

caringkind

The Heart of Alzheimer's Caregiving

FORMERLY KNOWN AS THE ALZHEIMER'S ASSOCIATION, NYC CHAPTER

THE CAREGIVER'S
GUIDE

I'm Exhausted!

What do I do next?

Medicare?

Home Care?

Nursing Homes?

Where do I get help?



FALL 2016

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Dear Friends,

While no one will ever confuse this CaringKind Caregiver's Guide with *The Hitchhiker's Guide to the Galaxy*, there are more similarities than you might think.

This comedy science fiction novel follows the interstellar misadventures of Arthur Dent, the last man on Earth, as he is thrown into a foreign world facing crisis after crisis, all the while trying to make sense of his new reality. While Alzheimer's is no laughing matter, this new reality is something that family caregivers can certainly relate to.

Even before you turn the page to open the book, the message on the cover has as much significance for the interstellar hitchhiker as it does for the Alzheimer's caregiver: DON'T PANIC! CaringKind is here for you.



As an Alzheimer's caregiver, you will enter a world where topsy-turvy is the new normal. You'll face situations that will scare you, perplex you, anger you, frustrate you, and maybe even amuse you.

But as one of the *Hitchhiker* characters says, "Funny, how just when you think life can't possibly get any worse it suddenly does." This is often a truism for caregivers.

CaringKind has been New York City's leading expert on dementia caregiving for more than 30 years. If there's one thing you should walk away with after reading this edition of the newsletter, I want you to remember that you are not alone.

From your very first call, we will guide you through the unsettling universe of Alzheimer's, dementia and caregiving. We will provide you with the right resources, at the right time. We will empower you with the solutions you need, when you need them.

The first, and most important, step for every dementia caregiver is to know what you don't know. If you don't have the right questions, you won't get the right answers.

No matter how tough-minded, independent and strong you might be, you cannot do this by yourself. Ask for help. The sooner you reach out for assistance and advice, the better off you will be. And that translates into better care for your family member.

As this guide demonstrates, the problems you will confront as a caregiver are myriad. Memory loss. Combativeness. Personality changes. Problems with eating and bathing. Wandering. Wading through the morass of Medicaid materials. Caregiver stress and health problems. Financial and estate planning. Dealing with cultural stigmas in your community. Finding appropriate home care or long-term care. And finally, end of life care.

But for every problem, CaringKind has a solution. Caregiver support groups. Education seminars. The Wanderer's Safety Program. Expert social workers. Legal and financial planning. A state-of-the-art Early Stage Center. Assistance



LOU-ELLEN BARKAN
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finding home and residential care. As I've said before: if you've seen one person with Alzheimer's, you've seen one person with Alzheimer's. We understand that one caregiver's experience is not like any other.

My parting words for you are, don't be like Arthur Dent, who lamented:

"I really wish I'd listened to what my mother told me when I was young."

"Why, what did she tell you?"

"I don't know, I didn't listen."

So, listen and learn from the experts at CaringKind. They are here to make sure you travel through this new universe of Alzheimer's and dementia caregiving safely and with all the help you need to care with confidence and make each day a little bit brighter!

Dear Readers,

Much has changed in the more than 25 years that I have been on staff, but one thing remains the same: a diagnosis of Alzheimer's or another dementia hits like a bombshell. It destroys futures, devastates dreams and rewrites the script for the final acts of our lives.

Caregivers often feel helpless and hopeless. Unfortunately, medical science has not progressed to the point where we have therapies to cure the disease or stop the progression.

What has changed? We know much more about caring for a person with dementia and, equally important, we know more about the importance of caring for the caregiver. Our knowledge, based on and supported by empirical evidence, shows that when families talk with dementia care specialists soon after a diagnosis, outcomes improve. Family caregivers report less depression, less stress, and improved well-being. The person with dementia does better as well, and healthcare costs are reduced.

Government is beginning to acknowledge the importance of family caregivers. New York State has recognized the value of care and support for Alzheimer's families. Governor Cuomo approved the largest single allocation of state dollars in the nation for this purpose, and we are pleased to be the recipient of a number of grants from the state to expand our care and support services.

The New York City Council Speaker Melissa Mark-Viverito, Committee on Aging Chair Margaret Chin, and Council Members Debi Rose, Annabel Palma and Ydanis Rodriquez have introduced legislation that would address the needs of "informal" or family caregivers in New York City. CaringKind was pleased to provide testimony supporting this legislation.

The federal government is also focused on the issue. The National Alzheimer's Plan has recommendations that support this effort nationally. A new bill, the Alzheimer's Beneficiary and Caregiver Support Act, if passed, will authorize Medicare to conduct a demonstration program with caregiver support and counseling to provide relief to millions of unpaid family caregivers.

If you or someone you know is concerned about a person with dementia, you don't have to go it alone. We know that many caregivers are isolated; many friends and family members are no longer in touch and as caregiving takes up more and more time, there is less time to maintain these important social and family relationships. We can help.

Call our 24-hour Helpline at 646-744-2900. Talk to a caring professional who will listen and provide confidential guidance and support, as well as connections to the extensive resources of CaringKind and our community partners and services.

Come to an education meeting. Knowledge is power; the more you know, the better you will be able to care for your family member and for yourself, and the better prepared you will be for the future. Attend a Family Caregiver Workshop to learn the skills of good dementia care.

Join a support group. Support group members tell me all the time that once they joined, they were able to keep their



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head above water. There is no substitute for sharing with others who are going through similar situations. The sense of relief and community is palpable and healing.

Enroll your relative (and yourself) in the MedicAlert® NYC Wanderer's Safety Program and get peace of mind. Even the most vigilant caregiver can't watch their relative every second of every day. Wandering is real, serious, and life-threatening. Enrolling in the program connects you to a 24-hour network of support and response in the event someone goes missing.

Speak to a CaringKind social worker who will help you navigate the complex system of long-term care and provide support to deal with the complicated issues of dementia caregiving, as well as the day-to-day priorities of family and professional life.

Call us. We can help. You don't have to do this alone.

A handwritten signature in black ink that reads "Jed A. Levine".

P.S. Please see our Year-End letter on page 19. We hope you will support us so that we can continue to expand our reach to all who need us in New York City.

Interview with Dr. Richard Isaacson



RICHARD S. ISAACSON, M.D.

Richard S. Isaacson, M.D., serves as Director of the Alzheimer's Prevention Clinic, Weill Cornell Memory Disorders Program, and Director of the Neurology Residency Training Program at Weill Cornell Medicine/NewYork-Presbyterian Hospital.

Dr. Isaacson specializes in Alzheimer's disease (AD) risk reduction and treatment, mild cognitive impairment due to AD and pre-clinical AD. His research focuses on nutrition and the implementation of dietary and lifestyle interventions for AD management.

This is part two of three of our interview with Dr. Richard Isaacson.

Jed Levine (JL): I know that people with diabetes are at greater risk for developing Alzheimer's, and there's been a lot of study about insulin resistance. What is insulin resistance and what can you do to control that?

Dr. Richard Isaacson (RI): While I am a neurologist by trade, I often feel like I am also one-third cardiologist and one-third diabetes doctor.

Insulin resistance is where the body becomes less sensitized to the effects of insulin, which is produced by the pancreas when someone needs any sort of sugar or carbohydrate. All carbohydrates break down into sugars, but there are good and bad carbohydrates. Certain carbohydrates, like plain sugar, baked

goods, high fructose corn syrup, cakes, and candies will cause the pancreas to secrete insulin. Insulin is the hormone that breaks it down. If you eat too much of these carbohydrates or your pancreas isn't working, you will have greater risk for the negative effects of diabetes.

While insulin resistance can be caused by dietary and genetic factors, we are finding additional, more confusing reasons for insulin resistance. Someone can look perfectly healthy on the outside, but when we look closer we find that they have a high amount of fat on the inside, where we can't see it. This is called visceral fat.

Insulin resistance can come from any metabolic problem in the body. It can be worsened or caused by diet and by genes. The key here is it's always an interplay between genetics and the environment. Insulin resistance is among the most modifiable pathways for a lifestyle or dietary change to push someone off the road to Alzheimer's disease.

My philosophy is, and I'm in the minority since less than five percent of Alzheimer's specialists believe this, that while amyloid and tau are bad, if we can intervene before amyloid gets on the metabolic pathway, we can change the outcome. Since insulin resistance is one of the key precursors to amyloid deposition, if we are proactive, we can change the course of the development of Alzheimer's disease.

We take a very deep dive (some would say too deep). What we're realizing is there's a core of five to eight habits that we can change if a person is insulin resistant. We look at blood sugar level, fasting blood sugar level, and fasting insulin level. We also look at the hemoglobin A1c, which is checked for anyone with diabetes. We determine if any of these are higher than they could be or should be.

If any of these are borderline, it may not be pre-diabetes, but it may mean pre-pre-diabetes, which is worrisome for someone at risk for Alzheimer's. We take a long-term, preventative approach, literally a decade or even up to three decades before the onset is likely. Before we put someone on a personalized intervention plan, we try to understand why they're insulin resistant.

Half my patients just change their diets and their insulin resistance goes away. For the other half, the beta cells in their pancreas aren't working right. We have markers for that. For some, their body fat is increasing. This is common, probably a third of my patients seem pretty healthy but haven't been exercising as much as they had in the past, so their muscle mass is decreasing and body fat is increasing. This is normal as we age, but the question we ask is, "Is there is something we can do about it?" We fight insulin resistance from every angle, but we first try to figure out if the person has it rather than just say, "Oh, you need to eat less carbs." Some people may eat all the right carbs and still have a problem.

There's actually a fascinating Alzheimer's prevention study going on right now called the Tomorrow Study. Doctors are using a diabetes drug called pioglitazone, which is an insulin sensitizing agent, to figure out who can benefit from the drug.

JL: There are so many dietary things that we hear about in terms of coffee, red wine, antioxidants, blueberries, etc., but changing diets is very difficult. If you look at this as a public health issue, once you get data, will you have recommendations? How will you get the message across? We know it takes a long time to change behavior.

RI: There's two parts to your question. First, there's no one-size-fits-all approach to Alzheimer's risk reduction,

Alzheimer's treatment, or overall brain health. There is a brain-healthy diet, but different people need different brain-healthy foods depending on their metabolic and nutritional status.

The second is determining the best way to communicate to affect behavior change. For people who have insurance, we can send them to our nutritionist, who puts a very detailed plan together. For others, we have online material. There is a two-page summary of good vs. bad carbs and a top ten list of what you need to eat. Does this really help? Maybe a little bit.

There are two things that have helped the most. First is online education, where people can go on their computers and watch interactive modules about nutrition and find explanations about what a carbohydrate is, what fiber is. People don't understand that while fiber is a carb, it's actually not digested, so it doesn't really count as a carb. And with online education, people can learn in the comfort of their own home.

The other thing that's affected change most is asking our patients to track the food they eat. It's difficult to get the patients to track, but once they do it, it works. We ask them to track at least three days in a week every six months. This *really* works.

When I tried it myself, I was surprised. I thought I was eating very healthy food, but when I tracked it, I found that I had eaten 226 grams of carbohydrates in one day! The RDA is 130. I'm supposed to know this, right? The problem is that even highly motivated patients have a tough time tracking data consistently.

JL: When I track everything I eat or even just count carbs, either on Weight Watchers or MyFitnessPal, it's the only way I lose weight. But it's demanding.

RI: It took me 35 minutes, so we developed tips and tricks for both online and paper tracking. People don't have 35 minutes. If they do, they should be exercising for those 35 minutes.

We tell people to track their weight and their percent body fat, and to get a scale. I check the Health app on my iPhone because I want my 10,000 steps every day, even if I've had a busy, terrible day. Last night I was at 9,485 steps, and I walked the dog one extra time at 11:00 because I have to achieve those 10,000 steps.

There is some data to suggest that if you weigh yourself more than 15 times a week, you lose more weight. I check my body fat every month on a percent body fat scale. We teach our patients to do these things. If people don't have any time, we teach them ways to incorporate the time.

For example, we have a balance ball in the office. I sit on it one to two hours a day, because sitting in a chair for eight hours a day causes my metabolism to plummet. A balance ball will actually activate the core. I might get a standup desk. Whatever little tips and tricks you can do to help. With diet, you have to make your brain and belly happy. With lifestyle, you have to stay in balance with kids and school and this and that. It's hard.

JL: There is also the difficulty of delivering the message that there is a difference between maintaining cognitive health and preventing diseases like Alzheimer's or other cognitively impairing illnesses.

RI: In our Alzheimer's Prevention Clinic, which provides direct clinical care to people at risk for Alzheimer's before they have symptoms, we try to apply the best evidence we have towards reducing risk and maintaining cognitive health. The problem is that so many of these studies

use cognitive health, or Alzheimer's prevention, but do they really look at Alzheimer's? Do they use biomarkers? Was it dementia prevention? Was it cognitive health prevention? The data is so muddy. It's really tough to tease out.

To know if we're truly preventing Alzheimer's, it's going to take time. We finally have funding to study Alzheimer's biomarkers. We can look at amyloid and glucose metabolism in the brain. The Holy Grail here is not just showing that we're improving cognitive health, because we've shown this with the FINGER study, which was the first multi-domain intervention that showed that lifestyle change, plus nutrition, exercise, socialization and regular healthcare follow-up can delay cognitive decline in an elderly cohort. It was a well-done, landmark study. We practice that clinically today, but we also add clinical precision by looking at genetics and stratifying based on genes, looking at biomarkers and taking a personalized approach.

Will this impact glucose hypometabolism or amyloid deposition? That's what we need to prove. We began a new study in January. So yes, we are looking at this, but, it's going to take at least five to ten years to truly know if this approach affects Alzheimer's onset or not. Right now, we don't have enough information.

Read the final part of the interview in the winter 2017 newsletter.

“ I am the primary caregiver for my father who was diagnosed with Alzheimer's disease about three years ago. I had him move in with me since I couldn't continue traveling back and forth to his apartment to check on him. He is very dependent on me and I'm beginning to feel trapped. I am still working and find that I must rush home to be with him in the evening, as well as on weekends. I can't see my friends as often as I used to. I don't want to resent my father, but feel that I am starting to. I am an only child and have no relatives in the area. What can I do? ”



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

On the CaringKind Helpline we often get calls from caregivers who are feeling overwhelmed and stressed with all of the responsibilities of caregiving. This can certainly have a negative impact on your work, as well as your social life. It is as important for your father to have stimulating activities as it is for you.

Our Helpline Specialists can provide you with the locations of adult day programs for your father to attend while you are at work. An adult day program would grant your father the opportunity to socialize with other people with dementia, and some even provide transportation to and from the program. If an adult day program is not appropriate for your father, a Helpline Specialist can discuss home care options with you. They can give you information about agencies that provide home care workers who may tend to your father for a few hours a day, or as needed. Here at CaringKind, we offer Dementia Care Training for Professional Caregivers (DCTPC), which is specifically designed to empower home and personal care workers to provide the highest quality of care to persons with dementia. Graduates of the DCTPC are given the opportunity to create and post a profile on TogetherWeCare.com, a resource created by CaringKind to bridge the gap between home care workers who have completed the training and

families seeking to hire trained aides to provide care. Caregivers like you are able to view and search profiles, as well as post job ads.

It is crucial to remember that your health is as important your father's. Sometimes stress can affect one's physical health, and then both you and the person you are caring for are adversely affected. We always suggest that caregivers take care of themselves throughout the caregiving time. It would be best if you arranged home care to include a weekday evening and/or one day on the weekend so that you can be with friends on a regular basis. Going out to eat or to the movies, having a massage, or just visiting a friend are wonderful ways of relaxing. You need not feel guilty about doing this. It will relieve your stress and provide you with a way of balancing the responsibilities of caring for your father as well as yourself.

You also need not feel alone in caring for your father. Joining a support group can be a huge help. Our support groups aim to provide caregivers with an opportunity to discuss the

many challenges of caring for a family member with Alzheimer's disease or related disorders with others who understand. Our goal is to provide a safe setting which promotes mutual support, both practical and emotional, throughout the course of the disease.

Take advantage of all of CaringKind's programs and services, which are free of charge. And remember you can always call our 24-hour Helpline to speak with a Helpline Specialist so that you can receive the information, comfort, and support you need.

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It Takes a Village – A Caregiver's Journey to Self-Care



ANNE M. FOERG

Director of Social Work

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The word “self-care” in today’s culture may evoke images of quiet meditation or a blissful massage. However, ask most caregivers of people with dementia about the concept and a frequent response is “that would be nice, but who has time?” To better understand the idea of self-care in the life of a current caregiver, I sat down with a longtime client of CaringKind, Ann Burgunder, in September to explore its reality in her caregiving journey.

When Ann’s partner, Ti, began to show frightening symptoms of memory loss and disorientation, eventually receiving a diagnosis of Mild Cognitive Impairment in 2006, Ann’s initial focus was on his well-being and how to keep him as engaged as possible. Ti’s evaluation came with a recommendation to reach out to CaringKind. Ann first connected with Paulette Michaud, the inaugural Director of the Early Stage Program. Ti began attending a group, and after he had done so for about a year, Paulette suggested that Ann consider attending a support group for herself. This group, which she has now attended for nine years, introduced the idea of self-care in the form of the respite, emotional support, and practical advice on navigating the peaks and valleys of caregiving that it provided.

Ann soon learned that self-care in the context of dementia caregiving requires moving beyond the idea of self. For her, it necessitated creating another support

group of sorts, this one, in Ann’s words, “a community of caregivers for myself,” so she was “taking care of Ti, but not alone in doing it.” Ann reached out to friends and neighbors, eliciting their help to ensure that Ti was engaged, supported, and, eventually, never alone. Some friends accompanied him to Meet Me at MoMA, a program for individuals with cognitive impairment, while others participated with Ti in The Unforgettables, a chorus for people with dementia and their caregivers. Ti’s roommate made sure that his needs were met on the two nights that he stayed in his apartment each week, providing Ann with some respite from the five nights that she and Ti spent together at her apartment. As Ti’s condition progressed, so too did his need for more structured care. Ann eventually facilitated the introduction of professional caregivers, and also enrolled Ti in two adult day programs to ensure his stimulation and increase his social engagement. She never used these formal supports to replace the network she had developed, only to expand it so that she and Ti would continue to receive the help they needed and deserved.

Before his diagnosis, Ti and Ann used to enjoy attending theater and cultural events together. But as the disease progressed, such activities became more challenging for Ti. Ann came to recognize that she can and needs to continue to participate in these things for herself. Doing so, even alone, provides her with another opportunity for self-care and honors the spirit of the commitment she and Ti have made to each other. Ann also found that restorative practices, such as exercise and tai chi, are helpful forms of self-care. However, going to her own full-time job, along with coordinating Ti’s care, often made it difficult to incorporate these practices

into her routine. Through this challenge, Ann recognized that having her own work was a form of self-care, providing a structure and routine that helped maintain her well-being. For a significant portion of her caregiving journey, Ann worked full-time, enjoying the benefit of a supportive workplace. She retired in 2014. But following a year to complete long-neglected projects, Ann recently decided to return to working part-time, reclaiming the benefit of a structured schedule to keep her priorities and their related tasks in relative balance. The network of caregivers that she has so meticulously cultivated over the years again remains essential in allowing Ann the ability to return to work that she finds personally meaningful.

The path of incorporating self-care into the fabric of a caregiver’s life is a journey as unique as that of the person with dementia’s experience through his or her illness. Ann’s creativity in curating a network of support and services – including people, cultural institutions and programs, and even work – gives new meaning to the concept that “it takes a village” and shows that such support is crucial to caring for all those impacted by dementia. Yet, self-care in all its forms is not a panacea for the struggles of caregiving. In a follow-up email pursuant to our conversation, Ann reflected on the reality that despite finding ways to practice self-care, the experience of caregiving remains an exhausting one with ever-continuing challenges. The journey of the caregiver, caring for the person with dementia and caring for oneself, is taken one day at a time.

Many thanks to Ann for generously sharing her story with us.

Strategies for Living with Early Stage Memory Loss



LAUREN VOLKMER
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Last fall, 22 people living with Mild Cognitive Impairment (MCI) and early stage dementia gathered at The Harry and Jeanette Weinberg Early Stage Center at CaringKind. They participated in a three-session workshop titled Strategies for Living with Early Stage Memory Loss. Together they expressed support, commiseration, humor, and resiliency in the face of their diagnosis.

Participants were eager to engage in a dialogue with one another that was peer-driven, rather than relying heavily on the perspective of professional facilitators. They wanted to strategize with one another about practical approaches to daily challenges, and also to share the results of the discussion with other people facing a dementia diagnosis.

The comments below were compiled by Early Stage Center staff using words directly from the workshop conversations. Participants agreed that each person needs to develop a system that builds on his or her own strengths, accommodates for changes in memory and functioning, and honors individual preference. We hope that these suggestions can be a starting point for others to discover which strategies are right for them.

To learn more about our Early Stage Center programs, or to get support with early stage issues, please call our 24-hour Helpline at 646-744-2900.

Talking With My Doctor About My Diagnosis

- "I bring a family member or friend with me to appointments. Their experience is objective, mine is subjective."
- "Follow-up testing can be overwhelming and lengthy, and I come out feeling that I'm worse than I thought I was. I need to find ways to combat the anxiety and negative emotions associated with being tested that can make it more difficult, like planning something enjoyable afterwards."
- "If possible, I prepare for testing by practicing strategies for things like counting backwards by seven."
- "I step away from the conversation and let my care partner talk to the doctor if it becomes too much for me to handle emotionally."
- "I keep track of potential side effects from my Alzheimer's medications and report them to the doctor. I also tell the doctor if I'm taking any additional vitamins or supplements."
- "I try to be realistic about my expectations of what the Alzheimer's medications can do. However, I also enrolled in a clinical trial so that I can be a part of something that helps others, and hopefully myself too. Some trials have new medications that are being tested and others test existing medications for new purposes."

Talking With Friends And Family About My Diagnosis

- "I realize that it is helpful when people ask about my experience, but I know that it can alienate some people who are uncomfortable with the subject. I ask for help as needed."
- "I disclose my condition as needed, saying directly: 'I have Alzheimer's.' or 'I have MCI.' When I do, I find that people respond in a supportive way."
- "People sometimes minimize my experience by telling me 'I forget things all the time too.' I have to remind them that 'memory issues' and Alzheimer's are very different, and that there is variation in every person's experience."
- "Be prepared that some people are ignorant about the diagnosis and what it means to be early stage. Sometimes I choose to educate people about my condition so they understand my needs, even though this can be exhausting. But, I don't HAVE to educate people if I don't want to."

Managing My Medications

- "I sometimes have difficulty remembering to take my medication, or remembering if I have already taken it. So, I use a plastic pill box labeled with the days of the week. Some pill boxes have a knob on top that you can push over after the pill has been taken, and others are automatic and have timers. You can find them at www.alzstore.com."
- "I keep the medications accessible, visible, and always in the same place."
- "I put reminder notes in common places, like the bathroom mirror, kitchen table, or a calendar."
- "My care partner periodically checks to make sure my pills are being taken correctly. It's important to me to have a system in place so that the burden on her is reduced."

Recalling The Location Of Items

- "I try to put items, especially important things like eyeglasses and keys, in the same place every time. It's like a ritual I've developed."
- "Sometimes I can see something with my eyes just fine, but it doesn't register in my brain what the object is. If I can't find something, I go take a walk, come back, and I can often find it."
- "Frustration can absolutely get in the way of finding something, so I have to relax."
- "All my similar items are in the same area: all my shoes in one closet, all my underwear in one drawer, etc., so that I don't lose time looking in multiple places."
- "I try to find it on my own first, and then if needed I ask for help."

Recalling Important Information

- "I write reminder notes listing what I need before I leave home. I have to leave the notes in a prominent place so that I remember to read them. If I have something on my schedule for the day, I put a note on the table next to my bed so I will see it when I wake up."
- "I put everything on one calendar, rather than different notebooks or calendars scattered everywhere."
- "I carry a large bag that holds everything I need."
- "I always carry a notepad and pen with me."
- "I use a smartphone for notes, reminders, time, maps, and directions. The Siri feature on my iPhone has been helpful so that I can use voice recognition instead of typing on those tiny keyboards. And the phone camera is helpful when I want to remember something and can take a picture of it."

Doing Household Chores

- "I have hired somebody to help around the house."
- "I do different chores on different days: Monday is for floors, Tuesday is for laundry, etc. Routine has helped me make sure I get everything done."
- "I make sure to wash dishes right after a meal or I will forget to do them."
- "I give myself permission to ignore a mess as needed and just close the door to that room. Self-care is my number one priority."
- "As soon as I run out of an item in the kitchen, I write it down on a shopping list that is always kept in the same place."

Managing Finances

- "I'm always cautious because I know that I'm at risk for being financially exploited. I have alerts set up on my accounts to detect fraudulent activity."
- "I try to be aware of any compulsive behaviors with spending that are associated with this disease."
- "I set up automatic bill payments so that I don't have to write checks every month."
- "Financial decisions have become more difficult. I try to make big decisions in collaboration with my care partner."
- "If I get a notice about a free trial membership to something, I use caution because I may forget to cancel it and then get charged a fee once the trial membership expires."

Motivating Myself And Staying Active

- "Motivation becomes difficult when everything I do requires a lot of energy, focus, and effort. Sometimes I have to remind myself that it's ok to take breaks."
- "I make time for exercise, even if it's just a walk around the block."
- "I try to follow a healthy diet. I also make sure to drink a lot of water and stay hydrated, if not then I tend to get more confused."
- "My support systems are many: family and friends, like-minded people, faith-based communities, and groups at the Early Stage Center!"
- "Photography is a good tool to help me engage and also to take a break from trying to engage."
- "I get a lot of pleasure from gardening and watching something grow."
- "I have found meditation to be very helpful."
- "I pursue hobbies like art, listening to music, auditing college classes, and connect2culture® museum tours for people with memory loss."
- "I tend to sleep in, so I schedule things later in the day if possible."
- "The senior center near my house has been fabulous in helping me interact with lots of interesting people and activities."

Managing Social Situations

- "It takes extra effort now to attend social gatherings and stay engaged, but I think the effort is worthwhile. The first step is to show up!"
- "I let family and friends know how I'm doing so they'll know how to support me."
- "In a conversation, I can't always wait for the best timing to say what I want to say, or I'll forget it. I sometimes need to just get it out there and speak my mind, even if it's not the best timing."
- "When I have difficulty recalling names, I...
 - write the name down.
 - ask the person to repeat: 'Tell me your name again...?'
 - repeat the name to myself.
 - have familiar names written on a card in my wallet and study it.
 - try to be vague but still social: 'Hi how are you? I haven't seen you in awhile!'
 - say 'I have trouble with names.'
 - don't stress about it – I'll just be myself and if they care I don't want to be friends with them anyway.
 - use pictures on my smartphone to associate faces with names.
 - make associations based on the sound of someone's name, personality, or appearance to help me remember the name."

Giving Advice To Others Living With A Diagnosis

- "Be brave!"
- "Reframe your situation."
- "Build on your strengths."
- "Use humor and see the humor in it."
- "Recognize that once you have Alzheimer's, you're in a new phase of your life."
- "Understand that society needs to change in how it responds to this diagnosis."
- "Try to stay as independent as possible. The more times I do something the right way, the better I feel."
- "Leave a legacy to allow other people to understand who you are and what you're going through."
- "Acceptance means not giving up, and then knowing when to give up."

Staying Safe In My Home

- "I find my sense of smell and taste has changed, so I can't always tell when food in the fridge has gone bad (and can't remember when it was prepared). I have a friend or family member help me dispose of spoiled food as needed."
- "I routinely check the stove to ensure it is off and that the gas is turned off. Any day may be the day when I don't turn off the burners. Everyone's path with this disease is different, so I make sure to take precautions now."
- "I always use a timer when cooking, otherwise I end up with a bunch of burned pots!"
- "I make sure that safety alarms are up to date: smoke detectors, as well as carbon monoxide and natural gas detectors."

Staying Safe When Getting From Place To Place

- "I had to retire from driving because of my Alzheimer's. I had an accident and thank goodness nobody was hurt."
- "I've noticed changes in attention, response time, and physical ability that would make driving unsafe. I don't want the liability risk of driving with Alzheimer's."
- "When walking, I take the same route each time. I write down my route in advance and I use landmarks to orient myself."
- "Even in a taxi, I try to know the approximate route. One time I got in the wrong car service and ended up in a different borough before I noticed it!"
- "On the bus, I ask the driver to make sure it will stop near where I need to get off."
- "On the subway, I write down what stop I'm going to. Even if I'm traveling with someone else, I do the same thing in case we get separated in the subway."
- "If I get lost, I stop to take a breather to regroup and calm down. Above all, I have to be patient with myself. If needed, I ask for directions or call someone for assistance."
- "I wear a MedicAlert® NYC identification bracelet."

Caregiver's Guide to Enrolling in MedicAlert® NYC



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A caregiver helps the person they are caring for every day with all kinds of tasks and has countless roles. Whether it be grocery shopping, meal preparations, taking the person with dementia to the doctor or managing medication, caregivers have many responsibilities for that person's health and safety.

A caregiver's responsibilities can become very demanding and, over time, exhausting and stressful. The diagnosis of Alzheimer's disease or a related dementia affects not only the person diagnosed, but everyone who cares for them.

The MedicAlert® NYC Wanderer's Safety program provides identification jewelry for people with a diagnosis of Alzheimer's disease or a related dementia to protect them in the event that they wander, and also provides a valuable option specifically designed for caregivers. While completing the application for



A sample MedicAlert NYC Wanderer's Safety Program identification necklace for caregivers

their relative with cognitive impairment to enroll in the Wanderer's Safety Program, the primary caregivers can also apply to receive their own caregiver identification product. For members who are already enrolled, caregivers can submit a separate application filling out only the information in the optional caregiver enrollment section.

Caregivers should complete the entire section that pertains to their health, including medical conditions, medications, any known drug or food allergies, and emergency contact information.

Caregivers have a choice of a necklace or bracelet. While we recommend the bracelet for individuals with Alzheimer's or dementia who enroll in the program because it is difficult to take off on one's own, caregivers should note that if they select the bracelet for themselves that they should add an additional half inch to the wrist measurement, so that the bracelet doesn't fit too tightly.

Although we require current photographs of enrollees with cognitive impairment, caregivers do not need to submit a picture of themselves. When the application is submitted, the caregiver's information will be linked to the information that we have for the person they are caring for.

Taking advantage of this enrollment will help you have some peace of mind while at home or out in the community. In the event of an emergency where you are unable to care for your relative, your caregiver identification jewelry will indicate to others that you are the caregiver of a person with Alzheimer's or dementia, and that this person must be helped. Once the Wanderer's

Safety Program staff is notified of your emergency, we will contact the people that you have designated to assist with care until you are able to do so again. Additionally, the Wanderer's Safety Program staff can communicate your personal health information disclosed in your application to emergency responders.

The MedicAlert NYC Caregiver Service provides the following:

- A bracelet or pendant with an inscription stating who you are the CAREGIVER FOR ____.
- The 24/7 Emergency Hotline number, 800-625-3780, and family notification service.
- Your assigned alphanumeric code that will be linked to your personal health record.
- All the resources of CaringKind will be available to your emergency contact to help them provide care for the person with Alzheimer's or dementia in your absence.

Taking this precaution is an important way to take care of yourself and to give yourself some peace of mind that the person you're caring for will be attended to while you recover from an emergency. Scholarships are available for the initial enrollment of all new members and caregivers through generous support from the New York City Council and other funders.

Please visit caringkindnyc.org/wandersafety to learn more, download the MedicAlert NYC Wanderer's Safety Program application, or enroll in the program online. You can also call the 24-hour Helpline at 646-744-2900 if you have any questions or concerns.

Caregiving in the Chinese Community



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One day, I received a 60-year-old daughter's phone call stating that her 92-year-old mother woke up at midnight, packed her luggage and said she wanted to go home. She is living in her home with her daughter and son-in-law. However, the mother persistently said it was not her home and insisted she must leave. She was upset that her daughter wouldn't open the door to let her out and yelled at her and her son-in-law, which woke their neighbors. She repeated this nightly for two weeks, leaving her daughter and son-in-law feeling exhausted and helpless.

Although Alzheimer's disease occurs gradually, those affected may show sudden changes in behavior, especially in the middle stage of the disease. These unusual behaviors give unprepared families great distress and frustration, especially in the Chinese community. There is a lack of awareness of Alzheimer's; people think about Alzheimer's as a mental illness and a shameful thing. Therefore, they are resistant to seek help or medical treatment. This resistance gives Chinese caregivers more challenges and pressures.

There are several ways that Chinese caregivers can become better caregivers, while at the same time taking care of themselves. Here's how to start:

- **Become an educated caregiver.** As the disease progresses, new caregiving skills may be necessary. CaringKind offers Chinese programs to help you better understand and cope with the behaviors and personality

changes that often accompany Alzheimer's disease and dementia.

- **Know what resources are available in the Chinese community.** Managed Long Term Care, adult daycare programs, Visiting Nurse Services and Meals on Wheels can help you manage daily tasks.
- **Take care of yourself.** Take breaks each day, spend some time with friends, keep up with your hobbies and interests, eat healthy foods, and exercise as often as you can.
- **Join a caregiver support group.** Caregiver support groups provide you with a safe place to share advice and compassion with other caregivers, and to relieve your emotional distress. Call the 24-hour Helpline at 646-744-2900 to learn more about joining a support group.

Caregiving in the African American Community



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As a former caregiver and support group leader of two African American support groups, I am very much aware of the cultural challenges, myths, and barriers specific to the African American community when it comes to caring for a person with dementia (PWD). Myths, such as believing that

memory loss is a normal part of aging, delay an early diagnosis, which can result in missing out on treatments that are most effective in the early stages of the disease. These delays can also result in missed opportunities for advance legal and financial planning and establishing a care plan for the PWD and the family caregiver. A lack of advance planning can mean the difference between operating in dysfunction and chaos or having a quality relationship between the caregiver, the family, and the PWD. Quality relationships foster healthier outcomes for the caregiver, such as reduced stress and avoiding burnout or financial demise. Therefore, being educated about the disease and knowing the difference between normal forgetting and memory loss should be a priority for any caregiver.

When historical and cultural barriers, such as a mistrust of the system or simply feeling uncomfortable exposing personal family business, come into play, families miss out on the essential help needed to support caregivers in their journey. Help can come in the form of emotional support, financial support, professional support, or respite, but without it, the caregiver's well-being can be compromised.

So be educated, be prepared, and be supported in your journey by reaching out to CaringKind's dedicated staff of professionals who can direct you to educational seminars, support groups, legal planning, respite and more. No caregiver should have to do this alone.

Caregiving in the Latino Community



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“Yes, my mom has Alzheimer’s, but **NO** she doesn’t need the bracelet. She isn’t that bad yet.”

“My dad doesn’t need a home attendant. I can take care of him myself! No one will care for him the way I can. He provided for me my whole life so I will take care of him.”

If I had a dollar for every time I’ve heard those phrases, and countless others like them, I would be living comfortably in a tropical setting. As Latinos, we assume the responsibility of caring for our loved ones with an unrivaled passion. We cannot be turned from what we feel is our duty. Culturally, it is frowned upon if you are **NOT** taking care of those who provided for you.

So many of us assume the caregiving responsibility without fully understanding what it will mean and are not prepared to fulfill this complex and exhausting task. Often, caregivers have their own medical conditions that require attention. It is not unusual for caregivers to neglect themselves because every waking moment is dedicated to the care of a family member. However, if you become ill, who will care for your mother or father?

We at CaringKind completely understand the caregiver’s perspective. We help make the caregiving experience a better one for both the person with dementia and the caregiver. Our Helpline is available to you 24 hours a day. Our Social Work Services staff will work with you to guide you and put you in touch with the specific resources and tools you will need to care for your loved one. Our Family Caregiver Workshops provide a foundation of knowledge and practical tips so you can provide the best care to your relative, and take care of yourself as well.

You don’t have to work yourself to an early grave caring for someone. We are here to help. We *can* help. All our services are provided by bicultural and bilingual dementia care specialists, who can provide guidance in Spanish. Call our 24-hour Helpline at 646-744-2900 to speak to a caregiving professional today.

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Interview with Dr. Max Gomez



DR. MAX GOMEZ

Dr. Max Gomez is an Emmy Award-winning Medical Correspondent for WCBS-TV with more than 32 years of experience. An expert moderator, speaker and emcee, Dr. Gomez is renowned for his clear, concise presentations of complex medical information to a wide range of audiences. Dr. Gomez is committed to helping the public understand and navigate the world of medicine, and healthcare and science.

Lou-Ellen Barkan (LEB): Max, how, with your outstanding credentials, including an NIH postdoctoral fellowship at Rockefeller University, did you end up on television?

Dr. Max Gomez (MG): When I had a year left on my grant, I realized I was going to have to get a real job. There were some research and academic jobs, but my interests were broader. At the time, I was head of the Young Alumni Committee for Princeton. We were running career counseling seminars, which got me thinking about doing things outside of academics. A Princeton classmate reminded me that I was a radio DJ and a news director at the college radio station. She said, "Well, you did radio and you like science. Why don't you try to do science and television?" And I thought, "That's a good idea."

Someone suggested I talk to a news director at WNEW, Channel 5 and to the editor-in-chief of *Popular Science*

magazine, who had been doing part-time work as a health and science correspondent. The news director agreed it made more sense to take a scientist and teach him television than to do it the other way around. I did a one-month informal tryout. That was 36 years ago.

LEB: To attend Princeton, your family must value education and excellence. How did your father influence your decisions?

MG: He influenced me in ways that were more indirect than parents today. My father influenced me by example. My parents were supportive, but not overly involved in my school life. I did what felt like the right thing and I had, fortunately, a peer group that was both academic and civic-minded.

My parents divorced when I was very young. My friends' parents became mentors and role models. One close friend had been recruited to play tennis for Princeton and convinced me to apply. On my own, I set up interviews and filled out applications and was accepted. For a Cuban kid from public school in Miami, Princeton was a big culture shock, but I adapted, graduated with honors, and the university became my doorway to mostly everything that followed.

LEB: Telling the story of how your father, who had Alzheimer's disease, was taken advantage of financially is so important. And coming from you, as a journalist, it made an even greater impact. It was a brave thing to do. When you went public with the story, did you think it was a story your father would want you to tell?

MG: He taught by example and I strive to do the same. Telling a personal story makes you more approachable, not some aloof television personality. You have vulnerability and are no different from anyone else. I've done stories about my skin cancer, my neck, and reflux surgery. Since I ask people to share their

stories publicly when they are at a very vulnerable point in their lives, it would be hypocritical to think that others should do this and I shouldn't.

LEB: You've won many awards. Is there one that is particularly special to you?

MG: The one that sticks in my mind is a little Lucite thing that I received from the New York City Department of Health for "Excellence in Time of Crisis," after 9/11.

It was clearly a very difficult time for every New Yorker. I can't tell you the number of people I had to talk off a ledge: viewers, friends and acquaintances who were stockpiling Cipro because there was Anthrax in the city. I worked with the Health Department, the Health Commission, and others from the Columbia University Mailman School of Public Health.

When Anthrax was found in our building, 30 Rock, people in the newsroom freaked out. Fear and anxiety levels were out of control in the city, but we were spending the first 20 minutes of every broadcast scaring the living daylight out of people and then, as my news director said, at the end of the show I had 90 seconds to talk them off the ledge.

I would interview some top people and if the segment ran two minutes, they wanted me to cut it to 90 seconds. I refused. If they could spend 20 minutes scaring everyone to death, they could give me enough time to tell people what they needed to calm them down; as their fear was a function of absence of control and knowledge. When I received that award, it was very meaningful, because I fought hard to get the information on the air.

LEB: At that moment, it's remarkable to remember that even though we were terrified, we came together as a community. Information gives people a sense of control, but it needs to be

accurate and come from a reliable source. For example, people believe that stem cells are going to be a therapeutic silver bullet for Alzheimer's. Is there any scientific validity about use of stem cells in Alzheimer's research?

MG: We were taught that you're born with all of the brain and heart cells you're ever going to have. But in the past 10 years, we've found examples of stem cells in the brain, in fat, in skin, in the heart, all over the place, so that the need for using *embryonic* stem cells has become much less. Most of the action has moved to *adult* stem cells, which don't carry the moral and ethical baggage of embryonic stem cells, plus they're far more available. And it turns out that with appropriate manipulation, we might be able to get them to do almost as much as embryonic stem cells.

Using stem cells in Alzheimer's therapies has promise, but the devil is in the details. In Alzheimer's there is a loss of certain cell populations in the brain. Early on, this is likely in the hippocampus, so step one may be replacing those cells or getting them to regenerate. Or maybe, if we start early enough, we can preserve those cells. Eventually, we may be able to detect the decline at an early stage, before the cognitive effects become so obvious.

Once the decline is obvious, the challenge is figuring out how to replace those cells. That's where the stem cells will come in, but that's only a piece of it. For all neurodegenerative diseases, the keys include arresting the underlying disease process, then replacing the lost cells and finally, those cells have to make the right connections. The good news is that stem cells often seem to have an uncanny ability to "know" what and how to make those connections if the cells are placed or regenerated in the right location within the brain.

LEB: Science is so complex and interesting, but we don't teach people how to understand what they read and hear. I actually still get calls from people suggesting that aluminum causes Alzheimer's or that coconut oil prevents it. We believe that people should learn to be discriminating consumers of science and medicine. How do you help them do that?

MG: I try hard to not just to tell people there's a new study and this is the conclusion: coffee is good for you, coffee is bad for you. If you wait long enough, the conclusion changes from week to week. I want to help people **understand** the how and why of how we got to that conclusion.

So much of science and medicine seems like a magical black box. You have a shot and suddenly you're healthy or immune to polio. The public needs to understand at least a little of the process, because if they don't, then they are susceptible to coconut oil cures and aluminum scares. Now it's even worse since the internet has become the repository and distributor of rumors and scientific half-truths. "Dr. Quackenbush" puts up a website that looks every bit as authoritative as the Mayo Clinic or Sloan Kettering, but he may be selling nothing but snake oil.

LEB: I meet people who never ask questions like "Who wrote the study? How many people were in it?" Intellectual discipline seems to have declined.

MG: One thing I hammer into my interns all the time is to "consider the source" as the first question. Number two is, regardless of where you read it, always go back to the primary source. I might read an article in *The New York Times*, for example, written by a well-known journalist, and after reading it multiple times, I've been shocked that it just wasn't right or missed the point entirely.

LEB: I believe that we shouldn't have anybody writing about science, unless they are truly scientists and/or medical professionals. This is why you are such a huge asset to our organization. We are so grateful for your consistent engagement and support.

MG: What motivates me is honoring my father, but there is also the issue of the coming Alzheimer's epidemic; that's the only way you can really describe it. If even half the numbers of those predicted to get Alzheimer's get sick, we are in big trouble. We will never be able to afford it. People need to know about the disease, about the issues and how funding for research and care should be allocated.

It's too late to help my father, of course, but my engagement might help others. That's why I donated his brain to the NYU Alzheimer's Disease Center. Why I helped him volunteer for some of the spinal fluid research studies, neurocognitive testing, and MRIs that he had done. I did it because I thought I could help others, and he did it because he trusted me and my judgment. I'm not sure if he fully comprehended the how and why, but he trusted me.

LEB: His faith in you is similar to what we all feel, when we turn on the news and hear your reports. We trust you and we know you have our best interests at heart. And we thank you for that and for talking with us today.



CAROL BERNE

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More than 30 years ago, CaringKind started its life as a New York City nonprofit organization, founded by family caregivers who needed support and guidance about a disease they and the public knew little about. Alzheimer's and other forms of dementia were rarely mentioned and even less understood.

Today, our support groups – almost 100 strong – are still the foundation for all that we do. Over time, we have built on this foundation and added personalized social work counseling, education and training programs, specialized workshops for family caregivers, a 24-hour Helpline knowledgeable about local resources, and The Harry and Jeanette Weinberg Early Stage Center for those with early memory loss or mild cognitive impairment.

Because we are located in the ethnically and culturally diverse New York City, we reach the Latino, African American, and Chinese communities with culturally competent programs. Throughout our long history we have remained dedicated to providing the best in dementia care to help families make the best decisions possible throughout the progression of this devastating disease.

As we return to our roots as a local, independent charity, we are proud and honored that the New York City donor community has truly embraced our cause. Every year, we raise roughly 90% of our \$10 million budget privately. These funds keep the lights on and the doors open, and cover our outstanding staff, including licensed social workers, Helpline specialists, outreach staff, dementia care trainers, and our support

group director – all integral to making our programs and services available and free of charge, to all who need our help. As one grateful client stated, “My mother was diagnosed with Alzheimer's ten years ago and your organization was a singular lifeline, serving varied purposes at many different points along the way in those first few tumultuous years. What you have going is pretty incredible and I shall always be grateful.”

As 2016 comes to close, and you consider your charitable priorities, please know that we are a lifeline for you today, and will be tomorrow. As we build on our 30-year commitment to New York City, we are proud to have pioneered a future for Alzheimer's and dementia caregiving that responds to the urgent needs of caregivers today. No one should have to face Alzheimer's or dementia alone.

Please read our Year-End letter on the following page and be as generous as you can. Your gift can also be a way to honor or pay tribute to someone important in your life. This year, 100% of your contribution will stay in New York City to support New Yorkers who need our help. On their behalf, I thank you for your support and your commitment to our work. We, and all New Yorkers, need you now more than ever before.

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 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 if you would like additional information.

Dear Friends of CaringKind,

One year ago, we left the Chicago-based, national Alzheimer's Association and returned to our roots as an independent, New York City organization. At that time, we were gratified that New Yorkers stepped up with over **one million dollars** in contributions, both large and small, to support our Year-End Campaign. And every dollar stayed in New York City to support New Yorkers.

This year, we ask you to do the same and, if possible, more. Together, we can save the lives of those who wander, enhance the dementia care skills of home care workers, change the culture of care in nursing homes, and transform the lives of dementia caregivers and their families.

As one client said, "I was at my wits' end with nowhere to turn, and the counseling, resources and ongoing support you provided made all the difference. I will always be grateful."

CaringKind remains steadfast in our commitment to deliver personal, high-touch programs, serving thousands of New Yorkers each year. Now, with 100% of every donation staying in New York City, we can ensure that you, your neighbors, friends and colleagues have access to the gold standard of dementia care, when and where you need it, 24-hours a day, and all free of charge.

Research indicates that dementia caregivers are at greater risk for anxiety and depression than those who care for persons with other medical conditions. At CaringKind, we provide in-depth, personalized consultations with licensed social workers, a 24-hour Helpline, an extensive network of resources and programs, close to 100 support groups throughout all five boroughs, caregiver workshops, and education and training seminars to provide the foundation for navigating the complexities of dementia caregiving. And, our Early Stage services ensure that a person with early memory loss has specialized programming, support and consultation.

In the absence of an effective treatment, the best therapy is good care, which we have provided to New Yorkers for over 30 years. Today, even with recent advances in research and greater awareness, we remain the only organization in New York City providing a broad range of customized programs and services targeted specifically to families affected by a dementia diagnosis.

With your help and support, we are proud to have made significant progress over this transformative year and we are pleased to share with you the following highlights:

- Our 24-hour Helpline responded to over 10,000 calls from family caregivers, persons with the disease, professionals in the field, and the "worried well."
- Our Social Work Services provided over 4,500 in-depth, personalized consultations.
- We enhanced our Dementia-Capable Palliative Care Program by establishing a Palliative Care Advisory Group, comprised of physicians, social workers, and community partners.
- Our Dementia Care Training for Professional Caregivers trained over 350 home care workers to become specialized in dementia care. Through our web-based job matching tool, Together We Care™, we connect families with aides trained by us.
- Our diversity outreach teams work in all five boroughs to bring public awareness and access to our culturally competent programs for the Latino, African American and Chinese communities.
- Our connect2culture® program advises New York City's finest art, theatre and dance institutions on how to enrich the experience for individuals with dementia and their caregivers.
- Our public policy activities are creating new alliances to support caregiver initiatives as well as federal funding for research.

Whether you have been personally helped by CaringKind, know someone who has or will need us in the future, today we need you more than ever. With your generosity, we can ensure that no one has to face the journey of dementia care alone.

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

Sincerely,



Lou-Ellen Barkan
President and CEO



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

P.S. Donations may be made at our secure website at caringkindnyc.org/yearend.

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 18 for further information or please contact Carol Berne at 646-744-2905 or cberne@caringkindnyc.org.

For more than 30 years, we have been a leader in dementia care, setting the gold standard.

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
- Long Island Alzheimer's Foundation (LIAF)
- Staten Island Alzheimer's Foundation (SIAF)



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.

Over the past few months, CaringKind has taken advantage of many opportunities to get the word out through the media about the work we do to ensure that caregivers in New York have the tools and resources they need to care with confidence.

Lou-Ellen has continued to explore a wide variety of issues confronting people living with dementia and those who care for them in “Care Chronicle” – a well-read monthly column that runs in several local newspapers, including *Manhattan Express*, *Chelsea Now*, *the Bronx Times*, *Caribbean Life*, *East Villager*, *The Villager*, *Times Ledger*, *the Brooklyn Paper* and *Downtown Express*. Her most recent columns covered the importance of advanced directives and other legal documents in preparing for the future and what to do when a person who has dementia insists on driving.

Lou-Ellen also continues to contribute regularly to *The Huffington Post*. In her most recent op-ed titled, “Our Short-Sighted Approach to Alzheimer’s Funding,” she wrote, “The lack of funding available to support an effective system of dementia care is an egregious oversight...If philanthropists, foundations, government and other funders play their part to support those who care for people with Alzheimer’s and dementia, a national crisis can be mitigated.”

The CaringKind Alzheimer’s Walks in Manhattan, Brooklyn, Queens and Staten Island were well covered by the media with stories on local news stations and borough-based media. Staten Island

Community Television sat down with Brenda Green, CaringKind’s Staten Island Outreach Social Worker, for a 30-minute interview about the Staten Island Walk and CaringKind’s programs and services. The Manhattan Walk, emceed by television news journalist Bill Ritter, was featured on television, online, and in print media, including WABC-TV, *The Wall Street Journal*, *El Diario Mexico*, and *World Journal*, a widely-read Chinese language newspaper.

Coverage of the July 25th Golf Outing at Glen Head Country Club which honored our good friend CBS 2 Medical Reporter Dr. Max Gomez appeared in the *New York Nonprofit Media* and in *Glen Cove Record Pilot*. The event raised over \$158,000 for CaringKind.

We also garnered solid media attention for two great new partnerships with Cure Alzheimer’s Fund, a nonprofit that supports and funds research utilizing a venture philanthropy approach, and MedicAlert Foundation. The “care and cure” alliance with Cure Alzheimer’s Fund will allow CaringKind clients access to state-of-the-art information and resources on medical advances in the diagnoses and treatment of Alzheimer’s. Pieces on the “care and cure” alliance ran on *New York Nonprofit Media* and *Alzheimer’s News Today*. Our

partnership with MedicAlert Foundation received nationwide coverage including outlets such as Yahoo! Finance, *Mercury News*, *Star Tribune*, *Journal Sentinel*, and *The Buffalo News*. MedicAlert Foundation will continue to be our ally in the NYC Wanderer’s Safety Program and provide the 24-hour identification and communication assistance to our community’s most vulnerable members.

CaringKind was proud to announce the recent appointment of Niurqui “Nikki” Mariano as the new Manager of Healthcare Outreach. Nikki was previously with CaringKind for over seven years, most recently as our Latino Outreach Manager, and we are excited to welcome her back. Nikki’s appointment was covered in *Newsday*, *Alzheimer’s News Today*, *New York Nonprofit Media*, *Geosnews*, and *LongIsland.com*.

Last, but certainly not least, Jed Levine was featured in a CUNY-TV episode of Science & U! His wide-ranging interview with award-winning reporter Donna Hanover explored many aspects of younger onset Alzheimer’s and how CaringKind helps caregivers and people with the disease. To watch a replay of the show go to www.cuny.tv/show/scienceandu.

2016 Annual Meeting – Traumatic Brain Injury: Prevention, Treatment, and the Consequences

On Tuesday, October 18, CaringKind hosted more than 200 guests at our 29th Annual Research Meeting. This year’s program was entitled “Traumatic Brain Injury: Prevention, Treatment, and the Consequences”. Dr. Max Gomez, CBS 2 Medical Reporter, moderated a discussion between panelists, Dr. Robert A. Stern and Dr. Sam Gandy, focusing on their latest research and the relationship of head trauma and brain injury to memory loss, cognition and dementia.



From Left: Drs. Max Gomez, Robert A. Stern, Sam Gandy

caringkind
Alzheimer's

Walk

On Sunday, October 16, we closed out our first Walk season under our new name. The CaringKind Alzheimer's Walks brought thousands of New Yorkers together in Brooklyn, Queens, Staten Island and Manhattan, all with the mission to #GIVECARE.

Sporting our bright new look, 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.

Thank you to our 2016 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 champion David Hyde Pierce, and all of our sponsors.

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- Our Town, Upper East Side
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- City & State New York
- Community News Group
- Home Reporter and Sunset News

Junior Committee Gala and Allocation

By **Laurel Crosby**
Junior Committee President



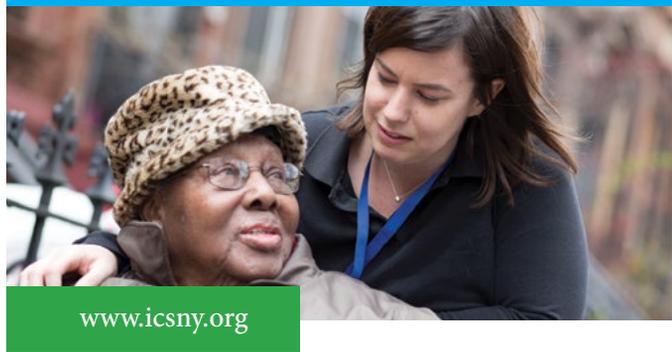
The Junior Committee (JC) is a network of young professionals who support and engage each other and the larger Alzheimer’s community, advocate for legislation, and raise funds to finance research and programs. As the 2016 President of the Junior Committee, it’s an honor to lead a dedicated group of young men and women - most of whom are impacted by an Alzheimer’s diagnosis - and champion their efforts to make a difference through our collective support of CaringKind. Along with our VP Brittany Krygowski, Treasurer JC Hay, and Secretary Maxine Squires, I am delighted to update you on our progress.

In August, the JC allocated \$75,000 to the following CaringKind services and projects: Dementia Care Trainings for Professional Caregivers, Family Caregiver Workshops, Healthcare Outreach,

rebranded CaringKind publications, and a Cure Alzheimer’s Fund research project.

On September 23rd, the JC stepped fully into the new CaringKind brand at our annual Gala. This year’s theme, Masked in Manhattan, was a throwback to a JC favorite with a classic masquerade ball, and provided a touchpoint to our support of the local community CaringKind serves each day. Our Gala Chair, Lauren Longobardi, led a fantastic Planning Committee, and together these dedicated volunteers helped us transform the Metropolitan West Ballroom into a night to remember for over 250 guests. The Gala was generously supported by People’s United Bank, who served as our Bronze sponsor and alcohol was donated by Svedka Vodka, The Prisoner Wines, Piper Sonoma, Stella Artois, and Michelob Ultra. Our other in-kind sponsor list is simply too-long to name, as we secured dozens of items for our gift bags and tables of Silent Auction items! CaringKind’s Executive Vice President Jed Levine provided opening remarks that introduced our guests to the new brand. The highlight of the evening came early on as we honored the four tremendous leaders who laid the foundation of this iteration of the Junior Committee. When the 2016 Executive Board of the Junior Committee formed back in January, we set out to champion the new brand of CaringKind, but it was equally important for us to preserve the amazing JC legacy that had been established by the 2015 Executive Board. And so, we were thrilled to use the Gala as a platform to honor former JC leadership Marielle Mindlin Bernstein, Julie Scherr, Gabrielle Maguire, and Maxine Squires, who has generously stayed on as our Secretary in 2016.

Independence Care System proudly supports CaringKind and its commitment to assist individuals and families affected by dementia.



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In total, Masked in Manhattan raised \$58,000, which is immensely significant now that every dollar raised stays with the JC until we allocate it to CaringKind programs! In fact, knowing that all of our fundraising efforts remain local has become a turning point in our Junior Committee support and fundraising efforts, and we’ve seen a renewed strength and commitment. I look forward to next opportunities we have to support one another and CaringKind as the Junior Committee, and to all left ahead of us this year!

2016 CaringKind Golf Outing

On Monday, July 25, CaringKind held our 5th Annual Golf Outing, sponsored by GCP Capital, LLC, at the Glen Head Country Club on Long Island. The event was a huge success, raising over \$168,000! As our 21 foursomes hit the course, they found Ron Duguay, Emmy Award-winning Broadcast Analyst and former NHL All-Star, on Hole 16, where he challenged them to a Beat the Pro contest. Although thunderstorms loomed, the rain held out until the end of the day when it was time for the cocktail reception and dinner. At the dinner, CaringKind honored Dr. Max Gomez, CBS 2 Medical Reporter, with the Community Partner Award for his outstanding dedication to Alzheimer's advocacy.

We could not have held this tournament without the help of our incredible Golf Committee. A special thanks to our Board member and Golf Committee Chair, Nathan Halegua, who started this event with us in 2011, and his fellow Committee Chairs, David Azus and Josh Halegua, for all of their hard work. We would also like to thank all of our sponsors for their contributions to the event. We hope to see you in 2017!



From left: Dr. Ken Kahaner; Nathan Halegua, CaringKind Board member and Golf Outing Committee Chair; Ron Duguay, former NHL All-Star and Emmy Award-winning Broadcast Analyst; Dr. Alan Schechter; Stephen Beyer



CaringKind President & CEO Lou-Ellen Barkan presents Dr. Max Gomez with the Community Partner Award



Golf Outing Committee Chairs Josh Halegua (left) and David Azus address the attendees at dinner



From left: Michael Imperiale; Stephen P. Casper, CaringKind Board Co-Chair; Ron Duguay; Dr. Max Gomez, CBS 2 Medical Reporter; Allan Keene



John Fiore and CaringKind Board member Marianne Dziuba-Fiore

How Support Groups Can Help



ABBY NATHANSON
Director of Support Groups
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It's common to feel alone when caring for someone with dementia and to worry that you're the only one feeling this overwhelmed, or this angry, sad, scared and drained. It's normal to worry you're not doing a good enough job, or feel guilty for doing too much or too little. Often, we're angry at how much the situation is demanding of us. It can feel relentless.

Sometimes you find new meaning in being a caregiver, and wonder what will happen later when you're not always waiting for the phone to ring and will have to go back to your life. Sometimes it feels like no one understands how hard it is to witness and care for someone whose disease is ruthlessly taking away what's familiar.

When we add in the uncertainties of the cognitive and functional decline, coupled with the emotional and logistical challenges of taking care of someone with dementia, it can exhaust all of our energy and resources at times.

Friends and family can be invaluable supports during the often difficult experiences of caregiving. However, they may not always be emotionally or physically available, or understand what you're going through. Sometimes it helps to talk to someone *who gets it*.

So where do you turn? At CaringKind, we have a multitude of free services to

help you during this process, including support groups.

Support groups provide an opportunity to give and receive support from people who understand what you're going through. They are a great resource for people who are not actively in a crisis, have the desire and ability to connect with others and are generally functioning normally outside of the caregiving experience, though it's not the best way to meet everyone's needs. Our trained Helpline specialists and social workers can help you figure out if a support group is right for you. Sometimes when we talk to people about their situation, we recommend they speak individually with one of our trained Social Workers instead, because we think that will better support them in their situation.

At CaringKind, our support groups meet weekly or a few times a month, with the same people who are all making a commitment to attend regularly, so you have a chance to build relationships with other caregivers. Our support groups focus on the emotional connection between caregivers. We find that while people can usually get the information they need from our other educational programs and referrals, caregiving skills from our Family Caregiver Workshops and one-on-one emotional support from the Social Work Services team, our support groups are often the best place to connect emotionally with other people who understand the caregiving predicament.

It's not always a common practice in every culture to openly share your feelings with others. Many people are taught that sharing negative feelings makes them worse, is a burden to others, or makes them seem weak. Some people are so used to "thinking" about everything; they don't always know how they feel and that's ok!

At the end of the day, we all have feelings. By taking the time to put your feelings into words, and express them to other people, we gain a measure of mastery over them and have the opportunity to make choices about how to cope with them. We can end up feeling less stressed and more connected when we share our experiences with other people – the good, the bad and the ugly.

Learning to express your feelings to others can feel uncomfortable at first if you're not used to it, but like any skill, it gets better with practice, and the benefits are enormous.

Support group members tell us there are many reasons they're glad when they share their experiences with others:

- They learn healthier ways to manage difficult emotions.
- They realize it's ok to be sad, angry, guilty, resentful, relieved, or healed by the experience of caregiving.
- They meet their deep-seated, human need for social support.
- They see other people surviving what they're going through, and it gives them hope.
- They help other people survive what they're going through, and it gives them purpose.

Call our Helpline at 646-744-2900 today, and we can help you figure out if one of our close to 100 support groups across the five boroughs is right for you.

Interested in running your own group? If you're a former caregiver or a mental health professional and would like to learn more about getting trained to run your own support group, please give me a call at 646-744-2917 or email me at anathanson@caringkindnyc.org to find out more!

Supporting Cognitive and Emotional Health Through the Arts



MEREDITH WONG
 Manager of connect2culture®
 mwong@caringkindnyc.org

Connect2culture® at CaringKind seeks to enrich the lives of people living with dementia and their caregivers through the arts. Funded by the New York State Department of Health Alzheimer's Disease Community Assistance Program, connect2culture supports cultural and educational institutions that are already giving people with dementia and their caregivers opportunities to engage in art through guided experience. It also helps organizations create programs that invite diverse perspectives and responses, and assists caregivers in identifying and exploring existing programs appropriate to their interests and needs.

I am excited to be in a position where I can support different types of organizations that encourage this population to make time for creative exploration in their busy lives. Participatory programs like those in many of New York's cultural institutions seek to create a space where self-expression is encouraged, helping to reassure participants that their responses are valid and welcome. Program participants often tell me how appreciative they are to spend time discovering a work with an educator's guidance. When I visit a museum, I prefer spending time with a small number of my favorite works, rather than rushing to see everything in the galleries. It's much more meaningful to take time to visually explore a work of art, to think about the artist's choices and to connect

it with personal experiences, or just to appreciate the artist's vision and imagination. These are some of the ideas that museums hope their visitors take away with them as they walk through the galleries.

When a visitor expresses a unique perspective or draws attention to a part of a painting that they connect with, they take ownership of the program in that moment. Perhaps they discuss the meaning of a gesture or another of the artist's creative choices. When participants are asked to talk with their partner about a work, it's gratifying to know that art was at the root of the interactions. It's then that I know how meaningful this experience is to them. Caregivers are given the freedom to think about something creative and fun, and to engage with the person they are caring for in a different and sometimes new context. Gradually, as these participants become repeat program visitors, they develop friendly relationships with museum staff, from the security guards to education staff, and also become familiar with the galleries.

Facilitated gallery discussions and art-making experiences give visitors alternative ways of appreciating works of art. While one person may understand artistic concepts by just looking, another may find it easier and more enjoyable to experiment with the ideas by using a piece of clay or a paintbrush. Educators also have been increasingly integrating movement and music into their programs to help bring a work to life. For example, a pair of jazz musicians enlivened an exhibition of abstract paintings that had similar visual energy. In a separate exhibition, participants mirrored the synchronized

movements in a contemporary video installation to feel the rhythms set down on paper by its choreographer.

For museums and other cultural organizations, connect2culture offers ongoing trainings and discussion forums specifically tailored to the educator's needs and those of the general museum staff. In addition, an annual symposium brings together educators and other interested professionals to discuss current issues and research, best practices, or perhaps to participate in a model tour.

We look forward to growing this program through partnerships with local organizations, and by talking with and supporting museum colleagues so that they may better serve this audience. We are pleased to welcome educators from other learning environments – living collections such as aquariums, zoos and botanical gardens; performing arts organizations; and history and natural history museums – who will bring diverse voices to the conversation and help to broaden the reach of connect2culture.

Connect2culture holds a unique position at CaringKind, building relationships between cultural institutions and people affected by Alzheimer's, and also facilitating new conversations and interactions through the arts.

For a list of programs that connect2culture supports, please visit caringkindnyc.org/connect2culture.

The Value of Training



AMY TORRES
Director of Training
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Family members, friends, and professional caregivers who regularly interact with a person diagnosed with Alzheimer's or dementia understand how complex and multifaceted the condition can be. Most caregivers may be at a loss on how to best communicate and interact with that person to preserve their existing relationship or create new connections. CaringKind's training programs seek to highlight the importance of preserving the person with dementia's "personhood" and to help caregivers develop and understand the world through the lens of somebody with dementia. CaringKind's training department offers two distinct tracks of training: the Family Caregiver Workshop and the Dementia Care Training for Professional Caregivers.

The Family Caregiver Workshop is a 10-hour training program designed to educate family members and friends who are actively involved with the care of a person with dementia. This workshop provides the information, tools, and skills necessary for the caregiver to manage personal needs while at the same time supporting the person with the illness. The workshop meets once a week for four weeks, two-and-a-half hours per session. Each session covers a key component to good dementia care; the topics include understanding dementia, enhancing communication, managing challenging behaviors, and self-care. Each session builds on the previous one, so that participants can best tackle the

issues around the disease that most affect them. Participants are encouraged to share and learn from each other, while simultaneously providing the emotional support that is necessary to meet the challenges of caring for someone with dementia. Family Caregiver Workshop participants are invited back quarterly for follow-up sessions; the goal of these sessions is to provide participants with the opportunity to reconnect with fellow caregivers, brush up on important topics, and receive the most up-to-date information about dementia care.

The Dementia Care Training for Professional Caregivers (DCTPC) is one of our most successful and sought-after programs, and it has evolved significantly since its inception over 20 years ago. The training program for direct care workers – home health aides, home attendants, and certified nursing assistants, among others – meets for one full day a week for six weeks, totaling a 45-hour commitment. It is capped by a graduation ceremony and celebration in the seventh week. The DCTPC stresses the importance of building skills and understanding dementia from an emotional point of view, as well as from a practical one. The goal is to ensure that persons with dementia receive the highest quality of care possible. Graduates are invited back for quarterly follow-up sessions where lessons are reinforced and their successes and challenges are shared and explored. Graduates are also eligible to participate in CaringKind's web-based employment resource, TogetherWeCare.com, which matches families with trained professional caregivers who have completed our training program.

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Knowledge is Power



MARILUCY LOPES

Manager of Education
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CaringKind's educational programs aim to empower caregivers by making sense of their experiences with dementia. When caregivers are thrust into the world of dementia, they may feel confused or lost. However, caregivers often uncover that they hold crucial information about those they care for. Sometimes, the difficult part is making sense of information and understanding its value. Some caregivers may find themselves asking, "What is there to learn about a disease with no cure?" Lack of clarity or feelings of helplessness can make things hard. We wonder about what's happening to the person we are caring for. What kind of information might improve the situation? Are there things I

can or should be doing? After attending our free education programs, it starts to become clear.

Concentrating on facts and researched evidence can help answer tough questions. Our Understanding Dementia: What You Need to Know and Where to Go seminar is offered in English, Spanish and Chinese in Manhattan, Queens and Brooklyn, with more locations coming soon. This meeting addresses the difference between dementia and Alzheimer's and informs caregivers about the changes they can expect as the disease progresses. Other courses offered, such as the Legal and Financial Seminar and Medicaid Home Care Seminar: A Practical Guide to the System, are led by attorneys who specialize in elder law. They cover important topics including power of attorney, guardianship, Medicaid eligibility, long-term care insurance, healthcare proxy, the Medicaid Home Care application process, and more. The meeting titled Placing Your Relative in a Nursing Home educates caregivers about the steps involved in nursing placement.

Both professionals and caregivers are encouraged to attend our Monthly Education Meetings. The topics for these meetings vary and are based on issues caregivers and professionals would like to learn more about. Recent topics include: Activities for People with Dementia, Managing Challenging Behaviors, Early Stage Issues, and Dementia and Driving. Professionals are also encouraged to ask about our Continuing Education credit courses, which are recognized by the New York State Education Department's State Board for Social Work.

The power that comes with knowledge can answer questions, provide direction, and improve lives. CaringKind encourages caregivers and professionals to call our 24-hour Helpline at 646-744-2900 to register for our educational offerings. Please visit our website at caringkindnyc.org/education or turn to page 34 in this issue to view our upcoming educational opportunities calendar.

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Practices for Responding to Dementia Behaviors



ANN WYATT

Manager of Palliative & Residential Care
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We have been very gratified by the response to our new publication, *Palliative Care for People with Dementia: Why Comfort Matters*, which describes our work with three New York City Nursing Homes (Cobble Hill Health Center, Isabella Geriatric Center, and The New Jewish Home, Manhattan) to implement a palliative approach to the care of people with advanced dementia. As we have discussed in past issues, this approach is based on the groundbreaking model developed by The Beatitudes Campus in Phoenix which, using a comfort approach, identified a number of strategies specifically for people with advanced dementia living in residential settings. Care is based on knowing as much as possible about the individual with dementia, with full recognition that the resident may not be able to verbally articulate their needs, so they may express them in other ways.

We have learned that when we see "behavior," we should instead label it "distress." Typically, the term "behavior" is used to describe what someone with dementia is doing that is disconcerting or disturbing in ways we don't understand. "Behaviors" may include calling out, taking someone else's food, or hitting a staff member during bathing. Why does this matter so much? When we think "behavior," there is a tendency (however unconsciously) to assume the person has control over something he or she should stop. It is often hard in the



From left: Deirdre Downes, Isabella Geriatric Center; Sharon Blake and Maria Bennett, The New Jewish Home, Manhattan; Karen Harper, Isabella Geriatric Center; Karen Mitchell, Comfort Matters®; Liza Long and Robert Herel, Cobble Hill Health Center.

moment to understand that the person doesn't "know" why they are behaving in such a way. Our first response is often directed to stopping the behavior. When we think "distress," however, we are much more likely to think that something is happening to the person that is causing him or her to feel badly. Then we are more likely to focus on getting to the root of the problem and relieving the person's discomfort. Beatitudes offers specific practice improvements to address the needs underlying behaviors rather than the behaviors themselves.

All three of our partner homes have been working to implement these practices on their dementia units, and are currently working to achieve accreditation by Beatitudes (through their Comfort Matters® program) later this year. Our new publication is intended to share what we have learned with other homes, in hopes that they too will be inspired and assisted in adopting these practices. We have sent copies out to the more than 500 homes in New York State, and another 1,500 copies to individuals and provider and advocacy organizations in the metropolitan area, as well as throughout the country. Copies can also be downloaded free of charge at caringkindnyc.org/palliativecare.

As we have focused on this work over the past few years, we and representatives from our partner homes have made presentations both locally and nationally, including at the annual meetings of LeadingAge, the American Society on Aging, the National Consumer Voice, the Center to Advance Palliative Care, and, most recently, the Pioneer Network at their meeting in New Orleans this past August. Above is a photograph from that event.

Going forward, we have established a Palliative Care Advisory Group, composed primarily of clinicians with expertise in long-term and palliative care, to provide us with ongoing support and assistance in advancing the adoption of these principles and practices. Representatives from all three of our partner homes, and from the three hospice programs with which they work (Calvary Hospital Hospice, MJHS Hospice and Palliative Care, and Visiting Nurse Service of New York Hospice and Palliative Care), will also be participating.

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Marie Knapp 1930-2015
Daughters are what their mothers help them to become.
Joyce, Susan, and Nancy
caringkind The Heart of
Alzheimer's Caregiving

Today, there are nearly 400 Memory Chairs in Bryant Park (located adjacent to the New York Public Library on 42nd Street and 5th Avenue), and every chair tells a story. The Chairs have been dedicated to mothers and fathers, sisters and brothers, husbands and wives, and partners and friends – all of whom have been impacted by Alzheimer's disease or a related dementia.

The Bryant Park Memory Chair program is an opportunity to claim a special place in the heart of one of New York City's most celebrated parks, while honoring a loved one with dementia, thanking an extraordinary caregiver, or marking a special milestone in your life.

Your personalized plaque will be mounted on one of the chairs in Bryant Park, and inscribed with your personal message and the CaringKind logo. Not only will you contribute to the legacy of a loved one, but your donation will support the work of CaringKind, raise awareness about one of the most devastating diseases of our time, and support the ongoing efforts to maintain the beauty of Bryant Park.

For more information contact Crissy Vicendese at
cvicendese@caringkindnyc.org or 646-744-2927.
www.caringkindnyc.org/bryantpark



Dedicated to all the caregivers who never gave up.
Stay Strong!
Alex W.

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Thank you, Joe. You were always there for me.
Love, Terri.
"Joe will take care of it."

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New & Expanded Programs



connect2culture®

Works with art museums and other cultural institutions to provide programming for persons with dementia and their family caregivers.



Respite Specialist

Social Worker on our 24-hour Helpline provides guidance to families in need of a break from caregiving, referring to community respite programs and access to short-term financial assistance.



Training Offerings in Chinese

Will facilitate Dementia Care Training for Professional Caregivers and Family Caregiver Workshops in Chinese.



Social Workers

Added new staff to our social work department who will provide individuals and families with personalized support, information and guidance including care planning, counseling and advocacy.

Brooklyn

Dementia Care Specialist provides outreach and support to families in Brooklyn.



Staten Island

Outreach Social Worker provides education and support to families in Staten Island.



Queens

Outreach Social Worker provides education and support to families in Queens.



Bronx

Outreach Social Worker provides education and support to families in the Bronx.



New Helpline Specialists

We now have enhanced capacity in the CaringKind office to respond to more callers with information, education and support.



Expanded Education Programs

Our Education Manager is expanding our education offerings in Manhattan and the boroughs, creating new topics and responding to the needs of caregivers across NYC.

**Please call our
24-hour Helpline
at 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
community partners:**

AHS Caring Communities
Atria Senior Living, Kew Gardens
Carter Burden/Leonard Covello
Senior Program
The Elly & Brochie Kleinman OHEL
Heights & Hills
Queens Community House
Regional Family Center
Riverstone Senior Life Services
Selfhelp Alzheimer's Resource Program

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 3	3:30 - 5:30 p.m.	Queens
November 8	5:30 - 7:30 p.m.	Manhattan
November 11	12:00 - 2:00 p.m.	Manhattan
November 16	5:30 - 7:30 p.m.	Manhattan
November 16	5:30 - 7:30 p.m.	Northern Manhattan
November 16	6:00 - 8:00 p.m.	Brooklyn
December 7	6:00 - 8:00 p.m.	Queens
December 9	12:00 - 2:00 p.m.	Manhattan
December 13	5:30 - 7:30 p.m.	Manhattan
December 21	1:00 - 3:00 p.m.	Brooklyn
December 21	5:30 - 7:30 p.m.	Manhattan
January 5	6:00 - 8:00 p.m.	Queens
January 10	5:30 - 7:30 p.m.	Manhattan
January 13	12:00 - 2:00 p.m.	Manhattan
January 18	6:00 - 8:00 p.m.	Brooklyn
January 18	5:30 - 7:30 p.m.	Manhattan

Upcoming Dates Just for Professionals:

December 14	3:00 - 5:00 p.m.	Manhattan
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Upcoming Dates in Spanish:

November 9	6:00 - 8:00 p.m.	Northern Manhattan
December 16	12:00 - 2:00 p.m.	Manhattan East Harlem

Upcoming Dates in Chinese:

November 19	10:30 a.m. - 12:30 p.m. (Mandarin)	Brooklyn
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Placing Your Relative in a Nursing Home

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

Upcoming Dates:

Manhattan		
November 15	5:30 - 7:00 p.m.	
January 17	5:30 - 7:00 p.m.	

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:

November 3	5:30 - 7:00 p.m.	Manhattan
December 1	5:30 - 7:00 p.m.	Manhattan
January 5	5:30 - 7:00 p.m.	Manhattan

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 Series Dates:

Mondays	November 7, 14, 21, 28	5:30 - 8:00 p.m.	Manhattan
Tuesdays	November 8, 15, 22, 29	12:00 - 2:30 p.m.	Manhattan
Thursdays	December 1, 8, 15, 22	12:00 - 2:30 p.m.	Manhattan
Thursdays	January 19, 26 & February 2, 9	12:00 - 2:30 p.m.	Manhattan

Upcoming Series Dates in Spanish:

Fridays	January 13, 20, 27 & February 3	12:00 - 2:30 p.m.	Manhattan
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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 16

"What's That Supposed to Mean?" Communication and Dementia

- Learn how to detect changes in communication at different stages of dementia.
- Find out which visual and environmental cues can support daily activities.
- Uncover verbal and non-verbal ways to communicate.

Speaker: Lauren Volkmer, LMSW, CaringKind

December 12

Design for Dementia: Is Your Home Ready?

- Learn how design can increase function, safety, mobility and well-being.
- Explore hallmarks of dementia-friendly designs and how they can make caregiving easier.
- Understand the connection between home safety, furnishings, flooring, and memory cueing.

Speaker: Rosemary Bakker, MS, ASID, Director of ThisCaringHome.org

January 9

A Caregiver's Guide to Maintaining Oral Health

- Learn about the importance of oral care for individuals with dementia.
- Uncover home remedies and tricks to treat common causes of dental discomfort.
- Develop new ways to ease the need for dental treatments and care.

Speaker: Dr. James Soberman, DDS.

Legal & Financial Seminar

An attorney specializing in elder law discusses important topics 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 7	12:00 - 1:30 p.m.
November 21	5:30 - 7:00 p.m.

December 5	12:00 - 1:30 p.m.
December 19	5:30 - 7:00 p.m.
December 22	5:30 - 7:00 p.m.

January 16	5:30 - 7:00 p.m.
January 26	5:30 - 7:00 p.m.

Queens

December 7	12:00 - 1:30 p.m.
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Upcoming Dates in Mandarin & Cantonese:

Manhattan

December 15	1:30 - 3:30 p.m.
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The Heart of Alzheimer's Caregiving

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