

caringkind

The Heart of Alzheimer's Caregiving

FORMERLY KNOWN AS THE ALZHEIMER'S ASSOCIATION, NYC CHAPTER

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SPRING 2017

• Please Support Our Spring Campaign on page 19

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begins on page 7

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The expansion of
CaringKind's programs
is made possible
through a grant from
The New York State
Department of Health.



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Dear Friends,

I recently asked a dozen people to say the first thing that popped into their heads when I said "social worker." Not surprisingly, I got a dozen different answers: collaborative, compassionate, empowering, highly qualified, perceptive; building resilience, helping families, problem solving; advocate, counselor, educator; and coping skills.

At CaringKind, we are blessed with a staff that includes 18 licensed social workers who are the embodiment of those terms. Their knowledge and expertise touch every aspect of our services. From our educational programming and support groups to our counseling services and 24-hour Helpline, their training and skill set CaringKind apart from any other local organization working in the field of dementia care.

Not too long ago, I had a visit from a young woman – well educated, professional and articulate. She thought she could care for her mother all by herself. But being a dementia caregiver was much tougher than she had expected. When she called me, she was at a breaking point and needed help. After hearing her story, I suggested that she speak with one of our social workers. She was not receptive and asked, "What can a social worker possibly do for me?" I suggested that she give it a try and see how she felt after the first meeting.

Fast forward a few months. I ran into this same woman at CaringKind as she was coming from a meeting with her social worker. As she hugged me, she said, "You were right. I feel like a different person. I have someone to help me consider the decisions I have to make. My mother and I are both in a better place. I am so thankful that I listened to you."

People who don't understand the role of a social worker in the context of dementia care may not initially appreciate the value

they will add. But we have over 30 years of experience listening to thousands of clients thank our social workers for getting them through the most difficult time of their lives. We say, "If you've met one family dealing with an Alzheimer's diagnosis, you've met one family dealing with an Alzheimer's diagnosis." Our social workers know that good dementia care must be customized, personalized.

In this issue of the newsletter, to help you better understand how clients work with our social workers, we've created a fictional family and we'll follow them as they take advantage of CaringKind's programs to provide the best care for their families and themselves. This is a fictional family, not your family or mine. At CaringKind, we know that each family has different needs, circumstances, cultural backgrounds and problems.

The truth is, no matter who you are, social workers make an enormous contribution to your peace of mind and quality of life when you are caring for someone with dementia. They help you communicate better with the person with the disease. They teach you how to interview and find the right home care worker. They counsel you as you decide on the best long-term care facility as the end of life nears. They help you understand and accept your own feelings. They give you the tools you need to survive.

As always, I look forward to hearing from you, our clients, as you are counseled by our social workers, participate in our



LOU-ELLEN BARKAN
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programs and services and take advantage of our resources, all free of charge. Until then, I ask you to join me in celebrating our social workers and the work they do to make our lives better each day!

**Please support our
Spring Campaign
on page 19
and honor
someone you love
for Mother's Day
or Father's Day.**



Dear Readers,

Before a diagnosis of Alzheimer's or another progressive dementia, there is often an effort to deny or rationalize the momentary memory lapses and confusion. When the diagnosis is made, you are thrown into an experience that has been described by an early stage client as "a bombshell going off." It is frightening, disorienting and disruptive.

But until you are thrown into the experience, you cannot fully understand or prepare for a future that includes a diagnosis of a progressive dementia. And, it's hard to accept that there is nothing to significantly slow down the progression of the disease. True, we do have some symptom modifying drugs that are somewhat effective for some people, some of the time, but no therapies exist that prevent the disease, cure the disease, or stop the progression.

Medical science has triumphed in so many areas that we remain hopeful that there will be effective therapies. However, until such therapies exist, good care is the best treatment. After years of working with individuals and families affected by a dementia diagnosis, we have learned that with good care, people with dementia can experience better quality of life and with support, the caregiver can do the same.

CaringKind should be your destination whether you are worried about yourself or someone you know. Initially, we guide you to the best diagnostic resources. We educate you about what to ask, and what to expect. We help you navigate the increasingly complex system of health and long-term care throughout the progression of the disease. We can help if you are thinking ahead about the end of life and the services you and your family may need. And most importantly, we listen and we support you.

CaringKind's 24-hour Helpline, education programs, social work services and family caregiver workshops provide this guidance and expertise as our clients navigate the choppy and unfamiliar waters of dementia care. We help families and professional caregivers become skilled dementia caregivers. And just as important, we teach the skills of self-care, so that caregivers don't burn out or sacrifice their physical and mental health doing this exhausting and difficult job.

Our support groups are a lifeline, a safety net and a place where a caregiver is truly understood. Our MedicAlert® NYC Wanderer's Safety Program provides peace of mind, providing protection for the person with dementia and for the caregiver. Connect2culture® brings NYC's rich cultural resources to families with dementia in partnership with our finest museums, performing arts centers, and botanical gardens.

And, as the disease progresses and families need help to access the increasingly complex system of long-term care, CaringKind's 24-hour Helpline and personalized, customized social work services are always available for one on one care to get you the help you need, when you need it.

Finally, our work with three local nursing homes has brought our revolutionary Palliative Care program for Advanced Dementia to late stage dementia patients and their families. And after the death of



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the person with dementia, CaringKind is there to support the bereavement process, often complicated by the "long goodbye," which can last 20 years.

At CaringKind, we see a world where no one is afraid to ask for help. We offer a hand to hold, a light in the darkness. You don't have to take the long journey alone.

If you, or anyone you know, is struggling with challenges of symptoms or a diagnosis, make that call to 646-744-2900. I promise you, you will be glad you did.

Correction

In the previous issue, we stated "Our Wanderer's Safety Program enrolled over 25,000 people" in 2016. During 2016, CaringKind enrolled 1,792 New Yorkers in the MedicAlert® NYC Wanderer's Safety Program bringing the total enrolled to over 25,000.

Earlier this year, CaringKind announced the successful implementation of a new palliative care initiative for people with advanced dementia in three New York City nursing homes — Cobble Hill Health Center, Isabella Geriatric Center and The New Jewish Home.

Called Comfort Matters®, it was developed by Beatitudes Campus in Phoenix, Arizona and brought to New York by CaringKind which found funding for the project and coordinated the training, implementation and certification process.

News of the program was reported on hundreds of news and health websites around the country and was also the subject of an hour-long program on “Alzheimer’s Speaks Radio” featuring Jed A. Levine, Executive Vice President, Director of Programs & Services.

As Jed noted, “Whether it’s allowing residents to sleep until noon or giving them a favorite brand of frozen pizza at midnight, Comfort Matters puts the comfort of the patient first. This program is having an enormous effect on the quality of life in nursing homes.” We’re glad the media took notice!

CaringKind continued its outreach to caregivers in New York City’s many diverse communities. New Chinese-language caregiver training programs and workshops, as well as our English- and Spanish-language Understanding Dementia seminars, were featured on more than 100 local events websites and calendars. CaringKind’s dedication to meeting the needs of the Chinese-speaking community also inspired a Chinese Outreach Day and a Chinese Lunar New Year Celebration that received press in several well-read Chinese-language newspapers.

In a one-on-one, 30-minute radio interview with reporter Deb Gordon

of WCBS FM 101.1, Fresh 107.2 and the CBS Sports Network, President & CEO Lou-Ellen Barkan discussed the impact of Alzheimer’s and dementia on the lives of caregivers around New York City. The far-reaching interview focused on all aspects of CaringKind’s mission and the importance of good care in the absence of effective therapies or a cure.

Lou-Ellen has also continued to get the word out to caregivers through her monthly column, “Care Chronicle,” which appears in about a dozen local newspapers across the boroughs. Recent columns have focused on problems that affect the day-to-day lives of caregivers, including wandering and fraudulent schemes targeted at seniors.

As Lou-Ellen wrote, “Senior citizens are particularly vulnerable when it comes to the seemingly endless array of scams, schemes, and frauds prevalent today. If an older person is also coping with Alzheimer’s or dementia, the odds of being duped by a devious claim or offer increase exponentially. The best way to avoid falling victim to a fraudulent scheme is by being well-informed.”

Also bringing attention to the growing issue of fraud against seniors was U.S. Senator Kirsten Gillibrand who invited Lou-Ellen to participate in a “round-table” press conference on the need for protective legislation. CBS2-NY, FOX5-NY, NY1, and News 12 all covered the event.




The New York Nonprofit Media reported on the appointment of Brenda Green as our new Staten Island Outreach Social



Worker. Brenda, a longtime Staten Islander, is spearheading CaringKind’s Island-based social work services and introducing us to other local service providers.

CaringKind’s Senior Vice President of Caregiver Services, Matt Kudish, was featured on the Broadway World website for his expert perspective in a post-performance discussion following the play *The Mother of Invention*. Showing at the June Havoc Theater, the play focused on one family’s Alzheimer’s journey.

Finally, CaringKind continues to work closely with local media to assist when any person with Alzheimer’s or dementia wanders and becomes lost. Through our partnership with MedicAlert® and our contacts at local TV news stations and print outlets, the MedicAlert® NYC Wanderer’s Safety Program was able to bring public attention to these cases and contribute to the safe return of several missing persons over the past few months.

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George and Claire's Journey Begins: a Call to the Helpline – Step 1

Dear Helpline,

My husband, George, a retired mail carrier, just turned 75 years old. Both my children and two granddaughters have noticed that he is having issues with his memory. For example, my granddaughter recently got married and my husband misplaced the speech that he had written. My son had to speak on his behalf. George also forgot our anniversary this year, which was devastating because he has always gone out of his way to make it a special day. My husband has always been the backbone of our family and I'm not sure who to turn to for help. What can I do?



STEPHANIE ARAGON

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— Claire

Dear Claire,

Many families are in a similar position and I am glad to hear that you are reaching out to CaringKind for support. Although symptoms of Alzheimer's disease vary from person to person, if your husband is experiencing any problems with his memory outlined in the list below I would suggest seeking out an evaluation at one of the many diagnostic centers in New York City.

- Memory loss that disrupts daily life
- Difficulty planning or solving problems
- Forgetting how to do familiar tasks
- Confusion with dates, time or place
- Trouble with spatial relationships
- New problems with words in speaking or writing
- Misplacing objects and the inability to retrace steps
- Altered decision making; poor judgment
- Withdrawal from work or social situations
- Mood swings and changes in personality

When was George's last office visit with his primary care physician? Have you discussed these concerns with his doctor? If the doctor notices a significant change in your husband he might suggest further testing. There are diagnostic centers in the five boroughs where your

husband would be able to get a thorough evaluation. There George will be seen by a variety of specialists over a few visits. It would be best if you or another family member accompanies him during the visit since you will be asked to give a history of family illnesses. Physicians may request a CT scan or an MRI. The diagnostic evaluation goes into many aspects of health in order to rule out other illnesses. These details help to focus on what might be the cause or causes of your husband's memory issues. Medicare will pay for the evaluation as he is over 65. With a full evaluation you will be better able to deal with George's changes appropriately.

You can call our 24-hour Helpline at 646-744-2900 for assistance selecting a diagnostic center in your area. Once your husband is given a diagnosis you can also call our Helpline to register for our Understanding Dementia seminar. This is our introductory seminar which focuses on dementia and the resources and services that can help you and your family cope with the challenges today while you plan for the future. Feel free to attend alone or with your family but please note that the meeting will touch upon all stages of Alzheimer's disease and it is not appropriate for George to attend. If your husband is diagnosed with Mild

Cognitive Impairment (MCI) or early stage Alzheimer's disease, and is open to being in a group with other people experiencing similar changes in their memory, he may want to consider participating in our Early Stage Center. Also, remember we have various seminars and workshops that you can attend with your children as well as nearly 100 support groups throughout the five boroughs. We also have a Junior Committee, a group of young professionals who support and engage each other and the larger Alzheimer's community, which may be of interest to your granddaughters.

George and Claire's Journey continues on the next page...

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

Claire Attends an Education Seminar – Step 2



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"I hope this will be helpful," Claire thought to herself. She had just registered for the Understanding Dementia Seminar with the assistance of a Helpline Specialist. Claire knew something didn't feel right about her husband, George, and after he was diagnosed with Mild Cognitive Impairment (MCI) Claire felt like she needed more information. After reaching out to CaringKind, a Helpline Specialist suggested Claire attend the Understanding Dementia Seminar: What You Need to Know and Where to Go. Claire was unsure about what lay ahead for her, her husband, their children and grandchildren. She wondered if the seminar would be applicable to her situation. Would it be helpful? Would it result in more questions? Nonetheless, Claire decided to take the opportunity to learn more about dementia and what CaringKind could offer.

The night of the Understanding Dementia Seminar was Claire's first time at CaringKind. She was pleasantly surprised at how comfortable and inviting the space was. She settled into her chair and wondered what the relationship between her husband's MCI and dementia might be. The seminar began, and she listened carefully to the information the presenter shared. Claire learned about the differences and similarities between MCI, dementia, and diseases like Alzheimer's. She learned about the diagnostic process, disease progression, and medications for symptom management. Claire began to understand some of the issues her husband

faced, and recognized behaviors the presenter referenced as being similar to George's recent behavioral changes. Claire also found herself agreeing with concerns other caregivers shared throughout the seminar.

Claire realized that to understand her husband and meet his needs she was going to need support.

"I guess I'm not the only person who needs help," Claire thought. As the seminar came to a close, Claire had many different feelings ranging from sadness and anger, to relief and clarity. Claire described feeling a step closer to understanding George. "I know he's been having a hard time managing the bills and gets confused with dates a lot, but I didn't understand why that was happening or what I could do about it," she shared with the presenter.

Claire realized that to understand her husband and meet his needs, she was going to need support and George was going to need more than just help with managing bills. Among many things, he would need legal and financial support in the form of a durable power of attorney and a healthcare proxy. Claire felt supported when she learned she could return to CaringKind for a Legal and Financial Seminar that would address topics such as power of attorney, health care proxy, guardianship, Medicaid

eligibility, long-term care insurance and more. She felt even more supported when she learned there were several other educational seminars for caregivers. The Medicaid Home Care Seminar walks caregivers through the application process for Medicaid home care service, and the Placing Your Relative in a Nursing Home Seminar educates caregivers about the steps involved in nursing home placement, paying for care, easing the transition and becoming a successful advocate for the resident.

Claire also learned that CaringKind hosts a Monthly Educational Seminar with rotating topics based on concerns voiced through the 24-hour Helpline. Recent seminars have included topics such as: managing behavior, communication and dementia, home design for a person with dementia, oral hygiene, meal planning, and more. These seminars are suitable for both family and professional caregivers.

Claire felt relief when she learned CaringKind provides all their educational seminars, programs and services such as social work services, support groups, workshops and caregiver trainings, free of charge. She arrived home and called her children. She encouraged them to register for the Understanding Dementia Seminar, which they eventually did. Claire also shared information with George about CaringKind's Early Stage Center. Claire felt the Understanding Dementia Seminar helped scratch the surface of what the future held for her and her family. For the first time in a while, she felt a sense of direction and that CaringKind could help pave the way.

George and Claire's Journey continues on the next page...

George and Claire Discover the Early Stage Center – Step 3



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"I think it's about time I face up to this," George told an Early Stage Center (ESC) staff member. "For a long time I didn't think there was anything wrong, even though my wife kept pointing out all these little things I was forgetting. I thought this was just what happened when you get older. Now I can see how all those little things have added up." George, a retired mail carrier, had reached out to us after his wife Claire had attended an Understanding Dementia seminar and came home with information about The Harry & Jeanette Weinberg Early Stage Center programs. After an initial phone assessment, George and Claire came to CaringKind to meet with staff about the possibility of joining a group.

George's initial diagnosis, obtained through a series of tests at a large Brooklyn diagnostic center, was Mild Cognitive Impairment (MCI). People with MCI generally experience mild changes in their memory, language, and thinking abilities that are measurable, however, these changes are not severe enough to significantly affect their everyday activities. MCI increases the risk of developing a more severe condition like Alzheimer's disease (AD) in the future. Several years after George's MCI diagnosis, he began noticing major changes in his functioning. After a minor accident in the car, he stopped driving, but he was still able to take the train and bus by himself. He noticed difficulty doing simple, familiar tasks like keeping track of appointments and calculating a tip in a restaurant. He returned to the

diagnostic center for more testing, and at that time was informed that his MCI had indeed progressed to early stage AD.

George told the ESC staff member that he had been devastated to learn that his MCI had progressed. He felt betrayed. He had taken the doctor's recommendations seriously. He took his medication regularly, he did crossword puzzles (which he had always enjoyed), and he stayed physically active (by going to the gym). He and Claire also started going to a social dance program at their local senior center. He wondered whether it was worth continuing to do these things if he was going to progress anyway. The ESC staff member validated his feelings of frustration and anger. The ESC staff member also pointed out George's strengths: his wry sense of humor, his social connections with a wide circle of friends and family, and his willingness to reach out for help.

"I thought this was just what happened when you get older. Now I can see how all those little things have added up."

George decided to join a MemoryWorks® group. MemoryWorks provides mentally stimulating exercises, like word puzzles and trivia questions, which help keep the brain active and alert. George asked if MemoryWorks would make his memory better, or make his AD progress slower. Unfortunately, there is no evidence that any type of medication or brain exercise can slow or stall the underlying progression of AD in the brain. What the group can do, however, is provide a socially and mentally stimulating experience that connects people with

one another, and makes them feel good about their own abilities. Participants have reported an increase in self-confidence as well as a profound relief that they can look around the room and see a group of others who are living and coping with their condition with grace, humor, and dignity.

George went on to become an active member of the ESC community. He participated in the weekly MemoryWorks group for several years, rarely missing a session. He often said that the day he came to the Center was his favorite day of the week. He frequently arrived early for groups and stayed afterwards to have lunch with other participants. His sense of humor and witty social banter, honed over so many years with the customers on his mail route, continued to shine through despite his cognitive difficulties.

Over a long period of time, staff began to notice that George was struggling more and more to participate in the MemoryWorks exercises. Other participants noticed it as well. He no longer left the group feeling positive about his own abilities. He also began having difficulty traveling by himself, and he became tired more quickly. ESC staff connected George and Claire to a different program closer to their home. George was still very much able to be social and to use his fabulous sense of humor, but he needed a different, more supportive setting to better meet his evolving needs. The ESC staff was extremely sad to see him leave, but also grateful for the time he spent in the program. Staff also referred Claire for additional CaringKind services, so that our organization could stay connected with George's family and continue to provide information and support.

George and Claire's Journey continues on the next page...

George and Claire Attend a connect2culture Program – Step 4



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When we're involved in the activities that make us happy and give us purpose, we are motivated to stay engaged with the world around us. However, when dementia affects a family member, these fun experiences are often put on the back burner, being replaced by doctor's appointments, caregiving issues, and a growing number of stressful situations that require attention.

After George was diagnosed with early stage Alzheimer's, his family became concerned about his ability to function independently. He eventually withdrew from his daily routines and interactions with family and friends. He had become quiet, no longer enjoying walks along his old postal route. Now, he just wanted to stay at home and listen to music.

After CaringKind's 24-hour Helpline assured Claire, George's wife, that she had come to the right place for advice and support, she was referred to other CaringKind programs for further assistance. Claire was interested to hear more about connect2culture®. This initiative helps cultural institutions around New York City create programs for people living with dementia and their caregivers. This would be a great opportunity for both Claire and George to enjoy each other's company away from the doctors and other stresses that now seemed to define their daily schedule.

Claire, who loved to spend time in their community garden, and George, who had enjoyed being part of the community while working for USPS, learned through connect2culture about an afternoon program at the Brooklyn Botanic Garden

where they could enjoy being outdoors together. They asked their oldest child, Lily, to join them.

Annabel, the educator leading the program, warmly welcomed the family to the botanic garden, giving each a name tag to create a sense of comfort within the group. Claire appreciated the gesture, knowing that George needed a bit more prompting to catch his attention. While they waited with the other participants, Claire talked with some of the other caregivers. It was comforting to talk with someone who understood. The caregiver she spoke to told her about other programs that she and her husband enjoyed, like JM Journeys at the Jewish Museum and Mindful Connections at the Rubin Museum of Art. She had heard that the Queens Museum had also recently started a program which she planned to look into. There were a growing number of programs around the city, and connect2culture was a great resource for exploring them.

As soon as the group was assembled in a quiet corner of the education center, Annabel guided the group to the Japanese garden. After talking about its design, she asked the group how they felt about it. Was this a place they would want to explore? George and Claire shared a memory of a similar garden they had seen on a trip to Japan with their children. Claire made a note in the notebook she always carried with her to look at the photo album of that trip with George when they got home. They might reminisce about other experiences they had enjoyed on the trip, like the rows and rows of fish at one of the world's largest fresh fish markets or the smell of incense in the quiet temples that they had visited.

Annabel's next stop took them to the Fragrance Garden, where they were encouraged to touch and smell some of the well-tended herbs and spices. Some people started to make connections

to smells that they had grown up with, memories of favorite dinner dishes. Reluctant to interrupt these wonderful memories, Annabel took everyone back to the classroom where she gave them tools and supplies to pot herbs that they could take home. Claire immediately recognized the strong perfume of rosemary that filled the room as they entered. George also smelled something, but couldn't identify it. It smelled like the apartment did after Claire made her delicious rosemary chicken for dinner.

As they sat at the table, and Annabel talked to them about the herb they held in their hands, Claire, George, and Lily all felt relaxed and content. Rubbing the rosemary leaves through their fingers, smelling the slightly spicy scent of the oil on their skin, made all three of them enjoy the moment. They dug their fingers into the soil and worked together to make sure their rosemary was firmly planted before taking it home. The earthy smell and sensation of the moist soil around his fingers made George happy. While Lily lived and worked in Manhattan, she was glad to have taken the afternoon off to share this experience with her parents.

This program gave the family a chance to walk in a safe and welcoming environment that was not too far from where they lived. Claire was happy that this program was practically in their backyard. The logistics of traveling around the city had become a challenge, so to learn that this was just a short distance from their house was a relief. The garden gave the whole family a sense of calm to be outside, relaxing, learning, and being around other people. George listened to the birds singing, smelled the fresh cut grass, felt a breeze on the back of his neck, all the while holding his wife's hand as Lily walked beside them.

George and Claire's Journey continues on the next page...

George is Enrolled in the MedicAlert® NYC Wanderer's Safety Program – Step 5



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On December 19 at 5:30 a.m., MedicAlert® received a call from the New York City Police Department Missing Persons Unit. A man by the name of George was missing from his Brooklyn home. His wife, Claire, had notified authorities that his wallet with identification was left on their kitchen table. George was out there alone with no way to identify himself. The MedicAlert Emergency Response Team searched the national database, but his information was not in the system. A “Missing Person Not Enrolled” report was immediately generated with pertinent information about George: name (George), gender (male), age, physical description (5' 10", 165 lbs., medium build, brown eyes, salt and pepper hair), address (lives near the intersection of Altantic and Washington Avenues in Brooklyn), primary language (English) and the clothes he was wearing (blue pants, black coat, hat, shoes, and beige over-the-shoulder satchel).

The police department confirmed they had canvassed the area around his home and the surrounding hospitals and there had not been any sightings of George. The police department granted permission to send out a missing person bulletin.

As per our protocol, the MedicAlert® NYC Wanderer's Safety Program received a call from our partners at MedicAlert® informing us that we had a missing person who was not enrolled in the program. I asked for the report to be emailed so that

I could follow up with the family. The holiday season was in full swing with busy city streets and very cold temperatures. I was concerned about George's safety.

I picked up the phone and called George's wife. I introduced myself and informed her I would be working with the police department to help locate her husband. Although this was a difficult time for Claire, and she might not be thinking too clearly, I needed to ask some follow-up questions to ensure we had all the information about George we needed. Through that questioning I learned that George was a veteran and former employee of the United States Postal Service. He had worked as a mail carrier in the Bronx, Brooklyn, and Manhattan until he retired several years ago. Claire confided in me that she was feeling very guilty because she procrastinated and never enrolled George into the Wanderer's Safety Program. With the history Claire provided she helped me better understand George and where he might be heading.

I asked Claire's permission to send a Missing Person bulletin to the media: TV, radio and newspapers. She readily agreed and asked her daughter to email me a photo of her father from her iPhone. I started to send out missing person bulletins throughout the five boroughs and Long Island. Our social media department also posted the information on Facebook and Twitter. Lastly, the public relations firm we work with quickly got the story and photograph out to the media.

It was getting dark and cold outside and snow was in the forecast for later that night. Claire's family was getting progressively worried and concerned about George's well-being. After the first 24-hours, everyone became extremely worried and anxious. Time was of the essence.

On December 24, a social worker from North Shore Hospital in Valley Stream was informed by a colleague that NY1 aired a report about a missing person who had gone missing three days earlier.

The person's name was George and fit the description of a patient who had been admitted to her unit three days earlier. It was in fact the same George and he had been admitted to North Shore Hospital through its emergency room late on the evening of the day he left home, December 19.

He was found walking along the expressway. George was admitted with a diagnoses of dehydration and frost-bitten fingers. Thankfully the nurse had written down the number to call provided by the news anchor. The hospital called us and we were informed of George's whereabouts. We were going to be able to reunite George with his family!

During my follow up with Claire we quickly enrolled George in the Wanderer's Safety Program to be prepared for any future wandering incidents. I suggested that she speak with one of CaringKind's social workers to help create a long-term plan for his care.

George and Claire's Journey continues on the next page...



Social Work Services Assist Claire – Step 6



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After George was found safe at a local hospital, the Wanderer's Safety Program referred Claire to speak with a member of the social work team. Claire needed support following this traumatic experience and guidance as to what could be done to prevent it from happening again. When our social worker connected with Claire, she shared the story of what happened, a common one for those caring for people with dementia in the middle stage. George usually woke early in the morning, a habit acquired from his career as a mail carrier. Claire tried to wake at the same time, or even earlier, to prepare her husband's breakfast and often remind him that he no longer worked. But this time she woke to find that he was already gone. George was found, but Claire was understandably shaken by the experience. She spoke of how overwhelmed she had become as George's functioning declined, barely able to carve out a minute to herself, as he often followed her around the house. George also often wanted to go out, and Claire spent a significant amount of time arguing with him about the fact that it was no longer safe for him to do so alone.

As Claire was wrestling with her guilt about what happened, our social worker assured her that no one can care for a person with dementia every day, all day, without some relief. Not only was Claire entitled to her sleep, she also needed time to herself, to relax and participate in activities that restored her, both

physically and emotionally. Thankfully, George had been found safe and the social worker explained that Claire could now focus on crafting a plan to help her husband and herself.

Our social worker initially guided Claire in thinking about how to prevent George from wandering again. They discussed tactics such as removing cues that might prompt him to go outside, such as the presence of shoes and coats by the door. The social worker also introduced Claire to items such as door chimes and alarmed door mats that would alert her if George tried to go out, and confounding door locks, safety devices designed so that a person with dementia would not be able to use them.

As Claire was wrestling with her guilt about what happened, our social worker assured her that no one can care for a person with dementia every day, all day, without some relief.

Understanding why the wandering or "exit seeking" might have occurred in the first place was also an important part of preventing it. Wandering behavior often signals that a person with dementia needs something to do. A proud mail carrier for the U.S. Postal Service, George was used to rising early for his job. He loved being outside and active during the day, and his busyness continued when he returned home in the evenings, often socializing with friends and neighbors. The social worker explained that George's disease did not change his need for meaningful engagement and social activity. It may have been why he was often trying to leave their apartment or following his wife. He was looking for something to do, but he could no longer initiate an activity for himself.

The social worker suggested that Claire explore George's participation in a social adult day program, a structured, activity-based socialization opportunity for people with dementia. This would keep him engaged with others and provide respite for Claire to take care of her own needs. In addition to identifying such programs near the couple's home, the social worker counseled Claire about managing the cost, as she expressed concern given the couple's fixed income. The social worker introduced Claire to the concept of Medicaid, the only form of public health insurance that pays for this type of long-term care, and how George may become eligible for it in order to cover the cost of the day care, as well as home care.

This was a lot of information for Claire to process and she wanted to discuss it further with her children. Claire arranged for her son to stay with George while Claire and her daughter met with the social worker to discuss these issues and to begin making a long-term plan. Claire's children had been eager for her to have help with their father's care, as their full-time jobs made it difficult for them to do more. Meeting with the social worker allowed them to develop a plan for care and divvy up the tasks necessary to implement the plan. Their daughter agreed to set up a consultation with an elder law attorney to begin the process of planning for Medicaid, while Claire would make appointments to visit the local adult day programs in order to find the one that would be the best fit for George. Claire expressed a huge sense of relief at finally seeing a light at the end of what had become a very dark tunnel.

George and Claire's Journey continues on the next page...

Claire Participates in a Family Caregiver Workshop – Step 7



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While connecting with our Social Work Services department to craft a plan of care for George, the social worker discussed the possibility of Claire attending Caringkind's Family Caregiver Workshop. This ten-hour workshop is facilitated in four sessions and meets once a week in two and a half hour increments. It provides friends and family members the opportunity to explore best dementia care practices in a supportive, non-judgmental environment. Topics discussed include: communication techniques, managing difficult behaviors and creating meaningful activities. The workshop is available in the afternoons and evenings to accommodate a variety of schedules.

Session One: Claire registered for an afternoon session while her daughter stayed home with George. During the first session, Claire spoke about the difficulties she was having caring for George and expressed a sense of loss because she could no longer connect with him as she had during earlier years in their married life. She talked about a recent doctor's appointment where it was suggested

that George take medication to reduce agitation which would help inhibit his desire to wander. After having received some suggestions from our social work department, Claire asked for a delay in the prescription and was hopeful that during the workshop she would learn more about dementia and how to implement interventions that would prevent George from wandering again.

During this first session, the caregivers learned what dementia is and how it affects the whole person, memory, cognition, behavior as well as physical functioning. Claire reflected during the discussion that she had been frustrated with her husband because he could remember everyone's name on his mail carrier route but could not remember the names of their grandchildren. However, after learning how dementia affects memory loss, she understood why that would happen. Claire also began to recognize how much her emotional state affected the interactions that she had with George.

Session Two: Claire returned for session two where the group discussed common symptoms experienced by people with dementia during the middle stages of their disease as well as best communication strategies. She relayed that George had a compulsive need to leave their home in the early morning after working for many years with the postal service. She realized her reaction and emotional state was exacerbating the problem. Due to all of the care George required, she was not caring for herself properly, was not getting enough sleep and often woke up exhausted. When George would attempt to leave their home in the morning, she would become frustrated and argue with him, countering his desire to leave by

informing him he had been retired for years and had no need to be anywhere. Claire would speak to him at length, hoping to jog his memory. This frequent scenario always escalated into an argument. Claire's children would try to intervene in other ways, ranging from a tough love approach mandating that George "stay put" or pleading with him to remember he had to stay home so he wouldn't get lost.

During this second session, Claire realized how a person with dementia often mirrors the emotional state of those interacting with them. She now understood that recognizing and meeting her own needs was a crucial step in mitigating many of the problems she was experiencing. The group also questioned the value of arguing with a person with dementia, and connected how a caregiver's opposition to a person with dementia's view of reality will often increase agitation, anxiety and frustration.

Session Three: At the start of the third session, the trainer explained the common causes of challenging behaviors and strategies to alter those behaviors. Claire was very animated and smiled when she relayed how she applied the skills she learned in session two in the early hours of the day when her husband was determined to leave the house. She made an effort not to argue and instead connected with his emotional state. She also spoke slowly and said only one thing at a time. George responded well to the change in Claire's approach and even though he continued to want to leave in the morning, she was able to more easily redirect him five out of seven mornings. Claire reported feeling hopeful for the first time in a long time. She noted her children were cautiously optimistic and

Continued next page

Training

Continued from page 13

after witnessing her success, began to mimic her approach.

Claire was surprised to learn the many possible motivations behind her husband's behaviors. The group learned how the environment, the person with dementia's physical body and emotional state, as well as how caregivers can impact the person with dementia's behavior. She reported that she was going to call a family meeting and ask her children and grandchildren to be detectives with her and investigate all of the factors that might influence George's behavior. She wanted to develop a plan on how to best mitigate those factors.

Session Four: Claire reported that her family met and came up with many possibilities that may be contributing to George's most challenging behaviors, as well as a few interventions. Claire discussed the methods of managing behaviors she learned in the workshop

and using those principals, developed strategies for the family to implement. Strategies included holding off bed time for an hour to offset the early morning rising and using black out shades to obscure the early morning light. She altered her bed time so she was well rested when her husband woke up. She made sure her husband went to the bathroom before bed to reduce the need to go early in the morning. The whole family rallied and came up with possibilities. They all knew that they would have to maintain the dialogue as the illness can quickly precipitate changes in behavior.

During this last session, the group was presented with an opportunity to sum up all they had learned throughout the workshop. Basic concepts such as disease process, common symptoms, communication techniques and managing behaviors were reviewed. The caregivers explored how to use this information to support the person with dementia's

level of independence and capacity while engaging in an activity.

Claire explained how her husband had loved his job as a mail carrier and how she had thought up ways to bring that job back into his life. She decided to buy stickers, which would serve as stamps, paper, and envelopes for him to address and mail. Claire would ask his help in writing cards to family members and mailing them. She also allowed him to sort the daily mail. Claire also finally understood the importance of self-care and reported feeling that she forgot what it was like to do something for herself. She was encouraged to list self-care activities she would enjoy and to make a plan to implement them. Attending this workshop proved to be extremely helpful to Claire and her family.

George and Claire's Journey continues on the next page...



A story about bringing family *together!*

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Claire Joins a Support Group – Step 8



ABBY NATHANSON

Director of Support Groups

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“It was amazing to talk to other caregivers in the Family Caregiver Workshop,” Claire said to the Helpline specialist. “George’s disease came on so slowly, I didn’t realize how lonely and overwhelming it had gotten for me.” She had called the Helpline, looking for information about support groups. She had gotten a taste of what it was like to connect with other people who understood what she was going through in the Family Caregiver Workshop, and she was looking for a way to keep that going.

Like many caregivers, her early experiences with caregiving focused heavily on getting information and education about what was happening, and preparing herself for what would come next. While George was able to manage a lot of his own needs, she was still able to relate to him, at least sometimes, in familiar ways. As his disease progressed, and she had to take over more of his care needs, she realized that, while substantial, it wasn’t just the loss of time and energy in taking care of him that was draining her. It was also the loss of her ability to connect to her husband and to enjoy the retirement they thought they would have. Those losses were harder to wrap her head around, because her husband was still present, physically.

When Claire called the Helpline, she spoke with a Helpline Specialist who talked to her about how support groups work, and what she might expect if she joined one. The specialist explained

that the support groups are ongoing and focus on the emotional experience of caregiving, and that members make a commitment to attend regularly and to support each other. Claire also learned that each leader meets with prospective members to get to know them and make sure that the group is the best way to meet their needs. The specialist reviewed her availability with Claire, and Claire selected a time and day that worked best with her other responsibilities. Right after that, she received the contact information for the leader of that particular support group.

She wasn't sure what the conversation would be like and was intimidated about the idea of joining a group where everyone already knew each other, and she would be expected to share her struggles.

Claire hesitated to call the support group leader. She wasn’t sure what the conversation would be like and was intimidated about the idea of joining a group where everyone already knew each other, and she would be expected to share her struggles. She was worried about feeling burdened by the experiences of the other caregivers, or not being able to relate to what they were saying. What if she had it easy? What if no one else had the same crazy thoughts that ran through her head? What if they thought she was a terrible, unloving wife for being so frustrated with George and sometimes wishing she didn’t have to do this anymore?

Eventually, Claire called Mary, a long-time volunteer support group leader, who immediately put Claire at ease with her warmth and interest. Mary asked Claire questions about her relationship and her family, what caregiving has been like, and what Claire hoped to get out of

a group. She talked to Claire about the other caregivers in the group and the kinds of things they discussed. Claire felt understood, and some relief at not having to pretend like it wasn’t as difficult as it actually was, the way she did sometimes with family and friends.

Claire joined the group a week later. She was nervous walking into the room, but she remembered what Mary had said about trying three sessions to see if the group was a good fit, and focused on getting to know the other caregivers. She talked about her situation, and felt gratified to see other people nodding and to hear their words of validation and support. When others spoke about their struggles, she felt a connection, realizing that despite their different circumstances and backgrounds, the struggles of all caregivers are similar. After a few months, Claire noticed that she was less distressed during the week, knowing that she had a place to talk and be understood. Thanks to the other members, she had a new perspective on the difficulties she was having with her husband. It didn’t make the sadness of her husband’s decline less acute, but the group gave her strength to cope and to work on figuring out what the next chapter of her life would look like.

As her husband declined and his care needs changed, and his ability to relate to her became diminished, Claire was grateful to have the support of the men and women who came together a few times a month to share and provide support. She was also happy to have Mary’s guidance, which kept the group focused and connected.

George and Claire's Journey continues on the next page...

Claire Finds Help at Home Through Together We Care™ – Step 9



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After taking the Family Caregiver Workshop, Claire realized the value of training and how much the information positively influenced her relationship with her husband George. She felt more secure stepping into his world and validating his experience. She found that she could connect with George and establish a new type of relationship, different than the one they had experienced prior to his disease but very meaningful nonetheless. These feelings were validated even more through the connections she made in the support group she attended regularly. She found her group and sharing her experiences and feelings with other caregivers invaluable. It was through speaking to her fellow support group members that she realized she could no longer provide care for George by herself and reached out to CaringKind again for assistance.

While George had been attending a day program two days a week, Claire now realized she needed more help caring for him at home. Claire was provided with information about CaringKind's Dementia Care Training for Professional Caregivers (DCTPC) program. This 45-hour training program is specifically designed to empower professional home care workers to provide the highest quality of care to persons with dementia. The program provides direct care workers – home health aides, home attendants, certified nursing assistants, private companions and others – with

six full days of training that stresses the importance of understanding dementia from an emotional point of view as well as from a practical one. In lieu of meaningful treatment or a cure, the best treatment for persons with dementia is quality care.

In order for families to connect with these trained professional caregivers, CaringKind created Together We Care™ (TWC). This web-based program matches families with trained professional caregivers who have completed CaringKind's training. Families have the opportunity to create an account, log on and view profiles created by DCTPC participants who are seeking employment. To maximize search results and create good connections, families can filter search results by language and location.

After Claire created an account on TWC, she then had access to over a hundred profiles of professional caregivers who, having received training at CaringKind, shared her views on how a person with dementia should be cared for. One caregiver's profile in particular stood out to her – Ms. Cheryl R., who described herself as a morning person who loved to take her clients for walks, weather permitting. Claire contacted Cheryl and scheduled an interview in a coffee shop that was mutually accessible. During the interview, Claire was impressed with Cheryl's upbeat personality and extroverted nature. She saw how Cheryl would connect with her husband and decided to hire her on a trial basis.

Within the next several weeks, George became accustomed to his new caregiver and they were able to establish a routine that included walks around the

neighborhood after breakfast during which Cheryl would draw out stories of his days as a postal worker. When they returned home George would often turn to Cheryl and thank her for helping him with his route. He was then much calmer throughout the day, feeling accomplished because his morning “work” went well.

From Claire's perspective, she now felt more relaxed and well rested having someone trusted to depend on, who understood George's illness and could be sensitive to his preferences and needs. Hiring a professional caregiver provided her with the respite she so desperately needed. She found herself becoming more patient with George and was able to enjoy his company in a way she hadn't when she was responsible for all of his care. Claire was able to set aside some time for herself and enjoy some of the activities she hadn't been able to prioritize while being the sole caregiver. She scheduled a weekly brunch with her close friends and made sure she made time for her grandchildren, secure in the knowledge that George was receiving excellent care.

At CaringKind, we recognize the difficulties caregivers providing support to people with dementia encounter on a day to day basis. No single caregiver can accommodate the increasing needs that a person with dementia will have throughout the duration of their disease; it takes a team of caregivers – whether informal or paid – to provide that level of support.

George and Claire's Journey continues on the next page...

Claire Considers Residential Care for George – Step 10



ANN WYATT

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George had been able to live at home with his wife for many years after his original diagnosis, with increasing amounts of support not only from his wife, Claire, and their children, but also from various programs at CaringKind. Among these, help at home from an experienced and carefully trained aide that Claire found through CaringKind's Together We Care™ website and from the social day program that George attended and enjoyed twice a week. This has provided George with variety and the opportunity for socialization, and has helped his wife find time to both maintain the household and also take care of some of her own needs. Claire has faced some increasing health challenges as well. Recently, she was diagnosed with glaucoma and also has considerable pain when she walks, due to a worsening problem with her hip.

At this point, however, Claire started to feel overwhelmed, and worried that she wouldn't be able to keep up with George's increasing care needs. In addition, staff at the day program had reported that George appeared restless, unable to engage with many of the activities they offered, and was in need of more assistance with eating and overall participation. While the home care aide was a huge help, the family's budget did not allow for more hours of care to be added. Finally, their children were helping as much as they could, but lived in different boroughs and with children of their own, were limited in what they could do. After wrestling with

the decision, Claire eventually accepted that more help was needed.

In conversations with CaringKind's social work staff, Claire decided that moving her husband to a nursing home would be the right thing to do, to assure that his care needs could best be met. The social work staff member advised Claire to attend one of the many education seminars offered by the organization called, Placing Your Relative in a Nursing Home. In that seminar Claire was reminded that dementia is progressive and eventually terminal; the average time between diagnosis and death is eight to ten years, but there is extreme variability with some dementias lasting up to 20 years or more. Typically, about 40% of time spent living with dementia means living in the advanced stages. Someone who reaches the age of 80 and does not have dementia has an approximately 5% chance of spending time in a nursing home, whereas someone who reaches the age of 80 and has dementia has an approximately 80% chance of spending time in a nursing home.

Her CaringKind social worker then helped Claire think through the kind of residential setting that would work best for George. The social worker encouraged Claire to talk about her feelings of guilt and her worry about what others would think even though she knew this was the right plan. They assisted her in finding a place that was fairly easy for her and her family to get to. It was also one with a particular focus on comfort, including great flexibility in activities of daily living, such as when to get up, when to go to bed, etc. This type of care was particularly important for George, as he had a habit of rising early (and going to bed early too) from his career as a U.S. Postal Worker.

Walking has always been important, and in this setting walking is encouraged (and assisted, when necessary); there is an enclosed garden where he is able to spend some time as well. George has a lifelong love of music, and this home also has an iPod with a personalized playlist (via the Music & Memory Project) for him. Both George and Claire found relief and comfort in their new situation.

When a move to a nursing home is being considered, it is important for family members to realize that this is not about them giving up; it is about finding a way to meet the changing, increasing and often challenging needs for care that they are experiencing. Transfer to a nursing home means family members can now work in partnership with staff at the home, helping staff to know and understand as much as possible about the personal comforts and preferences of the person with dementia, while at the same time being relieved from some of the pressures of physical care and supervision, and thus more available to provide emotional support and comfort.

George and Claire's journey with CaringKind continued with the family using programs and services as they needed them. The family participated in the CaringKind Alzheimer's Walk, honoring George and Claire's journey.

Thank you for reading about George and Claire, a fictional family that represents how CaringKind helps people with dementia and their caregivers.



CAROL BERNE

Senior Vice President of Development
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As this issue is focused on the crucial role of social work services in the continuum of care, I would like to highlight the importance of our social work team in fundraising. I often receive calls from grateful clients who wish to make a donation after they have been helped. These calls may come shortly after a first session, mid-caregiving, or years later, when the client has had time to reflect on CaringKind's significant role in their caregiving journey. You should know that just like any licensed professional, our social workers are well-trained in dementia care before they ever counsel one client. Our reputation as the leader in dementia care depends upon a highly skilled staff. We know that counseling a caregiver is more than a brief one-time call. It is a series of lengthy sessions over time, as the disease progresses and caregiving needs change. Our social work staff is skilled in the basics of dementia and dementia care. They undergo a two-month rigorous training beginning with basic disease education, common causes of dementia (beyond Alzheimer's), the warning signs, dementia as a disease process, and common symptoms that one can expect to see throughout the stages. We also provide education on CaringKind's approach to communication.

Our social workers become experts in the community-based resources that support

our work, such as the various benefit and entitlement programs, and other legal and financial tools with which we often intersect and rely on to support our clients. The complexities of Alzheimer's require skilled professionals – the best in the field – to be able to successfully support our clients with personal, high-touch counseling as they navigate the complex, complicated and ever-changing problems with which they must contend.

When you support CaringKind, you are supporting the best in the business. You are supporting the gold standard of dementia care. There is no place else like CaringKind in all of New York City, and there is no place else that provides this level of high-quality care, free of charge. About 90% of our operating budget is raised from private support. This means that keeping our doors open, salaries paid, programs running, and reaching all five boroughs in many languages, depends on donations, both large and small.

**Please read our
Spring Campaign
letter on the next
page, and please
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that we are here
for you, your
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Thank you.**

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.**

Mother's Day & Father's Day Campaign

May 2017

Dear Friends of CaringKind,

It was my wedding day. I married late in life to a wonderful man whom I had dated in my 30s and who came back to find me as I turned 50. My siblings and I had lost our mother ten years earlier. Being the only unmarried child in the family, I had the joy and ability to spend lots of time with my father. We supported each other through numerous joys and disappointments.

Dad has been a man of great humor with a strong moral code that he instilled in us and challenged us to uphold. He worked for IBM for 33 years and was an active sailor, skier, and long-distance walker until age 79. He is now 85 and lives on Long Island in the house where our family gathers in the summer. He was a daily churchgoer until about 12 months ago when we took the car away. Then one day we found him sitting on the front porch at 3 AM waiting to be picked up by his friends for an 8 AM mass.



When we look back the signs of dementia probably started showing around 2012, several years prior to my wedding. Every week you would think this cannot get any worse. Then there it was – another odd, non-customary action that appeared as Dad struggled to keep his life together and tackle each day. This photo was taken on my wedding day. Dad walked me down the aisle, a memory I will always cherish. Then, as the photographer gathered the family together, Dad pulled a little note out of his pocket. On it was written, “Dana,” my husband’s name. Dad was determined to not forget Dana’s name on my important day. Oh, how we laughed and laughed together. At the wedding, my Dad was not able to deliver a toast; however, he did stand with my brother, who spoke the words they had worked on together: “Dana, you are in for a treat!”

Dementia has now overtaken most aspects of Dad’s life. He no longer has notes in his pocket, can dial the phone, or understand the calendar or concept of time. These are all gone. His caregiver, Suzette, is our lifesaver. We, his children, could not continue our active lives without her. Her knowledge, compassion and caring for our father is priceless.

But Suzette does not approach caregiving alone. She has CaringKind’s 24-hour Helpline to support her every step of the way. When Suzette feels overwhelmed or has questions about a challenging behavior, the dementia experts at CaringKind are just one phone call away. Licensed social workers and Helpline Specialists have been specifically trained in dementia care, and draw upon more than thirty years of expertise in the field. Through the Helpline, Suzette has learned about dementia, and how to care for Dad with confidence, and this has provided peace of mind for our family. And whether Suzette calls the Helpline once or many times, this life-saving service is free of charge.

My heart breaks for Dad, but we love him dearly and we know that he loves us. Although his verbal skills have declined, he said to me last month, “You know I love you, Margot.” We can’t cure Dad’s dementia, but we can do the next best thing. We can ensure that Dad has the best care possible and a good quality of life. We would be lost without Suzette, but knowing that Suzette has CaringKind’s expert staff to support her has made all the difference in our lives, too.

I share my story so that no one has to face dementia caregiving alone. A call to CaringKind provides a connection to caring professionals who will listen and provide confidential guidance, as well as referrals to a host of programs and services, such as support groups, social work counseling, family caregiver workshops, or education and training seminars.

Please join me in making a charitable gift to CaringKind. Your contribution ensures that CaringKind is here for you, your family, neighbors and friends if and when you need them. Thank you.

Sincerely,

Margot Carr

P.S. You can also make a secure donation online at www.caringkindnyc.org/SpringCampaign.

Partnership for New York City Breakfast

On January 18, Frank Bisignano, Chairman and CEO of First Data, and brother of CaringKind Board member, Elvira Bisignano, hosted a breakfast for CaringKind to introduce members of the Partnership for New York City to our work.

Lou-Ellen Barkan, CaringKind's President & CEO, spoke before more than 30 corporate executives about the importance of our work to New York City employers and business leaders and how our programs and services can be of help to their employees and families. Employees are caregivers and often have to make the difficult decision of reducing their workload, missing work, or even remaining in the workforce, to care for a relative with dementia. By contacting CaringKind, we can provide the counseling and resources needed to ensure that an employed caregiver has the tools to confidently navigate the complexities of dementia caregiving.

The Partnership for New York City represents the city's business leadership and its largest private sector employers. Working with government, labor and the nonprofit sector it promotes economic growth and maintains the city's position as a global center of commerce and innovation.



Bar Association Event

On January 24, CaringKind co-sponsored the 2017 New York State Bar Association Elder Law & Special Needs Section's Annual Meeting reception, providing an opportunity to introduce our programs and services to over 120 of New York State's elder lawyers.



Jed A. Levine (left) and Pauline Yeung-Ha (center), CaringKind Board member and member of the NYSBA Elder Law & Special Needs Section Executive Committee, converse with a fellow elder law attorney.



David Goldfarb, Chair of the NYSBA Elder Law & Special Needs Section, and Lou-Ellen Barkan address the reception attendees.

Research Update

On February 8, CaringKind Board member Lori Oscher Friedman and her husband, Eric Friedman, hosted a conversation with Dr. Richard S. Isaacson, Director of the Alzheimer's Prevention Clinic at Weill Cornell Medical College/New York-Presbyterian Hospital, for special friends and donors of CaringKind. Dr. Isaacson led an informative and lively discussion titled "Can we reduce the risk for developing dementia?"



From left: Dr. Max Gomez, Dr. Richard S. Isaacson, Jed A. Levine, Lou-Ellen Barkan, Lori Oscher Friedman, Eric Friedman, Dr. Robert Krikorian

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



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.

What Does "No Estate Tax" Mean?

by John E. Crilly, CFP CFA

Managing Director

Wealth Planning Solutions US Trust

john.e.crilly@ustrust.com

To many, November's election came as quite a surprise. Consider the quandary that leaves for those charged with providing tax advice. It's not easy to sound convincing when the answer is "I don't know."

This we do know. There are four competing and, at the same time, complementary Republican tax proposals. President Trump, Speaker Ryan, Congressman Camp, and House Ways and Means Committee Chairman Brady all seek to lower marginal income tax rates, and eliminate the 3.8% Affordable Care Act surtax on net investment income. Capital gains rates for high income taxpayers seem to converge around a 20% rate. The proposed repeal of the Estate Tax among Republicans is highly likely, with the retention of the gift tax to avoid income tax "shifting" to those in lower tax brackets. Our current tax system allows for the elimination of unrealized gains at death. Commonly referred to as "step up in basis," the Republicans vary in terms of how inherited capital gains will be treated.

I am certain that many of you have seen on PBS the appeals for Planned Giving, a gentle euphemism for charitable giving after death. Presently, high net worth families see upwards of 50% of their net worth in excess of the federal exemption (\$5,490,000 for an individual, \$10,980,000 for a married couple) disbursed to federal and state tax coffers. Wealth can only be directed to heirs, government and

charity. The art of estate planning is to strike a balance between those three distinct interests. Giving to one impacts the other; more gifting to heirs increases the government's take; more gifting to charity lessens the amount to heirs and government.

Your passion for charitable giving must lead your decision as to how much and to what causes. Once established, there are choices that would hold up against the known tax reform scenarios that we face.

Retirement assets are the "low hanging fruit" of post mortem charitable planning. Unlike appreciated assets, embedded income taxes in retirement accounts do not vanish at death. We refer to this in the trade as "Income in Respect of a Decedent." For those that have IRA's, 401(k)'s, pension plans and annuities, a change in beneficiary designation from an heir to a charity sidesteps both estate and income taxes. It is estimated that only 25% to 30% of pre-tax retirement assets pass to our loved ones. Why not give a significant portion of retirement assets to charity, leaving other assets to your loved ones? This step is rather simple; it does not require complex legal drafting. Even if the estate tax is repealed; your family will receive a "back door" charitable deduction by not having to recognize taxable income in the future.

Old life insurance policies might still retain value, but no longer serve the owner's original purpose. Although insurance proceeds are generally income tax free, current law subjects death benefit proceeds from policies which we own or control to the estate tax. This is an easy fix; change the beneficiary designation to a charity, and your estate will receive an estate tax charitable deduction.

The world of estate planning is full of acronyms. Absent an estate tax, Charitable Lead Trusts (CLAT's and CLUT's) might lose their luster. However, Charitable Remainder Trusts (CRAT's and CRUT's) could provide lifetime income tax benefits to the donor, with the remainder payable to charity. CRAT's and CRUT's can survive the lifetime of the donor, provide an annuity to heirs, and benefit causes that you had supported during your life.

Last, but certainly, not least, is a specific bequest in your will. Before you distribute the remainder of your estate, i.e. the residuary, you can provide for heirs and charity. "I hereby bequeath \$1,000,000 to CaringKind" is a direct bequest that has priority over other heirs. You can also include a charity in your residuary. "I hereby distribute to CaringKind 25% of my residuary estate." This 25% share will be part of a pool of assets that are "last in line."

Regardless of the technique, charitable giving is about passion. Tax motivation is not the primary reason to give. Planning creates efficiency. Your charge is to communicate to advisors your desires, so that we can assist in seamless implementation.

John (Jack) E. Crilly is a managing director and senior wealth strategist at U.S. Trust, Bank of America Private Wealth Management. In this role, Jack provides wealth management services in the areas of financial planning, estate planning, insurance, risk management, and philanthropy to help clients reach their initial goals and objectives. This includes coordinating with the client's team of advisors and by conducting periodic reviews to help clients monitor progress.

caringkind
Alzheimer's
Walk

MANHATTAN
October 15
9 am
Riverside
Park

QUEENS
September 17
9 am
Flushing Meadows
Corona Park

BROOKLYN
September 24
9 am
Coney Island
Boardwalk

**STATEN
ISLAND**
October 1
9 am
South Beach

Join thousands of New Yorkers at the CaringKind Alzheimer's Walks this fall.
Nobody should have to face Alzheimer's alone.

Come walk with us.

walk@caringkindnyc.org

caringkindnyc.org/walk

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6th Annual Golf Outing benefiting

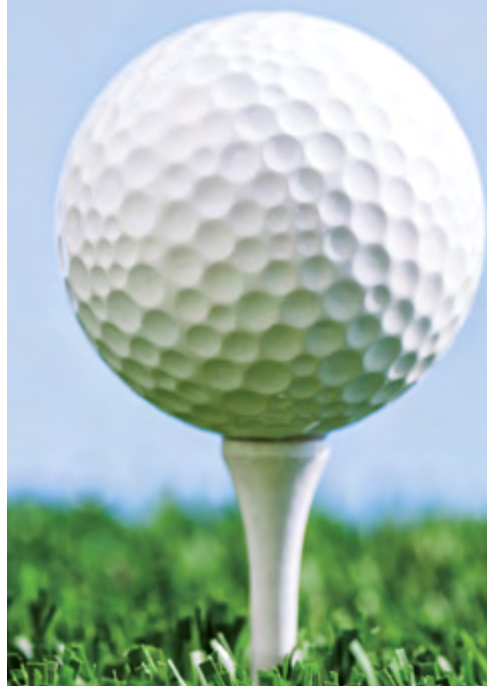
caringkind

The Heart of Alzheimer's Caregiving

Save the Date

Monday, July 31, 2017

Glen Head Country Club
240 Glen Cove Road
Glen Head, NY 11545



Chinese Lunar New Year, Year of the Rooster



Chinese Lunar New Year, the Year of the Rooster Celebration, took place on February 24 at CaringKind's office. About 85 people attended the event including people with dementia, caregivers, event sponsor representatives, media and volunteers. In keeping with tradition, the event included many activities: calligraphy greeting, health education by Dr. Cynthia Lien, Assistant Professor of Weill Cornell Medicine, viewing the Chinese documentary *Please Remember Me*, Chinese singing and dancing by the City Hall Senior Center Volunteer Chorus, a lucky raffle, and Chinese food tasting.



2017 New York State Association of Black and Puerto Rican Legislators Caucus Weekend in Albany, NY

This year (former) State Senator Bill Perkins and Assemblywoman Michaelle Solages co-sponsored a workshop during the Caucus for Caringkind and Citywide Behavioral Health Coalition for the Black Elderly. The workshop was titled, "Aging Alone: Behavioral Health and Dementia Among New York's Black Elders." Speakers for the panel included Paula Rice, Manager of African American Outreach at Caringkind, Warachal Faison, MD, Medical Director, Neuroscience, Pfizer Inc., and Martha Sullivan, DSW, Founder Citywide Behavioral Health Coalition for the Black Elderly.

This marked the first time the New York State Association of Black and Puerto Rican Legislators sponsored a workshop addressing dementia in the African American community. We thank them for their interest and support.



A Cure for Alzheimer's?

by Timothy Armour
President and CEO of
Cure Alzheimer's Fund

For those of us who have had a friend or family member with Alzheimer's, we know all too well the emotional strife the disease causes and the financial damage it brings. It is bankrupting families, not to mention the increasingly large share of public money that is needed to care for those afflicted. In a time of tight budgets and widespread demand for less government spending, Congress, the White House, and members of both parties agree that at least one priority should receive more money: research into the causes and possible cures of Alzheimer's disease.

The consensus on the need for additional research dollars comes from two compelling facts – one grim, and the other a cause for celebration. First, the bad news: Alzheimer's is now the most expensive disease in America, costing more than \$230 billion a year. Without a cure, as the population grows older, the bill to families, employers, insurers, and the government is going to skyrocket to approximately \$20 trillion cumulatively over the next 35 years, eating up a quarter of our Medicare spending. The federal government is increasing its commitment to Alzheimer's research with \$1.4 billion in Alzheimer's research funding through the National Institutes of Health (NIH) for FY 2018, but more is needed.

However, the grim toll of Alzheimer's – on our loved ones, friends and our economy – is not the sole reason the call for research funding is growing. The other reason is hope.

Across the spectrum of research, there are positive results – advances that let us know that funding the study of the brain is a promising use of our dollars. There is growing consensus by the field's best minds that scientific research is quickly opening new doors to slow, limit, or even stop the disease.

Cure Alzheimer's Fund, an independent 501(c)(3) nonprofit foundation, was established in 2004 to fund innovative research leading to preventing, stopping, or even reversing Alzheimer's disease. By the end of 2016, Cure Alzheimer's Fund will have distributed over \$50 million to more than 100 researchers around the globe. This initial funding for big, new ideas has paid off, with about \$60 million in additional funding given from NIH to extend the work of the Cure Alzheimer's Funded researchers – that is a very good “rate of return” for the initial philanthropic investment. Several world-class collaborations have grown out of this funding. For example, Drs. Rudy Tanzi and Doo Yeon Kim of Massachusetts General Hospital, working with Dr. Steve Wong of Methodist Hospital in Houston and others, have done groundbreaking research that has scientists around the globe attacking Alzheimer's in ways that were unthinkable only five years ago. ‘Alzheimer's in a Dish’ mimics in a petri dish both how brain cell networks are formed and how Alzheimer's genes influence neurons to create the disease's hallmarks – plaques and tangles. For the first time, researchers can directly monitor the way the disease grows and affects brain tissue and, then test drugs on its progress in real time.

This year, we have seen more exciting medical breakthroughs funded by Cure Alzheimer's Fund. Drs. Rob Moir and Rudy

Tanzi of Massachusetts General Hospital published a study that suggested that amyloid – previously thought only to be detrimental to the brain – also plays a protective role. And, Dr. Sangram Sisodia of the University of Chicago and his co-authors released a paper indicating that treatment with broad-spectrum antibiotics over a long period of time decreased the levels of amyloid plaques. Every day, scientists are developing a better understanding of what causes the disease – and how to prevent or treat it.

Cure Alzheimer's Fund recognizes the need for more and better care for Alzheimer's patients and support of their families. We are so proud to be associated with CaringKind and deeply appreciate CaringKind's recognition of the need for more fast, focused, and innovative research that will one day, we all hope, bring an end to Alzheimer's disease.

Find a Research Trial.

**Know your options
in 60 seconds.**

**Access the latest
treatments.**

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caringkindnyc.org/clinicaltrials/

Participating in Research

What is it really like to participate in a clinical research study?

Scientists are working hard to find better treatments and a way to prevent Alzheimer's disease (AD), but progress cannot be made without volunteers – both those with memory problems as well as healthy elders – to participate in the studies. The benefits of participating in a study may include the possibility of access to treatments not yet commercially available, receiving excellent care, helping the next generation, and knowing one is helping move science forwards.

However, people often have questions: “What will they ask me?” “How much time will it take?” “What actually happens when I go there?” The goals and time commitments vary considerably from study to study, and you need to pick one that fits with your schedule and comfort.

So let us walk you through a research visit for what we call the “A4” study! The A4 study – short for Anti-amyloid Treatment in Asymptomatic Alzheimer's disease is a clinical trial for those who may be at risk for developing AD and its goal is to prevent memory loss before it occurs.

The following is a description of the way the study is carried out at Mount Sinai Medical Center. Other sites may vary in how they conduct this and other studies.

Screening Visits:

Finding out if you are eligible. You and your study partner (family member or friend) come to the research center where you will be greeted by the friendly face of a young research coordinator – someone you will come to know very well.

We meet in a comfortable carpeted office and appointments are scheduled at your convenience. The coordinator explains the consent form which includes all of the information about the procedures and the risks and benefits, and answers questions you may have. When your questions are answered and you are comfortable with the study, you sign the consent as does the study staff and you receive your own copy. Afterwards, a professional health care provider will draw your blood and the coordinator will give you some paper and pencil type memory and thinking tests. Finally, you meet with one of our doctors, who will ask you some questions and have time to answer yours as well. The screening takes several hours and may need to occur across several visits to be sure you are healthy enough to participate, but there is plenty of time for breaks and lunch.

Neuroimaging Visits:

At these visits, which last several hours, you will have both an MRI (a way to take a detailed pictures of your brain) and a PET scan (a way to detect the presence of plaques in the brain possibly years before one would experience cognitive changes). There is minimal discomfort with having scans, but you do have to lie down on your back inside a large tube and it can be noisy. For the PET scan, an IV line will be started and a radiotracer will be injected into your body and allowed to circulate for about 50 minutes before you are placed in the scanner for about 45 minutes.

Eligibility Visit:

Once the scans are read, you and your study partner will meet with the doctor directing the study and discuss

the results. If the scan is positive for presence of amyloid plaque, then you are eligible to continue to the treatment phase. If the scan is not positive, then your journey in the A4 study comes to an end. However, it is important to note that in this study neither a positive nor a negative scan result determines that you have or you will develop dementia; rather, a positive scan infers increased risk of developing symptoms of AD.

Initiation Visit and Monthly for Three Years:

Eligible participants begin the treatment phase of the study. Half will be randomly assigned to the placebo group, but by the end of the study everyone will be offered the active treatment. The treatment phase includes monthly infusions (90 minutes) of the study medication solanezumab, with paper/pencil cognitive testing and imaging completed at regular intervals. The study coordinator is always with you, and there is plenty of time for chatting and reading. One of the things people say they enjoy most about research participation is the relationships you develop with the coordinators and doctors.

Remember, not every study is right for every volunteer. Take the time to review what studies are available and ask lots of questions so that you can find a way to participate that works best for you and your family.

Why the Recently-Revised Nursing Home Regulations are Vital for Nursing Home Residents

Developed by the National Consumer Voice for Quality Long-Term Care and Justice in Aging. Reprinted with permission of the National Consumer Voice for Quality Long-Term Care.

Almost all nursing homes accept Medicare or Medicaid, or both. As a condition of accepting federal reimbursement, these nursing homes follow quality of care standards set by the Nursing Home Reform Law. The Reform Law became effective in 1990, and corresponding regulations were issued in 1991.

The nursing home regulations became dated during the 25 years since they first were issued. To incorporate modern-day language, technological advances, and best practices, the Centers for Medicare and Medicaid Services (CMS) released a comprehensive revision of the regulations in September 2016.

The revised regulations contain important consumer protections that were not included in the previous regulations.

Protections Include:

Greater focus on addressing a resident's individual needs and preferences.

A nursing home must learn more about who the resident is as a person, provide greater support for resident preferences, and give residents increased control and choice.

Prompt development of a care plan.

The original regulations allowed a resident to be without a care plan for as long as 21 days following admission. Now, a facility must develop and implement a care plan within 48 hours of a resident's admission.

Comprehensive care.

Treatment and services have been expanded to include pain management, dialysis, and behavioral health services.

Improved training.

Training requirements have been expanded to apply to all staff, contractual employees, and volunteers. Mandatory topics include communication, residents' rights, and prevention of abuse, neglect and exploitation. Training for nursing assistants is expanded to include dementia management and resident abuse prevention.

Improved protections against abuse, neglect and exploitation.

A nursing home must not employ a licensed individual with a disciplinary action, and must report suspicions of a crime to law enforcement and the state survey and certification agency.

Better protection of resident property.

Nursing homes are now required to take reasonable care of resident belongings and can no longer seek waivers of their responsibility for lost or stolen property. Why the Recently-Revised Nursing Home

Regulations are Vital for Nursing Home Residents

Increased visitation rights.

A resident can accept visitors at any time of the day.

Protection against evictions. Eviction for non-payment is not allowed when a third-party payor (such as Medicaid) is evaluating a claim for payment. For evictions based on a nursing home's supposed inability to meet a resident's needs, the nursing home must document its attempts to meet the resident's needs, and the ability of a receiving nursing home to meet those needs.

Limiting nursing home's ability to "dump" a resident at the hospital.

In an effort to evade eviction safeguards, some nursing homes "dump" residents by refusing to readmit them from hospitalizations. Now, a nursing home must follow eviction procedures and give a hospitalized resident an opportunity to appeal, when the nursing home claims that the resident cannot return.

Prohibiting forced arbitration of claims of misconduct.

Currently, many nursing home admission agreements compel a resident to bring any future claims about abuse, neglect or other quality of care issues through private arbitration. The revised regulations prohibit nursing homes from forcing residents to arbitrate disputes, but allow voluntary arbitration agreed to after a dispute arises.

New York State's CARE Act: New Rules for Hospital Discharge Planning

by **Carol Levine**, UHF, Director
of the Families and Health Care
Project

A hospital stay ranks high on any list of stressful life events for both the person in the bed and the one at the bedside – the family caregiver. But coming home from the hospital can be just as scary as being admitted. There are often changes in medications, follow-up appointments, and new routines.

New York State's CARE (Caregiver Advise, Record and Enable) Act is intended to better prepare family caregivers by ensuring that they are part of the discharge planning process and receive instructions about providing care at home. Similar versions of the CARE Act, developed by AARP, have been enacted in more than 30 states.

To help patients and caregivers understand the CARE Act's impact on hospital discharge planning, United Hospital Fund (UHF) has prepared two free guides. The guides – a short version and a longer, more detailed document – are free and available online in English, Spanish, Chinese, and Russian. There is a user survey to provide feedback on the guides.

UHF has also created a toolkit that helps hospital staff meet CARE Act requirements (listed below) for engaging family caregivers and patients as they move from the hospital to home. The CARE Act materials were funded by The Fan Fox and Leslie R. Samuels Foundation, Inc.

According to the CARE Act, hospitals must:

1. Offer a patient an opportunity to identify a caregiver who will be able to help with care at home, and

document the caregiver's name and contact information (or the patient's unwillingness to name a caregiver) in the medical record;

2. Obtain written consent to share medical information with the designated caregiver or document refusal of consent;
3. Consult with the patient and designated caregiver about discharge options and post-acute care needs and inform the caregiver about the anticipated discharge date;
4. Provide any needed instructions to the caregiver as soon as possible, but no later than 24 hours before discharge.

Although each part of this process can be both supportive and challenging, requirements one and two are likely to be the most difficult for persons with Alzheimer's and other dementias and their caregivers. Here's why.

Requirement 1 : Naming a Caregiver

The CARE Act recognizes situations in which the patient is temporarily unable to identify a caregiver but not situations in which that status fluctuates or is permanent. If the hospital patient has Alzheimer's disease or a related dementia, the level of stress and the chances that the person will not be able to name a caregiver (or even understand what is being asked) increase.

Dementia may have contributed to the primary reason for hospitalization, such as a fall, or it may be secondary to another chronic disease such as diabetes or heart failure. In either case, hospital staff may not recognize that the person's confusion or resistance to being examined or questioned is related to an underlying neurological condition.

To address the situation at the outset, the family caregiver should inform the nurse

or doctor about the person's cognitive status. Being proactive can save a lot of time and anxiety. Caregivers should bring medication lists, personal health records, advance directives – anything that is helpful in establishing the person's medical history and prior relationships.

Requirement 2: Written Consent to Share Information

The same problem may arise with requirement two – written consent to share medical information. The person may not understand the reason for signing a paper or be suspicious for other reasons. It is important to reassure the person that this is just a formality so that the doctors and nurses can help the caregiver provide good care at home.

The person may be even more confused because of illness, pain, or the stress of being in the hospital. It may be helpful to suggest to the social worker or nurse that the person is more cooperative in a quiet space. Caregivers can also model good communication techniques by speaking with a calm voice, using short sentences and familiar words, and by sitting in front of and at the same level as the patient. Of course, this is not easy to accomplish in a crowded hospital room with a busy staff person but it may help. (See the Next Step in Care guide for health care providers on easing the stress of a hospital stay for people with dementia for more suggestions.)

Hospital staff is learning how to integrate the CARE Act requirements into their daily practice. Patients and caregivers can play an important role by knowing what to expect and how to respond to achieve the best outcomes.

Carol Levine directs the Families and Health Care Project at United Hospital Fund.

The Role of Rapid Referral

Jessica Zwerling, MD, MS
Teresa Santos, MSW, LCSW

“Mom, stop it! You don’t have a paper due! Stop it right now! You’re not in college.” It was 3 a.m., and the woman was trying to convince her 80-year-old mother that her need to hand in a dissertation to the professor was “all in her head.”

“I was standing there, helpless, crying, and all I wanted to do is pick up the phone and call you for help,” she told me days later at a support group that I run at the Montefiore Einstein Center for the Aging Brain for caregivers of people who have Alzheimer’s disease.

The woman knew that she couldn’t call me at 3 a.m., but I knew just the place that could help in those moments: CaringKind’s 24-hour Helpline, for 30 years the lifeline at the other end of the phone for overwhelmed caregivers in New York. The Helpline connects its callers with the resources they need when they need them.

CaringKind describes Rapid Referral as a program “to assist with meeting the non-medical needs of patients and clients with memory loss” and an easy way to link families directly to a CaringKind Helpline specialist by completing a simple, one-page form.”

The Rapid Referral consent form is a prescription of sorts that recommends “medications” – support groups, early stage programs, legal/financial assistance and the like – for people who have been diagnosed with Alzheimer’s disease or other dementias or for their caregivers. It connects them with a wealth of resources and support in hundreds of languages, closing the loop from the point of diagnosis to living with a new normal.

CaringKind’s Rapid Referral program is an essential component of the tapestry of services offered by the Center for the Aging Brain and the Memory Disorders Center in the Bronx. The CAB, as we call it, provides personalized and comprehensive treatment for a range of conditions facing older adults, including, memory loss, dementia, failure to thrive, functional decline, falls, suspected abuse and neglect.

Our multidisciplinary approach to care brings together under one roof the expertise of world-class doctors to provide comprehensive care for illnesses and quality-of-life issues associated with aging. The CAB provides access to a range of medical experts and specialists, including: geriatricians, neuropsychologists, neurologists, social workers, physiatrists, geriatric psychiatrists and care managers. After this multistep evaluation, it is an important component to know we can connect our patients and their caregivers to the programs at CaringKind to help ensure that they have the non-medical support they need.

We apply a compassionate, team-centered approach to caring for loved ones at both Montefiore-Einstein sites, and we try to open doors between our office and the community based resources. CaringKind’s Rapid Referral program is handled like any needed prescription given to a patient. But it’s free, and we follow up to ensure that it’s “filled.”

Caregivers have reported positive experiences with the program. They describe being home, feeling alone and isolated, when their phones ring and a warm, compassionate and skilled professional in the field of dementia holds their hand from the other end of the phone. Whether the call is to provide

the caregiver with information about diseases associated with memory loss or mailing a packet of information about long-term care and financial planning or how to apply for Medicaid homecare or the differences between homecare, adult day, and residential programs, it relieves the burden for caregiver of having to remember yet one more task.

And there’s the 24-hour Helpline, too. At her next appointment after she signed the Rapid Response consent form, the caregiver whose mother wanted to submit a dissertation, said that Helpline staff did contact her. She was taught the best strategies to use during her mother’s moments of delusion.

“The next time mom tried to submit her dissertation at 3 a.m., I called the 24-hour Helpline and they guided me through the experience,” she said. No longer alone, she was now able to navigate the complex realities of caring for her mother. A simple, one-page fax allowed us to bridge two worlds and enhance the care of both our patient and her caregiver.

Jessica Zwerling, MD, MS, is a board certified neurologist and neuromuscular specialist. She is currently the Program Director of the newly designated Montefiore-Einstein Center for Excellence in Alzheimer’s Disease, the Associate Director of the Center for the Aging Brain, and Director of Clinical Neurology at the NIH funded Einstein Aging Study. She is the Director of the Memory Disorders Center at Blondell Avenue, the Director of the UCNS Geriatric Neurology Fellowship, the head of the Neurodegenerative Clinical Trials Program and the site leader for the “Neurology of Aging” with Montefiore’s participation in the HRSA GWEP grant.

Teresa Santos, MSW, LCSW is certified in Medical Interpretation and is currently Behavioral Health Care Manager for both the Memory Disorders Center (under the Fan Fox & Leslie R. Samuels Foundation, Inc. grant) and for Montefiore Health System’s Center for the Aging Brain (under NYSDOH’s Centers for Excellence in Alzheimer’s Disease initiative).

13.1 Miles for the Cause



CANDACE DOUGLAS
Director of Constituent Events
cdouglas@caringskindnyc.org

In the week leading up to a big race, you find athletes bogged down with plenty of thoughts and questions: Have they been hydrating enough? (No.) Should they be eating more pasta? (Yes.) Is this the week to try out those new running shoes? (Absolutely not.) What songs make the final cut for their running playlists? (Beyoncé, clearly!) But for this 2017 United Airlines NYC Half, there was a new question on the table: Would they have to hurdle over snow banks in order to cross the finish line? (Maybe.)

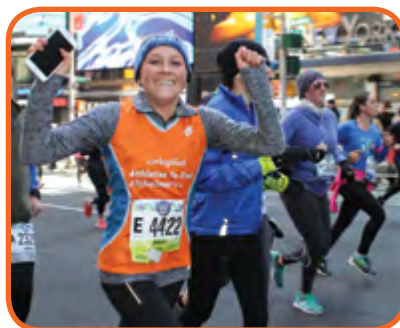
Just a few short days before this year's half marathon, the New York City area was bracing for a major winter storm. While Snowstorm Stella would end up having more bark and less bite, the residual effect of sleet and ice still caused serious concern about what condition Central Park would be in come race morning. Fortunately, CaringKind's Athletes to End Alzheimer's® team was familiar with the world throwing

unexpected curve balls their way and persevering through them. With so many of them having been caregivers themselves, they knew what resilience looked like. They were determined to complete the race in honor of those they knew personally the millions of other families in New York and beyond who are on the Alzheimer's journey and need the types of programs and services that CaringKind has been providing for over 30 years. Together, the 50 member team raised incredible awareness for the cause, and over \$130,000, which will directly help families in need immediately.

Over the course of the season, our runners become a team by sharing their stories, attending practice runs, communicating in a team Facebook group and cheering each other on throughout the race course. This year, the CaringKind team was also supported by a group of runners who had another special connection: colleagues working to come up with effective pharmaceutical treatments for Alzheimer's patients. This year's team featured 14 runners from Otsuka Pharmaceutical, which lists Alzheimer's as one of their priorities for drug development. With the generous support of their corporate office, and their own fundraising efforts, they were able to fundraise over \$33,000 this year. Otsuka's efforts as part of CaringKind's team highlighted their real commitment to support the Alzheimer's community, which included searching for the cure while also actively supporting care.

A diagnosis of Alzheimer's or dementia can be a real moment to pause for any family. But, as seen throughout this newsletter with George and Claire's story, there are ways to move forward, including getting educated, taking more safety precautions, reaching out, accepting help and much more. And for our athletes, they take another step forward, literally, by grabbing their favorite pair of sneakers and taking on the streets of New York City. We're all doing our part to help, whether it's the staff members at the CaringKind office, the caregivers in their own homes, or the runners blazing through the car-free streets of Times Square. Let's continue to keep moving forward.

Interested in joining CaringKind for the TCS NYC Marathon this year? Visit www.caringskindnyc.org/athletes today to learn more!

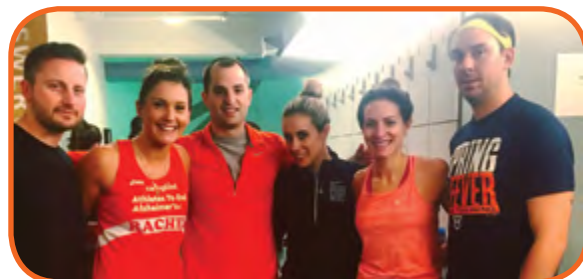


A Ride To Remember

By Lauren Longobardi
Junior Committee President

On April 6, Junior Committee members and friends attended the Junior Committee's 4th annual Ride to Remember at SWERVE Fitness in Midtown Manhattan. Ride to Remember, one of the largest fundraisers held by the Junior Committee and the second fundraiser in 2017, is a spin event where riders raise awareness and funds for CaringKind. Riders signed up as teams or individuals and spent the night spinning and having fun! Participants received bottles of water sponsored by CORE and a goody bag filled with donated items, including Hippeas snacks, Sparkling Ice beverages, and Justin's Vanilla flavored almond butter.

The top fundraiser, Rachel Braunwell Komyati, raised a total of \$1,235 and was recognized at the event by the Junior Committee Executive Board. This year, we raised over of \$7,400, and over the past 4 years have raised over \$60,000 to support caregivers and research efforts for Alzheimer's disease and related dementias.



Save the Date

Junior Committee Gala

Friday, October 27th

8:30 p.m.

404 10th Ave, NY, NY 1001



Be the first to know when the Junior Committee announces the 2017 gala theme by signing up for their newsletter! Visit www.caringkindnyc.org/juniorcommittee to join and for more information.

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

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

Upcoming Dates in English:

May 7	3:00 - 5:30 p.m.	Queens
May 9	5:30 - 7:30 p.m.	Manhattan
May 12	12:00 - 2:00 p.m.	Manhattan
May 17	5:30 - 7:30 p.m.	Manhattan
May 17	6:00 - 8:00 p.m.	Brooklyn
June 9	12:00 - 2:00 p.m.	Manhattan
June 13	5:30 - 7:30 p.m.	Manhattan
June 21	1:00 - 3:00 p.m.	Brooklyn
June 21	5:30 - 7:30 p.m.	Manhattan
July 11	5:30 - 7:30 p.m.	Manhattan
July 14	12:00 - 2:00 p.m.	Manhattan
July 19	5:30 - 7:30 p.m.	Manhattan
July 19	6:00 - 8:00 p.m.	Brooklyn

Upcoming Date in Spanish:

June 9	12:00 - 2:00 p.m.	Manhattan
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Upcoming Dates in Chinese:

May 20	10:30 a.m. - 12:30 p.m. (Mandarin)	Queens
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Seminars for Professionals: Enhancing Communication for Persons with Dementia

June 12	3:00 - 5:00 p.m.	Manhattan
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Seminar for Professionals: Understanding Dementia

June 14	3:00 - 5:00 p.m.	Manhattan
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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 Date in English:

Manhattan	
May 16	5:30 - 7:00 p.m.
July 18	5:30 - 7:00 p.m.

Legal & Financial Seminar

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

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

Upcoming Dates in English:

Manhattan	
May 15	5:30 - 7:00 p.m.
May 25	5:30 - 7:00 p.m.
June 5	12:00 - 1:30 p.m.
June 19	5:30 - 7:00 p.m.
June 22	
July 10	12:00 - 1:30 p.m.
July 17	5:30 - 7:00 p.m.
July 27	5:30 - 7:00 p.m.

Upcoming Date in Chinese (Mandarin):

Manhattan	
June 15	1:30 - 3:30 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 in English:

May 4	5:30 - 7:00 p.m.	Manhattan
June 1	5:30 - 7:00 p.m.	Manhattan
July 6	5:30 - 7:00 p.m.	Manhattan

Upcoming Dates in Spanish and new locations coming soon.

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.):

May 8

Connect2culture®: Using Arts and Culture to Improve Quality of Life

Connect2culture supports museums and other cultural organizations to develop ongoing programs for people living with dementia and their caregivers

- Learn how CaringKind's connect2culture program can support you
- Review the importance of meaningful activities in dementia care
- Uncover cultural dementia programs throughout NYC

Speaker: Meredith Wong, MAT, Manager of connect2culture at CaringKind

June 12

You've Applied for Medicaid. Now Learn How To Access Home Care Services.

This meeting is intended for caregivers who've already applied for Medicaid, or are currently enrolled. To learn about the Medicaid Home Care application process, dementia caregivers can register for our Medicaid Home Care Seminar via our 24-hour Helpline 646-744-2900.

- Understand health plan options under Medicaid
- Learn how to get and keep services for the person with dementia under their Medicaid health plan
- Find out how the Independent Consumer Advocacy Network (ICAN), a Medicaid managed long term care ombudsprogram, can support you

Speaker: Peter Travitsky, Esq. Staff Attorney, New York Legal Assistance Group

July 10

Care for the Dementia Caregiver

Caring for someone else, starts with caring for yourself.

- Review the importance and benefits of self-care
- Learn how to use self-care techniques in your everyday life
- Practice the art of breathing, chair yoga, and other techniques used to reduce stress

Speakers: Marilucy Lopes, LMSW, Manager of Education, CaringKind; Maria Mursch, LMSW, CaringKind, Certified Chair Yoga Instructor; Kathleen Booker, The Jedi of Calm™, Breathing Technician, Breathe Deep to Live Deeper, www.KathleenBooker.net

**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
for providing meeting space:*

Atria Senior Living, Kew Gardens
Carter Burden/Leonard Covello
Senior Program
Heights & Hills
Selfhelp Alzheimer's Resource Program
Queens Library
Avis – South Shore JCC
The Brielle at Seaview

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 in English:

Tuesdays	May 9, 16, 23, 30	12:30 - 2:30 pm	Manhattan
Thursdays	July 13, 20, 27 & Aug 3	12:30 - 2:30 pm	Manhattan
Saturdays	June 10, 17	9:00 am- 5:00 pm	Manhattan

Upcoming Series Dates in Spanish:

Thursdays	June 1, 8, 15, 22	12:30 - 2:30 pm	Manhattan
Wednesdays	July 12, 19, 26, & Aug 2	12:30 - 2:30 pm	Manhattan

Upcoming Series Dates in Chinese:

Wednesdays	May 31, June 7, 14, 21	12:30 - 2:30 pm	Manhattan
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Summer Weekend
Family Caregiver
Workshop Sessions
coming soon.

Please call our
24-hour Helpline for
more information.

646-744-2900.

Walking Home Together: A Support Group Leader's Continuing Journey

by Lorraine Ruggieri, LMSW

For the past quarter of a century I have known no other death other than death by dementia. As the facilitator of a support group for 25 years, I have been there with over 100 caregivers who stood at the threshold between life and death, who completed the journey with their loved one and walked them home. For over 1,000 sessions, I have listened, hugged, held hands, comforted and shed tears as they undertook the prolonged agony of gradually saying goodbye.

How did this come about? Twenty-five years ago I myself first became a caregiver. I walked into the office of CaringKind (then known as Alzheimer's Disease and Related Disorders, Inc. and, later, the Alzheimer's Association NYC Chapter) seeking understanding and help for my father, who had been diagnosed with a disease so little known that it was often referred to merely as "what Rita Hayworth had."

I originally came to CaringKind, not in search of a support group, but to buy a book, *The 36-Hour Day* (still considered a how-to guide and primer for dealing with dementia). Newly married at that time and trying to maintain my small business as a fashion designer, I found myself in an overwhelming state of dismay and chaos because of the demands of my father's illness and my mother's failing health. After buying the book, I was invited to join a support group. What's that, I wondered? Wasn't it my father who needed help, not I? But I quizzically attended my first meeting, showing up with spiral notebook and pen under the assumption that I was taking Alzheimer's 101. Only subsequently did I discover that the support group was for me, the caregiver!

At that time, there weren't as many services as there are now. It was a fledgling, grassroots organization with fewer than a dozen staff and numerous volunteers, most of whom were or had been caregivers. It was a place to go to where others understood the physical, mental and emotional deterioration of the sufferer and the caregiver. The original logo was of two figures close together, which I subtitled in mind: the journey, walking home together. There was always someone to talk to, the helpline was manned by volunteers who used their home phones on weekends to answer harried calls. It was a place where you could get information, some general legal advice and understanding. And there were the support groups. For me, this became my haven.

I vividly remember the comfort I received from others in my group when I talked about my father's hospitalization when, confused and combative, he pulled all the IV tubes from his body. When I visited him, his hands were tied to the bedrail (this was before physical restraints were not permitted). He looked at me and said: "Untie me, Lorraine, I'm not an animal." Then there was the bittersweet moment when I visited my mother at home. To help her emotional state, I designed and made dresses for her. When I arrived, I found them hanging all over the house on various doors and moldings. When questioned, she explained: "I want to look at them, like paintings."

Yes, she too suffered from dementia. But over a decade had passed since my father's death and I had already embraced the challenge of dealing with this relentless disease. I had trained and became a support group leader and



Lorraine (far left) as team captain of Wednesday's Adult Child with caregivers Elaine Cobos and Alexandra Sobell at the CaringKind Alzheimer's Walk 2016.

pursued further education to acquire a master of social work. CaringKind had grown as well: support groups numbered into the hundreds; a website was created; a 24/7 helpline was staffed by professionals; educational programs, training programs and partnering with other organizations were developed.

When my mother died we were holding hands; another journey completed. Soon after her death I became a licensed social worker. Throughout my academic studies, work experience and designing, I always arranged time to lead my support group. I have continually sought to hone my skills and empathy as a support group leader. CaringKind has been my touchstone because I still consider myself a caregiver for other caregivers. I hope that I have learned to listen, to be authentic, and to encourage others to find their strengths and appreciate the good moments. I also hope that I have been able to bring these resources into all my relationships, as I continue in my role as a support group leader for CaringKind, helping others to continue the journey, walking home together.

Lorraine Ruggieri, LMSW, ASW-G continues as a volunteer support group leader at CaringKind while working as a learning specialist/academic coach at Marymount Manhattan College. When time permits, Lorraine designs concert gowns for performing artists who have remained clients from her previous profession as a fashion designer. Contact Lorraine: lorraine.ruggieri@gmail.com

caringkindchronicles

Writer: Jennifer Camper Artist: Ivan Velez

Episode 2 Previous episodes: caringkindnyc.org/comic



Through our MedicAlert® NYC Wanderer's Safety Program, CaringKind offers identification jewelry for people who wander. For more information, call CaringKind's 24-hour Helpline at 646-744-2900 or go to caringkindnyc.org/wandersafety.



The Heart of Alzheimer's Caregiving

360 Lexington Avenue, 4th Floor
New York, NY 10017

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caringkindnyc.org

646-744-2900 — 24-hour Helpline

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Bryant Park Memory Chair Program

Every Chair Tells A Story

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There are over 400 Memory Chairs in Bryant Park
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on 42nd Street and 5th Avenue), and every chair
tells a story.

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 help
maintain the beauty of Bryant Park.

For more information contact:

Kelly Keenan at KKeenan@caringkindnyc.org
or 646-744-2927.

www.caringkindnyc.org/bryantpark



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