

Dear Friend:

We are pleased that you have contacted CaringKind. We want to be sure you have information about our programs and services which can help you throughout your caregiving journey.

Caring for a person with a diagnosis of dementia is not easy. CaringKind helps people learn about the challenges of Alzheimer's and strategies for coping. We want you to know that you are not alone.

If you and/or your family would like to speak to one of our Dementia Care Specialists for a more in-depth discussion regarding your situation, we are available by phone and in person. Please call our Helpline at **646-744-2900** to schedule a dementia consultation free of charge.

We have enclosed the following information that we hope will be useful:

- Our Programs and Services flyer, which describes the range of supportive services that are offered by CaringKind
- Information on Alzheimer's disease
- Current educational calendar

For over 30 years CaringKind (formerly known as the Alzheimer's Association, NYC Chapter) has provided thousands of New York families with compassionate counseling, practical information and informed referred for families and individuals affected by a dementia diagnosis.

As President and CEO, I remain committed to providing these resources free of charge for all who need them and, thanks to the generous support of our community, we continue to do so. As you embark on your journey to support a friend or family member, please consider supporting our work with a generous contribution. You will be helping those who need our help today and the many more who will need our help in the future.

If you need further information, please call our Helpline at 646-744-2900. You can also e-mail us at [helpline@cknyc.org](mailto:helpline@cknyc.org).

Sincerely,



Eleonora Tornatore-Mikesh  
President and CEO



Edward Cisek, PhD  
Chief Program Officer & VP of Program Evaluation

# Programs and Services

**caringkind**

*The Heart of Alzheimer's Caregiving*



For more information on any of CaringKind's Programs and Services,  
please call our **CaringKind Helpline: 646-744-2900**  
or visit us at [www.caringkindnyc.org](http://www.caringkindnyc.org)

## Helpline and Dementia Consultation

Our Helpline is staffed by Dementia Care Specialists who are trained to provide you with the most up-to-date information, education, and support regarding dementia. Some of our Dementia Care Specialists are licensed social workers and provide in-depth, personalized consultations for individuals and families facing the decisions and challenges associated with Alzheimer's disease and other dementias.  
**CaringKind Helpline: 646-744-2900**

## Education

### Caregiver Education

Our caregiver education programs help family and friends understand and navigate the challenges of Alzheimer's disease and caregiving. We provide knowledge and skills to help family and friends more successfully care for someone living with dementia and take care of themselves.

To learn more, visit us at [www.caringkindnyc.org/CaregiverEducation](http://www.caringkindnyc.org/CaregiverEducation)

### Professional Education

Our experienced staff offers educational programs to sensitize professionals and para-professionals to the special needs of people living with dementia and their families. To learn more, visit us at [www.caringkindnyc.org/ProfessionalEducation](http://www.caringkindnyc.org/ProfessionalEducation)

## Early-Stage Services

Our early-stage services provide a supportive environment and specialized programs for people with Mild Cognitive Impairment (MCI) or early-stage dementia. To learn more, visit us at [www.caringkindnyc.org/EarlyStage](http://www.caringkindnyc.org/EarlyStage)

## Support Groups

Support Groups provide a comfortable place to discuss caregiving challenges, share your feelings and find emotional support. Talking with people who truly understand will help you feel less alone as you confront the many challenges of caregiving. Support Groups take place in multiple languages virtually and in-person throughout the five boroughs. To learn more, visit us at [www.caringkindnyc.org/SupportGroups](http://www.caringkindnyc.org/SupportGroups)

**caringkind** *The Heart of  
Alzheimer's Caregiving*

*Formerly known as the Alzheimer's Association, New York City Chapter*

360 Lexington Avenue, 3<sup>RD</sup> Floor  
New York, New York 10017

CaringKind Helpline: 646-744-2900 [caringkindnyc.org](http://caringkindnyc.org)

[f/caringkindnyc](https://www.facebook.com/caringkindnyc) [@caringkindnyc](https://twitter.com/caringkindnyc) [@caringkindnyc](https://www.instagram.com/caringkindnyc)

### MedicAlert® NYC Wanderer's Safety Program

A 24-hour nationwide emergency response service providing assistance for finding persons diagnosed with Alzheimer's disease or related dementia who wander locally or far from home or have a medical emergency. To enroll, visit [www.caringkindnyc.org/WanderSafety](http://www.caringkindnyc.org/WanderSafety)

### Together We Care™

Are you a family member looking to hire private home care workers? Together We Care posts profiles of graduates of our Dementia Care Training for Professional Caregivers, making it easier for families to find the right person for their needs. Create a free profile, post an ad, and start searching online at [www.TogetherWeCare.com](http://www.TogetherWeCare.com)

### connect2culture®

Our cultural arts program, connect2culture®, creates unique opportunities for people living with dementia and their care partners to stimulate conversation and engagement through art, music and dance. To learn more, visit us at [www.caringkindnyc.org/connect2culture](http://www.caringkindnyc.org/connect2culture)

### Community Outreach

CaringKind provides targeted outreach to the African American, Chinese, Latino, and Jewish communities in NYC, and we have created linguistically appropriate informational materials and offer educational sessions to community members and professionals in Spanish and Chinese. Our outreach team seeks to meet the specific needs of these diverse communities by increasing awareness of, and participation in, our programs and services. To learn more, visit us at [www.caringkindnyc.org/outreach](http://www.caringkindnyc.org/outreach)

### Palliative and Residential Care Program

The Palliative and Residential Care program addresses the need for improving the quality-of-life and care for individuals diagnosed with moderate and advanced dementia, whether they live at home or in a residential setting, by promoting a palliative, comfort-focused approach to care. This approach involves taking active steps to bring comfort, thus helping to prevent or ease pain and distress. To learn more, visit [www.caringkindnyc.org/PalliativeCare](http://www.caringkindnyc.org/PalliativeCare)

### Concierge Services

CaringKind can work with organizations, on-site or on-line, to maximize staff learning and cultivate best practices in dementia care. We offer individualized educational programs to staff of: home care providers, adult day care programs, nursing homes, assisted living residences, social service agencies, pastoral ministries, and others. For more information or to request a quote, visit [www.caringkindnyc.org/ConciergeServices](http://www.caringkindnyc.org/ConciergeServices)

#### OUR MISSION

The mission of CaringKind\* is to create, deliver, and promote comprehensive and compassionate care and support services for individuals and families affected by Alzheimer's disease and related dementias, and to eliminate Alzheimer's disease through the advancement of research. We achieve our mission by providing programs and services for individuals with dementia, their family and professional caregivers; increasing public awareness; collaborating with research centers; and informing public policy through advocacy.

*\*Formerly known as the Alzheimer's Association, New York City Chapter*

**caringkind**

*The Heart of Alzheimer's Caregiving*

**CaringKind Helpline: 646-744-2900**  
**caringkindnyc.org**

# What is Alzheimer's Disease?



*Information about dementia and  
Alzheimer's disease.*

**CaringKind**

**360 Lexington Avenue, 3<sup>rd</sup> Floor**  
**New York, New York 10017**

**CaringKind Helpline: 646-744-2900**  
**caringkindnyc.org**

**f/caringkindnyc @caringkindnyc @caringkindnyc**

*Formerly known as the Alzheimer's Association, NYC Chapter*

## **CaringKind Programs and Services**

**CaringKind Helpline**

**Education**

**Early-Stage Services**

**Support Groups**

**MedicAlert® NYC Wanderer's Safety Program**

**Diversity Outreach & Inclusion**

**connect2culture®**

**Palliative and Residential Care Program**

**And more...**

# Alzheimer's Disease – Get the Facts

- Changes in the Brain
- Signs and Symptoms
- What Causes Alzheimer's
- Diagnosis
- Treatment
- Participating in Clinical Trials
- Support for Families and Caregivers
- For More Information



**The brain** is an extremely complex organ which controls all aspects of how we function and interact with our world. There are specific areas of the brain responsible for different, highly specialized tasks: one part processes language, another part regulates emotion, another part is responsible for vision, for hearing, for balance, for impulse control, and so on. The neurons, or nerve cells, in each of these areas constantly communicate with each other via connections called synapses in order for us to accomplish even the most basic tasks. When the cells and synapses become damaged by disease, they can no longer do their jobs properly. Basic tasks can become difficult, familiar environments can seem strange and disorienting, and abstract concepts can become challenging to understand. Logic and reason are no longer effective tools for communication.

Alzheimer's disease is currently ranked as the sixth leading cause of death in the United States, but recent estimates indicate that the disorder may rank third, just behind heart disease and cancer, as a cause of death for older people.

Dementia is NOT a normal part of the aging process, but the result of a disease or other physical damage to brain cells. The symptoms of dementia vary from person to person, but generally involve changes severe enough to affect a person's daily life in at least some of these areas:

- Cognition (memory, thinking, language)
- Behavior (mood, personality, social skills)
- Physical functioning (motor skills, incontinence, visual field changes)

The causes of dementia can vary, depending on the types of brain changes that may be taking place. There are various types of dementias. Examples include:

- Lewy Body Dementia
- Frontotemporal disorders
- Vascular dementia

There are over 75 different causes of progressive dementia. Alzheimer's disease (AD) is the most common and accounts for approximately 70% of all dementia

diagnoses. If someone has AD, she or he is experiencing dementia, but if someone has dementia, the cause may or may not be AD. The symptoms could be a result of any one of those other 75 causes.

## The History of Alzheimer's Disease

Alzheimer's disease is named after Dr. Alois Alzheimer. In 1906, Dr. Alzheimer noticed changes in the brain tissue of a woman who had died of an unusual mental illness. Her symptoms included memory loss, language problems, and unpredictable behavior.

After she died, he examined her brain. He found unusual clumps and tangled bundles of fibers. The unusual clumps are now referred to amyloid plaques. In addition, the tangled bundles of fibers are now called tau tangles.

These plaques and tangles in the brain are still considered some of the main features of Alzheimer's disease. Another feature is the loss of connections between nerve cells (neurons) in the brain. Neurons transmit messages between different parts of the brain, and from the brain to muscles and organs in the body.

## Changes in the Brain

Scientists continue to unravel the complex brain changes involved in the start and development of Alzheimer's disease. It seems likely that damage to the brain starts a decade or more before memory and other cognitive problems appear. During the earliest stages of Alzheimer's disease there are no signs, but changes are taking place in the brain. Unknown to the person, abnormal deposits of proteins start to form amyloid plaques and tangles throughout the brain. These cause neurons that were healthy to stop working and lose connections with other neurons. They eventually die.

The damage initially appears to take place in the hippocampus, the part of the brain essential in forming memories. As more neurons die, other parts of the brain begin to shrink. By the final stage of Alzheimer's, damage is widespread, and brain size has shrunk significantly.



## Signs and Symptoms

### First Signs of Alzheimer's Disease

Memory problems are typically one of the first signs Alzheimer's disease, but not always. Some people with these symptoms have a condition called mild cognitive impairment (MCI). In MCI, people have more memory problems than normal for their age, but their symptoms do not interfere with their everyday lives. Movement difficulties and problems with the sense of smell have also been linked to MCI. Older people with MCI are at greater risk for developing Alzheimer's, but not all of them do. Some may even go back to normal cognition.

The first symptoms of Alzheimer's vary from person to person. Besides memory problems, other symptoms for early Alzheimer's includes:

- Word finding (the ability to find the right words for speaking and writing).
- Poor reasoning or judgment.

### Stages of Alzheimer's Disease

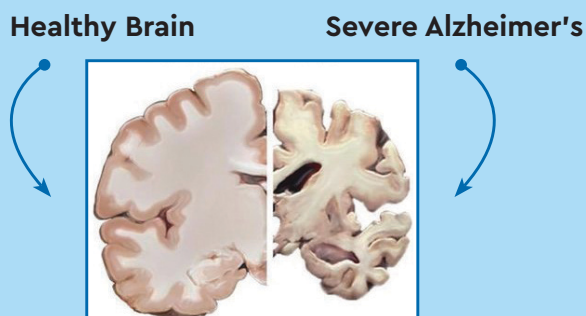
Each person's experience with Alzheimer's and the symptoms varies from person to person. There are different stages of the disease with common symptoms to be aware of.

#### Mild or Early Stage Alzheimer's Disease

As Alzheimer's disease advances, people experience greater memory loss and other problems with thinking, often referred to as cognitive difficulties. Problems can include:

- Trouble handling money and paying bill.
- Repeating questions.
- Taking longer to complete normal daily tasks.
- Personality and behavior changes.

People are often diagnosed at this stage.



Cross sections of the brain: a person with severe Alzheimer's will show more shrinking of brain tissue.

### Moderate or Middle Stage Alzheimer's Disease

In this stage, damage occurs in areas of the brain that control language, reasoning, sensory processing, and conscious thought.

Problems during this age include:

- Increase in memory loss and confusion, such as having trouble recognizing friends and family.
- Difficulty learning new things.
- Unable to carry out multistep tasks such as getting dressed, or cope with new situations.
- Wander or get lost in familiar places.
- Experience hallucinations, delusions, paranoia and may behave impulsively.

### Severe or Late Stage Alzheimer's Disease

Ultimately, amyloid plaques and tangles spread throughout the brain, and brain tissue shrinks significantly. People with severe Alzheimer's have little or no communication abilities 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.

## What Causes Alzheimer's?

Scientists don't yet fully understand what causes Alzheimer's disease in most people. In people with early-onset Alzheimer's, a genetic mutation is usually the cause. Late-onset Alzheimer's arises from a complex series of brain changes that occur over decades. The causes probably include a combination of genetic, environmental, and lifestyle factors. Each person's risk factors for developing the disease is different.

### The Basics of Alzheimer's

Scientists are conducting studies to learn more about amyloid plaques, tangles, and other biological features of Alzheimer's disease. Advances in technology allow researchers to see the development of amyloid plaques and tangles through brain imaging. They are also able to see changes in the brain structure and how it is working. Scientists are also exploring the very earliest steps in the disease process by studying changes in the brain and body fluids that can be detected years before Alzheimer's symptoms appear. Findings from these studies will help in understanding the causes of Alzheimer's and make diagnosis easier.

## Why Does Alzheimer's Strike Older Adults?

One of the great mysteries of Alzheimer's disease is why it largely strikes older adults. Research on normal brain aging is shedding light on this question. For example, scientists are learning how age-related changes in the brain may harm neurons and contribute to Alzheimer's damage.

These age-related changes include:

- shrinking of certain parts of the brain
- inflammation
- production of unstable molecules called free radicals
- mitochondrial dysfunction (a breakdown of energy production within a cell)



### Genetics

Most people with Alzheimer's have the late-onset form of the disease. With late-onset, symptoms of the disease begin showing when the person is in their mid-60s. The apolipoprotein E (APOE) gene is involved in late-onset

Alzheimer's. This gene has several forms. One of them, APOE  $\epsilon$ 4, increases a person's risk of developing the disease and is also associated with an earlier age of disease onset. However, carrying the APOE  $\epsilon$ 4 form of the gene does not mean that a person will definitely develop Alzheimer's disease, and some people with no APOE  $\epsilon$ 4 may also develop the disease.

Also, scientists have identified a number of regions of interest in the genome (an organism's complete set of DNA) that may increase a person's risk for late-onset Alzheimer's to varying degrees.

Early-onset Alzheimer's disease occurs in people age 30 to 60 and represents less than 5 percent of all people with Alzheimer's. Most cases are caused by an inherited change in one of three genes, resulting in a type known as early-onset familial Alzheimer's disease, or FAD. For others, the disease appears to develop without any specific, known cause, much as it does for people with late-onset disease.

Most people with Down syndrome develop Alzheimer's. This may be because people with Down syndrome have an extra copy of chromosome 21, which contains the gene that generates harmful amyloid plaques.

For more about Alzheimer's genetics research, see the Alzheimer's Disease Genetics Fact Sheet, available at [www.nia.nih.gov/alzheimers/publication/alzheimers-disease-genetics-fact-sheet](http://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-genetics-fact-sheet).

## Health, Environmental, and Lifestyle Factors

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 in other theories. For example, the relationship between mental decline and chronic disease 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.

Following a healthy diet, exercising and interacting with others socially have all been associated with helping people stay healthy as they age. These factors might also help reduce the risk of cognitive decline (problems with thinking) and Alzheimer's disease. Clinical trials are testing some of these possibilities.

### Diagnosis of Alzheimer's Disease

Doctors use several methods and tools to help determine whether a person who is having memory problems has "possible Alzheimer's dementia" (dementia that may be caused by something else) or "probable Alzheimer's dementia" (no other cause for dementia can be found).

To diagnose Alzheimer's, doctors may:

- Ask the person and a family member or friend questions about overall health, 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.
- Perform brain scans, such as computed tomography (CT), magnetic resonance imaging (MRI), or positron emission tomography (PET).

These tests may be repeated to see any change in memory or mental functions. There is currently only one sure way to diagnose Alzheimer's disease and that is after the person has died with an autopsy and examination of the brain.

People with concerns should speak to their doctor to find out the cause. The symptoms could be caused by something else such as:

- Stroke
- Tumor
- Parkinson's disease
- Sleep disturbances

- Side effects of medication
- An infection
- A non-Alzheimer's dementia

Some of these conditions may be treatable and possibly reversible.

If you or a family member is diagnosed with Alzheimer's disease, beginning treatment early can help save quality of life. Alzheimer's disease development cannot be stopped or reversed.

An early diagnosis also helps families plan for the future. They can take care of financial and legal matters, address potential safety issues, learn about living arrangements, and develop support networks. A great resource for help is the CaringKind Helpline at 646-744-2900.

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

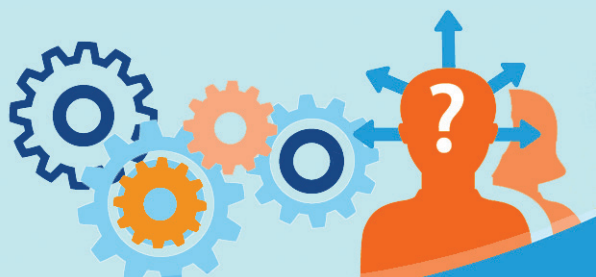
## Treatment of Alzheimer's Disease

Researchers hope to develop treatments that stop or prevent the actual cause of the disease rather than treat or cure it once it has already developed. Alzheimer's disease is complex, and it is unlikely that any one drug or other intervention will successfully treat it.

Current approaches focus on treating certain symptoms such as maintaining mental function and managing behavioral symptoms. Others try to slow or delay the symptoms of disease.

## Maintaining Mental Function

Several medications are approved by the U.S. Food and Drug Administration to treat symptoms of Alzheimer's. Donepezil (Aricept®), rivastigmine (Exelon®), and galantamine (Razadyne®) are used to treat mild to moderate Alzheimer's (donepezil can be used for severe Alzheimer's as well). Memantine (Namenda® and Namzaric®) is used to treat moderate to severe Alzheimer's. These drugs work by regulating neurotransmitters, the brain chemicals that transmit messages between neurons. They may help maintain thinking, memory, and communication skills, and help with certain behavioral problems. However, these drugs don't change the underlying disease process or stop the disease. They may not work for everyone, and they will not help relieve symptoms forever.



## Participating in Clinical Trials

Everybody — those with Alzheimer's or another form of dementia and those without — may be able to take part in clinical trials and studies. Participants in Alzheimer's clinical research help scientists learn how the brain changes in healthy aging and in Alzheimer's.

Currently, at least 70,000 volunteers are needed to participate in more than 150 active clinical trials and studies that are testing ways to understand, diagnose, treat, and prevent Alzheimer's disease.

Volunteering for a clinical trial is one way to help in the fight against Alzheimer's disease. Studies need participants of different ages, sexes, races, and ethnicities to ensure that results are meaningful for many people.

The National Institute on Aging (NIA) at the National Institutes of Health (NIH) leads the Federal Government's research efforts on Alzheimer's. NIA-supported Alzheimer's Disease Centers throughout the United States conduct a wide range of research, including studies of the causes, diagnosis, and management of Alzheimer's. NIA also sponsors the Alzheimer's Disease Cooperative Study (ADCS), a consortium of leading researchers throughout the United States and Canada who conduct clinical trials.

To find out more about Alzheimer's clinical trials and studies:

- Talk to your health care provider about local studies that may be right for you.
- Visit the ADEAR Center website at [www.nia.nih.gov/alzheimers/volunteer](http://www.nia.nih.gov/alzheimers/volunteer).
- Contact Alzheimer's disease centers or memory or neurology clinics in your community.
- Search the ADEAR Center clinical trials finder for a trial near you or to sign up for email alerts about new trials: [www.nia.nih.gov/alzheimers/clinical-trials](http://www.nia.nih.gov/alzheimers/clinical-trials).

*Additional information about participating in clinical trials:*

<http://www.caringkindnyc.org/clinicaltrials/> and

<http://www.nia.nih.gov/alzheimers/publication/participating-alzheimers-research>



## Managing Behavior

Common behavioral symptoms of Alzheimer's include:

- Sleeplessness
- Wandering
- Agitation
- Anxiety
- Aggression

Scientists are learning why these symptoms occur and are studying new treatments — drug and nondrug — to manage them. Research has shown that treating behavioral symptoms can make people with Alzheimer's more comfortable and makes things easier for caregivers.

## Looking for New Treatments

Alzheimer's disease research has advanced to a point where scientists can look beyond treating symptoms to think about what causes the disease and how to stop or slow down the process. In ongoing clinical trials, scientists are developing and testing several possible interventions, including immunization therapy (using things like vaccines), drug therapies (using drugs), cognitive training (memory and thinking games or exercises), physical activity, and treatments used for cardiovascular disease and diabetes.

Researchers are studying biomarkers (biological signs of disease found in brain images, cerebrospinal fluid, and blood) to see if they can detect early changes in the brains of people with MCI and in cognitively normal people who may be at greater risk for Alzheimer's disease. Studies indicate that such early detection may be possible, but more research is needed before these techniques can be relied upon to diagnose Alzheimer's disease in everyday medical practice.



## Support for Families and Caregivers

Caring for a person with Alzheimer's disease can have high physical, emotional, and financial costs. The demands of day-to-day care, changes in family roles, and decisions about placement in a care facility can be difficult. There are several evidence-based approaches and programs that can help, and researchers are continuing to look for new and better ways to support caregivers.

Becoming well-informed about the disease is one important strategy. Programs that teach families about the various stages of Alzheimer's and about ways to deal with difficult behaviors and other caregiving challenges can help. At CaringKind, we offer a seminar titled "Understanding Dementia," and recommend that all caregivers attend it. Please call our CaringKind Helpline at 646-744-2900 for more information.

Good coping skills, a strong support network, and respite care are other ways that help caregivers handle the stress of caring for a person with Alzheimer's disease. For example, staying physically active provides physical and emotional benefits.

Some caregivers have found that joining a support group is a critical lifeline. These support groups allow caregivers to find respite, express concerns, share experiences, get tips, and receive emotional comfort. CaringKind offers a wide variety of support groups all over New York City. Please call our Helpline at 646-744-2900 to find one for you.

*Information taken from  
the National Institute on Aging,  
part of the National Institutes of Health.  
[www.nia.nih.gov/health/alzheimers](http://www.nia.nih.gov/health/alzheimers)*

### For More Information

To get more information about Alzheimer's and to learn about support groups and services for people with the disease and their caregivers, please call

**CaringKind's Helpline**

**646-744-2900**

**[helpline@caringkindnyc.org](mailto:helpline@caringkindnyc.org)**

**[caringkindnyc.org](http://caringkindnyc.org)**

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Drug Name	Drug Type and Use	How It Works	Common Side Effects
<b>Aducanumab</b>	Disease-modifying immunotherapy prescribed to treat mild cognitive impairment or mild Alzheimer's	Removes abnormal beta-amyloid to help reduce the number of plaques in the brain	Amyloid-related imaging abnormalities (ARIA), which can lead to fluid buildup or bleeding in the brain; also headache, dizziness, falls, diarrhea, confusion
<b>Donepezil</b>	Cholinesterase inhibitor prescribed to treat symptoms of mild, moderate, and severe Alzheimer's	Prevents the breakdown of acetylcholine in the brain	Nausea, vomiting, diarrhea, muscle cramps, fatigue, weight loss
<b>Rivastigmine</b>	Cholinesterase inhibitor prescribed to treat symptoms of mild, moderate, and severe Alzheimer's	Prevents the breakdown of acetylcholine and butyrylcholine (a brain chemical similar to acetylcholine) in the brain	Nausea, vomiting, diarrhea, weight loss, indigestion, muscle weakness
<b>Memantine</b>	N-methyl D-aspartate (NMDA) antagonist prescribed to treat symptoms of moderate to severe Alzheimer's	Blocks the toxic effects associated with excess glutamate and regulates glutamate activation	Dizziness, headache, diarrhea, constipation, confusion
<b>Manufactured combination of memantine and donepezil</b>	NMDA antagonist and cholinesterase inhibitor prescribed to treat symptoms of moderate to severe Alzheimer's	Blocks the toxic effects associated with excess glutamate and prevents the breakdown of acetylcholine in the brain	Headache, nausea, vomiting, diarrhea, dizziness, anorexia
<b>Galantamine</b>	Cholinesterase inhibitor prescribed to treat symptoms of mild to moderate Alzheimer's	Prevents the breakdown of acetylcholine and stimulates nicotinic receptors to release more acetylcholine in the brain	Nausea, vomiting, diarrhea, decreased appetite, dizziness, headache

Drug Name	Delivery Method	For More Information
<b>Aducanumab</b>	<ul style="list-style-type: none"> <li>Intravenous: Dose is determined by a person's weight; given over one hour every four weeks; most people will start with a lower dose and over a period of time increase the amount of medicine to reach the full prescription dose</li> </ul>	<a href="#">Prescribing information</a> (PDF, 343K)
<b>Donepezil</b>	<ul style="list-style-type: none"> <li>Tablet: Once a day; dosage may be increased over time if well tolerated</li> <li>Orally disintegrating tablet: Same dosing regimen as above</li> </ul>	<a href="#">Prescribing information</a> (PDF, 594K)
<b>Rivastigmine</b>	<ul style="list-style-type: none"> <li>Capsule: Twice a day; dosage may be increased over time, at minimum two-week intervals, if well tolerated</li> <li>Patch: Once a day; dosage amount may be increased over time, at minimum four-week intervals, if well tolerated</li> </ul>	<a href="#">Prescribing information</a> (PDF, 284K)
<b>Memantine</b>	<ul style="list-style-type: none"> <li>Tablet: Once a day; dosage may be increased in amount and frequency (up to twice a day) if well tolerated</li> <li>Oral solution: Same dosage as tablet</li> <li>Extended-release capsule: Once a day; dosage may increase in amount over time, at minimum one-week intervals, if well tolerated</li> </ul>	<a href="#">Prescribing information</a> (PDF, 604K)
<b>Manufactured combination of memantine and donepezil</b>	<ul style="list-style-type: none"> <li>Extended-release capsule: Once a day; initial dosage depends on whether the person is already on a stable dose of memantine and/or donepezil; dosage may increase over time, at minimum one-week intervals, if well tolerated</li> </ul>	<a href="#">Prescribing information</a> (PDF, 455K)
<b>Galantamine</b>	<ul style="list-style-type: none"> <li>Tablet: Twice a day; dosing may increase over time, at minimum four-week intervals, if well tolerated</li> <li>Extended-release capsule: Same dosage as tablet but taken once a day</li> </ul>	<a href="#">Prescribing information</a> (PDF, 1M)

## Alzheimer's Caregiving Tips: Wandering

Many people with Alzheimer's disease wander away from their home or caregiver. As the caregiver, you need to know how to limit wandering and prevent the person from becoming lost. This will help keep the person safe and give you greater peace of mind.

**First Steps:** Try to follow these steps before the person with Alzheimer's disease wanders:

- Make sure the person carries some kind of ID or wears a medical bracelet. If the person gets lost and can't communicate clearly, an ID will let others know about his or her illness. It also shows where the person lives.
- Consider enrolling the person in the Wander's Safety Program.  
Visit [www.caringkindnyc.org/WanderSafety](http://www.caringkindnyc.org/WanderSafety) or call 646-744-2900 to enroll.
- Let neighbors and the local police know that the person with Alzheimer's tends to wander. Ask them to alert you immediately if the person is seen alone and on the move.
- Place labels in garments to aid in identification.
- Keep an article of the person's worn, unwashed clothing in a plastic bag to aid in finding him or her with the use of dogs.
- Keep a recent photograph or video recording of the person to help police if he or she becomes lost.

**Tips to Prevent Wandering:** Here are some tips to help prevent the person with Alzheimer's from wandering away from home:

- Keep doors locked. Consider a keyed deadbolt, or add another lock placed up high or down low on the door. If the person can open a lock, you may need to get a new latch or lock.\*
- Use loosely fitting doorknob covers so that the cover turns instead of the actual knob.\*
- Place STOP, DO NOT ENTER, or CLOSED signs on doors.
- Divert the attention of the person with Alzheimer's disease away from using the door by placing small scenic posters on the door; placing removable gates, curtains, or brightly colored streamers across the door; or wallpapering the door to match any adjoining walls.
- Install safety devices found in hardware stores to limit how much window can be opened.
- Install an "announcing system" that chimes when the door opens.
- Secure the yard with fencing and a locked gate.
- Keep shoes, keys, suitcases, coats, hats, and other signs of departure out of sight.
- Do not leave a person with Alzheimer's who has a history of wandering unattended.

*\* Due to the potential hazard they could cause if an emergency exit is needed, locked doors and doorknob covers should be used only when a caregiver is present.*

For tips on home safety, see **Home Safety for People with Alzheimer's Disease**, online at: [www.nia.nih.gov/health/home-safety-and-alzheimers-disease](http://www.nia.nih.gov/health/home-safety-and-alzheimers-disease)

Information taken from the National Institute on Aging, part of the National Institutes of Health  
[www.nia.nih.gov/alzheimers/topics/caregiving](http://www.nia.nih.gov/alzheimers/topics/caregiving)

**CARINGKIND NYC WANDERER'S SAFETY PROGRAM: NEW ENROLLMENT FORM**
**MEMBERSHIP ENROLLMENT**

(All fields required)

LAST NAME

FIRST NAME

ADDRESS

**NY**

APT # CITY STATE ZIP

CELL PHONE

HOME PHONE

BIRTHDATE (MM/DD/YYYY)

LAST 4 DIGITS OF SSN

EMAIL:

 IS THE MEMBER A VETERAN? ☐ YES ☐ NO

GENDER (CHECK ONE)

☐ Female ☐ Male ☐ Prefer to self-describe:

PRIMARY EMERGENCY CONTACT – FULL NAME

ADDRESS (NO P.O. BOX)

APT # CITY STATE ZIP

CELL PHONE

HOME PHONE

EMAIL:

SECONDARY EMERGENCY CONTACT – FULL NAME

CELL PHONE

HOME PHONE

EMAIL:

**INFORMATION FOR YOUR EMERGENCY HEALTH RECORD**
**MEDICAL CONDITIONS & DEVICES**
☐ Alzheimer's ☐ Other Dementia

(For medical device, please include model number)

**ALLERGIES**

List all known food, drug, or other allergies

**MEDICATIONS**

List all medications and dosages, including inhalers

Are you a veteran?

☐ Yes ☐ No

**RECENT PHOTO OF MEMBER PROVIDED?**
☐ Yes ☐ No

Send original photo – passport size or larger. Photo will not be returned. Please write member's name on back of photo.

**Optional Caregiver Enrollment:**  
 visit [www.cknyc.org](http://www.cknyc.org) or call  
 our HelpLine at 646-744-2900

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## MEMBERSHIP ENROLLMENT

There is a fee for any replacement product due to an incorrect wrist size.



☐ **Orange Classic Steel  
ID Bracelet  
(A656) – \$29.99**

Engraving space: 5 lines

Exact wrist measurement: \_\_\_\_\_  
(Required for bracelet. Measure wrist snugly and add ½ inch.)



☐ **Large Red Classic Steel  
ID Bracelet  
(A091) – \$32.99**

Engraving space: 6 lines

Exact wrist measurement: \_\_\_\_\_  
(Required for bracelet. Measure wrist snugly and add ½ inch.)

### WHAT DO YOU WANT ENGRAVED ON YOUR ID?

At a minimum, your bracelet will be engraved with either Alzheimer's or Dementia. It should also list other medical conditions or allergies that are important to communicate in an emergency. For example – Diabetes, Hypertension, Allergic to Penicillin, No MRI

Choose one: ☐ Alzheimer's ☐ Other Dementia

Line 1

Line 2

Line 3

Line 4

Line 5

Line 6

☐ By checking this box I opt out of including anything besides Alzheimer's or Dementia on my bracelet  
(Note: this is not recommended.)

## ADVANTAGE ANNUAL MEMBERSHIP \$49.99

- 24/7 Emergency Response Team
- Emergency Health Profile
- 24/7 Wandering support
- Emergency Contact Notification
- Personal Profile
- Portrait Photo (selfie)
- Printable Health Profile

<b>PAYMENT</b>	ID TOTAL	_____
	MEMBERSHIP TOTAL	<b>\$49.99</b>
	SHIPPING	<b>\$9.95</b>
	<b>TOTAL</b>	_____

For your convenience & to ensure uninterrupted membership with MedicAlert, your credit card will automatically be charged for your membership on your annual renewal date.

## SHIP TO

NAME

AGENCY NAME

ADDRESS

APT # CITY STATE ZIP

PHONE

EMAIL:


## PAYMENT TYPE

☐ Check (make payable to MedicAlert Foundation)

☐ MasterCard® ☐ Visa® ☐ Discover® ☐ AMEX®

No other cards accepted. No CODs. Payment must accompany order.

CREDIT CARD NUMBER

EXPIRATION DATE (MM/YY) SECURITY CODE

CARD HOLDER'S NAME

CARD HOLDER'S BILLING ADDRESS

CITY STATE ZIP

SIGNATURE FOR CARD AUTHORIZATION

## CONSENT

Important: By accepting membership in MedicAlert Foundation, for yourself as member or caregiver and/or as caregiver on behalf of the member named above (collectively, "you"), you authorize MedicAlert to release all medical and other confidential information about you in emergencies and to other health care personnel you designate. If you choose to terminate membership, you must notify us in writing and return your jewelry. MedicAlert relies upon the accuracy of the information that you provide. You, therefore, agree to defend, indemnify, and hold MedicAlert (including its employees, officers, directors, agents, and organizations with which it maintains a marketing alliance for the provision of services hereunder) harmless from any claim or lawsuit brought by member or others for injury, death, loss or damages arising in whole or in part out of your provision of incomplete or inaccurate information to MedicAlert. Furthermore, as caregiver for the member named above, you hereby represent and warrant to Medic Alert that you have full power and authority, as the duly authorized representative of such member, to enroll and act on his or her behalf. **To update any changes to your enrollment (e.g. address, primary contacts, medication, etc), please call 1-800-432-5378.**

SIGNATURE OF REPRESENTATIVE

DATE

**caringkind**

*The Heart of Alzheimer's Caregiving*

CaringKind Helpline: 646-744-2900

[caringkindnyc.org](http://caringkindnyc.org)

Alzheimer's Caregiving Tips:

# Caring for Yourself



*Taking care of yourself is  
one of the most important things  
you can do as a caregiver.*

## CaringKind Programs and Services

CaringKind Helpline

Education

Early-Stage Services

Support Groups

MedicAlert® NYC Wanderer's Safety Program

Diversity Outreach & Inclusion

connect2culture®

Palliative and Residential Care Program

And more...

CaringKind

360 Lexington Avenue, 3<sup>rd</sup> Floor

New York, New York 10017

CaringKind Helpline: 646-744-2900

[caringkindnyc.org](http://caringkindnyc.org)

[f/caringkindnyc](https://www.facebook.com/caringkindnyc) [@caringkindnyc](https://twitter.com/caringkindnyc) [@caringkindnyc](https://www.instagram.com/caringkindnyc)

*Formerly known as the Alzheimer's Association, NYC Chapter*

**Taking care of yourself** is one of the most important things you can do as a caregiver. This could mean asking family members or friends to help out so that you can do things you enjoy. You could also use support services such as adult day care services or getting help from a local home health care agency. Taking these actions can bring you some relief. See some of our suggestions below. It also may help keep you from getting ill or depressed.



### **Here are some ways you can take care of yourself:**

- Ask for help when you need it.
- Join a caregivers' support group.
- Take breaks each day.
- Spend time with friends.
- Keep up with your hobbies and interests.
- Eat healthy foods.
- Get exercise as often as you can.
- See your doctor on a regular basis.
- Keep your health, legal, and financial information up-to-date.

### **It's Okay to Ask for Help**

Many caregivers find it hard to ask for help. They feel like they should do everything themselves, or that no one will help even if they ask. They may think it's not right to leave the person with Alzheimer's disease with someone else. Maybe they cannot afford to pay someone to watch the person for an hour or two.

It's okay to ask for help from family and friends. You don't have to do everything yourself.

### **If you have trouble asking for help, try these tips:**

- Ask people to help out in specific ways like making a meal, visiting the person with Alzheimer's, or taking the person out for a short time.
- Join a support group to share advice and challenges with other caregivers going through a similar experience.
- Call the CaringKind Helpline at 646-744-2900 to find out what support is available for you, such as home health care or adult day care services.
- If you are a veteran or caring for one, the U.S. Department of Veterans Affairs (VA) might be of help to you. To learn more, visit the VA caregivers' website at [www.caregiver.va.gov](http://www.caregiver.va.gov) or call toll-free at 1-855-260-3274.





## Your Emotional Health

Emotional health is the ability to have and accept all of your feelings and maintain balance between feelings of sadness and happiness. You may be busy caring for the person with Alzheimer's disease and don't take time to think about your emotional health. But, you need to. Caring for a person with Alzheimer's takes a lot of time and effort. Sometimes, you may feel discouraged, sad, lonely, frustrated, confused, or angry. These feelings are normal.

### Here are some things you can say to yourself that might help you feel better:

- I'm doing the best I can.
- What I'm doing would be hard for anyone.
- I'm not perfect, but that's okay.
- I can't control some things that happen.
- Sometimes, I just need to do what works for right now.
- Even when I do everything I can think of, the person with Alzheimer's disease will still have problem behaviors because of the illness, not because of what I do.
- I will enjoy the moments when we can be together in peace.
- I will try to get help from a counselor if caregiving becomes too much for me.

## Meeting Your Spiritual Needs

As the caregiver of a person with Alzheimer's, you may need more spiritual resources than others do. Meeting your spiritual needs can help you cope better as a caregiver and find a sense of balance and peace.

Some people like to be involved with others as part of a faith community, such as a church, temple, or mosque. For others, simply having a sense that larger forces are at work in the world helps meet their spiritual needs.

For more information,  
please call our Helpline at  
**646-744-2900**  
or find us online at  
**[www.caringkindnyc.org](http://www.caringkindnyc.org)**





# caringkind connect 2 culture®

A resource for families  
seeking cultural programs that  
engage people living with  
dementia and their care partners  
through creative programming.



Photo: Joanne D'Auria

**Connect2culture®** seeks to build a bridge between cultural organizations and individuals living with dementia and their care partners. Through art, dance, music, science, history, natural history, and living collections, these organizations understand that you and the person you're caring for are looking for ways to share experiences outside of your daily routine. Educators have been trained to support connections through ability-appropriate conversations and interactions using multi-sensory activities. Smelling herbs at a botanic garden might suggest a favorite food memory, or hearing a piece of music may stimulate memories connected to growing up or life events.

“The best thing is to spend time with people and make new friends.”

— Memory Tour participant,  
Brooklyn Botanic Garden

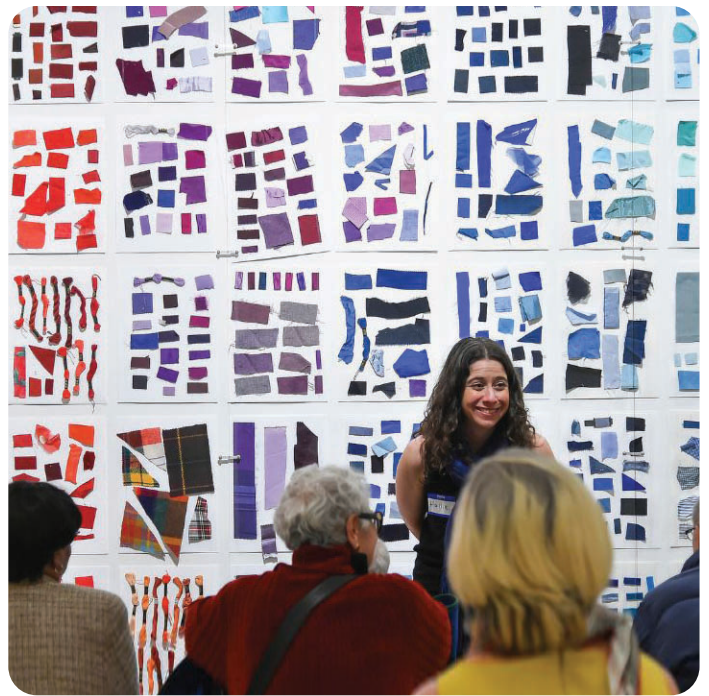
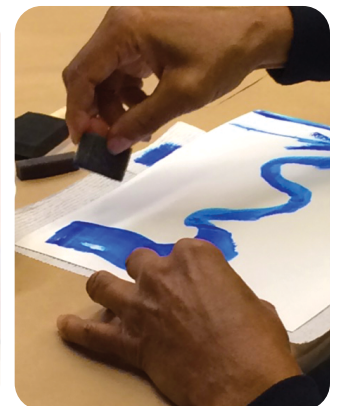


Photo: Ben Gabbe/SocialShutterbug.com

**Visual arts programs engage people through looking and storytelling.** What do you see in the artwork in front of you? The story starts with your responses to sensory stimuli – visual or tactile clues, sounds or music, and even scents. Programs that involve a short discussion in the galleries followed by related art-making activities offer different ways of exploring art and memory. The reward is the enjoyment of a shared experience, and being emotionally and intellectually stimulated in a creative, enriching, and non-judgmental environment.

“Art taps into cognition, emotion, and memory and takes us to the heart of what it means to be human.... Through shared artistic experiences, care partners learn that, despite cognitive changes, they are able to interact with a greater sense of who they are.”

— Carolyn Halpin-Healy  
Executive Director, Arts & Minds



Photos: CaringKind





Photo: Jesse Chan-Norris

## Music programs help to build social and emotional connections to memories long after the initial diagnosis.

When a person hears a familiar song, it may inspire them to move to the rhythm, hum the tune, or to sing the lyrics. Since memories of favorite songs are stored long-term, a person living with dementia can access and connect to that part of their lives and discover emotional connections. These connections have been known to lift mood and encourage positive interaction.

“After singing together *In the Good Old Summertime*, we asked one of our members to sing it as a solo. When he got to ‘she’s my tootsey-wootsey,’ tears were rolling down his cheeks remembering his beloved wife.”

— Participant, Unforgettables Chorus

## Dance programs provide dynamic experiences.

These programs combine three essential elements to improving mood: music, movement, and touch. Music stimulates long-term memory, making those recollections more easily accessible for the person living with dementia. A generation of songs that are connected to life moments can have someone moving in their chair or on the dance floor. While movement and music go hand in hand, touch introduces social interaction and physical connection. With these components wrapped up in one activity, the result can be improved mood and engagement.

“There is spirit and joy abounding here. It is tangible. There is extraordinary and unusual magic of connection that is fostered in this setting for all who attend!”

— K.W. , Professional Care Partner,  
Rhythm Break Cares Touch Social Tea Dance



Photo: CaringKind

**Cultural partners include:** Ailey Arts in Education, American Folk Art Museum, Arts & Minds, Brooklyn Botanic Garden, Brooklyn Museum, Brooklyn Public Library, Intrepid Sea, Air & Space Museum, The Jewish Museum, Lincoln Center for the Performing Arts, Manhattan School of Music, The Metropolitan Museum of Art, Museum of Modern Art, New York Botanical Garden, Orpheus Chamber Orchestra, Queens Museum, Rhythm Break Cares, Rubin Museum of Art, Unforgettables Chorus

# connect2culture®

For more information about connect2culture  
call the CaringKind Helpline

646-744-2900

or visit

[caringkindnyc.org/connect2culture](http://caringkindnyc.org/connect2culture)

**caringkind** The Heart of  
Alzheimer's Caregiving

360 Lexington Avenue, 3<sup>rd</sup> Floor  
New York, New York 10017

Connect2culture thanks all of its partners in their  
pursuit of excellent and engaging programs for people  
living with dementia and their care partners.

Lincoln Center Moments. Photo: Kevin Yatarola

