



# caringkind

*The Heart of Alzheimer's Caregiving*

It Takes  
A Village

**SPRING 2018**

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Dear Friends,

**In the aftermath of the release of Hillary Clinton's 1996 book, *It Takes a Village*, cultural scholars debated the origins of the proverb from which the title is derived: "It takes a village to raise a child." Was it Swahili? Native American? To this day, no one knows for sure.**

But this much, I do know: regardless of its source, this important concept resonates deeply here at CaringKind because it truly takes not just a village, but an entire city of dedicated Alzheimer's professionals to make sure that the people who come to us for help are getting the best and most comprehensive services available anywhere.

And it all starts with one simple phone call to our 24-hour Helpline. Dialing these 11 digits, 1-646-744-2900, opens an entire world of support for you. This call introduces you to a CaringKind Helpline Specialist who figures out what you need and then connects you to members of our "village" – a coordinated network of partners dedicated to helping New Yorkers who are dealing with dementia or Alzheimer's.

From neurologists who make an initial assessment to the experts who run adult day care programs and from the elder lawyers who plan for end of life decisions, to the health care providers who run long term care residential homes, our trusted collaborators are a big part of CaringKind's success. We rely on them day in and day out because they are the best at what they do. And our clients deserve nothing less.

Here's one example of how we rely on that village: After calling our Helpline, a family came in to meet with a CaringKind social worker. The family was distraught. Their father's behavior had been uncharacteristic for some time and he was now showing symptoms they

thought could be dementia. From our roster of doctors, we recommended a few neurologists and the family chose one to do an assessment. When we learned that Dad's internist had retired, we provided the names of a number of doctors with experience diagnosing and treating people with dementia. Once they had a firm diagnosis and ongoing medical support, they had turned a corner. The family now turned to CaringKind's programs and services to select an adult day care program located near their home.

Dad's late-night wandering was a major concern. This dangerous behavior can result in serious injury or even death. We immediately registered Dad in CaringKind's MedicAlert® NYC Wanderer's Safety Program, which works in close partnership with the New York City Police Department. But to move ahead, Dad needed to wear a MedicAlert identification bracelet, and he refused to wear any kind of jewelry. To the rescue came our CaringKind social workers. She suggested that the man's beloved grandson give Grandpa a MedicAlert bracelet for Christmas to match the one that the grandson would wear. It worked! Grandpa was successfully enrolled in the program and wore his bracelet proudly.

Our community partners are an essential component of our work. From the medical community to the social service agencies to experts in legal and financial issues to the Missing Persons Bureau of the NYPD, our organization is built on twin



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pillars: CaringKind expertise and loyal, long-term community partnerships. The village we have built is strong, diverse and responsive. The people who populate that village are among the most dedicated and caring dementia experts in the world.

In reflecting on these extraordinary relationships with NYC doctors, lawyers, nursing home administrators, home health aides, nurses, pharmacists, researchers, scientists, nonprofit organizations, and other service providers, I am proud of what we accomplish together every day to improve the lives of thousands of New York families affected by an Alzheimer's or dementia diagnosis. And with CaringKind at the helm, our village will continue to grow and serve New Yorkers with expertise and compassion.



Dear Readers,

**We say that to raise a child, "it takes a village." And this is no less true when caring for someone with a progressive, long term illness. But today, this is more challenging than ever. Families are smaller and more mobile than in previous generations and family members may live far from siblings and parents. Typically, this leaves the responsibility for care of an aging parent, spouse or partner with dementia to a primary caregiver who can get quickly overwhelmed. As the disease progresses, the person with dementia is less able to independently manage the activities of daily living – eating, bathing, dressing – and behavioral symptoms become harder to manage. Our hope is that, before things get out of hand, the caregiver remembers one of CaringKind's key messages: "You cannot do this alone."**

Medical science remains limited in its ability to treat Alzheimer's and related disorders. We know that, in the absence of an effective therapy, the best treatment is good care. And that is CaringKind's role. We are the only organization with over 30 years of experience providing dementia-specific patient and family education, care and support in multiple languages, throughout the continuum of the disease. Our staff creates a community where dementia caregivers feel welcome and safe. In this environment, they are open to learning the most effective way to care for an individual with a progressive dementia. We are, at CaringKind, the village that caregivers need.

We hope our clients will start by calling our 24-hour Helpline Specialists, who provide information, guidance and hope. Clients may be directed to a social worker, who will help each caregiver navigate the confusing and complex system of social and medical organizations and resources. Social workers ensure that the person with dementia is enrolled in the MedicAlert® NYC Wanderer's Safety

Program and that, if appropriate, they enroll in our Early Stage programs.

These and other CaringKind programs and services are enhanced and supported by over 200 community partners and hundreds of volunteers including our Support Group leaders. The success of our outreach effort depends on the strong, mutually beneficial relationships cultivated with community leaders and persons of influence in the Latino, African American, Chinese, LGBT, Orthodox Jewish and healthcare communities. Our comprehensive database provides access to information and resources including diagnostic centers, adult day care programs, home care providers, residential care, hospice, legal and financial resources and so much more.

Research and advocacy remain an important part of CaringKind's mission. We work closely with all the major research and treatment centers, and with partners in advocacy like LiveON NY and AARP who help us advocate for services on the local and state level. LEAD



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(Leaders Engaged on Alzheimer's Disease) Coalition and USAgainstAlzheimer's help us advocate for increased funding for research, care and support on the federal level.

You can see, it takes a village. Dementia caregiving is hard, but with CaringKind, you are not alone. If you or someone you know needs help, please reach out today. Call the 24-hour Helpline at 646-744-2900 or email us at [helpline@caringkindnyc.org](mailto:helpline@caringkindnyc.org). We will welcome you to the CaringKind village.

## CaringKind's Education Village



**MARILUCY LOPES**

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At CaringKind we often stress that one person can't do it alone when it comes to dementia and Alzheimer's caregiving. We at CaringKind are no exception. Together, staff with varying expertise and community partners, make up a "dementia village" built to be a caregiver's haven for support. This haven includes opportunities to learn in seminars such as: Understanding Dementia for Family Caregivers, Monthly Educational Seminars (topics vary), and Placing Your Relative in a Nursing Home. One stop which is often encouraged and sometimes necessary on your road to building knowledge, is attending our Legal and Financial and Medicaid Home Care Seminars.

All of our educational seminars are led or structured by CaringKind staff, depending on their area of expertise. However, being an expert in dementia care is not the same as being an expert in legal affairs. This is why CaringKind's education village also includes elder law attorneys. Our expertise in dementia and their expertise in elder law build a bridge to connect you with practical legal information meant to facilitate caregiving.

The National Elder Law Foundation (NELF) defines "Elder Law" as "the legal practice of counseling and representing older persons and persons with special needs." The NELF also explains how

elder law attorneys are responsible for "[counseling] a person's representatives about the legal aspects of health and long-term care planning, public benefits, surrogate decision-making, legal capacity..." and more. In other words, the world of Elder Law is vast and its own neighborhood in a "dementia village". CaringKind understands that meeting with a qualified elder law attorney is often required for dementia or Alzheimer's disease care planning.

CaringKind does not endorse any one attorney but can help you identify a need for an elder law attorney and will provide you with an opportunity to learn from one. When attending any of our free Legal and Financial or Medicaid Home Care Seminars, caregivers have an opportunity to learn how dementia or Alzheimer's disease impacts legal matters such as: power of attorney, guardianship, Medicaid eligibility, long-term care insurance, health care proxy, and more. Every presenting attorney defines and explains the importance of these legal matters and documents, utilizing their expertise, while following a curriculum of topics developed by CaringKind. The attorney explains these matters understanding the unique challenges related to dementia or Alzheimer's disease.

Moreover, during these meetings, caregivers are (re)introduced to specific legal documents, how they can be used, and what can be done to protect a person's rights and choices. Caregivers also have an opportunity to ask questions. Questions sometimes range from, "My parent has a power of attorney from 15 years ago, should it be updated?" to, "Will I lose my money and home when my spouse needs a nursing

home?" Of course, the purpose of the seminar is to offer an understanding of how simple or complicated legal issues can be but not to provide legal advice. Not every question will have a simple answer, but understanding how simple or complex an issue may be is key to understanding what step might come next.

The Legal and Financial and Medicaid Home Care Seminars are offered on a rotating basis. Though each seminar may be presented by a different attorney, the information shared is the same. Each attorney aims to provide legal information, and notably do so on a volunteer basis. In addition to experience working with dementia clients or caregivers, many are motivated to teach these seminars because of a personal connection to the disease, and their primary goal in these seminars is to connect caregivers with valuable information and resources.

CaringKind and our partners are here to help you learn more about dementia and Alzheimer's disease. If you would like to learn more about any of these seminars, or to be connected to an elder law attorney, please visit our website at [www.caringkindnyc.org](http://www.caringkindnyc.org) or call our 24-hour Helpline at 646-744-2900.



## The Importance of Diagnostic Centers



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The 24-hour Helpline is the heart of CaringKind's programs and services. It provides trained specialists who offer information, referrals and support to family members, professional caregivers, and people diagnosed with dementia.

The Helpline works closely with CaringKind's Outreach Program. The Outreach Managers build and maintain relationships with professionals in various social service and healthcare fields. The Outreach Managers educate professionals in various disciplines about Alzheimer's disease and related dementias, as well as programs and services offered by CaringKind.

Diagnostic centers make numerous referrals to CaringKind's 24-hour Helpline in response to relationships with the CaringKind Outreach Program. These relationships are vital to both the person with dementia and his or her care partner as they embark on their caregiving journey.

Located in all five boroughs of New York City, diagnostic centers provide a one-stop shop for a person with memory concerns to undergo a thorough evaluation. The advantage of going to a diagnostic center, instead of just seeing one physician, is that the patient sees a variety of specialists, both medical and non-medical, over two or

three days' time. A neuropsychologist administers tests involving memory for words, stories, shapes and numbers. An internist performs a general physical exam. A neurologist gives a physical exam including checking balance and reflexes, and rules out the possibility of other conditions such as Parkinson's. A geriatric psychiatrist interviews the client and his or her care partner, usually a family member, to explore the family history and the person's current functioning. The psychiatrist will ask the client questions to ascertain his or her awareness of vocabulary and general knowledge. The client may also undergo an MRI or PET scan.

After the evaluation, a social worker may meet with the person with memory loss as well as his or her care partner to discuss the diagnosis. Reactions vary from confusion to denial to fear. This is a good time for the social worker to make a Rapid Referral to CaringKind's supportive services.

Our Healthcare Outreach Manager connects with diagnostic center staff members and educates them about CaringKind's programs and services, as these healthcare professionals are instrumental in facilitating patient and caregiver connections to CaringKind's supportive services via the Rapid Referral. The Rapid Referral is a form that healthcare professionals complete and send to CaringKind. The Rapid Referral has information about the person diagnosed with dementia as well as contact information and consent for a call to his or her care partner. Once received, a Helpline Specialist will contact the referred individual to inform him or her about CaringKind's programs and services. The Helpline Specialist will

assist with the non-medical challenges inherent in dementia care. For all medical needs, clients will be referred back to the healthcare provider.

These are the benefits of CaringKind's HealthCare Outreach and the 24-Hour Helpline working together with diagnostic centers:

- Patients and caregivers dealing with dementia are connected to resources and support in a timely manner.
- Education and support helps to create healthy, informed patients and caregivers.
- Patients and families receive assistance in understanding the impact of dementia.
- Families have an opportunity to build a support network and plan early in the disease process.
- Materials are made available for healthcare professionals to keep in office for future referrals.

**The 24-hour  
Helpline is available  
around the clock,  
365 days a year  
at 646-744-2900.**

## Bringing Communities Together Through Partnerships



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“Are there programs in my community that my dad and I can enjoy together?” “How can I find activities that are fun for Mom when her responses are unpredictable?” These questions may sound familiar to a caregiver. Looking for ways to keep Mom or Dad meaningfully engaged while a caregiver gets things done around the house or in the community is often a challenge.

With connect2culture® training, a growing roster of cultural partners in New York City has developed programs that offer shared experiences for caregivers and the person in their care. Ongoing support ensures that the staff of our cultural partners understands the disease and the needs of people with dementia and their caregivers. While primarily art museums respond to the need for activities that supported emotional and social connections, connect2culture also emphasizes the need for respite through shared experience. Three of the newest connect2culture community partners that seek to do this are Orpheus Chamber Orchestra, the New York Botanical Garden, and Music & Memory®.

The Grammy Award-winning Orpheus Chamber Orchestra had thought about doing more community-based performances when connect2culture came up during conversation. It wasn't long until the two organizations realized

it was a good match. A funder who had learned about connect2culture recognized that through its support of the partnership they would enable two community organizations to create meaningful experiences through music, With Music in Mind. The first of these programs will be hosted by one of connect2culture's cultural partners, the Brooklyn Museum, a long-established public cultural institution. In contrast, the second program will be hosted by Hebrew Home at Riverdale and available to the residents living in the memory care neighborhoods accompanied by their families.



For individuals with dementia living at home, CaringKind's Music & Memory at Home pilot creates customized playlists based on guided feedback from family caregivers. Using donated kits that include easy-to-use portable music equipment, individuals with dementia can reconnect with memories through music. In partnership with Music & Memory, an organization that brings customized playlists to residents in healthcare centers, CaringKind reaches individuals living at home, for whom these

playlists have helped with transitions in daily activities which might have caused anxiety or feelings of isolation and depression.

To connect with the botanical resources in New York City, CaringKind has partnered with the New York Botanical Garden, combining the expertise in horticultural therapy with cultural programming and dementia care, to create a curriculum for the botanic gardens across the five boroughs. While New York City is fortunate enough to have botanic gardens in every borough, there is only one known program serving people with dementia and their caregivers, the Memory Tour at the Brooklyn Botanic Garden. Botanic gardens are a rich source of sensory experiences, and a wonderful way to spend time with family outdoors – to smell, taste, touch, hear, and see signs of nature, especially the new growth that emerges with this season. This curriculum will be a tool that horticultural sites can use to implement a guided shared experience in their gardens for families affected by Alzheimer's and other dementias.

The team effort essential to building and perpetuating a strong community partnership is what makes the relationship rewarding, successful and sustainable. Connect2culture relies on developing relationships to support more local cultural institutions looking to engage this audience. By pooling resources and expertise with its partners, connect2culture builds a network of organizations dedicated to making their collections accessible and enjoyable for caregivers and the people under their care.

## Partnering with Faith-based Organizations Proves Successful



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“Pastor, my dad has been acting strange lately. He is very forgetful and gives all of his money away to anyone whom he feels needs it. He refuses any assistance and gets angry when I try to give him advice. He insists he does not have a problem and that he is just doing God’s work. Last week he went to the store four times to buy eggs. I don’t know what to do anymore. I pray every day for him, but this is really scaring me. Could you please speak with him? Please, help us.”

Often people with religious roots turn to their faith-based organization in times of need and uncertainty. Therefore, it is not unlikely that when signs of dementia or Alzheimer’s disease start to present themselves in a person, families turn to their religious leaders for guidance and support. The African American, Chinese and Latino communities have deep religious roots and forging relationships in these communities is essential to

spreading awareness about Alzheimer’s, related dementias, and CaringKind’s unique programs and services.

Historically churches have played an essential role in the lives of African Americans. African American churches serve not only as places of worship but also as safe havens for social gatherings and for discussions about healthcare, education, and politics. Partnering with community churches affords CaringKind the opportunity to spread awareness to a broad base of people: families, spouses, siblings, adult children, doctors, social workers and professionals from the health community. Presentations are conducted on Sundays after church services and it is possible to participate in health fairs, symposiums through church health ministries, and holiday themed activities during Christmas and Easter. CaringKind has also been featured on several religious internet radio stations. African Americans are two times more likely to develop Alzheimer’s than whites and the church has proven to be one of the most effective ways to get this message into the community.

Partnering with faith-based organizations has also proven helpful for our Chinese Outreach Program. Dr. Samuel Fook Wong, a Pastor of Chinese Promise Baptist Church in Sunset Park, Brooklyn, is the head of the Chinese Christian community and he also is a well-known community leader. He uses the church as a community facility to provide various health, social and educational events for people in the neighborhood. CaringKind’s strong relationship with Rev. Wong has allowed us to dive into the Chinese Christian community quickly. In the last two years, Rev. Wong introduced us to the Chinese Christian Association and gave

us a chance to make a presentation about CaringKind to more than 20 pastors at the quarterly meeting of the Chinese Christian Association. Rev. Wong also collaborated with CaringKind’s Chinese Outreach to conduct an Annual Health Fair Day at the Chinese Promise Baptist Church.

The Latino Outreach program is also busy spreading the word to clergy. Through outreach efforts, CaringKind has partnered with the Bronx Clergy Task Force (BCTF), to bring educational information to those that are most often asked for assistance. The BCTF is a coalition of multi-denominational pastors that work to bridge gaps in the diverse Latino communities by having open conversations about community-based issues.

Partnering with faith-based institutions has always been an integral part of CaringKind’s outreach strategy. Our relationship within these communities is robust and we will continue to nurture them in days to come. CaringKind aims to provide additional tools for the members of faith to employ when dementia and Alzheimer’s issues arise.



## Partnership with the New York City Police Department



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Beginning in 1993, the MedicAlert® NYC Wanderer's Safety Program has had the privilege of working with some of the most dedicated and committed police officers and detectives in the New York City Police Department. Together, we've made an enormously positive impact on the lives of people with Alzheimer's disease or related dementias and their caregivers.

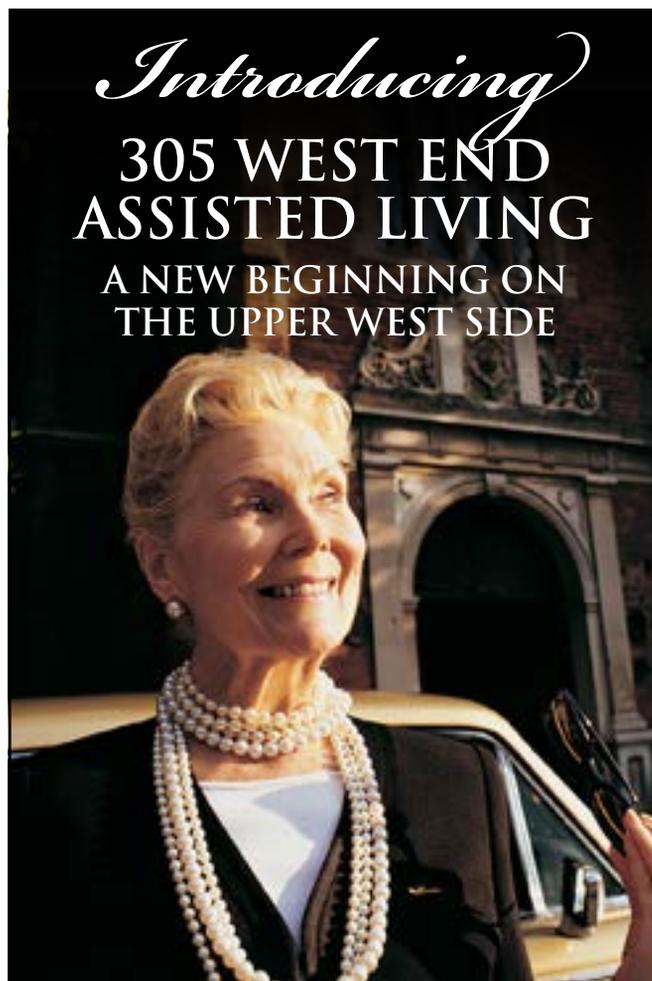
Few people realize that wandering is a common and potentially life-threatening behavior of persons with dementia. Statistically, six out of ten people will wander and if a wanderer is not found within a 24-hour period, there is a possibility he or she could be found seriously injured or deceased.

Because of our long-standing partnership and communication, during the last 12 months we have had a 97 percent success rate reuniting missing and found persons with their caregivers and enrolled over 1,500 new members into the MedicAlert NYC Wanderer's Safety Program.

As soon as a report is generated by the police department and called into the MedicAlert NYC Wanderer's Safety Emergency Line, the staff begins to assist by contacting family members, confirming identifying information, getting permission to go forward with our protocols, including faxing missing person bulletins, and initiating media attention. The Wanderer's Safety Program team always updates the detectives on the case with any additional information. This can be a stressful and emotionally draining time for caregivers. CaringKind is always available to assist caregivers by providing support during the period that a person with dementia is missing and afterwards to provide guidance and care planning to ensure the safety of the person with Alzheimer's disease or a related dementia.

Grants are available to cover the cost of the identification product for all persons living in the five boroughs diagnosed with Alzheimer's disease or a related dementia.

For more information or to enroll someone into the MedicAlert NYC Wanderer's Safety Program, please call our 24-hour Helpline at 646-744-2900 or visit [www.caringkindnyc.org/wandersafety](http://www.caringkindnyc.org/wandersafety).



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## Addressing the Modern Patient's Dental Dilemma with an Old Fashioned Solution

The iconic doctor's black bag – stuffed full of instruments and cures, it calls to mind an era when medicine literally packed its bags to meet the needs of its most frail patients where they need it the most: at home. Until the 1950's, nearly half of all doctor-patient visits occurred in the home. Access to care continues to grow for our elderly and special needs population, prompting today's physicians and passionate care at home. Mount Sinai Hospital's visiting doctors program recently found that 92% of its homebound elderly patients needed some form of dental treatment beyond oral hygiene. So why not implement the house call model in delivering dental care?

Although modern dentistry has never truly had the same portable pedigree, House Call Dentists is channeling the spirit of the original house call physician to address the modern patient's dental dilemma with an old solution. House call dentistry still remains largely unheard of, limited by the dearth of transportable equipment and willing providers – until now.

With recent advances in dental technology, House Call Dentists are able to take x-rays, restore cavities, and ultimately provide comprehensive dental care from the patient's favorite recliner or even in their bed. This innovation couldn't have arrived at a more opportune time.

The elderly population in the United States is expected to rise over the coming decades, and with it, new problems regarding access to care. Traditionally, these patients have been seen in hospitals or in offices at the mercy of often costly and time-consuming

transportation. At best, arranging for this transport is a nuisance. At worst, the burden placed on patients and their families prompts them to simply give up on seeking quality dental care, resulting in a population of underserved adults with oral pain and infection. According to the aforementioned Mount Sinai group, although there was a need for it, 96% of patients surveyed had not seen a dentist since becoming homebound. These patients are then resigned to dealing with dental issues on an emergent basis, when it is most costly, inconvenient, and limited.

House Call Dentists' goal is to preempt the costly emergency and provide a continuum of preventative dental care from the moment a patient becomes homebound. An initial appointment with our team typically includes a full set of dental radiographs and a comprehensive oral evaluation in the home or care facility. We then work closely with the patient's primary care team and family/primary decision makers to determine the best treatment plan. While palliative dental care may be the best route for someone who is terminally ill, more extensive restorative work, including bridges and crowns, would best serve a patient who is merely homebound but still enjoys chewing food.

Most often, treatment can begin and end in the home. For patients who are more medically compromised or non-compliant, however, we are able to offer a full range of sedation services in our office under the direct supervision of a physician anesthesiologist, or in the hospital. In any case, we are committed to offering the highest quality dental treatment in the safest and gentlest setting possible.

In addition to serving the homebound population, we are also experienced dental providers for adults with special needs, as well as those with dental phobias. Treatment of these patients is also complex and often requires utilization of our anesthesia services. Finally, if the only barrier to care is a busy schedule or feeling inconvenienced, our dentists can also visit any general patient desiring to be seen at home or work.



Ultimately, House Call Dentists is trying to solve the common problem of how patients can be treated when they are unable or unwilling to leave their home. We've come a long way from merely carrying a big bag of instruments around. Remaining at the forefront of dental technology while embracing the spirit of the original house call physician allows us to modernize dentistry in a way that will provide essential care to future generations in this country.

**House Call Dentists**  
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**www.HouseCallDentists.Com**



*Dear Friends,*

In 2018 CaringKind celebrates the “Year of the Hero”. **As an important member of our community, I invite you to remember and recognize the heroes who have faced the challenge of caring for someone with Alzheimer’s or a related dementia.** As a former caregiver, I know these financial, emotional, social and physical challenges well. But it wasn’t until I took on the role caring for my mother, that I truly understood the sacrifices she had made at the end of her life to care for my father. She is truly my hero.

My father’s dementia progressed over a twelve-year period, during which my parents moved four times. Each of these moves was intended to allow my father to stay at home with 24-hour care, much of which was provided by Mother. As my father’s behavior became harder to manage, my mother got creative. To ensure that he didn’t wander out of the house while she was sleeping, she put giant cowbells on the doorknob. That way, even if it was 3 a.m., she could catch Dad before he wandered off.

Mom’s grocery list increasingly included Dad’s favorite foods: applesauce, banana bread, oatmeal, none of which she ever ate herself, but all of which she lovingly fed him three times a day. Getting Dad to the doctor was no picnic, but Mom, who was 5’1” and 115 pounds, somehow managed to get this giant man into the wheelchair and into the car. Her bravery and strength in this period was truly heroic. Needless to say, all of this took a toll on her health and well-being.

Many years have passed. Both Mom and Dad are no longer with us, and thankfully, we have happy memories of both. **But as I look back, I’m reminded how much easier things would have been for Mom with the assistance of a CaringKind social worker and access to our programs and services.** She would have had a Wanderer’s Safety bracelet to put her mind at ease in case Dad wandered. She would have had information and referrals for financial planning, home care services and, eventually, long term care, all of which she had to work out on her own. And she would have joined a support group to help her through the journey.

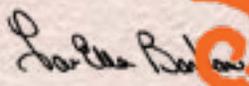
When Dad died, my parents had been married over 60 years. Thanks to Mom’s dedicated loving care, Dad’s passing was peaceful and pain free. Mom had made caring for him her first priority and it wasn’t until he was gone that she took a deep breath. By that time, her own health had been compromised and I took over her care. It was only then that I understood how hard she had worked and the sacrifices she had made to care for Dad and to keep the burden from me.

It’s late now to offer thanks, but I can use the opportunity to recognize and remember her heroic efforts and remind our community how many heroes there are doing this difficult job all across New York City.

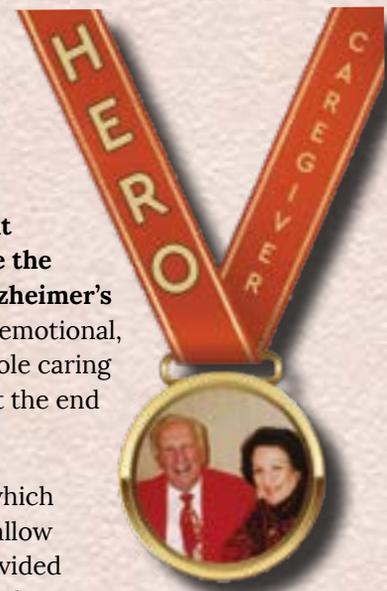
**I am asking you to consider making a gift of \$100 today.** While you are making your gift, I would like to encourage you to share your story about yourself or the hero in your family.

So, this year, please remember and recognize a hero in your life and help ensure that CaringKind can continue to provide the programs and services we need to serve all who need them. In this way, we can honor those we love and encourage others to share their heroic stories.

Thank you,



Lou-ellen Barkar  
President and CEO CaringKind



**P.S. Share your hero story with us by filling out the attached form or by visiting [www.caringkindnyc.org/hero](http://www.caringkindnyc.org/hero).**

## Planning Today for Tomorrow

When CaringKind expanded to the third floor in March 2013 to build our Program Center for Education, Training, and the Harry and Jeanette Weinberg Early Stage Center, we were able to do so because of the generosity of individuals who had planned ahead and left us in their estate plans. The bequests that we receive are from grateful clients who wish to give back in appreciation for the support and help they receive during the very difficult journey of caring for, or knowing, an individual with dementia.

Planned giving is a way to support CaringKind through your will, a retirement account, a trust, or other vehicles to make a charitable contribution after your death. Through estate planning, you can make a meaningful impact helping others who are heartbreakingly affected by a diagnosis of Alzheimer's disease or a related dementia. For more than 30 years, we have been a leader in dementia care, setting the gold standard for care.

Though we all hope for a cure or an effective treatment or therapy, we know that in its absence, the best course of treatment is good care. Your contribution enables us to plan ahead so that we can develop innovative, creative, and leading-edge caregiving initiatives to ensure that caregivers today and tomorrow have a place to turn for the best in dementia care.

Gifts of any size are appreciated and every single gift is important to helping us.

Please contact Carol Berne at 646-744-2905 or via email at [cberne@caringkindnyc.org](mailto:cberne@caringkindnyc.org).

CaringKind is a tax-exempt organization under Section 501(c)(3) of the Internal Revenue Code (Tax ID number 13-3277408) and your gifts are tax deductible to the full extent of the law.



CaringKind meets the Better Business Bureau Wise Giving Alliance Standards for Charity Accountability.

## Know Your Charity

The following organizations ARE NOT affiliated with CaringKind:

- Alzheimer's Association
- Alzheimer's Association, New York City Chapter
- Alzheimer's Disease Resource Center (ADRC)
- Alzheimer's Drug Discovery Foundation
- Alzheimer's Foundation of America
- Bright Focus Foundation

### Ways to Give

#### Giving by Check

Please make checks payable to CaringKind and mail to:  
360 Lexington Avenue, 4<sup>th</sup> Floor  
New York, NY 10017

#### Online/Credit Card

Visit [www.caringkindnyc.org](http://www.caringkindnyc.org) and click on Donate or call 646-744-2908 or 2927. We accept MasterCard, Visa, and American Express.

#### Appreciated Securities

Gifts such as stocks or bonds may offer substantial tax advantages. Please speak to your tax advisor.

#### Bequests

By remembering CaringKind in your will, you can have a significant impact on improving the quality of care for those affected by Alzheimer's disease. Your bequest may have estate tax planning benefits as well. The following is sample bequest language for discussion with your attorney:

I, \_\_\_\_\_ (first and last name, city, state, zip), give, devise and bequeath to CaringKind (or Alzheimer's Disease and Related Disorders, New York City, Inc.) with offices located at 360 Lexington Avenue, 4th Floor, New York, New York 10017, (insert written amount of gift, percentage of the estate, or residuary of estate, or description of property) to be used for (insert "its unrestricted use" or name of CaringKind program).

#### Life Insurance and Retirement Plans

CaringKind can be named a beneficiary of your retirement plan or insurance policy.

#### Donor Advised Funds

If you have established a donor advised fund through another organization (e.g., community foundation, investment firm) you may recommend the award of a grant to CaringKind. Please check the guidelines pertaining to your donor advised fund.

#### Corporate Giving

Payroll deductions, matching gifts, and event sponsorships are ways to support CaringKind.

100% of your donation supports New York City individuals and families affected by an Alzheimer's or dementia diagnosis.

Please contact Carol Berne at  
646-744-2905 or  
[cberne@caringkindnyc.org](mailto:cberne@caringkindnyc.org) if you would  
like additional information.

# In My Opinion: Driving & Dementia

**LOU-ELLEN BARKAN**  
President & CEO  
lbarkan@caringkindnyc.org

Watching a person with dementia gradually lose independence is very difficult, not just for that individual but for the caregivers as well. Nowhere is this more evident than with driving. But, driving with dementia can have deadly consequences.

Too many times, I have met with someone concerned about a parent, spouse or partner and who, even after a diagnosis, is afraid to take away the car keys. When we explain the risks, family members push back. Here is some of what we hear:

“But I can’t take the car away. How will Mom get around?”

“It’s the only independent thing Dad still can do. It will break his heart.”

“Joe only drives in our neighborhood, so there is no danger that he will get lost.”

“Alice never drives alone. One of us is always with her.”

But getting lost should be the least of your worries and a family member’s presence in the car provides no protection against accidents. A person with dementia has slower reaction time, is easily distracted and is less likely to recover if a mistake is made. In those few seconds of confusion, the driver could easily harm not only himself or herself, but also other motorists or pedestrians, including innocent children. Families must understand the risks. It’s hard, but they need to have that difficult conversation. Every day people with dementia are behind the wheel, they pose a grave risk to themselves and others.

Consider the worst-case scenario. Mom has been driving herself to the local stores for years. She knows the neighborhood well. But one day, when she least expects it, a dog runs into the road and a small child follows. Mom doesn’t pick up on this in time. The outcome could be tragic.

Too many times, after a close call like this one, the family returns to CaringKind to discuss how to take the keys away and how to find alternative ways for Mom and Dad to get around. Our social workers are experienced at listening. They understand the challenges of taking away the keys. They will help you to protect your family from a disaster that is easily avoided.

California restricts individuals with a dementia diagnosis from driving. These sensible restrictions require families and physicians to take the license and the keys away from individuals immediately after they are diagnosed – no questions asked. Good for them!

If you are the caregiver or the decision maker for someone with a dementia diagnosis, I urge you to call our 24-hour Helpline at 646-744-2900 and discuss how to best approach this subject with your family member or friend to make the transition as easy as possible. The time you take today may avert a tragedy tomorrow.



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in NYC entirely devoted to  
Enhanced Memory Care*

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*We understand that no one  
wants to leave their home...  
That's why we are different.*

Our deliberately designed intimate environment creates days filled with curiosity, meaning, connection and joy.

Yesterday's Executives, Politicians, Educators and World Travelers can thrive once again.

*When the time comes, please  
know that we are here.*

**430 East 80th Street  
New York, NY 10075**

**[www.80thStreetResidence.com](http://www.80thStreetResidence.com)**

For Individuals with Mild Cognitive Impairment or Mild Alzheimer's Disease Dementia

## BURKE REHABILITATION HOSPITAL CLINICAL TRIAL

BURKE is currently conducting a clinical trial to evaluate whether increasing brain glucose utilization can slow cognitive decline in individuals with Mild Cognitive Impairment or mild Alzheimer's disease dementia.

Individuals who are at least 60 years old and have a diagnosis of Cognitive Impairment or Mild Alzheimer's disease may be eligible.

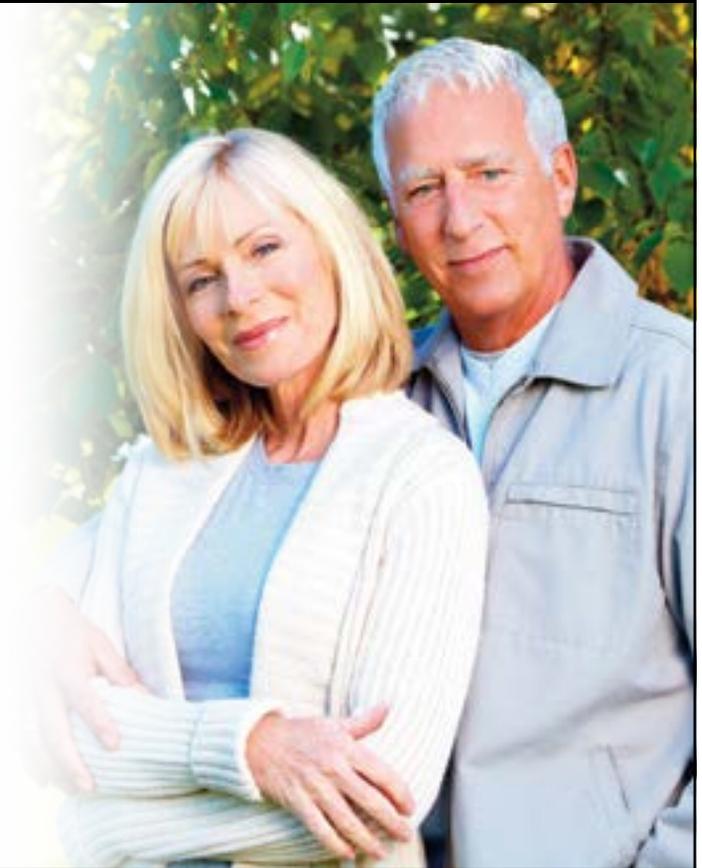
### STUDY PARTICIPANTS WILL RECEIVE:

- Neurological Exam
- Memory and Cognitive Testing
- Neuro-Imaging

For more information regarding this study, please contact: Rosanna Cirio, MA at 914-597-2476 or rcirio@burke.org.



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# Adult Day Care Programs: Crucial Members of the Caregiving Team



**ANNE M. FOERG**  
Director of Social Work

It is impossible for a person with dementia to have just one caregiver – whether partner, parent, sibling or friend. This is never truer than when the individual with dementia transitions from the early stages of the condition into the middle stages. A decline in memory, an increase in confusion, and a loss of insight into these deficits results in the person with dementia requiring consistent, in-person support to move through the day. While the person with dementia may still be physically capable of showering, dressing, and feeding him or herself, impaired cognition requires reminders to shower using soap and shampoo, guidance in picking out clothes to wear and how to correctly put them on, and assistance preparing a nutritious meal. Most importantly, the individual in the middle stage requires the presence of a competent caregiver to provide supervision to ensure safety, as dementia impairs the ability to process the environment and make reasoned decisions that keep us out of harm's way. A smoke detector can only do its job of warning danger if the person hearing its alarm understands what it means and is able to do what is necessary to keep himself or herself safe.

As such, it is quite common for caregivers to reach out during this period of transition when caring for the person has become too much for the primary caregiver to manage alone. They don't know where to turn when the person for whom they are caring can no longer

be left alone, but also cannot be taken on every errand to which the caregiver must attend. Many caregivers often find it challenging to keep the person with dementia engaged and entertained throughout the day, especially when laundry needs to be done, meals prepared, and the to-do list managed. When the caregiver calls CaringKind at this critical time, our social workers help families to understand the importance of building a care team by accessing supportive resources to help manage the needs of the person with dementia and to ensure that the caregivers receive a break from their 24/7 responsibilities.

One of our most important partners at this point can be an adult day program. Social or medical in nature, an adult day program offers numerous benefits to both a person with dementia and the caregiver. Adult day programs provide structured activity targeted to a participant's level of functioning. Structured routines help mitigate symptoms like confusion, agitation, and apathy by providing a consistent and enjoyable way to interact with the environment, to promote feelings of security. Targeting activities to an individual's interest and capacity helps limit frustration because they are never asked to do something they cannot.

Adult day programs also provide respite for the caregivers, allowing the opportunity to leave the person with dementia in a safe environment so they can attend to their needs. Caregivers may still be employed in addition to their caregiving responsibilities. Yet they also need time to do things like attend their own medical appointments, socialize with friends, or simply take an opportunity to be alone in order to recharge their batteries. Respite can often come in the form of improved

sleep for the person with dementia, as meaningful activity during the day tires them out in the evening. This, in turn, ensures that caregivers will also get a good night's sleep.

Consider Nadia, who was caring for her mother with dementia. Because her mother was also an undocumented immigrant, she did not qualify for benefits to help cover the cost of in-home care. Yet Nadia and her family still had to work. The CaringKind social worker linked Nadia to an adult day program in her neighborhood, which allowed her mother to attend several days a week through a subsidy provided by the NYC Department for the Aging. Nadia could finally get some quality, uninterrupted sleep while her mom attended the program, which was vital for her to be able to work her overnight job.

Wai was also caring for his mother with dementia when her wandering prompted him to realize that it was no longer safe for her to remain home alone when he went to work. Wai decided to try sending his mother to a local adult day program at the suggestion of the CaringKind social worker. The program provided supervision while Wai worked and his mother began eagerly bathing and dressing every morning, activities she had previously resisted, because she so much looked forward to attending!

Whether Riverdale Senior Services in the Bronx, the New York Memory Center in Brooklyn, Riverstone Senior Services in Manhattan, Sunnyside Community Services in Queens, or the JCC of Staten Island, call the 24-hour Helpline at 646-744-2900 for information on the adult day programs in your community and consider making this service part of your care team!

## Comfort On the Move



### ANN WYATT

Manager of Palliative & Residential Care  
 awyatt@caringkindnyc.org

Over the past few months, we've been asked to share our experiences in bringing *Comfort Matters*® to our three partner nursing homes in NYC: Cobble Hill Health Center, Isabella Geriatric Center, and The New Jewish Home on 106th Street. Representatives from Cobble Hill and CaringKind spoke about their approach to care planning and comfort at the national LeadingAge conference in New Orleans last summer, and Ann Wyatt from CaringKind presented, with Tena Alonzo from *Comfort Matters*®, at the national conference of the American Health Care Association in Las Vegas

in October. More recently, Ann also provided a half-day education session to members of the Continuing Care Leadership Coalition in New York City.

*Comfort Matters*®, developed by Beatitudes Campus in Phoenix, Arizona, is a model of palliative care for people with advanced dementia who reside in residential settings. Palliative care does not mean giving up; it means taking active steps to discover what comforts someone and even gives him or her pleasure, and taking active steps to prevent or avoid unnecessary pain and suffering before they take hold. As an individual's dementia advances, his/her actions, rather than words, are most likely to communicate distress. Unfortunately, all too often these behavioral expressions are not understood as distress; rather they are often assumed to be the inevitable consequences of the dementia itself. Palliation cannot occur if the reasons or

triggers for distress are not known or understood. Anti-psychotic and anti-anxiety medications do not take away pain, nor do they comfort if someone living with dementia is hungry, cold, too warm, tired, or frightened by noises or activity in his or her environment.

Since developing their model, Beatitudes now accredits residential settings who have successfully implemented dementia-capable palliative care. All three of the homes we worked with now have dementia-care units accredited by *Comfort Matters*®. Since CaringKind introduced this model in New York, Beatitudes has gone on to work with several other homes in the area, including The Lillian Booth Actors Home in Englewood, New Jersey, The New Jewish Home's Sarah Neuman Home in Westchester, and the Methodist Homes of New Jersey.

In April, the Health+Hospitals/Coler, working with Beatitudes and with CaringKind will begin implementation of an 18-month project with the aim of achieving accreditation. This effort, funded by the Fan Fox and Leslie R. Samuels Foundation, will build on work Coler has been engaged in since October, 2014. They have already achieved significant quality improvements and cost savings, and look forward to further progress.

CaringKind has also made presentations at a number of other NYC homes, and is continuing to do so. While we are sharing these standards for dementia-capable palliative care with long-term facilities, they really apply to any setting where someone with advanced dementia resides, whether it be a nursing home, assisted living facility, or at home. Advancing the implementation of these standards is a CaringKind priority.



Dementia Care staff at Health+Hospitals/Coler.

### Health Care Outreach

The Healthcare Outreach program continues to educate healthcare professionals in New York City about all our programs and services. At CaringKind, we recognize the important role pharmacists play in the lives of families affected by an



Alzheimer's or dementia diagnosis. Pharmacists have always been a trusted source when it comes to patient education, and because of that, we've developed our CaringKind Pharmacy Card, an easy way for pharmacists to connect the families they serve to our vital programs and services. Connecting families to CaringKind is as easy as inserting the card in the prescription bag of anyone on an Alzheimer's or dementia related drug.

We view our relationship with pharmacists in New York City as a partnership, working together to provide the best care and connection to resources for families dealing with this devastating disease. We also work with pharmacies to develop in-store events, informational displays and training for staff.

If you would like us to reach out to a particular pharmacy in your neighborhood, please email Niurqui "Nikki" Mariano at [nmariano@caringskindnyc.org](mailto:nmariano@caringskindnyc.org) or call 646-744-2969.

### Innovation Spotlight

Recently CaringKind collaborated with the Pratt Institute School of Design on a project in which students of the Industrial Design Department met with people with dementia, family and professional caregivers, and CaringKind staff to learn about the challenges of living with dementia and providing dementia care. The students, inspired by these meetings, designed 25 prototypes, several of which are showcased at The Cooper Hewitt Smithsonian Design Museum's Access + Ability exhibition.

Francesca Suman, a Pratt student involved in the project, shared her creative process with us:

*When learning about Alzheimer's disease and other dementias from the caregivers at CaringKind, several things immediately struck me. First, the unpredictable nature of this disease, and*

*secondly, how much caring for someone with Alzheimer's disease affects life at home. What might normally be a quick, mundane activity like changing clothes or brushing teeth can become an afternoon-long battle. With these observations in mind, I began exploring ways to bring joy to these tasks, both for the individual living with dementia and the caregiver. I began thinking of "universal" feelings of happiness. Pleasure from winning prizes and receiving presents came to mind as things that are universal across ages and cultures. Thus, Gift Anew was born: a collapsible, reusable water-resistant box that brings a little happiness to the routine. Suddenly when a caregiver presents the person's toothbrush in an attractive gift box, teeth brushing becomes a lot more enjoyable! The magnetic bows and easy assembly also allow for the caregiver and individual to wrap presents together for children or friends.*



# Caregiver Storyteller

## A storytelling podcast about Alzheimer's and dementia caregiving.

Every caregiver has a story to tell. Chris Doucette interviews caregivers to learn how they became caregivers, the ups and downs of their journeys, and how they've changed as a result.

Other podcasts teach. Through confessional storytelling, Caregiver/Storyteller helps listeners understand the first-person reality of what caregiving is actually like.

While all caregiving stories convey a sense of loss, there is also a surprising amount of fortitude, loyalty, gratitude, joy, and humor. These are their stories.

Listen,  
Subscribe,  
Rate, &  
Review

<http://www.caringkindnyc.org/podcast/>

Episode 1 -  
The Only Child: Keith Amparado



Episode 2 -  
Both Parents With Dementia: Lou-Ellen Barkan



Episode 3 -  
A Partner's Legacy: Nancy Shamban



*New episodes available bi-weekly.*

## 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, resources, and services available.

*Upcoming Dates in English:*

May 11	12:00 - 2:00 p.m.	Manhattan
May 15	2:00 - 4:00 p.m.	Brooklyn
May 16	5:30 - 7:30 p.m.	Manhattan
June 8	12:00 - 2:00 p.m.	Manhattan
June 19	5:00 - 7:00 p.m.	Brooklyn
June 20	5:30 - 7:30 p.m.	Manhattan
July 13	12:00 - 2:00 p.m.	Manhattan
July 17	2:00 - 4:00 p.m.	Brooklyn
July 18	5:30 - 7:30 p.m.	Manhattan

*Upcoming Dates in Chinese:*

May 12	10:30 a.m. - 12:30 p.m.	Queens - Mandarin
July 28	10:30 a.m. - 12:30 p.m.	Brooklyn - Cantonese

Contact our 24-hour Helpline at 646-744-2900 for more information.

## Legal & Financial Seminar

An attorney specializing in elder law discusses important topics Alzheimer's and dementia caregivers should understand before meeting with a personal attorney. Topics include power of attorney, guardianship, Medicaid eligibility, long-term care insurance, healthcare proxy, and more.

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

*Upcoming Dates in English:*

Manhattan	
May 7	12:00 - 1:30 p.m.
May 21	5:30 - 7:00 p.m.
June 4	12:00 - 1:30 p.m.
June 18	5:30 - 7:00 p.m.
July 2	12:00 - 1:30 p.m.
July 16	5:30 - 7:00 p.m.

*Upcoming Date in Chinese (Mandarin & Cantonese):*

Manhattan	
June 6	1:30 - 3:30 p.m.

## Seminars for Professionals

**Understanding Dementia for Professionals:**

June 13	3:00 - 5:00 p.m.	Manhattan
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**Enhancing Communication with Persons with Dementia:**

July 11	3:00 - 5:00 p.m.	Manhattan
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The Seminars are free of charge.  
Two (2) Social Work Continuing Education units are available for a fee.

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

Caregivers are guided through the application process for Medicaid home care service. Prior attendance at a Legal & Financial Seminar is required.

*Upcoming Dates in English:*

May 3	5:30 - 7:00 p.m.	Manhattan
June 7	5:30 - 7:00 p.m.	Manhattan
July 5	5:30 - 7:00 p.m.	Manhattan

## Placing Your Relative in a Nursing Home

Sessions educate caregivers about the steps involved in nursing home placement, paying for care, easing the transition, and being a successful advocate for the resident.

*Upcoming Dates in English:*

Manhattan	
May 18	5:30 - 7:00 p.m.
July 17	5:30 - 7:00 p.m.



THE HARRY AND JEANETTE WEINBERG  
**Early Stage Center**

Our specialized groups are for people with a diagnosis of Mild Cognitive Impairment (MCI) or an early form of dementia, including Alzheimer's disease. *An interview with an Early Stage Center Social Worker is required prior to joining any group.*

**Specialized Groups**



**MemoryWorks®**

Mentally stimulating exercises that help keep the brain active and alert.



**Connections**

A lively and fun discussion about everything from A to Z.



**Support Group**

A place for early stage people to talk with others about living and coping with their condition.

**Each group meets for 1.5 hours once a week, for a total of five weeks.  
The cost of a five-week cycle is \$250.**

Our Social Workers are available to provide support, information, and referral services to participants and their care partners.

Contact our **24-hour Helpline at 646-744-2900**  
to discuss if the Early Stage Center is right for you.

For more information visit: [caringkindnyc.org/EarlyStage](http://caringkindnyc.org/EarlyStage)

# caringkind chronicles

Writer: Jennifer Camper Artist: Ivan Velez

Episode 6 Previous episodes: [caringkindnyc.org/comic](http://caringkindnyc.org/comic)



At CaringKind's Legal & Financial Seminars, elder law attorneys discuss the legal and financial issues associated with planning and long-term care. For more information, call the 24-hour CaringKind Helpline at 646-744-2900 or go to [www.caringkindnyc.org/legalfinancial](http://www.caringkindnyc.org/legalfinancial).

# caringkind Alzheimer's Walk

2<sup>nd</sup> Annual  
Tech Fair!  
Caring for Today  
with the  
Technology  
of Tomorrow



Doggie Dugout Costume Contest! (Manhattan Walk)



## Walk Because You Care

CaringKind is NYC's central address for dementia care and has been providing free programs and services for individuals and families affected by Alzheimer's or other dementias for over thirty years.

### MANHATTAN

October 14  
9 am  
Riverside  
Park

### QUEENS

September 16  
9 am  
Flushing Meadows  
Corona Park

### BROOKLYN

September 23  
9 am  
Coney Island  
Boardwalk

### STATEN ISLAND

September 30  
9 am  
South Beach

**SIGN UP TODAY!**

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

24-hour Helpline 646-744-2900

[walk@caringkindnyc.org](mailto:walk@caringkindnyc.org)

*CaringKind was formerly known as  
the Alzheimer's Association, New York City Chapter*