

# caringkind

*The Heart of Alzheimer's Caregiving*



**FALL 2017**

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**2017 Year-End  
Campaign**

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## President's Message

Dear Friends,

**In 1982, 11-year-old Jeremy Abbate's mom told him not to be surprised if Grandpa didn't remember his name. She was hopeful, she told her son, that scientists would find a treatment for Alzheimer's soon. Fast forward 35 years and Mr. Abbate, now Publisher and Vice President of *Scientific American* magazine, is saying the same things to his kids.**



**LOU-ELLEN BARKAN**

President & CEO

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In a compelling essay, "With Every Alzheimer's Diagnosis, the Same Bleak Conversation," published in *The Wall Street Journal* in late August, Mr. Abbate laments, "Researchers have made so many breakthroughs in fighting disease over the past century that progress can seem inevitable. Ailments that once were death sentences – diabetes, HIV/AIDS, many forms of cancer – have been transformed into chronic but manageable conditions. But for Alzheimer's, as the old phrase goes, we got nothing."

I too have been perplexed by the inability of the research community to make faster progress in finding a cure for a disease that, today, directly impacts the lives of over five million Americans and is on track to affect five times that many in the not too distant future.

As a layperson, I cannot and will not criticize the many dedicated and brilliant scientists who are working tirelessly trying to unlock the mystery of this disease. But, as Mr. Maine, my high school science teacher reminded us, science is about formulating and testing hypotheses. It's about figuring out if something works and if those results can be replicated. And if they cannot, you either amend your hypothesis or try something entirely different.

For the past 30 years or so, Alzheimer's research, primarily funded through the National Institutes of Health (NIH), has largely focused on whether amyloid beta or tau protein is the key driver of

Alzheimer's. But after decades of little progress in finding effective therapies to slow the progression of the disease or cure it, I think Mr. Maine would agree that it's time to branch out in new directions. And scientists are doing just that, working together to share information and resources. There is renewed interest in the link between Alzheimer's and microbes, viruses and other pathogens. And researchers are taking a reinvigorated look at the relationship of brain inflammation to the disease and the role of lifestyle and diet.

This is all very encouraging, but we are very far behind, and the aging community is growing exponentially. What can we do now to support the many families and individuals affected by a dementia diagnosis today and the many more quickly coming down the road?

First, we can ensure that caregivers have the resources they need to provide good care while they take care of themselves and their families. At CaringKind, we know that the most effective therapy for Alzheimer's and related dementias is good care. And good care is provided one-on-one by caregivers – mostly family members, mostly women, mostly people who are dropping everything, including giving up economic and other opportunities, to take care of someone they love, or someone they don't necessarily love.

Caregivers make extraordinary sacrifices, and we must make them our priority. And

at CaringKind, they are. We support them with programs, services, and resources that they cannot get anywhere else. Until the day when we have effective treatments and a cure, CaringKind will be here, thanks to the community's support, implementing innovative, creative and leading-edge caregiving initiatives, and providing an unprecedented platform of programs that help caregivers care with confidence.

P.S. Please see our Year-End letter on page 17 where we highlight some of the terrific things we've been doing over the last year. Please support us so we can continue to expand and reach out to all who need us!



Dear Readers,

The face of caregiving is sitting next to you on the subway, waiting on your table at the diner, making your latte at Starbucks and cleaning your office at 10 pm. The face of caregiving works in a City Council member's office, cleans your teeth at the dentist, preaches the gospel on Sunday in churches, and welcomes the Sabbath every Friday night. It is your son's teacher and your mother's best friend. Caregiving is all around us. In the almost 30 years that I have worked at CaringKind, I have had the privilege of meeting some of the strongest, hardest working and selfless individuals who provide dementia care for friends and relatives.

Caregiving is often hailed as selflessness, but selflessness is not a trait that can be sustained. Caregivers must care for themselves to care for others. This is not selfish or self-serving; it is essential to do the heavy lifting over the long haul.

You might have noticed that I don't use the term "loved one" when referring to the care recipient. At CaringKind, we call the person we care for a "friend or family member with dementia." As someone who has worked in this field for over 40 years, with over ten years of psychoanalytic training, I feel strongly about the use of language and its impact on the individuals we serve.

At CaringKind, we make a conscious and deliberate effort to avoid the use of "loved one" when referring to the care recipient for several reasons:

- Not everyone is loved, either now or in the past.
- Even if you love someone, you don't have that feeling 24-hours a day (ask your married friends).
- Some caregivers are caring for ex-spouses, parents, friends or relatives who were abusive or unloving themselves. The term "loved one" creates or exacerbates feelings of guilt when a relationship was not or is no longer loving.

We encourage caregivers to acknowledge and accept all of their feelings – the positive and the negative ones, such as frustration, anger, sadness and love.

We've learned from our clients that there are many reasons to care for someone, regardless of how loving a relationship is

or was. Caregivers can be motivated by a sense of obligation, duty, morals and an understanding and appreciation of what they expect from themselves. We owe it to the families we serve to change the standard language we use to be as inclusive as possible in all our materials and resources.

Recently, I became a caregiver for my partner who had major surgery and a long and complicated recovery. As much as I love him, there were moments when I didn't feel particularly loving. I felt burdened, angry, resentful and scared. I became his advocate, nurse, nurse's assistant, physical therapist, pharmacy tech, nutritionist and insurance expert. Thankfully, he is recovering, and we are not facing years of progressive decline. However, this experience gave me a taste of what it is like to be a primary caregiver; holding down a full-time job, managing the household and keeping care on track. There is no time to think of anything else when visiting the hospital daily. Providing the history to new doctors or nurses, then, following discharge (with 17 pages of instructions), managing a home care team, scheduling appointments with the labs, the nurses, the nurse practitioners, the physical and occupational therapists, and arranging transportation to get there.

Following my partner's second hospitalization, I arranged rehab at a short-term care facility. After that, each day included trips to check in with nurses, doctors and therapists, checking to make sure laundry was done and the insulin pump was managed. I was grateful to find a superb facility with excellent care, but it still took a lot of vigilance on my part.



**JED A. LEVINE**

Executive Vice President, Director of  
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What I learned:

- It is critical to find time for yourself every day. Get exercise. Manage your diet. Pay attention to your body and sleep when you are tired.
- Ask for help and be specific. Family and friends want to help, but need to know what to do. If I needed someone to stay for a few hours so I could get my haircut or attend a meeting, I'd put it out on Facebook or text a group of family and friends and someone would come to help.
- Cut yourself some slack. Some chores must be put on the back burner.
- Be kind to yourself. If you can afford it, take a taxi from the nursing home on a rainy night. Take a day off from work just to rest if you can manage it.
- Find someone to talk to. You will feel better, lighter, readier to face the next challenge after speaking with colleagues, friends or a therapist.
- When possible, see friends and family for purely social occasions; dinners, a movie, a glass of wine. Enjoy a few minutes with people who care about you.

CaringKind can help too. We understand. Many of us have lived it. Now, I have as well. Call us at 646-744-2900, 24-hours a day, or email us at [helpline@caringkindnyc.org](mailto:helpline@caringkindnyc.org). You'll be glad you did.

**CaringKind made it "official" this summer by publicly declaring August to be NYC Alzheimer's Caregiver Month! With the support of NYC Councilwoman Margaret Chin and Caryn Resnick, the Deputy Commissioner at New York City Department for the Aging, dozens of members of the NYC Alzheimer's community gathered on the steps of City Hall in a show of support for more than 250,000 caregivers in NYC. The City Hall kick-off event was covered by *New York Nonprofit Media* and *WMBC-TV*, as well as Chinese-language news outlets *Sinovision*, *Sing Tao*, and *World Journal*.**

Because of CaringKind's outreach during NYC Caregiver Month, one of the most widely-read Spanish-language newspapers, *El Diario*, interviewed CaringKind's Latino Outreach Manager, Roberto Reyes in a front-page article on Latino caregivers in NYC. Roberto, his mother, and his grandfather, who has Alzheimer's, were all featured in the story.

Just a few weeks later, CaringKind hosted the Annual Latino Heritage Conference, which featured expert presentations and discussions on the impact of Alzheimer's and dementia in the Latino community. In addition to this conference, we continue to reach caregivers across the boroughs and diverse communities through caregiving training programs and workshops. Offered in English, Spanish, and Chinese, the Understanding Dementia seminars continue to be featured on more than 100 local events websites and calendars.

In July, CaringKind and B&O Play, a division of audio company Bang & Olufsen, publicly premiered *Caring Through Music*, a film on how music is being used to reconnect those affected by Alzheimer's or dementia with memories of their past. In addition to co-creating the short film, now available on CaringKind's website, B&O

Play donated headphones, speakers and audio equipment to be used onsite at CaringKind's Early Stage Center. The news release on *Caring Through Music* and the B&O Play donation was covered by over 170 news outlets across the country!

In another terrific collaboration, CaringKind publicly announced an innovative partnership with Antidote Technologies, a digital health company that connects patients with clinical trials. Through this partnership, we now feature Antidote Match™, Antidote's unique clinical trial matching tool, on our website. The news release was covered by almost 180 media outlets across the country.

In widely-read local coverage, CaringKind's Sixth Annual Golf Outing was featured in *Crain's New York Business*. The website featured photos of the players, who raised over \$160,000 to support CaringKind's services and programs when they hit the links at Glen Head Country Club.

Local caregivers also continue to read Lou-Ellen's monthly column, *Care Chronicle*, which appears in several local newspapers, and offers information and practical advice on dealing with Alzheimer's and dementia. Recent topics have addressed



the differences between Alzheimer's and dementia, as well as early stage versus younger-onset Alzheimer's.

As temperatures (finally) cooled down, we closed the summer season with four incredible walks that took place in Manhattan, Brooklyn, Queens and Staten Island. The Manhattan walk was emceed by longtime CaringKind supporter and WABC-TV anchor Bill Ritter, and featured presentations by Tony Award-winning actor and Alzheimer's advocate, David Hyde Pierce and New York Ranger legend and Emmy Award-winning broadcaster, Ron Duguay. WABC-TV, NY1 and NY1 Noticias all broadcast television coverage of the event, featuring shots of the more than one thousand orange-clad walkers. Not to be outdone, New York City radio station 1010WINS also broadcast an on-location interview with Lou-Ellen Barkan.

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Dear Helpline,

My name is Jack, and I am a 30-year old man living in NYC. My 55-year old mother lives alone, although not far from my home, and was recently diagnosed with early-onset Alzheimer's disease. Life is very hectic right now, as I am expecting my first child to be born soon. Not only am I worried for my mother but now I am worried about myself. What can I do to help slow the progression of my mother's disease so she can enjoy as much time with her first grandchild? And, are there any tests I could take to determine if I carry the Alzheimer's gene?"

— Jack



**STEPHANIE ARAGON**

Director of Helpline

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Dear Jack,

Alzheimer's disease is an irreversible, progressive brain disorder and although there are medications, there is currently no cure. Medications such as Aricept (Donepezil), Namenda (Memantine) and Namzaric can help manage symptoms of the disease for some people, for some time. It would be very helpful if you could meet with your mother's doctor to discuss the most appropriate options for her.

For most people, symptoms of Alzheimer's first appear in their 70s, but the average age at diagnosis is about 80 years old. The risk for developing the disease is most commonly associated with the apolipoprotein E (APOE) gene. The APOE gene has several forms, one of them being APOE e4, which is associated with increased risk of late-onset Alzheimer's. Although carrying the APOE e4 form of the gene increases your risk of developing Alzheimer's disease, it does not guarantee that you will develop the disease. People who do not have APOE e4 may also develop Alzheimer's disease. You mentioned that your 55-year-old mother was diagnosed with early-onset Alzheimer's disease. Early-onset Alzheimer's disease occurs in people younger than 65 years old.

You shared that you are interested in genetic counseling. The genetics of the disease are very complicated, there are some very rare genes that are predictive

for Early-Onset Familial Alzheimer's Disease. However, not all early-onset Alzheimer's is caused by these genetic variations.

There is a blood test that can identify if you carry the APOE e4 form of the gene or the extremely rare genes that are associated with Early-Onset Familial Alzheimer's Disease. We strongly encourage that you meet with a genetic counselor before taking a genetic test and finding out the results. Our Helpline Specialists can provide you with referrals to genetic counselors who will help you understand genetic testing and explore with you what the results could mean.

But, a life-changing situation is coming up, the birth of your first child. You might want to put genetic testing on the back burner for now until your life becomes a little less hectic.

There are several ways to provide for your mother's care and safety as you await the birth of your baby. If your mother is having problems, as she lives alone, it would be helpful for you to be in touch with a friend or neighbor who lives close by. Check in with your mother, as well as with them, regularly and provide them with a number at which you can be easily reached, when necessary. Consider using FaceTime or Skype to keep in touch with your mom and involve her in the excitement of having a new grandchild.

We have an Early Stage Center at our office in Manhattan which hosts

programs for those diagnosed with early Alzheimer's and who are comfortable talking about their situation and enjoy socializing. There are also programs at the various NYC museums for those with memory loss.

If your mother is reluctant to socialize with other persons with dementia, then you should consider hiring a companion or home care worker to visit her at home on a regular basis. We have a list of home care agencies on our website as well as profiles of home care workers who have taken our Dementia Care Training for Professional Caregivers on the website: [www.TogetherWeCare.com](http://www.TogetherWeCare.com).

I would also suggest that you enroll your mother in our Wanderer's Safety Program. You can register her for a bracelet or necklace which will provide contact information should she ever take a walk by herself and become confused about how to return home.

Our website is full with a lot of information about our services and caregiver information. Jack, please feel free to call our 24-hour Helpline at 646-744-2900. If you would like more information on planning for your mother's future care, we can arrange for you to speak with a social worker on the phone or in person here at our Manhattan office or multiple locations in the other boroughs.



# Learning To Be “Good Enough”: MemoryWorks® at CaringKind

**by Maria Mursch, LMSW**

*former Manager of the Early Stage Center*

**Geri Taylor, RN, MPH**

*Early Stage Center participant*

The Harry and Jeanette Weinberg Early Stage Center at CaringKind in New York City was designed to meet the needs of people who have been diagnosed with Mild Cognitive Impairment, early Alzheimer’s disease, or a related dementia. The Early Stage Center serves people who are interested in meeting others who have similar experiences, and those who are learning to adjust to their diagnosis and changes over time. Geri Taylor has been a participant at the Early Stage Center since early 2014, and she was featured in *The New York Times* article “Fraying at the Edges” in the spring of 2016.

Geri is a person living with early stage Alzheimer’s disease. While she will still likely one day rely on a caregiver to assist her with daily tasks, for now she is determined to do what she can for herself. When Geri first noticed changes with her cognition, she sought out a diagnosis and took steps to become more active. Geri has utilized her background in public health, her inner strength, and many other qualities to support others living with the diagnosis. She also receives support in return from her peers who are experiencing similar changes. She is a passionate advocate for people with early stage Alzheimer’s disease, and has chosen this forum to share her experience with CaringKind’s MemoryWorks® program.

MemoryWorks is one of several core programs at the Early Stage Center. The primary goal of this weekly, professionally facilitated group is for participants to socialize and learn from others who

have similar cognitive impairments, while working together on stimulating brain exercises including word puzzles, spelling games, and trivia questions. MemoryWorks supports participants in feeling stimulated, successful, and provides a sense of camaraderie and cohesiveness. Participants report feeling a sense of relatedness to the others in the room who are sharing similar challenges. Many participants also report feeling better about themselves when their experiences are normalized and shared with one another. Here is Geri’s account of what she has learned from the group, in her own words:

“After attending the MemoryWorks sessions for 3-4 years as my Alzheimer’s gets a stronger hold on my word-finding abilities, I have gained personal compensatory strategies to aid my conversational participation. Most importantly, the MemoryWorks exercises give me greater confidence in conversation and independence.

I have increased emotional strength and acceptance of deficits, and I have embraced a new conversation style. For example: simpler sentences; fewer descriptive words (adjectives); fewer explanations of my thinking background. In essence, the MemoryWorks activities reinforce the use of habitual word and expression choices. Its best outcome, as I see it, is pulling to the foreground alternate word choices frequently passed over. Hence, my appreciation for the “good enough” word choice as it maintains the fluidity of the conversation. And that fluidity allows the conversation to continue and I remain a participant. Alzheimer’s and my word finding symptoms do not become the topics or a distraction.

### What I learned:

1. Being in communication/conversation with others is most important not

that the thought is most properly expressed.

2. Good enough is “good enough.” The perfect word is not as important as the intention to communicate feelings or thoughts.
3. Presence, body language and facial expressions are extremely important.
4. Faltering language is not the end of the conversation. Talking around and non-verbal expression is often just as effective as an exquisite sentence.
5. You and your intelligence are not exclusively packaged in your spoken communication.

In addition to learning this from interacting with family and friends, I feel this adaptation has been accelerated and enhanced by sitting with my Alzheimer’s peers. Together, we have gained confidence by seeing our peers’ intelligence and wonderful intention and we gain confidence to whether our mistakes, word choices, stuttering, “ummmm” and even the dreaded “blank” (The “dreaded blank” occurs when we are so fixated on getting a particular word, the whole point to be expressed is lost. “BLANK!” Recovery is often a laugh. This usually inspires someone to jump in. Let them or take it back graciously).

However, we do not withdraw but rather we stay in the game. More importantly, we take this with us into our daily lives.

It has been my pleasure to lead Geri’s MemoryWorks group and to support all of our early stage clients. As Geri so eloquently puts it, many of our participants learn how to accept what is “good enough” in order to participate actively in their lives while living with a cognitive impairment. For more information about the Early Stage Center, please visit [www.caringkindnyc.org/earlystagecenter](http://www.caringkindnyc.org/earlystagecenter) or call the CaringKind 24-hour Helpline at 646-744-2900.



# The Face of Caregiving and Education



## MARILUCY LOPES

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Educational seminars at CaringKind provide caregivers with the opportunity to develop their understanding of what it really means to be a caregiver or, more specifically, an Alzheimer's or dementia caregiver. Those who attend our seminars, report gaining a better sense of what to expect as Alzheimer's disease or dementia changes and progresses, and how their role as a caregiver changes and progresses too. Caregivers also report feeling less stress as they learn about what kind of support is available and where to go for assistance.

In our Understanding Dementia Seminar, we talk about the patterns and commonalities of dementia or Alzheimer's disease, but also teach how each person's experience of the disease is different. We often say, "If you've seen one person with dementia, you've seen one person." This is because each of us is unique in our experiences, even though we have things in common.

Being unique and having our own experiences with dementia applies to caregivers too. For example, when you picture a dementia or Alzheimer's caregiver, what do you see? Is this person a certain age, gender or race? Whatever you imagine, it's correct. There is no "wrong" way to imagine a caregiver. In fact, many caregivers who attend our seminars can quickly recognize the differences in their circumstances, while

still being able to relate and identify with the situations other caregivers face. With education, caregivers learn they're not alone and support is available.

At CaringKind, we purposefully design our educational seminars to be safe, open, shared spaces limited to Alzheimer's and dementia caregivers, but available for use at their own pace. Our seminars are uniquely intended to address topics that will support a caregiver's role. Caregivers have the option to attend an education meeting as often as they would like, and have the option to choose from multiple locations. This past summer, seminars were available in all five boroughs of New York City, and opportunities to learn are always expanding.

**At CaringKind, we purposefully design our educational seminars to be safe, open, shared spaces limited to Alzheimer's and dementia caregivers.**

Many caregivers are surprised to learn that in addition to understanding Alzheimer's disease and dementia, there are other important topics to learn about too. Our Legal and Financial Seminars give caregivers information about the legal system and what documents and legal processes are necessary to provide the best care. After attending that seminar, caregivers can attend the Medicaid Home Care Seminar,

which guides caregivers through the application process required in order to receive home care via Medicaid services. Caregivers stress how helpful these seminars are to them.

Educational seminars are very helpful for strategizing purposes too. The Placing Your Relative in a Nursing Home Seminar is designed to educate caregivers about the steps involved in nursing home placement, how this care is paid for, and how one might become a successful advocate for the resident. Sometimes a caregiver will say, "I'm not thinking about a nursing home yet," and that's okay. The seminar is offered so caregivers can learn about the subject and discover what it involves, in the event that level of care might become necessary. The idea is to allow education to inform your current and future choices. Our seminars are there to foster a proactive – rather than reactive – approach to care.

Lastly, once a month, caregivers can also attend our Monthly Educational Seminar which features rotating topics based on issues caregivers report they'd like to learn more about. In the past, we've offered information about managing challenging behaviors or how to enhance communication. These seminars are designed to develop more skills and offer more tools to enhance each caregiver's caregiving experience.

For more information about our Educational Seminars or how your caregiving experience can benefit from educational support, please contact our 24-hour Helpline at 646-744-2900.

# Caregiving and Immigration



**ANNE M. FOERG**

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**ANA ARAUJO**

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Dementia knows no racial, ethnic, socioeconomic, or geographic border. Black or white, young or old, rich or poor, city, suburb or rural-dwelling – dementia does not discriminate against those who suffer from this condition or those who care for them. Yet, each person's unique history, characteristics, and circumstances have an impact on how stressful and overwhelming the experience of having dementia or being a caregiver for someone who does. In the case of individuals who are immigrants to this country, this important element of their personal story can have significant consequences. At a time in our country when the merits and challenges of immigration are being debated, the story of caregiving through the lens of immigration should also be told.

Jenica came from the Philippines approximately ten years ago to visit Laila, the child she had raised as her own daughter despite never legally adopting her. During that visit, Jenica was diagnosed with Normal Pressure Hydrocephalus after her functioning rapidly deteriorated. Complications from the surgery to place a shunt in her brain to treat the condition left Jenica in a vegetative state, and without

proof of a legal relationship between the two, Laila could not sponsor her for legal permanent residence. This meant that Jenica did not qualify for health insurance, other than emergency benefits for acute care related to her condition. With no means to pay for the care Jenica required, Laila had to quit her job to provide that care.

Jorge and his mother, Luz, immigrated to New York City from South America several decades ago, and while Jorge had been able to travel a path to citizenship, his mother had not. Without legal documentation, Luz could not consistently work, and she ended up in a homeless shelter. It was there that her symptoms of vascular dementia began to surface, and Jorge eventually had to bring his mother to live with him when she could no longer safely function at the shelter. Jorge worked to provide for himself and Luz, but this left her alone during the day. She was vulnerable and became the victim of physical and financial abuse at the hands of neighbors.

Amelia's mother, Hyacinth, began showing symptoms of dementia and was often found wandering her small town on an island in the Caribbean. Reports from her mother's neighbors prompted Amelia to return to her home country to investigate. Upon arrival, Amelia found that her mother's husband had abandoned her after he had run away with her money. With no one else to provide care, Amelia brought her mother back to New York City to live with her, initially using a tourist visa that eventually expired. Amelia was unable to sponsor Hyacinth for legal residency because she could not meet the financial requirements for doing so. Amelia, a single mother of two children, struggled to keep a roof over their heads by working two low-paying jobs, all while trying her best to ensure that her mother could be kept safe.

The dedication of these caregivers cannot be overstated. Laila, Jorge, and Amelia sacrificed so much to ensure that their mothers were not left alone to face the ravages of their progressive conditions. And they did so without easy access to public benefits and systems

of support that people with dementia and their caregivers deserve, but to which individuals without permanent residence or citizenship are often not entitled. Fortunately, these caregivers were connected with CaringKind, whose programs and services are free of charge and available to all individuals in need of them, regardless of legal status. Each of these families received assistance from a CaringKind social worker, who provided both the emotional and practical support required to cope with these complex and challenging situations.

Laila benefitted from a CaringKind grant to help cover the cost of the medical supplies and liquid nutrition Jenica required, but for which she had no means to pay. Laila was also connected with legal services to explore the possibility of obtaining a humanitarian visa for Jenica, which would entitle her to Medicaid-funded home care, as well as local programs that could provide respite care services in the interim.

Our social worker connected Jorge and Luz with an immigration advocate who assisted Luz in reapplying for a special visa. They were also connected to a local social service organization that provided Luz with free adult day care services until she became eligible for Medicaid-funded home care, ensuring her safety while Jorge was working. When Jorge lost his job, CaringKind provided an emergency grant to help cover the cost of food until he found another position.

Amelia was also connected with legal services to assist Hyacinth in accessing Medicaid through a special program for individuals without legal documentation, but who the U.S. knows are in residence. A CaringKind grant also covered the cost of home care services until Medicaid was approved, so that Amelia could go to work every day with peace of mind that her mother was safe.

No one should feel alone throughout their caregiving journey regardless of their race, ethnicity or legal status. CaringKind is here for you! Please give us a call at 646-744-2900 to connect with a social worker.

## Working with LGBT Caregivers

### **Teresa Theophano**

*Assistant Director of Care  
Management Services, SAGE*

Rachel, a 66-year-old Latina lesbian, has been caring for her 96-year-old mother – who has a dementia diagnosis, and with whom she lives – for the last five years. Trudy is 78 years old and caring for her Alzheimer’s-affected partner Louisa; they have been together for nearly 35 years. Kevin, age 60, cares for his former partner Richard, who is HIV positive and medically frail, living in supportive housing with round-the-clock care.

Rachel, Trudy, and Kevin, like so many family and friend caregivers, show up every day for their care recipients, even when it’s not easy. All three of them are members of the LGBT community, and they faced caregiving in isolation before they got involved with the caregiver program at SAGE. Our caregivers support groups, including one specifically for dementia caregivers that is co-sponsored by CaringKind, have been a lifeline for many.

A member of the dementia caregivers support group since its inception, Rachel has often told the other members that

being in the group has made her feel more compassionate, and that it also contributes to her patience in caring for her mother. Being around a table of LGBT caregivers of adults with dementia has been so helpful to Rachel, who says, “We all speak the same language.”

Rachel is in good company: there are about three million LGBT caregivers in the U.S., according to a 2015 study, and while many LGBT caregivers are doing “horizontal caregiving” – in which they care for another LGBT adult, such as a partner, spouse, friend, ex-partner, or neighbor – we also see many adult children caring for their parents with dementia or other conditions. It’s not unusual for an LGBT adult among a group of siblings to act as a primary caregiver, and it is possible that LGBT adults become caregivers for their parents or other relatives at a higher rate than non-LGBT people. Families may presume that LGBT adults have more time and availability because they’re less likely to have children. Additionally, LGBT people’s families of origin may not be privy to their relationships, and their obligations and care for members of their families of choice may go unnoticed. Adult LGBT children may also find themselves caring

for parents who have not been affirming of their LGBT identity.

Many LGBT people rely on those families of choice rather than biological ones for their care, and LGBT caregivers may not be treated with the same respect or understanding. They can be especially vulnerable to caregiver burden, stress, and burnout, and less likely to seek out supportive services because of fears of being treated poorly. More apt than non-LGBT adults to care for each other in isolation, LGBT caregivers can face further strain because there is no one else involved to share the care. Solo caregivers are particularly vulnerable, with compounded health disparities and few opportunities for respite.

Culturally competent support is essential for LGBT caregivers, and SAGE is proud to collaborate with CaringKind to ensure this remains available. As Trudy put it, “It requires a lot of grace and creativity to care for someone with dementia. It doesn’t get better and I can’t get ahead of it. It’s a lifesaver to come to this group and not feel alone.”

*Paid Advertisement*

# Humana

# Are Support Groups for People Like Me?



**ABBY NATHANSON**  
Director of Support Groups  
anathanson@caringkindnyc.org

At CaringKind, we think support groups are great. We know how they help caregivers who feel isolated, overwhelmed and wrung out. We hear over and over from people who wish they'd joined years sooner, and wonder why they waited so long. The truth is, most people wait too long to ask for help. Most people bear the experience for months or years by themselves or with friends and family when they're available. But why?

For some people, it can be intimidating to think about walking into a room full of people, sharing your personal experiences and feelings, and not knowing how other people will respond. Some people worry that hearing everyone else's problems will make them feel worse, or even just by focusing on their own feelings, the feelings will be magnified. Other people were raised not to "air their dirty laundry" to strangers and burden other people with their woes. Does this sound familiar? We hear this repeatedly from surprised caregivers who found out what the research already knew – support groups really help. They do.

People who join and regularly attend groups experience less distress, less isolation, and increased confidence. They feel better about the decisions that they make and get hope from seeing how

other people cope and deal. They face their fears and form new bonds. Talking to people who deeply understand what you're going through, having a room full of people committing every week to sharing the experience with you, knowing that you're not alone, knowing that other people survive this for years and years on end, too – it all helps, even if it's not always clear how.

But still, even though we know it helps, and we know that the 600+ people who attend our groups every month know it helps, people hesitate. In fact, we did an informal study ourselves. We looked at all the people who called our Helpline over a two month period asking about support groups, knowing this didn't include people who were sitting at home, just thinking about it.

Among everyone who called and was given a referral for a specific group, that was near them and at a convenient time, almost 80% of them never followed up. That means that eight out of every ten people who thought enough about joining a support group to pick up the phone, have a conversation with a Helpline specialist, and go through the process of finding a group that worked for their schedule, never called the group leader to take the next step. We asked ourselves – why?

We know caregivers are calling because they already have a lot on their plates, and sometimes, doing something for yourself is just last on the list. But we wondered what we could do better, to reach more people who already knew they wanted to be part of a group. Maybe they were intimidated or uncertain about what to expect, so they didn't call. Those people, we thought we could reach.

So we changed our system, and did a trial run over the summer. We asked the support group leaders to call the prospective members instead of asking the members to call the leaders. The results were remarkable! We re-evaluated at six weeks, and found that the numbers had totally reversed, and 80% of the people who called about joining ended up in a group! We were so excited to be able to reach so many more caregivers. We started creating new groups just to meet this new demand, at the time slots that were most requested. A diverse group of New Yorkers – from their 20s to their 90s; gay, straight, lesbian, bisexual, queer; African-American, Caucasian, Hispanic, Chinese, Russian and everything between; men, women, transgender and gender non-conforming; people with dementia at home, in a facility or far away; everyone comes to groups and belongs here.

We're hoping to reach hundreds more New Yorkers just like you, to see if a support group would be right for them, too. Even if you're not usually good at sharing your feelings, even if you're not sure about what would happen or help, and even if you haven't totally bought into the idea that talking to a bunch of people will help – give us a call, you might be surprised.

Call our  
24-hour Helpline  
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learn more about  
whether a support  
group is right  
for you.





Bloomberg participants at the CaringKind Alzheimer's Walk, October 2016.

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## Ron Duguay on Caregiving



RON DUGUAY

**Lou-Ellen Barkan (LEB):** Ron, thanks so much for talking with us about the challenges facing your family when they were taking care of your mom and dad. When did they first realize something was wrong?

**Ron Duguay (RD):** Mom was so protective of dad that she allowed almost two years to pass without saying much of anything to us. She tolerated his forgetting, his talking of the past and the other odd things he said and did. Two years into this, my sister got a call. Mom said, “You need to come over. Dad thinks I’m his mother.” That was also my sister’s first call to me. At the beginning, mom didn’t have patience, because she didn’t understand what was going on or what dad was going through. She thought he was just being silly. And she protected him for a long time.

**LEB:** My dad had always been absent-minded, so it took us a while to figure

out that there was more going on. At what point did your family decide to get medical help and an assessment?

**RD:** One Valentine’s Day, at midnight, dad woke up out of deep sleep and realized he hadn’t gotten mom a gift. He got in his car and drove off to get her favorite box of chocolates. Two hours later he had what was, fortunately, a minor accident. My sister got a call from the police at 2 AM. That was the tipping point for us, but it took six months to get dad to the doctor, have an exam and finally get a prescription.

**LEB:** Did you feel confident that he was seeing the right kind of doctor?

**RD:** Absolutely not. I wish I had done more. It was the middle of my season, so I relied on my sister. The medical system in Canada is different, so dad saw a general practitioner first and, in Canada, they aren’t qualified to do a whole lot. It took another year to get him medication.

**LEB:** Was the medication helpful? Were there other strategies that helped him and reassured your mom?

**RD:** This is where it gets complicated. Mom was at the beginning stages of dementia herself, so my sister and I started to visit more often. When we arrived, we would find medication on the kitchen table and we would remind mom. “Dad needs to take this.” She would cover up for him. “Well, he doesn’t want to take it.” Or, “He forgot to take it.” After another six months of not properly taking the medicine, a whole year passed and the disease progressed.

This was even more complicated because breaking up mom and dad felt like breaking up twins. Neither had any interest in moving apart to get better

care. But after another year, my mother was weaker and fell off a chair. When we took her to the hospital, we decided it was a blessing because the door was open to move dad into a hospital or nursing facility.

**LEB:** Your sister sounds like a superhero! I’ll bet both of you have good advice for other families.

**RD:** At my dad’s funeral, I called my sister an angel for all she did. Of all the kids, she was the one left behind to care for mom and dad. And even though it was extremely difficult, she never complained. I learned more when we started to share some responsibility. The one week that I took care of dad alone was the hardest week of my life. My advice to other families is, the minute you see early signs, find a way to take them to the best specialist you can find. That way, as soon as you have a diagnosis, you can make changes in their life and in yours.

**LEB:** When my dad was ill, my mother had to go unexpectedly into the hospital for a week. I didn’t have any help and my dad was a big guy. I couldn’t lift him. I couldn’t change his diaper, I couldn’t take care of him. And, although I thought of myself as a competent adult, I was very upset. Until I got someone in the house to help, it was one of the worst weeks of my life. I sure learned about the challenges of caregiving. How did it work when your mom returned home?

**RD:** We had seen what happened to my dad, so we moved very quickly to find the right place for mom. She moved back home for a bit, but as we saw her dementia progressing, we knew she should be in a safer place where she could have her own rooms, good nursing care and the company she loves. Within two months we found a good place and she

is happy there today. This move was also very helpful for my sister.

**LEB:** What kinds of strategies worked for your sister? How did she stay healthy during that stressful time? Did she have kids who helped? Did the whole family pitch in?

**RD:** She spent as much time as possible with our parents to make sure they were safe. That meant she spent a lot of time at their place. She gave up a lot of her own life until things stabilized.

**LEB:** And what about the rest of the community? Were there friends and neighbors that helped?

**RD:** My parents were so private and dad's whole life was his wife. So, the community was not involved. It was my sister who took this on.

**LEB:** Caregiving is often the role of the woman in a family. In our case, my brother was helpful, but left the decision making and care up to me. Women bear a lot of the burden and often with a good spirit. I worry about families where there are no daughters.

**RD:** Men can do physical stuff, but the mental and emotional issues are usually best left to women. When you need someone who's sensitive and caring, you're not going to necessarily turn to a guy.

**LEB:** Let's talk a bit about lifestyle. We've been following the work of Dr. Richard Isaacson, who is doing some fascinating work on lifestyle, including the impact of diet, exercise and social engagement.

**RD:** I see people in the gym looking at themselves in the mirror. They're putting in time caring for their physical body, but they're not thinking, "How do I care for my brain?" Today we know much more about the effect of nutrition, hormones,

vitamins and sleep. Five or six years ago, when I was tired and felt like I was losing the joy of life, a doctor tested my brain chemicals with a simple saliva test. He was able to treat me very successfully. I felt so much better and more engaged.

**LEB:** We underestimate the importance of keeping our brains active. Some folks think it's about playing games, but the most impactful form of social engagement is a good energetic conversation like the one we are having right now. You're animated in a conversation with a real-life person in a way that you can't get by just doing a crossword puzzle.

**RD:** You might have an interaction where you are frustrated, but you are still engaged. Or, even better where you laugh and feel good.

**LEB:** When my father's dementia began to progress, my mom used to keep him alert by telling him stories about their life together and these made him laugh. When I would visit, he could talk about his life playing baseball or tell us WWII stories. At the end of a couple of hours, he was animated emotionally and mentally and could walk up and down the beach with more energy. It didn't change the progression of his illness, but it certainly helped his quality of life.

**RD:** When I had that dull feeling, I didn't want to share or talk to anyone. If I had a story to tell, it was short. But once my brain was happier, the storytelling became better, a little bit more colorful. And it's was just the joy of life returning. I really had to pay attention to this. In my work, I'm on Cobble Hill TV, I'm constantly around fans and I'm often asked to speak. I can't just show up being dull with a fake smile. When they hand me the mic, I need to have joy and energy that demonstrate that I love what I do.

**LEB:** We certainly felt that joy and energy from you at the CaringKind Golf Outing.

Our guests told us over and over what a lovely, gracious, engaging guy you are. And you have the patience of a saint. That's a special kind of personality and we are very grateful to have your support.

**RD:** Well, thank you, I appreciate that. But those are the rewards that I'm receiving now for the commitment that I've made to be the best that I can be and not just physically. I want to look like an athlete, but it's more important to have an active, healthy brain that helps me appreciate the people I meet at these events. They're generously willing to contribute to helping others. I love being in those situations.

**LEB:** It was a great day and so many of our guests returned to tell us they wanted to get more information and get more involved. You will meet many more of our great supporters at the CaringKind Alzheimer's Walk on October 15<sup>th</sup> in Riverside Park. We will look forward to seeing you then and we thank you for taking time to talk with us today!

*Ron Duguay is a former NHL All-Star. In his twelve-year NHL career (1977-1989) Duguay played for the New York Rangers, Detroit Red Wings, Pittsburgh Penguins and Los Angeles Kings. Currently, Duguay is a two-time Emmy award-winning broadcast analyst for MSG Network's television coverage of NY Rangers games. He also appears regularly as both a hockey and lifestyle personality on network television throughout the U.S. and Canada.*

*Duguay also serves as an ambassador for CaringKind, New York City's leading expert on Alzheimer's and dementia caregiving and Northwell Health's Feinstein Institute as an advocate to help educate and support those affected by Alzheimer's and dementia.*





### CAROL BERNE

Senior Vice President of Development  
cberne@caringkindnyc.org

Some time ago, I was asked, “Even when a caregiver is no longer caring for someone, do they still see themselves, and describe themselves, as a caregiver?” I found this question compelling and thought-provoking. How do caregivers see themselves? A caregiver is defined as an individual who assumes responsibility for the physical and emotional needs of another person. But sadly, the definition does not do justice to the emotional and physical toll that caregiving, and particularly dementia caregiving, takes on the caregiver.

At CaringKind, we recognize the frustration, the stress, the depression, the loneliness and the isolation that caregivers experience. We recognize how hard and relentless caregiving can be, even for those for whom caregiving is a rewarding experience. CaringKind’s job is to make the journey a little easier and make each day a little brighter. Our work is informed by our social workers’ experience of working hand in hand with our clients for over 30 years.

We do the work in the here and now. We move each client from one stage to another with the knowledge that they are not alone on this often-terrifying journey. And each client is handled with the compassion that recognizes that each family is different. Social work is practical, thoughtful and kind. In the 30 years of doing our work, CaringKind social workers have helped thousands of caregivers face their challenges and emerge whole.

We have been fortunate to have supporters – individuals, foundations and corporations – help us along the way. We recently received a generous gift from a caregiver who had attended our Family Caregiver Workshop and donated to support this program so that others could be helped. Two leading New York City foundations are co-sponsoring a pilot program to expand the number of home care workers trained by CaringKind. Additionally, our connect2culture® program recently received a generous grant to develop a curriculum specifically for horticultural sites, so that caregivers and persons with dementia, wherever they live, could have a meaningful and enriching experience.

We privately raise close to \$10 million annually. We count on every donation, large and small, to carry out our work. These funds ensure that the professional, smart social workers we need in growing numbers will be here when we need them, today or tomorrow. Be assured, this would not be possible without your generous support. So, as you approach the end of the year, take a minute to read our Year-End letter on the next page and be as generous as you can. On behalf of our clients, I thank you.

P.S. Donations may be made on our secure website at [caringkindnyc.org/yearend](http://caringkindnyc.org/yearend). We also welcome stock donations.



### Ways to Give

#### Giving by Check

Please make checks payable to CaringKind. For your convenience, a self-addressed postage paid envelope has been provided in this newsletter.

#### 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.



# Dear Friends of CaringKind,

As we approach our third year as CaringKind, we are proud of what our donors have helped us accomplish; sustaining our role as an independent not-for-profit with the responsibility of improving the lives of individuals and families affected by an Alzheimer's or dementia diagnosis. We continue to deliver support, information, and resources, all free of charge, so that caregivers can continue to provide the best dementia care while maintaining their own quality of life.

Last year, the community showed their appreciation for our work with generous contributions, both large and small, to support our Year-End Campaign. This year, we ask you to do the same, and if possible more, so that we can meet our **one million dollar goal**. As the only organization in NYC with over thirty years of experience providing a comprehensive system of support for families throughout every stage of the disease, every dollar raised ensures that we can continue to offer these life-saving programs and services at no cost to those who need them most.

CaringKind has been called the "bright spot" in the caregiving experience by our clients because we understand that each caregiver finds comfort and hope in their own way. A husband caring for his wife finds solace in knowing that he can reach a caring, knowledgeable professional at any time by calling our 24-hour Helpline or scheduling an appointment with a social worker expertly trained in dementia care. An adult daughter caring for her father now feels empowered by learning new techniques for challenging behaviors at a Family Caregiver Workshop and obtaining crucial information on legal and financial planning at our education seminars. Many draw strength from the deep bonds made in one of our ninety support groups. Thousands sleep better at night knowing a family member is enrolled in the MedicAlert® Wanderer's Safety Program.

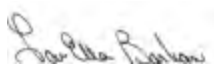
Our clients confirm that CaringKind's services have a positive impact on their wellbeing. They know that CaringKind is a safe place, where they can share their experiences with dementia care experts and other caregivers without being judged. As one client says, "CaringKind makes me feel less alone."

We are proud to share with you the highlights of the year, made possible with your generosity:

- Our 24-hour Helpline responded to nearly 9,000 calls from family caregivers, persons with the disease, professionals in the field, and the "worried well."
- Our Social Work Services provided over 4,600 in-depth, personalized consultations.
- We hosted our first annual Technology Fair, which introduced hundreds of caregivers to the latest products and applications designed to help them manage their daily care, improve communication, and ease social isolation.
- Our palliative care program provided education on dementia-capable palliative care to over 550 health care providers nationwide.
- Our Dementia Care Training for Professional Caregivers trained over 360 home care workers to become specialized in dementia care, and we connected trained aides with families through our web-based tool, Together We Care®.
- Our diversity outreach teams expanded its reach in all five boroughs to bring public awareness and access to our culturally competent programs for Latino, African American, Chinese, and Orthodox Jewish communities.
- Our connect2culture® program advises New York City's finest cultural institutions on how to enrich the experience for individuals with dementia and their care partners, continues its work with Lincoln Center, and is developing a curriculum for botanical gardens.
- Our public policy activities are creating new alliances to support caregiver initiatives and federal funding for research.

Whether you have been personally helped by CaringKind or know someone who has, today we need you more than ever. With your tax-deductible contribution, we can ensure that no one has to face the challenging journey of dementia care alone.

On behalf of the clients we serve, we wish you a peaceful and productive new year. Thank you.



Lou-Ellen Barkan  
President and CEO



Jed A. Levine  
Executive Vice President, Director of Programs and Services

P.S. Donations may be made on our secure website at [caringkindnyc.org/yearend](https://caringkindnyc.org/yearend). We also welcome stock donations.

## 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 see the **Ways to Give** section on bequests on page 16 for further information or please contact Carol Berne at 646-744-2905 or [cberne@caringkindnyc.org](mailto:cberne@caringkindnyc.org).

## 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



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

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.



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## CaringKind's 6<sup>th</sup> Annual Golf Outing

On Monday, July 31, CaringKind held our 6th Annual Golf Outing at Glen Head Country Club on Long Island. As always, the outing proved to be a huge success, as we raised over \$160,000! Our 2017 event sponsor, GCP Capital, LLC, has generously sponsored the outing for the last few years. The day's weather was the best we have had yet, and golfers played for the entirety of the day. The outing sold out, with 22 foursomes taking the course, including Dr. Max Gomez, CBS 2 Medical Reporter, who played with us. Ron Duguay, former NHL All-Star, New York Ranger Legend and Emmy Award-Winning Broadcaster, took his post at Beat the Pro once again on hole 16, where one player got a hole in one! After the cocktail reception, Lou-Ellen Barkan, CaringKind President & CEO honored Ron Duguay for his dedication to bringing awareness and sharing his personal story about this devastating disease.

Our outing would not be a success if it were not for our incredible Golf Committee. Thank you to our Board Member and Golf Committee Chair, Nathan Halegua and his fellow Committee Chairs Josh Halegua and David Azus. Since the outing began in 2011, it has raised over \$950,000! We would not have done it without the committee's hard work and dedication. We would also like to thank all of our sponsors and those that played in the outing. Finally, special thanks to the Glitz Girls for tirelessly working the day of the event to sell raffle tickets, raising additional donations for our cause.



John Weber, Ron Duguay, CaringKind Board Member Jon Henes, Chris Greco, and Matt Fagen



Marc Fuhrman, Matthew Azus, Golf Committee Co-Chair David Azus, Brandon Azus and Sheldon Nussbaum



Steve Maggio, Arnold Gamberg, Michael Rosenfeld and CBS 2 Medical Reporter Dr. Max Gomez



Golf Committee Co-Chair and CaringKind Board Member Nathan Halegua, Ron Duguay, and CaringKind President & CEO Lou-Ellen Barkan



Joe Koicim, Golf Committee Co-Chair Josh Halegua, Justin Schwartz and Scott Sher



Charles Lachman, Michael Imperiale, CaringKind Board Co-Chair Stephen Casper and Allan Keene

# The Value of Caregiver Support: How Research has Influenced Practice



**MARY MITTLEMAN**

*Mary S. Mittelman is research professor of Psychiatry and Rehabilitative Medicine at NYU School of Medicine and the director of the NYU Alzheimer's Disease and Related Disorders Family Support Program, which was launched in 2016 with funding from New York State to provide comprehensive services to family caregivers of people with dementia. Trained in psychiatric epidemiology, she has been developing and evaluating psychosocial interventions for people with cognitive impairment and their family members for three decades.*

An acquaintance, let's call her Susan, recently said to me, "I am going to have to leave my job pretty soon." She said her husband had become very forgetful, and sometimes got confused when he was not in his own home. She said she expected that at the rate things were going, within the next few months her husband would need full-time care and she wouldn't be able to go to work. "He forgets where he puts things and he also asks repeatedly what their plans are. When I insist that he try to remember, sometimes he does, so I sometimes think he just needs to try harder." Last year his regular doctor told her that this was just because he was getting older, and she wanted to believe that was true. In the past few months, however, he had become more forgetful and confused, and she decided to go to a neurologist, who recommended a comprehensive evaluation. In spite of her suspicions, she felt devastated when she learned that her husband was in the early stage of Alzheimer's disease. She told me that she hadn't told anyone else and felt very lonely and was always on the verge of

tears. She wanted to believe that nobody noticed the changes. Her friends had not said anything to her about it, trying to be kind, but that meant she had no one to talk to about what was most important to her.

It is not unusual for caregivers to be reluctant to disclose the diagnosis to friends and family. They may think people won't want to socialize with them if they know. But they do know, and those who care about her would probably be more supportive if they could discuss it, rather than everyone pretending nothing has changed.

Spouse or partner caregivers, who may have been used to confiding in their husbands or wives, may feel especially lonely when that seems no longer possible. Adult children, who may have thought their parents were fine on their own will have to become accustomed to the fact that their parents increasingly need help, and they will have to figure out how much help they can offer.

My research, and that of others, has demonstrated that social support is essential to the well-being of family members of people with dementia. Understanding why the person behaves the way he or she does is also important. How did we find this out?

We did a randomized trial, with funding from the National Institutes of Health, of a program we named The NYU Caregiver Intervention (NYUCI). The study began in 1987 and lasted for more than two decades. The NYUCI is individualized to the needs of each family, and the goal of all its components is to help caregivers get the support they need for as long as they need it. The NYUCI includes a comprehensive assessment, individual and family consultation within a fixed period of time, and the opportunity

to call the person who provided the consultation for additional counseling and support – in a crisis, whenever they feel the need for additional help or guidance or want information about resources. The NYUCI also provides education and training, as needed, so the primary caregiver and the rest of the family, understand the effect of the illness on the person with dementia, and how best to respond to needs, foster strengths and adapt activities to assure the best possible quality of life for themselves and the person for whom they are caring. They also learn about the symptoms associated with each stage of dementia, so they can adapt their expectations and provide the right balance of safety and independence for the person with dementia, and understand when another medical condition may be causing a symptom if it appears to be occurring earlier than one might expect. Our experience suggests that all components of the intervention are helpful, but that family consultation is the most important, as caregivers learn what help they need, how to ask for help, and what is reasonable to ask. Family members learn how to offer help and how to have positive supportive interactions, rather than being critical or telling the primary caregiver what they think would be best.

We proved that the NYUCI increased caregivers' satisfaction with emotional and practical support, and the number of people to whom the caregivers felt close. As a result, caregivers were less depressed, less stressed and enjoyed better physical health. Because their own well-being improved, they were able to keep their relatives at home with them longer than people in the study who did not get the NYUCI.

The demonstrated benefits of the NYUCI led to other studies around



the United States and abroad that corroborated our findings. We also showed that the intervention could save governments significant amounts of money by postponing nursing home placement. These findings led to funding of programs that offer services to caregivers throughout the state of New York, through grants from the Department of Health. One of these programs is based at NYU School of Medicine. Our program, based on the principles of the NYUCI, emphasizes improving social support, educating caregivers and health care professionals, and perhaps most importantly, helping and encouraging families dealing with dementia to have the highest quality of life possible. CaringKind is a subcontractor on this grant providing respite and support group services to caregivers in our program.

Often it takes time for families to fully accept that their lives will be forever changed once they receive news of a diagnosis. Caregiver “L” was referred to the NYU Family Support Program a year ago, as her husband had been diagnosed with early-onset Alzheimer’s. She met with a social worker and said she felt ambivalent: “I don’t really know why I’m here. I don’t really need anything right now.” After a couple of months, she called with some practical questions about getting a Power of Attorney and a Healthcare Proxy. She seemed to be interested in hearing how other people handled these issues, so a suggestion was made that she consider being matched with a Peer Mentor – someone who had

already experienced caregiving issues and could provide personal support and guidance. The Mentor helped her to see that she needed to have a conversation with her children about the diagnosis in order to begin to mobilize the family. At first, her children were not interested in meeting with her social worker. Over time, her daughter began to call the social worker, to ask questions about dementia and see how she could help out, as she saw how her mother benefited from the support. Eventually, L’s children joined family sessions, and found that having a neutral place to discuss uncomfortable issues and problem-solve together was helpful for the entire family. Meanwhile, L and her husband participated together in several arts programs, museum tours, mindfulness and meditation groups. This year, they joined our new chorus, which rehearses and gives performances at Riverside Church in Manhattan. The NYU Family Support Program and the comprehensive programs offered by CaringKind provide the essence of the NYU Caregiver Intervention – consistent personal and professional support over time, which is the key to navigating memory disorders.

What about Susan? What can she do right now to make her life, and that of her husband, easier? She consulted with one of the NYU Family Support Program social workers who suggested that she not assume that she has to leave her job at once as there are many ways to provide care, and she didn’t have to do it all herself. The social worker suggested

that Susan could get help with financial planning. She also suggested that when he says he cannot find something, she might say, “I don’t remember where it is either, so maybe we should look for it together,” which might make him feel less belittled. She might want to figure out what they both enjoy doing that he still can do, rather than trying to get him to be better at what seems now to be a struggle for him. But the most important thing she can do is figure out how to get the support she needs. The social worker suggested they meet with her husband’s children to discuss their understanding of the situation and what they would like to do to help? She also suggested that Susan might want to consider joining a support group so she could talk with others in a similar situation. The counselor suggested to the other family members that they might want to join one as well. The social worker helped Susan to see that she does not need to be alone with the new challenges she is facing. There are many ways to find help and support and it would be most kind to herself and her husband if she included those who care about them to help care for them.

**NYU Langone’s Alzheimer’s Disease and Related Dementias Family Support Program**

145 East 32 St., 8th Floor  
New York, NY 10016

646-754-2277

family.support@nyumc.org

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*The Family Support Program is offered free of charge to family caregivers who are residents of the five boroughs of New York City. Supported by a grant from the New York State Department of Health.*

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**The CaringKind Alzheimer's Walks** brought thousands of New Yorkers together in Brooklyn, Queens, Staten Island and Manhattan, all with the mission to support care, advocacy and research. Throughout the city, walkers raised their ribbons and their voices to #GIVECARE.

Sporting our bright orange color, our walkers joined together to honor and remember those affected by an Alzheimer's or dementia diagnosis, while also highlighting and celebrating the sacrifices and efforts of caregivers throughout New York City.

Honored with this year's "Community Partner Award" was Alex Schweder who is a Visiting Associate Professor at the Pratt Institute School of Design. Also honored with the "Good Samaritan Award" was CNA/mental health technician Shauna Hall.

Thank you to our 2017 Walk Team Captains, Walkers, and their families, co-workers and friends who supported our Walks.

Thank you to our staunch supporters, including our emcee, WABC-TV's Bill Ritter and celebrity champions David Hyde Pierce and Ron Duguay, and all of our sponsors.

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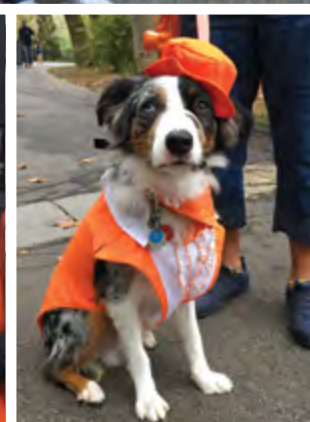
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## NYC Alzheimer's Caregiver Month Recap

### Anna Feldman

*CaringKind Summer Intern*

CaringKind provides countless services to the caregivers of New York City but this summer, we wanted to go beyond that.

"We realized that we were missing something," said CaringKind's President and CEO, Lou-Ellen Barkan. In addition to helping caregivers, we should take the opportunity to celebrate them as well.

This was the thought behind NYC Alzheimer's Caregiver Month. And, once the idea was conceived, there were enthusiastic thoughts and suggestions from staff, clients and volunteers, all energized by the possibilities of this brand new awareness initiative. With just a month to plan, we had to move quickly to organize, knowing that permits for parks, plazas, and public spaces take time to apply for and confirm. Despite the time crunch, we dreamed big. We

contacted our extended community partner networks, asked for help, spread the word and invited people to join. Our efforts were rewarded whenever someone said they agreed.

We focused on a few key events. The City Hall Kickoff became the keystone event. On August 2, dozens of supporters and staff in orange gathered on the front steps of this iconic landmark. Lou-Ellen and Jed Levine, EVP and Director of Programs and Services, spoke about the importance of dementia caregivers and how New York's City Council recently appropriated \$4 million for caregiving programs, a first in the city's budget. We were honored to have Council Member Margaret Chin in attendance as well as Robin Fenley and Caryn Resnick from the Department for the Aging. Caregivers gave heartwarming testimonies and shared their stories. Staff member Candace Douglas, an NYC caregiver for her grandmother, said, "Caregiving is tough but it also has its

rewards and its victories. It's the small things, like singing a Frank Sinatra song and coaxing a smile and a hum. And it's the big moments like joining together at the CaringKind Walk and seeing my grandmother's legacy grow with the next generation of my niece and nephews."

After the kickoff, as the month went on, New Yorkers were invited to numerous activities and events in honor of caregivers. The most notable of these included CaringKind tables at Grand Central Station and Flatiron Plaza. With so many balls in the air, and no blueprint to refer to, the staff and volunteers moved quickly to take advantage of the time we had for this first ever series of events.

Throughout, Lou-Ellen kept everyone grounded with the very appropriate mantra, "Perfection is the enemy of success." We would move ahead, learn as we went and set the stage for future years and success. Our inaugural NYC Alzheimer's Caregiver Month was a great success and we look forward to a bigger, better 2018 celebration!



Press conference at City Hall.



Information table at Grand Central.

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## CaringKind at National Night Out

CaringKind was invited to participate in the 35th annual National Night Out Against Crime. National Night Out is an event that promotes police-community partnerships and aims to make neighborhoods across the country safer, more caring places to live. We are glad to report our participation was well received by the community and proved to be a huge success! Staff and volunteers handed out over 500 packets of materials to residents in the Bronx, Brooklyn, Manhattan and Queens.

We appreciate the opportunity to work closely with the New York City Police Department and thank them for their commitment and partnership in working with the MedicAlert® NYC Wanderer's Safety Program.



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## THE TAUB INSTITUTE

FOR RESEARCH ON ALZHEIMER'S DISEASE AND THE AGING BRAIN



The Taub Institute for Research on Alzheimer's Disease and the Aging Brain at Columbia University Medical Center and NewYork-Presbyterian Hospital brings together researchers and clinicians across disciplines to uncover the causes of Alzheimer's, Parkinson's, and other age-related brain diseases, and to discover ways to treat, prevent, and ultimately cure these diseases. In collaboration with the Departments of Pathology & Cell Biology and Neurology, research in the Taub Institute integrates genetic analysis, molecular and cellular studies, and clinical investigation to better understand complex neurodegenerative disorders. Funding for the Taub Institute's Alzheimer's Disease Research Center is provided by the NIH National Institute on Aging. In 2016, the Taub Institute was designated a Center of Excellence for Alzheimer's Disease by the New York State Department of Health.

In 2014, the Taub Institute for Research on Alzheimer's Disease and the Aging Brain established a new strategic plan based on a model of "Research Platforms" and "Innovation Grants," as a means of accelerating progress toward understanding, delaying, preventing, curing and ameliorating Alzheimer's disease and the other dementias. With the continued development and refinement of these Platforms over the coming years, the Taub Institute is well positioned to centralize and streamline processes across Taub laboratories, accelerate data acquisition, broaden collaborations, and enhance our ability to rapidly respond to new challenges.

### TAUB INSTITUTE RESEARCH: How We Work, Present and Future

The **Patient Oriented Research Platform** serves all components of the Taub Institute by assuring the continued supply of highly characterized patient samples for our research projects. This Platform currently serves as the "nerve center" for trials of new drugs and allows for more rapid progress in the translation of research into treatment. To learn more about the **Patient Oriented Research Platform**, please contact Dr. Karen Marder at [ksm1@columbia.edu](mailto:ksm1@columbia.edu).

The **Stem Cell and Cellular Models Platform** centralizes a series of functions including lipid analysis (LCMS), microarray analysis, and high-throughput drug screening into a single service. It enables investigators to more rapidly evaluate whether a given compound is likely to have efficacy at an early stage of its development. To learn more about the **Stem Cell and Cellular Models Platform**, please contact Dr. Andrew Sporn at [as2003@columbia.edu](mailto:as2003@columbia.edu).

The **Genetics and Vectors Platform** was created to make better use of the Taub Institute's state-of-the-art instrumentation by expanding our computer capacity and building a team of people who can rapidly

analyze the vast amount of genetic data produced. To learn more about the **Genetics and Vectors Platform**, please contact Dr. Karen Duff at [ked2115@columbia.edu](mailto:ked2115@columbia.edu).

The **Brain Imaging Analysis Platform** will take advantage of Columbia's investment (in progress) in the latest generation of imaging apparatus for both animals and humans. This Platform will enable lab groups to routinely correlate their biochemical and clinical data with changes in brain structure and brain metabolism in a rapid and efficient manner, greatly increasing our bandwidth for both human and animal studies. To learn more about the **Brain Imaging Analysis Platform**, please contact Dr. Scott Small at [sas68@columbia.edu](mailto:sas68@columbia.edu), or Dr. Yaakov Stern at [ys11@columbia.edu](mailto:ys11@columbia.edu).

Lastly, the **Innovation Grants** are a novel approach to encouraging collaboration and maximizing the use of these Platforms. The grants would be for a maximum of 18 months and would require the use of one or more of the platforms. To learn more about **Innovation Grants**, please contact Dr. Michael L. Shelanski at [mls7@columbia.edu](mailto:mls7@columbia.edu).



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## 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:

November 10	12:00 - 2:00 p.m.	Manhattan
November 15	5:30 - 7:30 p.m.	Manhattan
November 21	5:30 - 7:30 p.m.	Manhattan
November 21	2:00 - 4:00 p.m.	Brooklyn

December 8	12:00 - 2:00 p.m.	Manhattan
December 12	5:30 - 7:30 p.m.	Manhattan
December 19	6:00 - 8:00 p.m.	Brooklyn
December 20	5:30 - 7:30 p.m.	Manhattan

January 9	5:30 - 7:30 p.m.	Manhattan
January 12	12:00 - 2:00 p.m.	Manhattan
January 16	2:00 - 4:00 p.m.	Brooklyn
January 17	5:30 - 7:30 p.m.	Manhattan

### Upcoming Date in Spanish:

December 8	12:00 - 2:00 p.m.	Manhattan
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### Upcoming Date in Chinese (Mandarin):

November 18	10:30 a.m. - 12:30 p.m.	Queens
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**For more  
information,  
please call our  
24-hour Helpline  
at 646-744-2900  
or go online at  
caringkindnyc.org**

## 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	
November 6	12:00 - 1:30 p.m.
November 20	5:30 - 7:00 p.m.
November 27	5:30 - 7:00 p.m.

December 4	12:00 - 1:30 p.m.
December 18	5:30 - 7:00 p.m.
December 28	5:30 - 7:00 p.m.

January 8	12:00 - 1:30 p.m.
January 22	5:30 - 7:00 p.m.
January 25	5:30 - 7:00 p.m.

Queens	
November 15	3:00 - 4:30 p.m.
Bronx	
November 15	3:00 - 4:30 p.m.

### Upcoming Date in Chinese (Mandarin): Manhattan

December 7	1:30 - 3:30 p.m.
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## Seminars for Professionals

### Understanding Dementia for Professionals

December 13	3:00 - 5:00 p.m.	Manhattan
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### Enhancing Communication with Persons with Dementia

January 10	3:00 - 5:00 p.m.	Manhattan
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Meeting topics vary.

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:

December 6	3:00 - 4:30 p.m.	Queens
December 7	5:30 - 7:00 p.m.	Manhattan
January 4	5:30 - 7:00 p.m.	Manhattan
February 1	5:30 - 7:00 p.m.	Manhattan



## Monthly Education Meetings

Meeting topics change monthly based on questions received from caregivers.

### Upcoming Series Dates

All meetings from 6:00 – 8:00 p.m

### November 13:

#### Elder Abuse: Through the Dementia Lens

- Discover and recognize different forms of abuse.
- Understand how dementia can increase the risk factor for abuse.
- Learn how to formulate a plan to protect against abuse.

**Speaker:** Beatrice A. Maloney, LCSW-R, Geriatric Social Work and Elder Abuse Expert

### December 11:

#### Alzheimer's Medications: What You Need to Know

- Learn about current FDA approved drugs used to manage Alzheimer's disease.
- Understand the benefits and drawbacks of medication.
- Find out what to expect from pharma in the future.

**Speaker:** Dr. Gary Kennedy, Director, Division of Geriatric Psychiatry and Fellowship Training Program; Vice Chair for Education and Professor of Psychiatry and Behavioral Sciences, Montefiore Medical Center; Albert Einstein College of Medicine

### January 8:

#### Behavior has Meaning

- Recognize how dementia impacts behavior.
- Understand root causes of behavioral changes.
- Formulate strategies to adapt and adjust responses to behaviors.

**Speaker:** Amy Torres, Director of Training, CaringKind

## 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 Date in English:

Manhattan

November 21 5:30 - 7:00 p.m.

January 9 5:30 - 7:00 p.m.

## Family Caregiver Workshops

During this 10-hour workshop series, 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. Attendance is required at all workshops in a series.

Upcoming Dates in English – In Manhattan:

November 13, 20, 27 Afternoons

December 4

January 23, 30 Afternoons

February 6, 13

Upcoming Dates in Spanish – In Manhattan:

November 10, 17 Afternoons

December 1, 8

**Please call our  
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646-744-2900  
to register.**

**Registration is required.  
Space is limited.**

All meetings are free of charge  
and subject to change.

You may notice that specific locations of  
upcoming meetings are not listed.  
You will receive location information  
during your registration call.

*We wish to thank the following  
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meeting space:*

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Queens Library  
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The Brielle at Seaview  
Hand in Hand Together Homecare

# Dementia Care Training For Professional Caregivers



**Our Dementia Care Training is specifically designed to empower personal care workers to provide the highest quality of care to persons with dementia.**

The training takes place over seven days,  
and is offered in English, Spanish, and Chinese.

**Please call our Helpline for upcoming dates.  
Trainings are held on a regular basis.**

Sessions include:

- In-depth information about all aspects of Alzheimer's disease and related dementias
- Communication strategies to connect with the person with the disease
- Understanding and managing behavioral changes associated with dementia
- Creating meaningful activities

*From one of our  
recent graduates:*

**"Before this training  
I thought I understood  
persons with dementia,  
but in truth I was  
just doing the best  
that I could."**

Please call our  
**24-hour Helpline at 646-744-2900**  
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*All trainings are free of charge  
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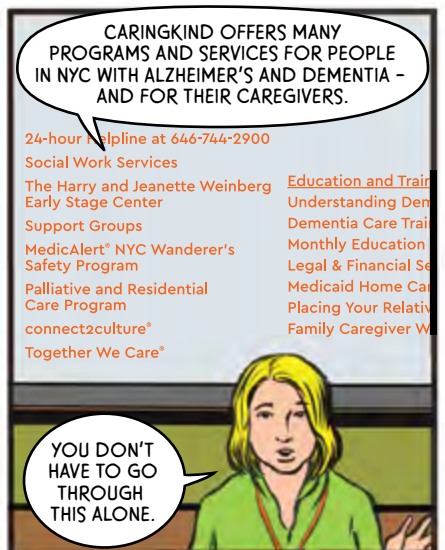
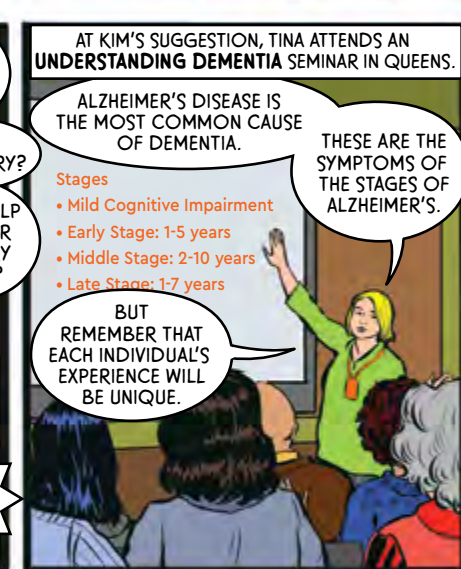
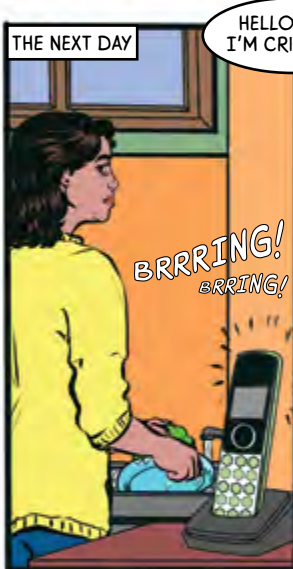
*Seating is limited and  
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# caringkind chronicles

Writer: Jennifer Camper Artist: Ivan Velez

Episode 4 Previous episodes: [caringkindnyc.org/comic](http://caringkindnyc.org/comic)



Understanding Dementia for Caregivers is one of CaringKind's free educational programs providing information about Alzheimer's and dementia and available resources and services. For upcoming seminars, call our 24-hour Helpline: 646-744-2900.



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

**646-744-2900 — 24-hour Helpline**

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## Programs and Services

**24-hour Helpline at 646-744-2900**

**Social Work Services**

**The Harry and Jeanette Weinberg  
Early Stage Center**

**Support Groups**

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

**Palliative and Residential  
Care Program**

**connect2culture®**

**Together We Care®**

## Education and Training

**Understanding Dementia for  
Caregivers & Professionals**

**Dementia Care Training for  
Professional Caregivers**

**Monthly Education Meeting**

**Legal & Financial Seminar**

**Medicaid Home Care Seminar**

**Placing Your Relative in a  
Nursing Home Seminar**

**Family Caregiver Workshop**