of Mild Alzheimer's Disease

In mild Alzheimer's disease, a person may seem to be healthy but has more and more trouble making sense of the world around him or her. The realization that something is wrong often comes gradually to the person and his or her family. Problems can include:

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

Alzheimer's disease is often diagnosed at this stage.

## Signs of Moderate Alzheimer's Disease

In this stage, more intensive supervision and care become necessary, which can be difficult for many spouses and families. Symptoms may include:

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

## Signs of Severe Alzheimer's Disease

People with severe Alzheimer's cannot communicate and are completely dependent on others for their care. Near the end, the person may be in bed most or all of the time as the body shuts down. Their symptoms often include:

- Inability to communicate
- Weight loss
- Seizures
- Skin infections
- Difficulty swallowing
- Groaning, moaning, or grunting
- Increased sleeping
- Loss of bowel and bladder control

# Mild Cognitive Impairment, Alzheimer's Disease, & Other Dementias

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## Vascular Contributions to Cognitive Impairment and Dementia

Vascular contributions to cognitive impairment and dementia (VCID) are conditions arising from stroke and other vascular brain injuries that cause significant changes to memory, thinking, and behavior. Cognition and brain function can be significantly affected by the size, location, and number of brain injuries. Two forms of VCID—vascular dementia and vascular cognitive impairment (VCI)—arise as a result of risk factors that similarly increase the risk for cerebrovascular disease (stroke), including atrial fibrillation (a problem with the rhythm of the heartbeat), high blood pressure, diabetes, and high cholesterol.

Symptoms of VCID can begin suddenly and progress or subside during one's lifetime. VCID can occur along with Alzheimer's disease. People with VCID almost always have abnormalities in the brain on magnetic resonance imaging scans. These abnormalities include evidence of prior strokes, often small and asymptomatic, as well as diffuse changes in the brain's "white matter"—the connecting "wires" of the brain that are critical for relaying messages between brain regions. Microscopic brain examination shows thickening of blood vessel walls called arteriosclerosis and thinning or loss of components of the white matter.

## Different Types of VCID

**Vascular dementia** refers to progressive loss of memory and other cognitive functions caused by vascular injury or disease within the brain. Symptoms of vascular dementia may sometimes be difficult to distinguish from Alzheimer's disease. Problems with organization, attention, slowed thinking, and problem solving are all more prominent in VCID, while memory loss is more prominent in Alzheimer's.

**Vascular cognitive impairment** involves changes with language, attention, and the ability to think, reason, and remember that are noticeable but are not significant enough to greatly impact daily life. These changes, caused by vascular injury or disease within the brain, progress slowly over time.

**Post-stroke dementia** can develop months after a major stroke. Not everyone who has had a major stroke will develop vascular dementia, but the risk for dementia is significantly higher in someone who has had a stroke.

**Multi-infarct dementia** is the result of many small strokes (infarcts) and mini-strokes. Language or other functions may be impaired, depending on the region of the brain that is affected. The risk for dementia is significantly higher in someone who has had a stroke. Dementia is more likely when strokes affect both sides of the brain. Even strokes that don't show any noticeable symptoms can increase the risk of dementia.

## Lewy Body Dementia

Lewy body dementia (LBD) is a disease associated with abnormal deposits of a protein called alpha-synuclein in the brain. These deposits, called Lewy bodies, affect chemicals in the brain whose changes, in turn, can lead to problems with thinking, movement, behavior, and mood. Lewy body dementia is one of the most common causes of dementia.

Diagnosing LBD can be challenging. Early Lewy body dementia symptoms are often confused with similar symptoms found in other brain diseases like Alzheimer's or in psychiatric disorders like schizophrenia. Also, Lewy body dementia can occur alone or along with other brain disorders.

There are two diagnoses of LBD—dementia with Lewy bodies (DLB) and *Parkinson's disease dementia*. The earliest signs differ but reflect the same biological changes in the brain. Over time, people with dementia with Lewy bodies or Parkinson's disease dementia may develop similar symptoms.

People with Lewy body dementia (LBD) may not have every LBD symptom, and the severity of symptoms can vary greatly from person to person. Throughout the course of the disease, any sudden or major change in functional ability or behavior should be reported to a doctor.

The most common symptoms include changes in cognition, movement, sleep, and behavior.

# Mild Cognitive Impairment, Alzheimer's Disease, & Other Dementias

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## Cognitive Symptoms of Lewy Body Dementia

LBD causes changes in thinking abilities. These changes may include:

- **Dementia** - Severe loss of thinking abilities that interferes with a person's capacity to perform daily activities.
- **Cognitive fluctuations** - Unpredictable changes in concentration, attention, alertness, and wakefulness from day to day and sometimes throughout the day.
- **Hallucinations** - Visual hallucinations—seeing things that are not present—occur in up to 80 percent of people with LBD, often early on.

## Movement Problems and Lewy Body Dementia

Some people with LBD may not experience significant movement problems for several years. Others may have them early on. At first, movement symptoms, such as a change in handwriting, may be very mild and easily overlooked. Parkinsonism is seen early on in Parkinson's disease dementia but can also develop later on in dementia with Lewy bodies. Specific signs of parkinsonism may include:

- Muscle rigidity or stiffness
- Shuffling walk, slow movement, or frozen stance
- Tremor or shaking, most commonly at rest
- Balance problems and repeated falls
- Stooped posture
- Loss of coordination
- Smaller handwriting than was usual for the person
- Reduced facial expression
- Difficulty swallowing
- A weak voice

## Lewy Body Dementia and Sleep

Sleep disorders are common in people with LBD but are often undiagnosed. A sleep specialist can help diagnose and treat sleep disorders. Sleep-related disorders seen in people with LBD may include:

- **REM sleep behavior disorder (RBD)** - A condition in which a person seems to act out dreams while asleep.
- **Excessive daytime sleepiness** - Sleeping 2 or more hours during the day
- **Insomnia** - Difficulty falling or staying asleep, or waking up too early.
- **Restless leg syndrome** - A condition in which a person, while resting, feels the urge to move his or her legs to stop unpleasant or unusual sensations.

## Behavioral and Mood Symptoms of Lewy Body Dementia

Changes in behavior and mood are possible in LBD and may worsen as cognition declines. These changes may include:

- Depression
- Apathy
- Anxiety
- Agitation
- Delusions
- Paranoia

# Mild Cognitive Impairment, Alzheimer's Disease, & Other Dementias

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## Frontotemporal Disorders

Damage to the brain's frontal and temporal lobes causes forms of dementia called frontotemporal disorders. Frontotemporal disorders are the result of damage to neurons (nerve cells) in parts of the brain called the frontal and temporal lobes. As neurons die in the frontal and temporal regions, these lobes atrophy, or shrink. Gradually, this damage causes difficulties in thinking and behaviors normally controlled by these parts of the brain. Many possible symptoms can result, including unusual behaviors, emotional problems, trouble communicating, difficulty with work, or difficulty with walking.

Symptoms of frontotemporal disorders vary from person to person and from one stage of the disease to the next as different parts of the frontal and temporal lobes are affected. In general, changes in the frontal lobe are associated with behavioral symptoms, while changes in the temporal lobe lead to language and emotional disorders.

Symptoms are often misunderstood. Family members and friends may think that a person is misbehaving, leading to anger and conflict. For example, a person with bvFTD may neglect personal hygiene or start shoplifting. It is important to understand that people with these disorders cannot control their behaviors and other symptoms. Moreover, they lack any awareness of their illness, making it difficult to get help.

## Behavioral Symptoms of Frontotemporal Disorders

- **Problems with executive functioning**—Problems with planning and sequencing, prioritizing, multitasking, self-monitoring and correcting behavior.
- **Perseveration** - A tendency to repeat the same activity or to say the same word over and over, even when it no longer makes sense.
- **Social disinhibition** - Acting impulsively without considering how others perceive the behavior. For
- **Compulsive eating** - Gorging on food, especially starchy foods like bread and cookies, or taking food from other people's plates.
- **Utilization behavior** - Difficulty resisting impulses to use or touch objects that one can see and reach.

## Language Symptoms of Frontotemporal Disorders

- **Aphasia** - A language disorder in which the ability to use or understand words is impaired but the physical ability to speak properly is normal.
- **Dysarthria** - A language disorder in which the physical ability to speak properly is impaired (e.g., slurring) but the message is normal.

## Emotional Symptoms of Frontotemporal Disorders

- **Apathy** - A lack of interest, drive, or initiative.
- **Emotional changes** - Emotions are flat, exaggerated, or improper.
- **Social-interpersonal changes** - Difficulty “reading” social signals, such as facial expressions, and understanding personal relationships.

## Movement Symptoms of Frontotemporal Disorders

- **Dystonia** - Abnormal postures of body parts such as the hands or feet.
- **Gait disorder** - Abnormalities in walking, such as walking with a shuffle, sometimes with frequent falls.
- **Tremor** - Shakiness, usually of the hands.
- **Clumsiness** - Dropping of small objects or difficulty manipulating small items like buttons or screws.
- **Apraxia** - Loss of ability to make common motions, such as combing one's hair or using a knife and fork, despite normal strength.
- **Neuromuscular weakness** - Severe weakness, cramps, and rippling movements in the muscles.

# Mild Cognitive Impairment, Alzheimer's Disease, & Other Dementia

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## Mixed Dementia

It is common for people with dementia to have mixed dementia—a combination of two or more types of dementia. A number of combinations are possible. For example, some people have both Alzheimer's disease and vascular dementia.

Some studies indicate that mixed dementia is the most common cause of dementia in the elderly. For example, autopsy studies looking at the brains of people who had dementia indicate that most people age 80 and older probably had mixed dementia caused by a combination of brain changes related to Alzheimer's disease, vascular disease-related processes, or another neurodegenerative condition. Some studies suggest that mixed vascular-degenerative dementia is the most common cause of dementia in older adults.

In a person with mixed dementia, it may not be clear exactly how many of a person's symptoms are due to Alzheimer's or another disease. In one study, researchers who examined older adults' brains after death found that 78 percent had two or more pathologies (disease characteristics in the brain) related to neurodegeneration or vascular damage. Alzheimer's was the most common pathology but rarely occurred alone

Source: <https://www.nia.nih.gov/health/what-dementia-symptoms-types-and-diagnosis>

Source: <https://www.nia.nih.gov/health/vascular-contributions-cognitive-impairment-and-dementia>

Source: <https://www.nia.nih.gov/health/what-lewy-body-dementia>

Source: <https://www.nia.nih.gov/health/what-are-frontotemporal-disorders>

Source: <https://www.mayoclinic.org/diseases-conditions/mild-cognitive-impairment/diagnosis-treatment/drc-20354583>





# What Causes Alzheimer's Disease?

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Scientists don't yet fully understand what causes Alzheimer's disease in most people. The causes probably include a combination of age-related changes in the brain, along with genetic, environmental, and lifestyle factors. The importance of any one of these factors in increasing or decreasing the risk of Alzheimer's disease may differ from person to person.

## **Aging and Alzheimer's Risk**

Older age does not cause Alzheimer's, but it is the most important known risk factor for the disease. The number of people with Alzheimer's disease doubles about every 5 years beyond age 65. About one-third of all people age 85 and older may have Alzheimer's disease.

Scientists are learning how age-related changes in the brain may harm neurons and affect other types of brain cells to contribute to Alzheimer's damage. These age-related changes include atrophy (shrinking) of certain parts of the brain, inflammation, vascular damage, production of unstable molecules called free radicals, and breakdown of energy production within cells.

However, age is only one risk factor for Alzheimer's disease. Many people live into their 90s and beyond without ever developing dementia.

## **Genetics of Alzheimer's Disease**

Many people wonder if Alzheimer's disease runs in the family. A person's chance of having the disease may be higher if he or she has certain genes passed down from a parent. However, having a parent with Alzheimer's does not always mean that someone will develop it.

There are two types of Alzheimer's—early-onset and late-onset. Both types have a genetic component.

## **Late-Onset Alzheimer's Disease**

Most people with Alzheimer's have the late-onset form of the disease, in which symptoms become apparent in their mid-60s and later.

Researchers have not found a specific gene that directly causes late-onset Alzheimer's disease. However, having a genetic variant of the apolipoprotein E (APOE) gene on chromosome 19 does increase a person's risk. The APOE gene is involved in making a protein that helps carry cholesterol and other types of fat in the bloodstream.

APOE comes in several different forms, or alleles. Each person inherits two APOE alleles, one from each biological parent.

APOE  $\epsilon$ 4 is called a risk-factor gene because it increases a person's risk of developing the disease. However, inheriting an APOE  $\epsilon$ 4 allele does not mean that a person will definitely develop Alzheimer's. Some people with an APOE  $\epsilon$ 4 allele never get the disease, and others who develop Alzheimer's do not have any APOE  $\epsilon$ 4 alleles.

## **Early-Onset Alzheimer's Disease**

Early-onset Alzheimer's disease is rare, representing about 5-6% percent of all people with Alzheimer's. It typically occurs between a person's 30s and mid-60s. Some cases are caused by an inherited change in one of three genes. Mutations in these genes result in the production of abnormal proteins that are associated with the disease. Each of these mutations plays a role in the breakdown of APP, a protein whose precise function is not yet fully understood. This breakdown is part of a process that generates harmful forms of amyloid plaques, a hallmark of Alzheimer's disease.

Scientists have identified rare changes (mutations) in three genes that virtually guarantee a person who inherits one of them will develop Alzheimer's. But these mutations account for less than 1% of people with Alzheimer's disease.

# What Causes Alzheimer's Disease?

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## Health, Environmental, and Lifestyle Factors that May Contribute to Alzheimer's Disease

Research suggests that a host of factors beyond genetics may play a role in the development and course of Alzheimer's disease. There is a great deal of interest, for example, in the relationship between cognitive decline and vascular conditions such as heart disease, stroke, and high blood pressure, as well as metabolic conditions such as diabetes and obesity. Ongoing research will help us understand whether and how reducing risk factors for these conditions may also reduce the risk of Alzheimer's.

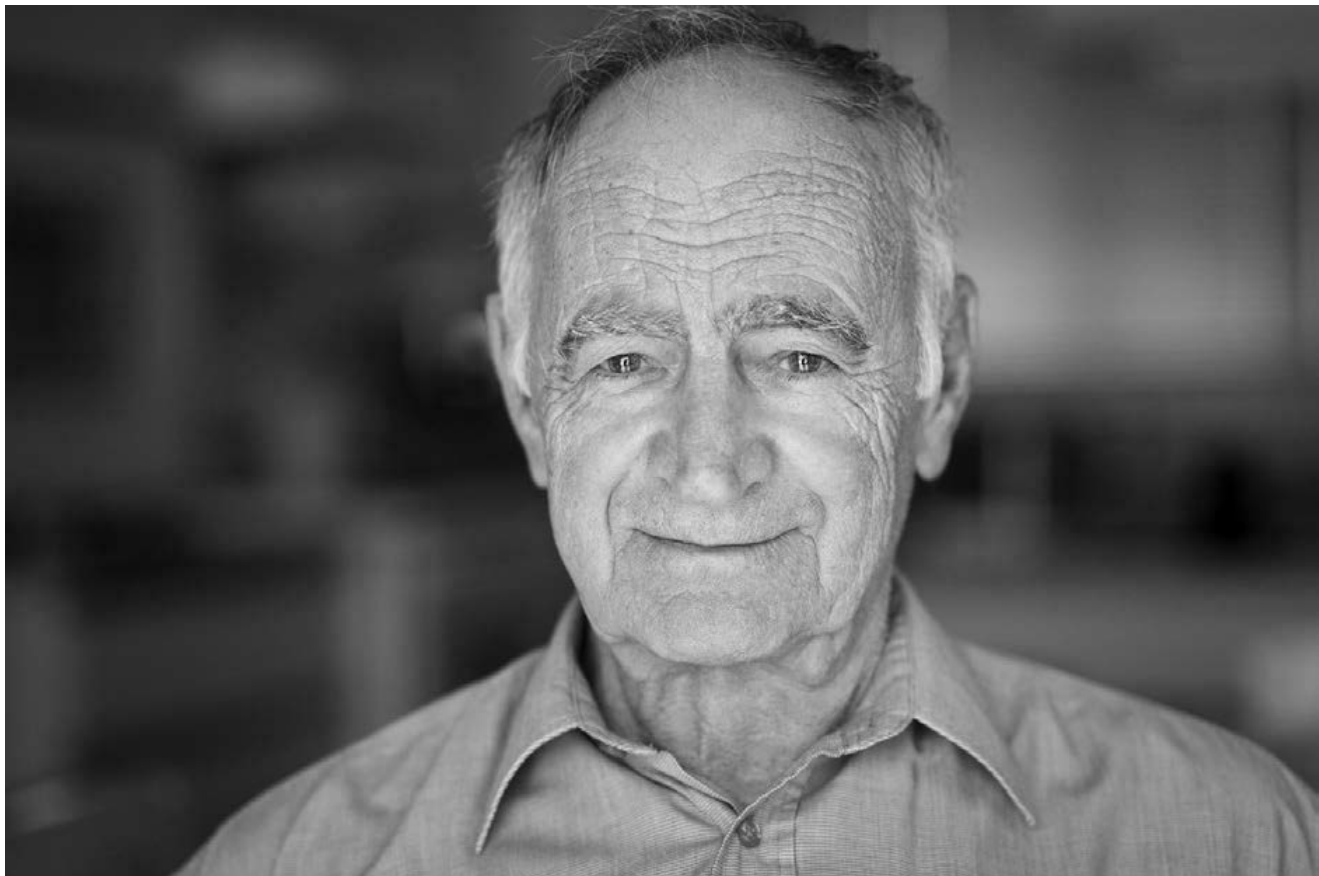
A nutritious diet, physical activity, social engagement, sleep, and mentally stimulating pursuits have all been associated with helping people stay healthy as they age. These factors might also help reduce the risk of cognitive decline and Alzheimer's disease. Clinical trials are testing some of these possibilities.

Early-life factors may also play a role. For example, studies have linked higher levels of education with a decreased risk of dementia. There are also differences in dementia risk among racial groups and sexes—all of which are being studied to better understand the causes of Alzheimer's disease and to develop effective treatments and preventions for all people.

Source: <https://www.nia.nih.gov/health/what-causes-alzheimers-disease>

Source: <https://www.nia.nih.gov/health/alzheimers-disease-genetics-fact-sheet>

Source: <https://www.mayoclinic.org/diseases-conditions/alzheimers-disease/symptoms-causes/syc-20350447>



# Is it Alzheimer's Disease?

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## How Alzheimer's disease is diagnosed

If you are concerned about changes in memory and thinking or changes in senses, behavior, mood, or movement that do not seem normal in yourself or a family member, talk with a doctor.

To diagnose Alzheimer's, doctors may:

- Ask the person and a family member or friend questions about overall health, use of prescription and over-the-counter medicines, diet, past medical problems, ability to carry out daily activities, and changes in behavior and personality
- Conduct tests of memory, problem solving, attention, counting, and language
- Carry out standard medical tests, such as blood and urine tests, to identify other possible causes of the problem
- Perform brain scans, such as computed tomography (CT), magnetic resonance imaging (MRI), or positron emission tomography (PET), to rule out other possible causes for symptoms

These tests may be repeated to give doctors information about how the person's memory and other cognitive functions are changing over time. They can also help diagnose other causes of memory problems, such as stroke, tumor, Parkinson's disease, sleep disturbances, side effects of medication, an infection, mild cognitive impairment, or a non-Alzheimer's dementia, including vascular dementia. Some of these conditions may be treatable and possibly reversible.

If a primary care doctor suspects mild cognitive impairment or possible Alzheimer's, they may refer the patient to a specialist who can provide a detailed diagnosis or further assessment.

Specialists include:

- Geriatricians, who manage health care in older adults and know how the body changes as it ages and whether symptoms indicate a serious problem
- Geriatric psychiatrists, who specialize in the mental and emotional problems of older adults and can assess memory and thinking problems
- Neurologists, who specialize in abnormalities of the brain and central nervous system and can conduct and review brain scans
- Neuropsychologists, who can conduct tests of memory and thinking

Memory clinics and centers, including Alzheimer's Disease Research Centers, offer teams of specialists who work together to diagnose the problem. Tests often are done at the clinic or center, which can speed up the diagnosis.

Early, accurate diagnosis is beneficial for several reasons. Beginning treatment early in the disease process may help preserve daily functioning for some time, even though the underlying Alzheimer's process cannot be stopped or reversed.

Having an early diagnosis helps people with Alzheimer's and their families:

- Plan for the future
- Take care of financial and legal matters
- Address potential safety issues
- Learn about living arrangements
- Develop support networks

In addition, an early diagnosis gives people greater opportunities to participate in clinical trials that are testing possible new treatments for Alzheimer's disease or other research studies.

Source: [www.nia.nih.gov/alzheimers/topics/diagnosis](http://www.nia.nih.gov/alzheimers/topics/diagnosis)

## Consultative Hospital-Based Diagnostic Centers

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### **Capital Health Medical Center**

Institute for Neurosciences  
Two Capital Way, Suite 456  
Pennington, NJ 08534  
609-537-7300

### **COPSA - Institute for Alzheimer's Disease and Related Disorders**

University Behavioral Health Care  
100 Metroplex Drive, Suite 200  
Edison, NJ 08817  
800-424-2494

### **The Hunterdon Center for Healthy Aging**

121 Route 31, Suite 1000  
Flemington, NJ 08822  
908-788-6373

### **Hackensack Meridian Health**

JFK Medical Center  
Neuroscience Institute  
65 James Street  
Edison, NJ 08818  
732-321-7010

### **Monmouth Medical Center**

Geriatric Health Center  
The Anna Greenwall Geriatric Program  
300 Second Avenue  
Long Branch, NJ 07740  
732-923-7550

### **Morristown Memorial Hospital**

Geriatric Assessment Center  
435 South Street – Suite 390  
Morristown, NJ 07960  
973-971-7022

### **Newark Beth Israel Medical Center**

Center for Geriatric Health Care  
156 Lyons Avenue  
Newark, NJ 07112  
973-926-8491

### **Overlook Medical Center**

**Atlantic Neuroscience Institute**  
**Memory and Cognitive Disorders Program**  
99 Beauvoir Avenue  
Summit, NJ 07902  
908-522-2829

### **Robert Wood Johnson Medical School**

Dementia Program  
1 Robert Wood Johnson Place  
New Brunswick, NJ 08901  
732-828-3000

### **Rowan University School of Osteopathic Medicine**

Memory Assessment Program  
University Doctors Pavilion  
42 East Laurel Road – Suite 1800  
Stratford, NJ 08084  
856-566-6843

### **Saint Barnabas Medical Center**

Center for Geriatric Health and Disease Management  
94 Old Short Hills Road  
Livingston, NJ 07039  
973-322-7636

### **Saint Peter's Physician Associates at Monroe**

Geriatric Evaluation and Management Services (GEMS)  
294 Applegarth Road Suite A  
Monroe, New Jersey, 08831  
Phone: 609-409-1363

### **Saint Peter's Physician Associates at Somerset - Primary Care Office**

Geriatric Evaluation and Management Services (GEMS)  
59 Veronica Avenue Suite 203  
Somerset, New Jersey, 08873  
Phone: 732-937-6008

### **Shore Medical Center**

Flora Baker Center for Alzheimer's Disease and Related Disorders  
At Shore Physicians Group's Neurology Office  
52 East New York Avenue  
Somers Point, NJ 08244  
609-365-6226

# Alzheimer's New Jersey™



## Helpline 888-280-6055

Our Helpline is a professionally staffed, toll-free contact center that provides callers with personal and confidential assistance about Alzheimer's and other dementias, and available community resources.

[alznj.org](http://alznj.org)®

**When the Diagnosis  
is Alzheimer's:  
Information  
and Resources**



## FDA-Approved Treatments

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Several prescription drugs are currently approved by the U.S. Food and Drug Administration (FDA) to treat people who have been diagnosed with Alzheimer's disease. Treating the symptoms of Alzheimer's can provide people with comfort, dignity, and independence for a longer period of time and can encourage and assist their caregivers as well. Most medicines work best for people in the early or middle stages of Alzheimer's. It is important to understand that none of these medications stops the disease itself.

### **Treatment for Mild to Moderate Alzheimer's**

Medications called cholinesterase inhibitors are prescribed for mild to moderate Alzheimer's disease. These drugs may help reduce some symptoms and help control some behavioral symptoms. The medications are Razadyne® (galantamine), Exelon® (rivastigmine), and Aricept® (donepezil).

Scientists do not yet fully understand how cholinesterase inhibitors work to treat Alzheimer's disease, but research indicates that they prevent the breakdown of acetylcholine, a brain chemical believed to be important for memory and thinking. As Alzheimer's progresses, the brain produces less and less acetylcholine; therefore, cholinesterase inhibitors may eventually lose their effect.

No published study directly compares these drugs. Because they work in a similar way, switching from one of these drugs to another probably will not produce significantly different results. However, an Alzheimer's patient may respond better to one drug than another.

### **Treatment for Moderate to Severe Alzheimer's**

A medication known as Namenda® (memantine), an N-methyl D-aspartate (NMDA) antagonist, is prescribed to treat moderate to severe Alzheimer's disease. This drug's main effect is to decrease symptoms, which could allow some people to maintain certain daily functions a little longer than they would without the medication. For example, Namenda® may help a person in the later stages of the disease maintain his or her ability to use the bathroom independently for several more months, a benefit for both the person with Alzheimer's and caregivers.

The FDA has also approved Aricept®, the Exelon® patch, and Namzaric®, a combination of Namenda® and Aricept®, for the treatment of moderate to severe Alzheimer's disease.

Namenda® is believed to work by regulating glutamate, an important brain chemical. When produced in excessive amounts, glutamate may lead to brain cell death. Because NMDA antagonists work differently from cholinesterase inhibitors, the two types of drugs can be prescribed in combination.

*Source: <https://order.nia.nih.gov/sites/default/files/2018-03/alzheimers-disease-medications-fact-sheet.pdf>*

# Alzheimer's and Related Dementias Clinical Research

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## What is Clinical Research?

Clinical research is medical research involving people. There are two types, observational studies and clinical trials.

- Observational studies observe people in normal settings. Researchers gather information, group volunteers according to broad characteristics, and compare changes over time. For example, researchers may collect data through medical exams, tests, or questionnaires about a group of older adults over time to learn more about the effects of different lifestyles on cognitive health. These studies may help identify new possibilities for clinical trials.
- Clinical trials are research studies performed in people that are aimed at evaluating a medical, surgical, or behavioral intervention. They are the primary way that researchers find out if a new treatment, like a new drug or diet or medical device (for example, a pacemaker) is safe and effective in people. Often a clinical trial is used to learn if a new treatment is more effective and/or has less harmful side effects than the standard treatment.

Other clinical trials test ways to find a disease early, sometimes before there are symptoms. Still others test ways to prevent a health problem. A clinical trial may also look at how to make life better for people living with a life-threatening disease or a chronic health problem. Clinical trials sometimes study the role of caregivers or support groups.

Before the U.S. Food and Drug Administration (FDA) approves a clinical trial to begin, scientists perform laboratory tests and studies in animals to test a potential therapy's safety and efficacy. If these studies show favorable results, the FDA gives approval for the intervention to be tested in humans.

## Why would I participate in Alzheimer's and related dementias research?

- To help future generations, including family members, who may be at risk for Alzheimer's disease or a related dementia
- To test new treatments that might work better than those currently available
- To receive close medical monitoring and care throughout the trial
- To learn about Alzheimer's disease and your health
- To allow your loved one with dementia to take an active role in their own healthcare
- To get information about support groups and resources
- To gain access to free diagnostic tools

Source: <https://www.nia.nih.gov/health/what-are-clinical-trials-and-studies>



## Communication Tips for Caregivers

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Communication is important at any age and at any stage of Alzheimer's disease. People can benefit from loving gestures and touch long after they lose their ability to communicate with words. Alzheimer's disease damages parts of the brain important for expressing oneself, and also for processing what others are saying. Called aphasia, this impairment tends to get worse as the disease progresses.

As the person with Alzheimer's disease loses his/her ability to express and understand language, non-verbal communication becomes more important. A loving and gentle tone of voice communicates reassurance and safety, even when the words are not understood. Steady eye contact communicates respect and concern. A head nod, or a soft touch on the hand lets the person with Alzheimer's disease know he/she is cared about.

### Communication in Early Stage Alzheimer's:

- Be sensitive.
- Treat the individual as an adult.
- Allow time for the person to process and respond.
- Do not downplay the disease.
- Have patience for repeated questions.
- Prepare simple answers to the person's questions.
- Offer reassurance and express your desire to provide ongoing support.
- Offer suggestions instead of asking questions.
- Use short statements; avoid multi-clause sentences.

### Communication in Middle Stage Alzheimer's:

- Use simple language.
- Don't argue or try to use logic.
- Allow the person to express his or her feelings. Avoid telling them they shouldn't feel that way.
- Decrease background noise and other distractions.
- Approach from the front.
- Encourage the person to use gestures to communicate— "point to what you want."

### Communication in Late Stage Alzheimer's:

- Use favorite music from the era of the person with dementia.
- Read or sing to them.
- Reminisce—old memories sometimes remain even after recent memories fade.
- Touch continues to be important. A loving voice and gentle touch are often soothing.
- Smile.
- Avoid loud noises and fast movement.

# Communication Tips for Caregivers

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## Behavior is Communication

All behavior has meaning. Even if the person is not intentionally communicating, caregivers can pick up on unmet needs or feelings by “tuning in” to their loved ones behavior changes. The person with Alzheimer’s disease who is agitated and pacing may be communicating that he/she needs to use a bathroom, is in pain, or is confused. Check to see that basic needs are met, and reassure and comfort the person who is agitated.

## Behavior changes can also be caused by reactions to:

- an unfamiliar or changing environment
- hallucinations or delusions
- the stress or anxiety of the caregiver or others nearby

Often, gentle reassurance and other communication tips will help calm the person. If the person is still very agitated, or if there is a sudden change in the person’s behavior, consult the physician, as there may be an underlying infection or other issue that requires medical assistance.

## Tips for Enhancing Interactions:

- Speak in a calm and reassuring tone.
- Talk slowly and distinctly.
- Use simple words.
- Approach the individual from the front to avoid startling them.
- Address the person by name.
- Maintain eye contact while speaking.
- Use positive reinforcements, such as smiles and a gentle touch.
- Allow an adequate period for a response when engaging in conversation.
- Ask only one question at a time.
- Eliminate distractions.
- Avoid negative-sounding statements. Instead of “Don’t go outside,” say “Let’s stay inside.”
- Use humor whenever possible, though not at the individual’s expense.
- Use non-verbal gestures for cueing, such as demonstrating hand washing



# Managing Behavior Changes

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A person with dementia may exhibit challenging behaviors for many reasons. Being sensitive to the emotion behind the behavior can help to manage stress and frustration. Try not to take behavior changes personally—it's the disease, not the person.

## Potential Causes of Problem Behaviors

**Inability to Meet Basic Needs:** Hunger, dehydration, elimination problems and fatigue can produce behavioral changes. They may show their discomfort through agitated and aggressive behavior.

**Reaction to Loss:** We all rely on information from the environment to guide us in activities and relationships. An individual with dementia has difficulty processing information and communicating needs. This may cause, fear, insecurity, and frustration.

**Medical Problems:** Pain and discomfort from a medical problem or medication side effects can go unnoticed because of the individual's inability to report it.

### Environmental Factors:

- Excessive noise
- Poor or glaring lighting
- Uncomfortable temperatures (hot or cold)
- Change in the environment/routines
- Boredom and conflicts

**Sensory Impairment:** Individuals with hearing or visual impairments tend to be more paranoid, hallucinate more, and feel more frightened and frustrated.

**Factors Related to the Caregiver:** A caregiver's approach and knowledge of dementia affect the care of individuals with the disease. The more one knows about dementia, the more likely they will be to understand behavioral problems.

## Coping with Wandering

- Do not leave the person with dementia home alone even just for a few minutes.
- Monitor and record wandering patterns.
- Consult with a physician to see if medications can help.
- Provide activities—music, physical exercise or movies, for example—to reduce boredom.
- Ensure that the individual is well fed, well hydrated, and using the bathroom at regular intervals.
- Reduce environmental stimuli like loud noise or overcrowding.
- Outfit the individual with an identification bracelet, and put some form of identification in every jacket or pocketbook.
- Have a current photo readily available and find out about leaving one on file at the police department.
- Add electronic chimes or doorbells so a caregiver is alerted if the individual is leaving.
- Identify rooms with colorful signs.
- Post a large sign that says “STOP” or “DO NOT ENTER” on exits.
- Mask exit doors with a curtain.
- Place a large black mat or paint a black space by an exit, which may look like an impassable hole to the person with Alzheimer's disease.
- Put away items that trigger thoughts of leaving, such as coats, shoes, pocketbooks.
- Tell neighbors about wandering behavior and make sure they have your phone number.

# Managing Behavior Changes

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## Coping with Agitation and Aggression

- Seek a doctor's advice to determine if there is a medical cause or if medications are causing adverse side effects.
- Limit outside noise, clutter or the number of persons in a room.
- Keep to the same familiar routines.
- Reduce caffeine intake.
- Do not move objects and furniture.
- Dot the environment with familiar objects that promote pleasant memories.
- Try gentle touch, soothing music, reading or walks.
- Speak in a reassuring voice.
- Distract the person with a snack or activity.
- Learn to recognize behaviors - an agitated state or pulling at clothing, for example, could indicate a need to use the bathroom.
- Do not try to restrain the person during an agitated reaction.
- Keep dangerous objects out of reach.
- If agitation increases at night, a nightlight may reduce confusion.

## Coping with Paranoia

- Discuss paranoid behaviors with the individual's doctor. Medications may need to be adjusted.
- Explain to family members and caregivers that suspicious accusations are a part of the illness.
- Respond to the feeling behind the accusation.
- Try non-verbal reassurances like a gentle touch or hug.
- If the individual suspects money is "missing," allow him/her to keep small amounts of money in a pocket or pocketbook.
- Help to look for a missing object. Try to learn where their favorite hiding places are for storing objects that are "lost."
- Avoid arguing. The person's reality is very real for him/her.
- Keep individuals awake during the day.
- Increase indoor lighting before dusk.
- Ensure that the individual is not suffering from hunger, thirst, pain or fear.
- Remove excess stimuli and clutter.
- Consult your doctor to see if medications may help.

## Sundowning

Sundowning is a dementia-related symptom that refers to increased agitation, confusion and hyperactivity that typically begins in the late afternoon and builds throughout the evening. To combat sundowning, increase indoor lighting before dusk, plan activities or outings in the morning, and remove excess stimuli and clutter as the day winds down. Consult your physician if sundowning continues to be an issue.



## Safety Considerations

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As Alzheimer's disease progresses, confusion, disorientation, changes in perception and judgement, as well as balance issues, all affect the individual's safety. Caregivers can adapt the home and daily activities to minimize risk, maximize independence, and assure the individual's access to help in an emergency. Here are some tips to increase safety.

### Home Safety Tips

- Make an ongoing assessment of safety, asking the doctor for guidance on the person's care needs, including when 24/7 supervision is required.
- If the person is not safe to be home alone, consider home care, adult day services and/or alternative living situations to assure 24/7 supervision.
- Notify your local police and fire department of the person's need for special assistance in an emergency or community disaster.
- Use grab bars and a bath chair in the tub and shower.
- Keep your floors smooth but not slippery.
- Make sure stairwells are lit.
- Get nightlights for bathrooms and hallways.
- Keep walking areas free of clutter.
- Minimize glare and shadows.
- Use contrasting colors. For example, painting the edge of a step a different color than the rest of the floor will make that step easier to see.
- Wear low-heeled, comfortable shoes when walking around. Avoid walking in slippery socks or slippers.
- Make sure carpets are fully tacked to the ground, and avoid throw rugs.
- When the person with memory loss can no longer safely self-administer medication, family can dispense medication or arrange for a home care agency to do this. Medication dispensing products may be appropriate.
- Lock up medicines and vitamins, cleaning products and hazardous materials.
- Consider installing a shut-off valve for the stove.
- Remove cords for power tools, and secure tools, gardening equipment and appliances that the person no longer remembers how to operate safely without assistance.
- Assure household safety by developing a plan for removing any guns from the home.
- Contact your local police for help if needed.

### Driving

- Have ongoing discussion with the doctor about the person's driving abilities. Share information about any changes that may impact driving: Has the person become more confused in handling familiar daily tasks? Has he/she gotten lost? Have there been any car accidents or traffic violations?
- A driving assessment by an occupational therapy driving rehabilitation specialist may assist family members and doctors in monitoring the driving safety of a person with dementia. Call Alzheimer's New Jersey to locate driver assessment centers in your area.
- Identify alternative transportation options before they are needed so when the person with memory loss is no longer able to drive safely, transportation is available to his/her usual activities.
- When the person is no longer able to drive safely, lock up the car keys so they are not accessible.
- Consider having a kill switch installed in the car.

# Caring for the Caregiver

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Caregivers face a number of challenges when caring for a loved one with Alzheimer's disease. Those challenges can lead to stress and physical issues for caregivers.

If you are a caregiver, there are some very important reasons to develop a daily self-care plan. It is very easy to lose sight of your own physical and emotional needs when you are caring for someone with Alzheimer's. Ignoring your own needs and health can lead to emotional burnout and even serious physical problems. Don't let this happen to you. Here are a few important steps to good self-care to keep your own physical and emotional batteries charged.

- First of all, accept that taking care of yourself is an essential part of taking care of your loved one. Good self-care is essential and you do not need to feel guilty about taking the time for your own needs.
- It is important that you take time for your own medical appointments. Do not put your physical and emotional needs on the shelf. If you need to see your doctor about physical or emotional symptoms, make sure to do so as soon as possible to avoid problems becoming bigger.
- Take time every day for some exercise, including stretching your muscles to relieve tension. Exercise is the best medicine for stress relief, and helps avoid muscle aches and other stress symptoms.
- Do not be embarrassed about asking for guidance on how to cope with the demands of caregiving and difficult behaviors that your loved one displays. This is not a job that only one person can do, so do not expect to have all of the answers. Allow people with experience and knowledge to support you with new ideas on how to care for your loved one.
- Educate yourself about the resources available in the community, such as support groups, caregiver trainings, adult day care, overnight respite, financial aid, in-home care, and other resources that can greatly help you on your journey as a caregiver.



## Important Community Resources

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Many community resources can assist you throughout the course of Alzheimer's disease. Alzheimer's New Jersey is here to help connect you to vital resources in your area. Please call our Helpline at 1-888-280-6055 to learn more. You can also participate in the following ALZNJ programs to find the support and guidance you need. We are here for you.

- Alzheimer's New Jersey Family Support Groups
- Online Education Programs
- Guest Speaker Programs
- The Respite Care and Wellness Program
- Clinical Trial Connections® Program
- Always Safe®

Listed below are a few of the services you can learn more about by calling the Alzheimer's New Jersey Helpline: 1-888-280-6055.

### Legal and Financial Services

Legal and financial planning related to Alzheimer's disease and other dementias is critically important. Alzheimer's disease typically spans a period of many years, and the majority of care and support needs are not covered under traditional health insurance programs. Care costs are high and can mount up quickly. For this reason, we strongly advise that individuals and families become educated about financial planning options related to catastrophic long term illness, and learn about what legal tools are important to assist and protect an individual and family impacted by Alzheimer's disease.

Elder law attorneys specialize in issues affecting older adults. A list of elder law attorneys in your area can be found on the website for the National Academy of Elder Law Attorneys (NAELA), <https://www.naela.org> or by calling NAELA at 703.942.5711.

For information about financial assistance programs, call your local Area Agency on Aging/Aging & Disability Resource Connection (AAA/ADRC) at 1.877.222.3737 or Alzheimer's New Jersey at 888.280.6055.

### Veterans Benefits

Veterans with dementia and their spouses may be eligible for financial assistance for homecare, free medical supplies, long-term care, and more. To learn more, call the Alzheimer's New Jersey Helpline -1-888-280-6055 or contact the Veterans Health Administration by visiting <https://www.va.gov/health-care/how-to-apply> or calling 1-877-222-VETS.

### Aging Life Specialists

An Aging Life Specialist, also known as a Geriatric Care Manager, is a professional in the field of human services (Registered Nurse, Licensed Clinical Social Worker, Psychologist) who is trained and experienced in assessment, coordination and monitoring of services for older adults. A list of Aging Life Specialists serving your area can be found on the website of the Aging Life Care Association, [www.aginglifecare.org](http://www.aginglifecare.org).

# Important Community Resources

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## Respite Care

A form of short-term relief for the primary family caregiver, respite care allows caregivers a break from day-to-day duties and provides the person with Alzheimer's opportunities to interact with others.

Three types of respite care most commonly available are:

- Adult Day Services – Programs in adult day centers can give the person with Alzheimer's an opportunity to socialize with others, exercise and engage in activities.
- Home Care – Homemakers and volunteers can offer companionship while family take a break, and certified home health aides can provide services at home such as assistance with bathing and dressing.
- Overnight Respite – Some residential facilities offer short-term stays of a few days or a few weeks.

Some individuals may qualify for financial assistance for respite care. Please call the Alzheimer's New Jersey Helpline for more information – 1-888-280-6055.

## Residential Care

The type of residential option you consider will probably vary depending on the care needs of the person with dementia. Housing options include:

- Assisted living facilities are residential care settings that combine housing, meals, and supportive and health care services. These settings offer more services than independent living but fewer than a skilled nursing facility. Assisted living facilities and programs are licensed by the New Jersey Department of Health, which provides information on facilities at their website, <https://www.nj.gov/health/facilities/index.shtml>.
- Nursing homes, also called skilled nursing facilities, provide a wide range of health and personal care services. Their services focus on medical care more than most assisted living facilities. These services typically include nursing care, 24-hour supervision, three meals a day, and assistance with everyday activities. Rehabilitation services, such as physical, occupational, and speech therapy, are also available. Nursing homes are licensed by the New Jersey Department of Health which offers information about long term care on their website: <https://www.nj.gov/health/facilities/index.shtml>.
- Additional information about long term care facilities can be found in the Nursing Home Compare section of the Medicare website, <https://www.medicare.gov/nursinghomecompare/search.html>.
- Continuing Care Retirement Communities (CCRCs), sometimes referred to as “life care communities,” provide increasing levels of care that meet the need of individual residents, beginning with independent living, and including, if necessary, assisted living, and nursing home care. The New Jersey Department of Community Affairs, which regulates CCRC's, provides information on their website, <http://www.state.nj.us/dca/divisions/codes/offices/ccrc.html>.

For more information you can call the ALZNJ Helpline -1-888-280-6055. You can also receive information on resources through a free publication created by the New Jersey Department of Human Services, Division on Aging Services called

“A Guide to Community-Based Long Term Care in New Jersey.” The publication can be found here: <http://www.state.nj.us/humanservices/doas/home/lcguide.html>.

## Hospice Services

Designed to help people near the end of life, hospice programs, licensed by the New Jersey Department of Health, combine at-home and skilled nursing services. Today, more hospices are offering specialized programs for persons with Alzheimer's disease. Information about hospices in your area is available from the New Jersey Department of Health at, <https://www.state.nj.us/health/healthfacilities/findhospital.shtml>.

## New Jersey Aging and Disability Resource Connection...

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An Area Agency on Aging (AAA) is designated in each of New Jersey's 21 counties to serve as the primary entity responsible for developing comprehensive, coordinated systems of community-based services for older adults. AAAs also serve as Aging & Disability Resource Connection (ADRC) lead agencies in their county, ensuring seniors, adults with disabilities and their caregivers have easy access to information and long term services and supports. Your local county can be reached by calling 1-877-222-3737.

### **Atlantic County**

(1-888-426-9243 or 609-645-5965)  
Atlantic County Division of Intergenerational Services  
Shoreview Building  
101 S. Shore Road  
Northfield, NJ 08225

### **Bergen**

(201-336-7400)  
Bergen County Division of Senior Services  
One Bergen County Plaza, 2nd Floor  
Hackensack, NJ 07601

### **Burlington**

(609-265-5069)  
Burlington County Office on Aging  
795 Woodlane Road  
Westampton, NJ 08060  
Mailing Address:  
PO Box 6000  
Mount Holly, NJ 08060

### **Camden**

(856-858-3220)  
Camden County Division of Senior and Disabled Services  
512 Lakeland Avenue, 4th Floor  
Blackwood, NJ 08012

### **Cape May**

(609-886-2785)  
Cape May County Department of Aging and Disability Services  
Social Services Building  
4005 Route 9, South  
Rio Grande, NJ 08242

### **Cumberland**

(856-453-2220)  
Cumberland County Office on Aging and Disabled Administration Building  
800 East Commerce Street, Room 29  
Bridgeton, NJ 08302

### **Essex**

(973-395-8365)  
Essex County Division of Senior Services  
900 Bloomfield Avenue  
Verona, NJ 07044

### **Gloucester**

(856-384-6900)  
Gloucester County Division of Senior Services  
115 Budd Blvd.  
West Deptford, NJ 08096

### **Hudson**

(201-369-4313)  
Hudson County Office on Aging  
830 Bergen Avenue, Suite 3B  
Jersey City, NJ 07306

### **Hunterdon**

(908-788-1361)  
Hunterdon County Division of Senior, Disabilities and Veterans' Services  
4 Gauntt Place, Building 1  
PO Box 2900  
Flemington, NJ 08822

### **Mercer**

(609-989-6661/6662)  
Mercer County Office on Aging  
640 S. Broad Street  
PO Box 8068  
Trenton, NJ 08650

### **Middlesex**

(732-745-3295)  
Middlesex County Office of Aging & Disabled Services  
75 Bayard Street, 5th Floor  
New Brunswick, NJ 08901

## ...and Area Agency on Aging (ADRC / AAA)

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### **Monmouth**

(732-431-7450)

Monmouth County Division of Aging, Disabilities and Veterans Services  
3000 Kozloski Road  
Freehold, NJ 07728

### **Morris**

(1-800-564-4656)

Morris County Division on Aging, Disabilities and Veterans  
340 West Hanover Avenue  
Morris Township, NJ 07961  
Mailing Address:  
PO Box 900  
Morristown, NJ 07963

### **Ocean**

(732-929-2091)

Ocean County Office of Senior Services  
1027 Hooper Avenue, Building #2  
PO Box 2191  
Toms River, NJ 08754

### **Passaic**

(973-569-4060)

Passaic County Department of Senior Services, Disabilities and Veterans' Affairs  
930 Riverview Drive, Suite 200  
Totowa, NJ 07512

### **Salem**

Salem County Office on Aging  
110 Fifth Street, Suite 900  
Salem, NJ 08079

### **Somerset**

(908-704-6346)

Somerset County Office on Aging and Disability Services  
27 Warren Street, 1st Floor  
PO Box 3000  
Somerville, NJ 08876

### **Sussex**

(973-579-0555)

Sussex County Division of Senior Services  
Sussex County Administration Building  
1 Spring Street, 2nd Floor  
Newton, NJ 07860

### **Union**

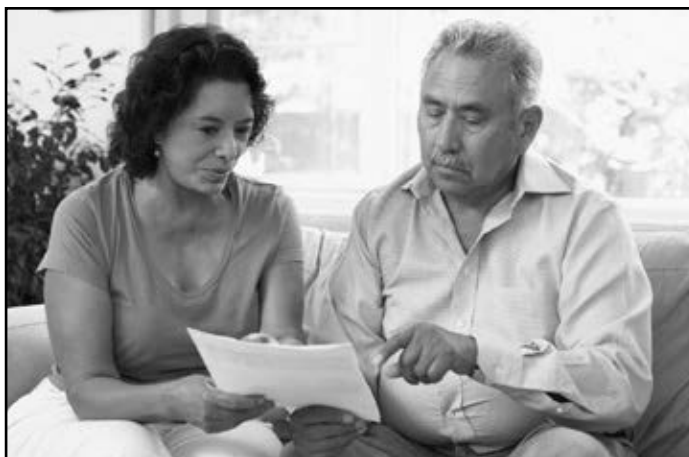
(908-527-4870 or toll-free 888-280-8226)

Union County Division on Aging  
Administration Building  
10 Elizabethtown Plaza  
Elizabeth, NJ 07207

### **Warren**

(908-475-6591)

Division of Aging and Disability Services  
Wayne Dumont, Jr. Admin. Bldg.  
165 County Route 519 South  
Belvidere, NJ 07823



# New Jersey County Boards of Social Services

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## **Atlantic County**

Department of Family and Community Development  
1333 Atlantic Avenue  
Atlantic City, NJ 08401  
(609) 348-3001

## **Bergen County**

Bergen County Board of Social Services  
218 Route 17 North  
Rochelle Park, NJ 07662  
(201) 368-4200

## **Burlington County**

Burlington County Board of Social Services  
Human Services Facility  
795 Woodlane Road  
Mount Holly, NJ 08060  
(609) 261-1000

## **Camden County**

Camden County Board of Social Service  
Althea R. Wright Administration Bldg.  
600 Market Street  
Camden, NJ 08102-1255  
(856) 225-8800

## **Cape May County**

Cape May County Board of Social Services  
4005 Route 9 South  
Rio Grande, NJ 08242  
(609) 886-6200

## **Cumberland County**

Cumberland County Board of Social Services  
275 North Delsea Drive  
Vineland, NJ 08360-3607  
(856) 691-4600

## **Essex County**

Department of Citizen Services  
Division of Family Assistance and Benefits (DFAB)  
320 University Avenue, 2nd Floor  
Newark, NJ 07102  
(973) 733-3000

## **Gloucester County**

Gloucester County Division of Social Services  
400 Hollydell Drive  
Sewell, NJ 08080  
(856) 582-9200

## **Hudson County**

Hudson County Dept of Family Services  
Division of Social Services  
257 Cornelison Avenue  
Jersey City, NJ 07302  
201 420-3000

## **Hunterdon County**

Hunterdon County Department of Human Services  
Division of Social Services  
PO Box 2900  
6 Gauntt Place  
Flemington, NJ 08822  
(908) 788-1300

## **Mercer County**

Mercer County Board of Social Services  
PO Box 1450  
200 Woolverton Street  
Trenton, NJ 08611  
(609) 989-4320

## **Middlesex County**

Middlesex County Board of Social Services  
PO Box 509  
181 How Lane  
New Brunswick, NJ 08903  
(732) 745-3500

## **Monmouth County**

Monmouth County Division of Social Services  
PO Box 3000  
3000 Kozloski Road  
Freehold, NJ 07728  
(732) 431-6000



# New Jersey County Boards of Social Service

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## **Morris County**

Morris County Office of Temporary Assistance  
PO Box 900  
340 W. Hanover Avenue  
Morristown, NJ 07960  
(973) 326-7800

## **Ocean County**

Ocean County Board of Social Services  
1027 Hooper Avenue  
PO Box 547  
Toms River, NJ 08753  
(732) 349-1500

## **Passaic County**

Passaic County Board of Social Services  
80 Hamilton Street  
Paterson, NJ 07505-2057  
(973) 881-0100

## **Salem County**

Salem County Board of Social Services  
147 South Virginia Avenue  
Penns Grove, NJ 08069  
(856) 299-7200

## **Somerset County**

Somerset County Board of Social Services  
PO Box 936  
73 East High Street  
Somerville, NJ 08876  
(908) 526-8800

## **Sussex County**

Sussex County Division of Social Services  
83 Spring Street, Suite 203  
PO Box 218  
Newton, NJ 07860  
(973) 383-3600

## **Union County**

Union County Division of Social Services  
342 Westminster Avenue  
Elizabeth, NJ 07208  
(908) 965-2700

## **Warren County**

Warren County Division of Temporary Assistance  
and Social Services  
1 Shotwell Drive  
Belvidere, NJ 07823  
(908) 475-6301



## Emergency Resources

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### New Jersey Office of the Ombudsman for the Institutionalized Elderly

The Office of the Ombudsman for the Institutionalized Elderly investigates allegations of abuse and neglect of people, age 60 and older, living in nursing homes and other long-term healthcare facilities. If you or someone you know may be abused or neglected, please contact the Elder Ombudsman Office. We investigate, resolve and/or refer complaints to the appropriate agency. By law, callers may remain anonymous and case files are closed to the public. For more information call

1-877-582-6995 or 609-826-5090 or go to [www.nj.gov/ooie](http://www.nj.gov/ooie). To file a complaint:

Call the Complaints Hotline: 1-877-582-6995

Email: [ombudsman@advocate.state.nj.us](mailto:ombudsman@advocate.state.nj.us)

Write: The Office of the Ombudsman  
P.O. Box 852, Trenton, NJ 08625-0852

Fax: 609-943-3479

### Adult Protective Services – County Provider Agencies

Adult Protective Services (APS) programs have been established in each county in New Jersey, to receive and investigate reports of suspected abuse, neglect and exploitation of vulnerable adults (person 18 years or older) living in the community. Reports may be made by anyone, and the person making the report is assured anonymity if requested. In cases where abuse, neglect or exploitation is confirmed, APS can assist with putting into place services to help protect the vulnerable person. These services may include home health care, meals on wheels, mental health services, legal and consumer protection services, and other vital community-based or long-term care services. To make a report, contact the appropriate County office.

#### Atlantic

Atlantic County Division of Intergenerational Services  
Shoreview Building  
101 S. Shore Road, Room 210  
Northfield, NJ 08225  
Phone: 609-645-5965 or 1-888-426-9243  
After Hrs: 911

#### Bergen

Bergen County Board of Social Services  
216 Route 17 North  
Rochelle Park, NJ 07662  
Phone: 201-368-4300  
After Hrs: 1-800-624-0275 or 911

#### Burlington

Burlington County Board of Social Services  
Human Services Facility  
795 Woodlane Road  
Mount Holly, NJ 08060  
Phone: 609-518-4793  
After Hrs: 856-234-8888 or 911

#### Camden

Camden County Board of Social Services  
600 Market Street, Lower Level  
Camden, NJ 08102  
Phone: 856-225-8191  
After Hrs: 911

#### Cape May

Cape May County Board of Social Services  
4005 Route 9 South  
Rio Grande, NJ 08242  
Phone: 609-886-6200  
After Hrs: contact local police or 911

#### Cumberland

Resources for Independent Living  
614 E. Landis Avenue, 1st Floor  
Vineland, NJ 08360  
Phone: 856-825-0255  
After Hrs: 911

#### Essex

FOCUS, Hispanic Center for Human Dev., Inc.  
441-443 Broad St.  
Newark, NJ 07102  
Phone: 866-903-6287  
After Hrs: 911

#### Gloucester

Gloucester County Board of Social Services  
400 Hollydell Drive  
Sewell, NJ 08080  
Phone: 856-582-9200  
After Hrs: 911

## Emergency Resources

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### **Hudson**

Hudson County Protective Services, Inc.  
6100 Adams Street  
West New York, NJ 07093  
Phone: 201-537-5631  
After Hrs: 911

### **Hunterdon**

Hunterdon County Department of Human Services  
Division of Social Services  
P.O. Box 2900  
Flemington, NJ 08822-2900  
Phone: 908-788-1253  
After Hrs: 911

### **Mercer**

Mercer County Board of Social Services  
200 Woolverton Street  
Trenton, NJ 08650  
Phone: 609-989-4346  
After Hrs: 911

### **Middlesex**

Middlesex County Board of Social Services  
P.O. Box 509  
New Brunswick, NJ 08903  
Phone: 732-745-3635  
After Hrs: 911 or local police

### **Monmouth**

Family and Children Services  
191 Bath Avenue  
Long Branch, NJ 07740  
Phone: 732-745-3635  
After Hrs: 911 or local police

### **Morris**

Morris County Aging, Disabilities and Veterans  
P.O. Box 900  
Morristown, NJ 07963-0900  
Phone: 973-326-7282  
After Hrs: 911 or  
Sheriff's communication center: 973-285-2900

### **Ocean**

Ocean County Board of Social Services  
1027 Hooper Avenue  
P.O. Box 547  
Toms River, NJ 08754  
Phone: 732-349-1500  
After Hrs: 732-240-6100 or 911

### **Passaic**

Passaic County Board of Social Services  
80 Hamilton Street  
Paterson, NJ 07505  
Phone: 973-881-2616  
After Hrs: 973-345-2676 or 911

### **Salem**

Salem County Office on Aging  
110 Fifth Street, Suite 900  
Salem, NJ 08079  
Phone: 856-339-8622  
After Hrs: 911

### **Somerset**

Somerset County Board of Social Services  
P.O. Box 936  
73 East High Street  
Somerville, NJ 08875-1144  
Phone: 908-526-8800  
After Hrs: 1-800-287-3607 or 911

### **Sussex**

Sussex County Division of Social Services  
P.O. Box 218  
83 Spring Street, Suite 203  
Newton, NJ 07860  
Phone: 973-383-3600 Ext. 5170 or Ext. 5150  
After Hrs: 911

### **Union**

Catholic Charities of the Archdiocese of Newark  
505 South Avenue E  
Cranford, NJ 07016  
Phone: 908-497-3902  
After Hrs: 911

### **Warren**

Warren County Division of Aging and Disability Services  
165 County Route 519 South  
Belvidere, NJ 07823  
Phone: 908-475-6591  
After Hrs: 911

# Emergency Psychiatric Screening Services

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In each of New Jersey's 21 counties, there are designated screening centers staffed 24 hours/7 days a week to assess the needs of individuals in crisis. The staff of the screening centers evaluate whether or not hospitalization is necessary in situations where there is concern about individuals being at risk to themselves or others. Screening center staff work in conjunction with other community emergency personnel.

## **Atlantic**

Psych Intervention Program at  
Atlanticare Regional Medical Center  
1925 Pacific Avenue  
Atlantic City, NJ 08401  
24 Hour Hotline: 609-344-1118

## **Bergen**

Care Plus NJ at Bergen Regional Medical Center  
230 East Ridgewood Avenue  
Paramus, NJ 07652  
24 Hour Hotline: 800-730-2762

## **Burlington**

Legacy Treatment Services  
Community Treatment Solutions Offices  
236 West Route 38, Suite 210  
Moorestown, NJ 08057  
24 Hour Hotline: 800-433-7365

## **Camden**

Oaks Integrated Care  
Jefferson Cherry Hill Hospital  
2201 Chapel Ave West  
Cherry Hill, NJ 08002  
24 Hour Hotline: 856-428-4357

## **Cape May**

Acenda Integrated Health at Cape May  
Regional Medical Center  
2 Stone Harbor Blvd.  
Cape May Court House, NJ 08210  
24 Hour Hotline: 609-465-5999

## **Cumberland**

Cumberland County Guidance Center at Inspira  
Medical Center  
333 Irving Avenue  
Bridgeton, NJ 08302  
24 Hour Hotline: 856-455-5555

## **Essex**

Clara Maas Medical Center  
1 Clara Maas Drive  
Belville, NJ 07109  
24 Hour Hotline: 973-844-4357

Newark Beth Israel Medical Center  
201 Lyons Avenue  
Newark, NJ 07112  
24 Hour Hotline: 973-926-7444

University Behavioral Healthcare  
150 Bergen Street  
Newark, NJ 07101  
24 Hour Hotline: 973-623-2323

## **Gloucester**

Acenda Integrated Health  
42 South Delsea Drive  
Glassboro, NJ 08028  
24 Hour Hotline: 856-845-9100

## **Hudson**

Jersey City Medical Center  
355 Grand Street  
Jersey City, NJ 07302  
24 Hour Hotline: 866-367-6023

## **Hunterdon**

Hunterdon Medical Center  
Emergency Services - Behavioral Health  
2100 Wescott Drive  
Flemington, NJ 08822  
24 Hour Hotline: 908-788-6400

## **Mercer**

Capital Health Regional Medical Center  
750 Brunswick Avenue  
Trenton, NJ 08638  
24 Hour Hotline: 609-396-4357 / 609-989-7297

## Emergency Psychiatric Screening Services

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### **Middlesex**

University Behavioral Health Care  
671 Hoes Lane  
Piscataway, NJ 08855  
24 Hour Hotline: 732-235-5700

### **Monmouth**

Monmouth Medical Center  
300 Second Avenue  
Long Branch, NJ 07740  
24 Hour Hotline: 732-923-6999

### **Morris**

Prime Healthcare Services- St. Clare's, LLC  
25 Pocono Road  
Denville, NJ 07834  
24 Hour Hotline: 973-625-6160 / 973-625-6400

### **Ocean**

Monmouth Medical Center South  
600 River Avenue  
Lakewood, NJ 08701  
24 Hour Hotline: 866-904-4474 / 732-886-4474

### **Passaic**

St. Joseph's Hospital Health Care System  
703 Main Street  
Paterson, NJ 07514  
24 Hour Hotline: 973-754-2230

### **Salem**

Healthcare Commons Inc. at  
Memorial Hospital of Salem County  
310 Woodstown Road  
Salem, NJ 08079  
24 Hour Hotline: 856-299-3001

### **Somerset**

Bridgeway Rehabilitation Inc.  
282 East Main Street  
Somerville, NJ 08876  
Phone: 856-299-3001

### **Sussex**

Newton Medical Center  
175 High Street  
Newton, NJ 07860  
24 Hour Hotline: 973-383-0973

### **Union**

Trinitas Regional Medical Center  
655 East Jersey Street  
Elizabeth, NJ 07206  
24 Hour Hotline: 908-994-7131

### **Warren**

Family Guidance Center of Warren County  
370 Memorial Parkway  
Phillipsburg, NJ 08865  
24 Hour Hotline: 908-454-5141



Helpline: 888.280.6055

Website: [alznj.org](http://alznj.org)<sup>®</sup>



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