

360 Lexington Avenue, 4th 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 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 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,

Jed Á. Levine, M.A. President & CEO

# **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.

#### 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

#### 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.