

360 Lexington Avenue, 3rd Fl. New York, NY 10017 caringkindnyc.org F: 212-697-6037 Helpline P: 646-744-2900 helpline@caringkindnyc.org

#### Dear Friend:

We are pleased that you have contacted CaringKind. We want to be sure you have information about our programs and services—all of which are available free of charge—which can help you locally.

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.

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

- Our *Programs and Services* brochure, which describes the range of supportive services for caregivers that are offered <u>free of charge</u> by CaringKind.
- Information about Alzheimer's disease.
- A medications fact sheet.
- Schedules for upcoming Education and Training sessions, such as Understanding Dementia: What You Need to Know and Where to Go, our Legal & Financial Seminar, and our Family Caregiver Workshop.

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 the Chief Program Officer, 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 one, 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.

On behalf of our Board, our staff, and most importantly, our clients, I thank you once again for reaching out to CaringKind for support.

Sincerely,

Edward Cisek, PhD Chief Program Officer Vice President of Program Evaluation

# **Programs and Services**

# caringkind

The Heart of Alzheimer's Caregiving

# For more information on any of CaringKind's free programs and services, please call our CaringKind Helpline: 646-744-2900

or visit us at www.caringkindnyc.org



#### **Education & Training**

Our training and education programs help you understand and navigate the challenges of Alzheimer's disease and caregiving. We provide knowledge and skills to help you more successfully care for someone with dementia and take care of yourself.

To learn more, visit us at www.caringkindnyc.org/ Education.

- Understanding Dementia for Caregivers A safe, comfortable place to learn about dementia and the resources and services that can help you cope with the challenges today while you plan for the future.
- Legal & Financial Seminars Volunteer elder law attorneys acquaint family members with the legal and financial issues associated with planning and long-term care.
- Medicaid Home Care Seminars Caregivers are guided through the application process for Medicaid home care service in New York City for a person with dementia.
- Placing Your Relative in a Nursing Home An overview of long-term care options, the steps involved in moving a person with dementia to a nursing home, paying for nursing home care, how to ease the transition for both the person and the caregiver, and how to successfully advocate for a nursing home resident.
- Monthly Educational Meeting Meeting topics change monthly based on questions received from caregivers. Past topics have included: Dementia and Driving, Activities for People with Dementia, Managing Challenging Behaviors, and Early Stage Issues.
- Family Caregiver Workshops A ten-hour, interactive program designed to improve the quality of life of a family caregiver and the person with dementia. Topics covered include: Understanding Dementia, Effective Communication Strategies, All Behaviors Have Meaning, Safety in the Home, Caring for the Caregiver, and Designing Strength-Based Activities.
- Dementia Care Training for Professional Caregivers A six-week, nationally recognized program that specifically aims to help direct care workers provide the highest quality of care to persons with dementia.
- **Support Group Leader Training** An opportunity for health care professionals and former caregivers to learn how to lead caregiver or early stage groups.

### **Social Work Services**

Our social workers provide in-depth, personalized consultations for individuals and families facing the decisions and challenges associated with Alzheimer's disease and other dementias. Our professional social workers address each family's unique concerns to develop a care plan. Social workers can meet, by appointment, in person in Manhattan, Brooklyn, Queens, and Staten Island, or by phone and email.

Beginnings at CaringKind	A social gathering for older adults with early or mid-stage Alzheimer's disease, dementia, and other neurocognitive disorders. Each meeting offers social, intellectual, and physical engagement in an uplifting and safe environment. To learn more, visit www.caringkindnyc.org/beginnings.
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 throughout the five boroughs. To learn more, visit us at www.caringkindnyc.org/SupportGroups.
MedicAlert® NYC Wanderer's Safety Program	Everyone with dementia is at risk for wandering. Our Wanderer's Safety Program, MedicAlert® NYC, provides a safety net for your family member and for you in the event someone is missing or found. Our 24-hour nationwide emergency response service provides assistance in finding people who have wandered locally or far from home, or who have a medical emergency. To enroll, visit 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 on www.TogetherWeCare.com.
connect2culture®	Our cultural arts program, connect2culture <sup>®</sup> , creates unique opportunities for people living with dementia and their caregivers to stimulate conversation and engagement through art, music and dance. To learn more, visit us at <b>www.caringkindnyc.org/Connect2culture</b> .
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 us at www.caringkindnyc.org/PalliativeCare.

#### **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



360 Lexington Avenue, 3<sup>RD</sup> Floor New York, New York 10017 CaringKind Helpline: 646-744-2900 caringkindnyc.org ✔ /caringkindnyc ✔ @caringkindnyc **Caringkind** The Heart of Alzheimer's Caregiving 360 Lexington Avenue, 3<sup>rd</sup> Floor, New York, New York 10017 CaringKind Helpline: 646-744-2900 ~ caringkindnyc.org Formerly known as the Alzheimer's Association, NYC Chapter

# **Alzheimer's Disease -- Fact Sheet**

## 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

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

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. Alzheimer's is the most common cause of dementia among older adults. 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. 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 daily living.

The causes of dementia can vary, depending on the types of brain changes that may be taking place. 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 disorders, at least one of which is dementia. For example, some people have both Alzheimer's disease and vascular dementia.

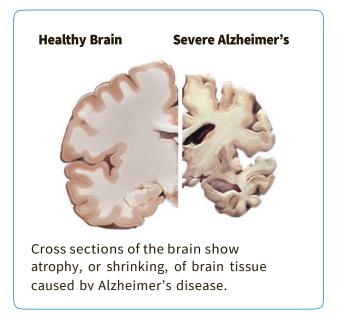
Alzheimer's disease is named after Dr. Alois Alzheimer. In 1906, Dr. Alzheimer noticed changes in the brain tissue of a woman who had died of an unusual mental illness. Her symptoms included memory loss, language problems, and unpredictable behavior. After she died, he examined her brain and found many abnormal clumps (now called amyloid plaques) and tangled bundles of fibers (now called neurofibrillary, or 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 onset and progression 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 this preclinical stage of Alzheimer's disease, people seem to be symptom-free, but toxic changes are taking place in the brain. Abnormal deposits of proteins form amyloid plaques and tau tangles throughout the brain, and once-healthy neurons stop functioning, lose connections with other neurons, and die.

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



# Signs and Symptoms

Memory problems are typically one of the first signs of cognitive impairment related to Alzheimer's disease. Some people with memory problems 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. For many, decline in non-memory aspects of cognition, such as word-finding, vision/spatial issues, and impaired reasoning or judgment, may signal the very early stages of Alzheimer's disease. 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.

## Mild Alzheimer's Disease

As Alzheimer's disease progresses, people experience greater memory loss and other cognitive difficulties. Problems can include trouble handling money and paying bills, repeating questions, taking longer to complete normal daily tasks, and personality and behavior changes. People are often diagnosed at this stage.

## Moderate Alzheimer's Disease

In this stage, damage occurs in areas of the brain that control language, reasoning, sensory processing, and conscious thought. Memory loss and confusion grow worse, and people begin to have problems recognizing family and friends. They may be unable to learn new things, carry out multistep tasks such as getting dressed, or cope with new situations. In addition, people at this stage may wander and get lost, have hallucinations, delusions, and paranoia and may behave impulsively.

## Severe Alzheimer's Disease

Ultimately, plaques and tangles spread throughout the brain, and brain tissue shrinks significantly. 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.

# 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. The importance of any one of these factors in increasing or decreasing the risk of developing Alzheimer's may differ from person to person.

## The Basics of Alzheimer's

Scientists are conducting studies to learn more about plaques, tangles, and other biological features of Alzheimer's disease. Advances in brain imaging techniques allow researchers to see the development and spread of abnormal amyloid and tau proteins in the living brain, as well as changes in brain structure and function. 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.

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

## Genetics

Most people with Alzheimer's have the late-onset form of the disease, in which symptoms become apparent 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  $\varepsilon$ 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  $\varepsilon$ 4 form of the gene does not mean that a person will definitely develop Alzheimer's disease, and some people with no APOE  $\varepsilon$ 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 lateonset 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.

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- geneticsfact-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, 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, 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.

# **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 may be due to another cause) 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, 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.

Alzheimer's disease can be *definitively* diagnosed only after death, by linking clinical measures with an examination of brain tissue in an autopsy.

People with memory and thinking concerns should talk to their doctor to find out whether their symptoms are due to Alzheimer's or another cause, such as stroke, tumor, Parkinson's disease, sleep disturbances, side effects of medication, an infection, or a non-Alzheimer's dementia. Some of these conditions may be treatable and possibly reversible.

If the diagnosis is Alzheimer's, beginning treatment early in the disease process may help preserve daily functioning for some time, even though the underlying disease process 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.

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.

# **Treatment of Alzheimer's Disease**

Alzheimer's disease is complex, and it is unlikely that any one drug or other intervention will successfully treat it. Current approaches focus on helping people maintain mental function, manage behavioral symptoms, and slow or delay the symptoms of disease. Researchers hope to develop therapies targeting specific genetic, molecular, and cellular mechanisms so that the actual underlying cause of the disease can be stopped or prevented.

## **Maintaining Mental Function**

Several medications are approved by the U.S. Food and Drug Administration to treat symptoms of Alzheimer's. Donepezil (Aricept<sup>®</sup>), rivastigmine (Exelon<sup>®</sup>), and galantamine (Razadyne<sup>®</sup>) are used to treat mild to moderate Alzheimer's (donepezil can be used for severe Alzheimer's as well). Memantine (Namenda<sup>®</sup>) is used to treat moderate to severe Alzheimer's. These drugs work by regulating neurotransmitters,

## Participating in Clinical Trials

Everybody—those with Alzheimer's disease or mild cognitive impairment as well as healthy volunteers with or without a family history of Alzheimer's—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*.
- 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*.

Learn more in Participating in Alzheimer's Research: For Yourself and Future Generations, at *www.nia.nih.gov/alzheimers/publication/ participating-alzheimers-research*.

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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. They are effective for some but not all people and may help only for a limited time.

## **Managing Behavior**

Common behavioral symptoms of Alzheimer's include sleeplessness, wandering, agitation, anxiety, and 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 developed to a point where scientists can look beyond treating symptoms to think about addressing underlying disease processes. In ongoing clinical trials, scientists are developing and testing several possible interventions, including immunization therapy, drug therapies, cognitive training, physical activity, and treatments used for cardiovascular disease and diabetes.

# 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 evidencebased 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.

Good coping skills, a strong support network, and respite care are other ways that help caregivers handle the stress of caring for a loved one 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. Many organizations sponsor in-person and online support groups, including groups for people with early-stage Alzheimer's and their families.

### For more information, see **Caring for a Person with Alzheimer's Disease: Your Easy-to-Use Guide from the National Institute on Aging** at

www.nia.nih.gov/alzheimers/publication/ caring-person-alzheimers-disease.

## For More Information About Alzheimer's

To get more information about Alzheimer's and learn about support groups and services for people with the disease and their caregivers, contact the following organizations:

#### Alzheimer's Disease Education and Referral (ADEAR) Center 1-800-

Referral (ADEAR) Center1438-4380 (toll-free)adear@nia.nih.govadear@nia.nih.govwww.nia.nih.gov/alzheimers

The National Institute on Aging's ADEAR Center offers information and publications for families, caregivers, and professionals on diagnosis, treatment, patient care, caregiver needs, long-term care, education and training, and research related to Alzheimer's disease. Staff members answer telephone, email, and written requests and make referrals to local and national resources. Visit the ADEAR website to learn more about Alzheimer's and other dementias, find clinical trials, and sign up for email updates.

### CaringKind

646-744-2900 (toll-free) helpline@caringkindnyc.org www.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. This could mean asking family members or friends to help out, doing things you enjoy, using adult day care services, or getting help from a local home health care agency. Taking these actions can bring you some relief. 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 understanding with other caregivers.
- Call for help from home health care or adult day care services when you need it.
- Use national and local resources to find out how to pay for some of this help. To learn more about government benefits, see www.nia.nih.gov/alzheimers/publication/when-you-need-help/getting-helpcaregiving.

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 or call toll-free at 1-855-260-3274.

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#### Your Emotional Health

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.



### **Fact Sheet: Medication**

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 patients with comfort, dignity, and independence for a longer period of time and can encourage and assist their caregivers as well.

It is important to understand that none of these medications stops the disease itself.

On June 7, 2021 the F.D.A. approved Aduhelm (Aducanamab) for the treatment of Alzheimer's disease. This is the first drug to modify the disease process in Alzheimer's disease with the goal of slowing cognitive decline. Please speak to your healthcare professional for further information, or call the CaringKind Helpline: 646-744-2900.

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

Medications called cholinesterase inhibitors are prescribed for mild to moderate Alzheimer's disease. These drugs may help delay or prevent symptoms from becoming worse for a limited time and may help control some behavioral symptoms. The medications include 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.

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360 Lexington Avenue, 3<sup>rd</sup> Floor, New York, New York 10017 CaringKind Helpline: 646-744-2900 ~ caringkindnyc.org Formerly known as the Alzheimer's Association, NYC Chapter This drug's main effect is to delay progression of some of the symptoms of moderate to severe Alzheimer's. It may allow patients to maintain certain daily functions a little longer than they would without the medication. For example, Namenda® may help a patient 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 patients and caregivers.

The FDA has also approved Aricept<sup>®</sup> and Namzaric<sup>®</sup>, a combination of Namenda<sup>®</sup> and donepezil, 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 very differently from cholinesterase inhibitors, the two types of drugs can be prescribed in combination.

#### **Dosage and Side Effects**

Doctors usually start patients at low drug doses and gradually increase the dosage based on how well a patient tolerates the drug. There is some evidence that certain patients may benefit from higher doses of the cholinesterase inhibitors. However, the higher the dose, the more likely are side effects. The recommended effective dosages of drugs prescribed to treat the symptoms of Alzheimer's and the drugs' possible side effects are summarized in the table (see chart).

Patients should be monitored when a drug is started. Report any unusual symptoms to the prescribing doctor right away. It is important to follow the doctor's instructions when taking any medication, including vitamins and herbal supplements. Also, let the doctor know before adding or changing any medications.

#### Testing New Alzheimer's Drugs

Clinical trials are the best way to find out if promising new treatments are safe and effective in humans. Volunteers are needed for many Alzheimer's trials conducted around the United States. To learn more, talk with your doctor or visit the ADEAR Center's listing of clinical trials at www.nia.nih.gov/alzheimers/clinicaltrials. More information is available at www.nia.nih.gov/alzheimers/volunteer.

Information taken from the National Institute on Aging, part of the National Institutes of Health www.nia.nih.gov/alzheimers/topics/caregiving

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# The Heart of Alzheimer's Caregiving

Drug Name	Drug Type and Use	How it Works	Common Side Effects
Aricept®(donepezil)	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
Exelon®(rivastigmine)	Cholinesterase inhibitor prescribed to treat symptoms of mild to moderate Alzheimer's (patch is also for severe Alzheimer's)	Prevents the breakdown of acetylcholine and butyrylcholine (a brain chemical similar to acetylcholine) in the brain	Nausea, vomiting, diarrhea, weight loss, decreased appetite, muscle weakness
Namenda®(memantine)	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
Namzaric®(memantine extended-release and donepezil)	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, decreased appetite
Razadyne®(galantamine)	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, weight loss, decreased appetite

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Formerly known as the Alzheimer's Association, NYC Chapter

Drug Name	Manufacturer's Recommended Dosage	More Information
Aricept® (donepezil)	<ul> <li>Tablet*: Initial dose of 5 mg once a day</li> <li>May increase dose to 10 mg/day after</li> <li>4-6 weeks if well tolerated, then to 23 mg/day after at least 3 months</li> <li>Orally disintegrating tablet*: Same dosage as above</li> <li>23-mg dose available as brand-name tablet only</li> </ul>	For current information about this drug's safety and use, visit www.aricept.com/prescribi ng-and-patient-info. Click on "Prescribing and Patient Information" to see the drug label.
Exelon® (rivastigmine)	<ul> <li>Capsule*: Initial dose of 3 mg/day (1.5 mg twice a day)</li> <li>May increase dose to 6 mg/day (3 mg twice a day), 9 mg (4.5 mg twice a day), and 12 mg/day (6 mg twice a day) at minimum 2-week intervals if well tolerated</li> <li>Patch: Initial dose of 4.6 mg once a day; may increase dose to 9.5 mg once a day and 13.3 mg once a day at minimum 4-week intervals if well tolerated</li> <li>Oral solution: Same dosage as capsule</li> </ul>	For current information about this drug's safety and use, visit www.fda.gov/Drugs. Click on "Drugs@FDA," search for Exelon, and click on drug-name links to see "Label Information."
Namenda® (memantine)	<ul> <li>Tablet: Initial dose of 5 mg once a day</li> <li>May increase dose to 10 mg/day (5 mg twice a day), 15 mg/day (5 mg and 10 mg as separate doses), and 20 mg/day (10 mg twice a day) at minimum 1-week intervals if well tolerated</li> <li>Oral solution: Same dosage as above</li> <li>Extended-release capsule: Initial dose of 7 mg once a day; may increase dose to 14 mg/day, 21mg/day, and 28 mg/day at minimum 1-week intervals if well tolerated</li> </ul>	For current information about this drug's safety and use, visit www.namenda.com. Click on "Full Prescribing Information" to see the drug label.
Namzaric® (memantine extended-release and donepezil)	<ul> <li>Capsule: 28 mg memantine extended- release + 10 mg donepezil once a day</li> <li>14 mg memantine extended-release + 10 mg donepezil once a day (for patients with severe renal impairment)</li> </ul>	For current information about this drug's safety and use, visit <u>www.namzaric.com</u> . Click on "Prescribing Information" to see the drug label.
Razadyne® (galantamine)	<ul> <li>Tablet*: Initial dose of 8 mg/day (4 mg twice a day)</li> <li>May increase dose to 16 mg/day (8 mg twice a day) and 24 mg/day (12 mg twice a day) at minimum 4-week intervals if well tolerated</li> <li>Oral solution*: Same dosage as above</li> <li>Extended-release capsule*: Same dosage as above but taken once a day</li> </ul>	For current information about this drug's safety and use, visit www.janssenpharmaceutic als.com/assets/razadyne_ er.pdf to see the drug label.

- 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.

For more tips on home safety, see "Home Safety for People with Alzheimer's Disease," www.nia.nih.gov/alzheimers/publication/home-safety-people-alzheimers-disease.

\* 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.



## 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 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.

### caringkind The Heart of Alzheimer's Caregiving

360 Lexington Avenue, 3<sup>rd</sup> Floor, New York, New York 10017 CaringKind Helpline: 646-744-2900 ~ caringkindnyc.org Formerly known as the Alzheimer's Association, NYC Chapter



**Wall Clock:** A precision wall clock that displays the time on a large, familiar clock face with hands, and also the day and date, using easy to understand three-letter abbreviations.

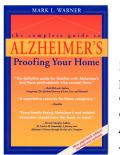
**The Memory Phone:** Forgetting a telephone number happens to all of us, but when you've been diagnosed with AD, it is especially frightening and frustrating. The problem is solved with the Memory Phone that allows you or your loved one to simply push the "picture" of the person they

want to call. The Memory Phone has nine frames for pictures of friends and family. Want to call Margaret, just push her picture the phone does the rest.



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<b>*</b>	

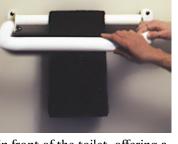
**Scoop Plate:** This 9" plate has a high, tapered, contoured back that allows the user to push and capture food that might otherwise be pushed off the plate or abandoned. The high back wall is useful also to grasp while scooping food. The plate has a slip-resistant base. Break-resistant plastic, microwavable, dishwasher safe (top rack). *Fork not included. Weighted utensils sold separately.* 



#### Complete Guide to Alzheimer's Proofing Your Home

Here is a book that will profoundly improve the environmental quality of caring for a person with Alzheimer's disease at home. *Author: Mark L. Warner* 

Helping Hands Bar (3 Sizes) Make it easier for your loved one to sit down and stand up from the toilet. The Helping Hand Grab Bar



attaches to the wall in front of the toilet, offering a secure bar to hold.

#### Lockable Automatic Medication Dispenser

You'll be delighted with this moderately priced medications dispenser that holds up to 28 doses and provides the right medications at the right time.



#### Stop Sign Banner



This durable, red and yellow nylon banner presents an imposing visual barrier. Deter wandering residents from entering restricted areas or rooms. Adjustable Velcro straps can span opening up to five feet wide.

Our goal is to provide you with the latest products and resources to guide you in your journey with Alzheimer's and Dementia...

Healthcare Products LLC d/b/a The Alzheimer's Store<sup>®</sup> www.alzstore.com 1-800-752-3238

Coupon Code 2% discount if this code is used

# The Alzheimer's Store

Products designed for people with Alzheimer's and Dementia and their Caregivers



www.alzstore.com 1-800-752-3238

www.alzstore.com

1-800-752-3238

#### **Product Categories:**

- Clocks
- Alarms
- Phones
- Motion Detectors
- Memory Stimulating Puzzles
- Baby Doll Therapy
- Medication Dispensers
- Bathing and Incontinence Products
- Dining Products

and Much More...

**Over 300 Products** 

- DVDs
- Books
- Music



Monitor

Please visit the Alzheimer's Store at www.alzstore.com for a complete listing of all of our products



These award winning, beautiful, 24-piece puzzles feature well-known works of art by famous artists on familiar and fun topics. Each puzzle piece is rather large, approximately 4" x 6" and can be wiped clean.

#### **Baby Doll Therapy**

Dolls have a remarkable effect on women and men. They are calming, soothing and bring the person back to a time in their life when they felt useful and had a sense of purpose. Giving someone a "baby" brings them back



to that safe and secure time in their life.



**Anti-Scalding Devices** 

Called a Temperature Activated Flow Reducer (TAFR), these easyto-install, screw-on, anti-scalding devices turn off the water if the temperature gets too hot. Install one at the bathroom sink. and kitchen sink and put your mind at ease, knowing that the chance of an accidental, severe burn is now greatly reduced. Also available for the Showerhead

#### Handyman's Box

The Handyman's Box is a unique activity product. A pride, source of fascination and fun. This superbly handmade. hardwood lock box has doors that open and close, each with a different lock. hasp or latch.





#### Adult Briefs/Underwear The absolute best briefs

on the market. Free sample before you order. You'll never order a different brief again.

#### **Cape with Pockets**

The Cape with Pockets is very soft and comfortable. It's oversized pockets are perfect for keeping hands warm on cold days. It can also be worn over the shoulders or laid on the lap to keep legs and lap warm.





**Bathing Without a Battle** (CD-Rom w/Instructional DVD or Book available)

#### Fiddle Twiddle

The FiddleTwiddle is a soft, comfortable hand muff with tactile features outside and a squishy ball inside. Feel the beads in the pouch, stroke the soft



fleecy "fur" or squeeze the hidden ball. Whether hands go inside or explore the outside features, the FiddleTwiddle provides entertainment, therapeutic activity and keeps busy hands warm and occupied.



#### Motion Detector with Remote Alarm

This is a wonderful product that can notify you when your loved one is on the move. Place the motion detector wherever

it needs to detect dangerous movement and locate the chime/alarm in your bedroom up to 120 feet away. As soon as your family member passes by the detector, you will immediately know

www.alzstore.com 1-800-752-3238

# Education and Training Opportunities

Seating is limited and registration is required.

Please call our CaringKind Helpline at 646-744-2900

to reserve a space.

All meetings are free of charge and subject to change.

# Understanding Dementia Seminar: What You Need to Know and Where to Go

Sessions provide family members and friends with information about Alzheimer's, other types of dementia, and resources and services available. Locations: Manhattan, Brooklyn, and Queens

# **Monthly Education Meetings**

The topics for these meetings vary on a monthly basis and are derived from issues we hear about through our CaringKind Helpline, to ensure relevance and timeliness. Recent topics include Bereavement, Activities for People with Dementia, Managing Challenging Behaviors, Early Stage Issues, and Partnering with Your Doctor. Location: Manhattan

# Legal & Financial Seminar

An attorney specializing in Elder Law will discuss important topics caregivers should understand before meeting with a personal attorney. Topics include Power of Attorney, Guardianship, Medicaid Eligibility, Long-Term Care Insurance, Health Care Proxy and more.

Location: Manhattan

It is recommended that you attend an "Understanding Dementia: What You Need to Know and Where to Go" prior to attending this meeting.

# Medicaid Home Care Seminar: A Practical Guide to the System

Caregivers are guided through the application process for Medicaid home care service.

Location: Manhattan

Prior attendance at a Legal & Financial Seminar is required.

# **Family Caregiver Workshops**

During this 10-hour workshop, caregivers learn to view the world from the perspective of the person with dementia. They also learn how to communicate more effectively with the person for whom they are caring and receive new insights on how to manage the challenging behaviors often associated with Alzheimer's disease, as well as the importance of self-care.

Location: Manhattan

# ¡Juntos Aprendemos!

Por favor llame a nuestra Línea de Ayuda al 646-744-2900 para más información. El espacio es limitado y es necesario registrarse. Todos los talleres son gratis y están sujetos a cambios.

## Entendiendo la Demencia

Este taller es para parientes y amigos de personas diagnosticadas con la enfermedad de Alzheimer u otras demencias. Proveemos un lugar seguro donde pueden aprender acerca de la enfermedad de Alzheimer y otros tipos de demencia. Este taller también le informa sobre los recursos y servicios que le pueden ayudar.

# Seminario Sobre Asuntos Legales y Financieros

Este Seminario le informa acerca de temas prácticos relacionados con cambios en Medicaid, planeación para el futuro financiero, acceso a servicios en el hogar o instituciones para ancianos y otros asuntos.

Ubicación: Manhattan.

Ubicación: Manhattan.

查詢或登記請聯絡服務熱線:646-744-2900 所有會議均免費及時間或有變動。座位有限。務必登記。

認識失智症講座: 你需要知 道的資訊和往哪裡去 課程提供關於阿滋海默症, 其他類型失智症的訊息,資 源及服務與家屬和朋友。

地點:民鐵吾,布碌崙及

# 皇后區

# 法律與財務講座

講座將由精辦老人法律的律師主 講,為家庭成員在約見他們的私人 律師之前提供重要的知識。 講座內容包括:授權書,監護權,醫 療補助的申請資格,長期護理保 險,醫療護理委託書等等。

# 地點:民鐵吾

特別推薦你在參加此講座之前先參加 <sup>\*</sup>認識失智症講座: 你需要知道的資 訊和往哪裡去<sup>\*</sup>。



PLEASE SEND COMPLETED FORMS & PHOTO TO: CaringKind NYC Wanderer's Safety Program 360 Lexington Ave, 3rd Floor, New York NY 10017



#### CARINGKIND NYC WANDERER'S SAFETY PROGRAM: NEW ENROLLMENT FORM

MEMBERSHIP ENROLLMENT	INFORMATION FOR YOUR EMERGENCY HEALTH RECORD
(All fields required)	MEDICAL CONDITIONS & DEVICES
LAST NAME	
FIRST NAME	
ADDRESS	
APT # CITY STATE ZIP	
CELL PHONE HOME PHONE	(For medical device, please include model number)
BIRTHDATE (MM/DD/YYYY) LAST 4 DIGITS OF SSN	<b>ALLERGIES</b> List all known food, drug, or other allergies
GENDER (CHECK ONE)	MEDICATIONS
Female Male Prefer to self-describe:	List all medications and dosages, including inhalers
PRIMARY EMERGENCY CONTACT - FULL NAME	
ADDRESS (NO P.O. BOX)	
APT # CITY STATE ZIP	
CELL PHONE HOME PHONE	
	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.
SECONDARY EMERGENCY CONTACT – FULL NAME	Optional Caregiver Enrollment: visit www.cknyc.org or call
CELL PHONE HOME PHONE	our HelpLine at 646-744-2900

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#### MEMBERSHIP ENROLLMENT

There is a fee for any replacement product due to an



Exact wrist measurement: (Required for bracelet. Measure wrist snugly and add 1/2 inch.)



Exact wrist measurement:

(Required for bracelet. Measure wrist snugly and add 1/2 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 Re	esponse Team
•	Emer	aencv Health F	Profile

- 24/7 Wandering support
- Portrait Photo (selfie)

• Personal Profile • Printable Health Profile

\$49.99

\$7.00

• Emergency Contact Notification

PAYMENT

ID TOTAL MEMBERSHIP TOTAL

SHIPPING

#### TOTAL -

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



#### **PAYMENT TYPE**

Check (make payable to MedicAlert Foundation) □ MasterCard<sup>®</sup> □ Visa<sup>®</sup> □ Discover<sup>®</sup> □ AMEX<sup>®</sup> No other cards accepted. No CODs. Payment must accompany order.

**CREDIT CARD NUMBER** 

EXPIRATION DATE (MM/YY)

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SECURITY CODE
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CARD HOLDER'S NAME

CARD HOLDER'S BILLING ADDRESS

CITY

ZIP

SIGNATURE FOR CARD AUTHORIZATION

STATE

#### 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.