

caringkind

The Heart of Alzheimer's Caregiving



Volume Three 2019

- See CaringKind Alzheimer's Walk information on page 4.

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

Dear Reader,

While dementia care is challenging and exhausting, there are moments of joy, connection and hope that there will soon be effective treatments. But CaringKind believes that hope is not a plan. While we advocate for and support research, our focus remains care. In *Dementia Reimagined*, Tia Powell, MD explains, "Here is where I, in my role as Debbie Downer MD, must remind you that 99.6% of experimental drugs to treat Alzheimer's fail... This problem is not going away. When we focus excessively on cure we undermine care."

You can view the Lorraine Halis Lecture on the Arts & Science of Caregiving with Dr. Powell and me online at www.caringkindnyc.org/caregivinglecture.

CaringKind supports caregivers by building a foundation of knowledge and emotional support. Our caregivers have access to both the rich resources of CaringKind and the assets of our community partners. Clients express appreciation for the guidance, education, skills and, most of all, for a staff that is never judgmental, always comforting and truly understands dementia caregiving challenges.

Whether on the Helpline, in a Social Work consultation, in a Family Caregiver Workshop or in a support group, it's healing to talk. And talk comes with a range of emotions: love, resentment, anger, sadness, grief, amusement, confusion, or simply fatigue. Caregivers experience it all – sometimes at the same time. One moment you are the soul of patience, and then you reach the end of your rope and explode in frustration.

A caregiver's mother returned home after 36 hours of wandering. The caregiver was distraught. "Why are you crying? Why are you so upset?" his mother asked. She had lost the capacity to appreciate her son's feelings or to comfort him. He was exhausted, emotionally drained and felt alone. He called CaringKind, where a social worker helped him process his feelings and enrolled his mother in our

Wanderer's Safety program. At the end of this call, he knew he was not alone.

Millie is caring for her husband. She not only spends her days performing traditional household chores like cooking, shopping, cleaning, she also deals with medical care, prescriptions, doctor's appointments, finances, and supervising a professional caregiver. No matter how tired or frustrated she is, there is always one more thing that needs to get done. Millie is in a support group learning how to care for herself as well as her husband. She now looks for things to distract and comfort her like reading, listening to music, and doing the daily puzzles in the newspaper. Most importantly, at CaringKind, Millie has learned to take it one day at a time.

None of this work is possible without the support of our donors and friends. We are so grateful to the foundations and individuals who generously support us. Many will be at our two Walks this fall – September 22nd on the Coney Island Boardwalk in Brooklyn and on October 13th in Riverside Park. We hope to see you there!

For 40 years, CaringKind has been focused on providing resources for dementia caregivers. Our commitment to caregivers



JED A. LEVINE
President & CEO
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is our highest priority. If you or someone you know needs help remember, help is only a phone call away at 646-744-2900.

P.S. Please join me in welcoming our newest staff members:

Adina Segal, LMSW, LCSW, will strengthen our presence in the Jewish Orthodox Community in Brooklyn. Thanks to a generous grant from the Sephardic Home for the Aged Foundation she will strategically formalize relationships with the many agencies we already count as partners and introduce us to new organizations.

We also welcome Emily Prawer, our newest CaringKind Social Worker. Emily will both support clients need for care planning as well as working on our 24-hour Helpline. She will also be a conduit to the city's healthcare providers.

It's Summertime and Giving is Easy



CHRISTIAN DOUCETTE
Director of Community Engagement
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Our Athletes to End Alzheimer's® program has had a phenomenal year! To date, 142 athletes have raised over \$323,000 in the United Airlines NYC Half Marathon, TD Five Boro Bike Tour, New York City Triathlon, TCS New York City Marathon, and TackleALZ flag football game. **We've also just opened registration for our annual CaringKind Alzheimer's Walks.**



Half
Marathon
runner
Mark
Angelicola

United Airlines NYC Half Marathon
Congratulations to our 22 runners who raised nearly \$50,000 as part of our team in the NYC Half Marathon! It was a cold day for spectators, but the weather was perfect for runners. Special congratulations go to our top fundraising individual, Karen Antell, and to our nine-member team from Otsuka Pharmaceutical, captained by our veteran runner Timothy Wojcik! It may have been a half marathon, but – to mix a metaphor – our runners made a full court press and we couldn't be more



Eugene Weil
and
Katherine
Borsecnik,
TD Five Boro
Bike Tour
cyclists

TD Five Boro Bike Tour
Congratulations to our 11-member team who rode through all five boroughs in the TD Five Boro Bike Tour on May 5th! They raised almost \$20,000. It was a really wet day but our team's spirit couldn't be dampened. Special congratulations go to our fundraising power couple, Katherine Borsecnik and Eugene Weil who raised over \$6,000 for Alzheimer's and dementia caregiving. Bravo!

TackleALZ
Congratulations to all 80 players and to our coaches who, together, raised \$214,788 – a record-breaking amount! Game Day between Blondetourage and Brucrew was on Saturday, May 18th at Riverbank State Park. The weather was glorious. The teams had spent months practicing for this game and their efforts paid off. Over 200 spectators cheered for some pretty amazing plays. In the end, Blondetourage took home the winning trophy, with a final score of 40-13. Each team raised over \$100,000 to support Alzheimer's and dementia caregiving. And on that score, everyone's a winner.



TackleAlz 2019 team photo

New York City Triathlon
Congratulations to our favorite triathlete, Esther Birnbaum! Esther raised over \$5,000 in support of Alzheimer's and dementia caregiving. Unfortunately, because of the heat wave, the Triathlon was canceled. But Esther swam, cycled, and ran her way into our hearts all the same. Thank you, Esther!

TCS New York City Marathon
The NYC Marathon is on November 3rd. Our team of 30 runners has already raised over \$50,000! Congratulations to all!

CaringKind Alzheimer's Walks
Registration is officially open for our two Alzheimer's Walks this fall! We're walking in Brooklyn on Sunday, September 22nd and Riverside Park on Sunday, October 13th. You can walk and fundraise as an individual or as part of a team. Join us for either Walk as we celebrate caregivers and relive cherished memories in this joyful gathering to support research, caregiving, and advocacy!
Visit caringkindnyc.org/walk to register!

CaringKind's 3rd Annual Technology and Caregiving Fair



ED CISEK

Chief Program Officer and
Vice President of Program Evaluation
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A Virtual Senior Center. An incontinence pad that detects urinary tract infections. The capability to monitor your family member's activity with your smart phone. These were just a few of the products on display at CaringKind's 3rd annual Technology and Caregiving Fair held on April 29th at our office. We welcomed over 200 caregivers, healthcare professionals,

and others interested in caregiving technology and meeting the minds behind those products.

The purposes of the fair, which was co-produced by Aging2.0 NYC, were to bring awareness to caregiving products and offer an opportunity for the public to provide valuable feedback to the 28 participating companies that are working hard to improve them. Both vendors and attendees continue to find this fair a invaluable opportunity and looking forward to joining us next year!

For a complete list of participating companies and products, please visit caringkindnyc.org/techfairvendors.



Becoming an Informed Donor



LOU-ELLEN BARKAN

Founding Director
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Last month, carefully inspecting a head of lettuce to establish its country of origin and organic status, I noticed that my trips to the market are longer. Not surprising, since I'm addicted to checking food packaging, lists of ingredients, sell by dates, and allergy warnings. Notwithstanding the time this takes, it's time well spent. I leave the market smarter about what I am putting in my body and secure that I've spent my food budget wisely.

Recently I decided to put the same effort into researching the charitable organizations soliciting my support. Rather

than react emotionally to puppies up for adoption, children who need medical care, seniors without a safety net and more, I do the research before I reach for my checkbook. I want to understand not only what an organization claims to do, but how they accomplish their mission, how they spend their funds and the outcomes of their work.

If a charity is local, I visit to see how my money is spent. I talk to staff, see the programs in action and chat with finance folks. It's true that, as a not for profit executive, I have a list of good questions (which I'm happy to share), but in my opinion if all donors, large and small, took the time to do this research, our communities would be well served.

I recognize that there are "watchdog" agencies trying to accomplish this. Unfortunately, these agencies use complex algorithms and don't always

In My Opinion

compare "apples to apples. For example, while charities funded by government have substantially different operations from those that rely on individual and foundation gifts, they are rated using the same criteria. This can make it very hard for us to compare or understand their reports.

So instead, let's take the initiative to learn more before we write our checks. If a charity is local, let's visit the organization and make calls to learn about the organization's outcomes and operations. That way, when we do write those checks, we will be secure that our investment adds real value to real people.

I'm proud to say that CaringKind's doors are open to all visitors who want to learn more. To schedule time to see us, just call our Helpline at 646-744-2900 and we will be happy to show you how we make a difference through the generosity of our community.

Dear Helpline,

My wife was diagnosed with Alzheimer's disease a few years ago. Over the last 6 months, I've noticed she's been more agitated and aggressive than usual. I can't seem to get her to settle down as easily as I once had. She is constantly pacing the hallways in our house, resists when preparing for bed, and lashes out verbally. I don't know what happened! Can you help me? »

— Robert



STEPHANIE ARAGON
Director of Helpline
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Dear Robert,

Alzheimer's is a progressive disease. Your wife's diagnosis may have been made when she was in an early stage of the disease. Changes have apparently been gradual, and with you there to help her, life may have continued smoothly.

There are different areas in the brain. For example, there are areas for memory, for speech, for planning, and for physical activities such as sitting and walking. There are several possible reasons for what you describe as her not being able to "settle down." As brain cells die, connective paths of thought and memory are broken. Your wife doesn't know what to expect, where to go, what do. Regular patterns of sleep and waking are affected. When the person with dementia becomes angry, words that we adults have been taught to censor pour out because judgment is impaired. Have you discussed your wife's changes in behavior with her doctor? Asking the doctor to assess for pain is a good place to start as pain sometimes causes agitation. If the root is not pain, the doctor may have other suggestions.

Pacing suggests your wife may need something to do. Activities are a great way to provide stimulation and keep a person with dementia busy.

Adult day programs can be a helpful resource for caregivers like yourself. There are two types of adult day programs, social and medical models. Social models provide opportunities for socialization as well as programming specific to people with Alzheimer's disease.



Medical models provide the same opportunities as social models, but also offer medical services such as occupational or physical therapies, or perhaps they have a doctor on site, or a podiatrist who visits regularly.

If your wife is on Medicaid, many social medical programs now accept Medicaid insurance under contracts with Medicaid managed care programs. To pay out of pocket for medical model programs can be quite expensive. That said, social model programs can be wonderful for people who do not (yet) have more medical needs.

Once you determine where you think your wife might fit in best, I suggest you call the Helpline at 646-744-2900 for a list of adult day programs. Or, if you think a day program is not right for her, you may want to consider home care. A home care worker can help with bathing, feeding, and dressing, preparing lunch, taking your wife for a walk or to the park. You can hire a home care worker for part or all of the day for some or all days of the week.

Routines play a key part for people with dementia. Have a bedtime routine – maybe a warm shower, glass of milk, being read to, or a gentle massage with soothing music before going to bed. You might also think of other routines for mealtime, snack time or getting ready to go outside. This is where you can get creative; try it out and see what works. You know your wife best and know what would work for her.



Caregiver Trainings at CaringKind



AMY TORRES
 Director of Training
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CaringKind's training programs foster a non-judgmental environment, where caregivers have the opportunity to discuss the most pressing concerns they are facing supporting a person with dementia. Throughout the program our trainers model best dementia care practices, providing hands on techniques so caregivers can care with confidence.

Family members, friends and professional caregivers who regularly interact with a person diagnosed with dementia understand how complex and multifaceted the condition can be. Caregivers may be at a loss in how to best communicate and interact with that person to preserve the existing relationship or create new connections. CaringKind's training programs seek to highlight the importance of preserving the person with dementias "personhood" and help caregivers develop

and understand the world through the lens of somebody with dementia.

CaringKind's training department offers two models of training. Our **Family Caregiver Workshop**, a 10-hour training program is designed to provide family members and friends who are actively involved with the care of a person with dementia. This workshop provides the information, tools, and skills necessary for the caregiver to manage their own needs while at the same time supporting the person with the illness. The workshop meets once a week for four weeks, two and a half hours per session.

Each session covers a key component to good dementia care, topics include: Understanding Dementia, Enhancing Communication, Managing Challenging Behaviors, and Self Care. Each session builds on the next, so that participants can have the opportunity to tackle the issues around the disease that most affect them. Participants are encouraged to share and learn from each other, while simultaneously providing the emotional support necessary to meet the challenges of caring for someone with dementia. Family Caregiver Workshop participants are invited back quarterly for follow up

sessions with the goal of reconnecting with fellow caregivers, brushing up on topics and receiving the most up-to-date information about dementia care.

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

For more information on any of these programs, please call 646-744-2900.

Dementia Care Training For Professional Caregivers

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

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



Please call our **24-hour Helpline at 646-744-2900** to reserve a space.

Foundation Support Makes CaringKind's Work Possible



CAROL BERNE
Senior Vice President of Development
cberne@caringkindnyc.org

In keeping with the theme of this issue, "Good Care is the Best Medicine," it seems only fitting that we should highlight the foundations that supported us this fiscal year since their generosity made many of our caregiver programs possible. We are proud to share that CaringKind received over one million dollars in foundation grants in fiscal year 2019, which ended on June 30th. This significant support is a reflection of CaringKind's fine reputation in the philanthropic community, and to the growing importance of care in the Alzheimer's spectrum.

Among our major supporters we welcomed The Sephardic Home for the Aged Foundation. With their very generous grant we are addressing the needs of the Jewish community by formalizing and expanding our caregiver programs and services especially to Orthodox Jewish families affected by dementia, initially in Brooklyn. For this project we draw on our lengthy experience in developing services for underserved and diverse communities, including the African-American, Latino, and Chinese communities, and building

on longstanding relationships within the Orthodox community.

Adina Segal, LMSW, has filled the new position of Orthodox Jewish Outreach Social Worker. Adina brings a wealth of experience in working with dementia caregivers as well as extensive knowledge of the Orthodox Jewish community. She will serve as the key link between the Orthodox community and CaringKind, and help ensure that caregivers feel comfortable expressing their concerns and receiving the support they need.

We are pleased to partner with both the Harry and Jeanette Weinberg Foundation, Inc. and the Stavros Niarchos Foundation, who together, are supporting the expansion of free caregiver programs and services to Bronx Latino caregivers affected by dementia. The Bronx is the poorest county in New York City and State and is the least healthy county in the State with the highest Medicaid population of all five boroughs. Hispanics are one and one-half times more likely to have Alzheimer's than older whites, and they face considerable cultural, linguistic, and socioeconomic barriers that limit their ability to access Alzheimer's caregiver support services.

In the next issue I will continue to focus on some of our foundation donors who have provided us with a source of revenue to grow and expand our caregiver programs, so that we can continue to better serve all New Yorkers who need our help.

Know Your Charity

The following organizations ARE NOT affiliated with CaringKind:

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

Ways to Give

Giving by Check

Please make checks payable to CaringKind and mail to:
360 Lexington Avenue, 3rd Floor
New York, NY 10017

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, 3rd 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.

CaringKind Partners with Coler Skilled Nursing Facility on Roosevelt Island



ANN WYATT
 Manager of Palliative & Residential Care
 awyatt@caringkindnyc.org

We are thrilled to share the news that NYC Health+Hospitals’s Coler Skilled Nursing Facility on Roosevelt Island recently achieved accreditation from the nationally-recognized Comfort Matters program in Phoenix, Arizona. Coler is being accredited for their work in caring for people with advanced dementia.

Staff at Coler have worked very hard over several years to improve and expand

their work in dementia care, and last year were awarded a grant from the Fan Fox and Leslie R. Samuels Foundation that allowed them to work closely with Comfort Matters with the goal of attaining accreditation.

That they have done so is a tribute not only to everyone’s hard work, but also to how much all disciplines within Coler came together, in recognition of the fact that truly good care means that every discipline, and every staff member, has a role in bringing comfort to people with dementia. There is no more important goal than bringing an improved quality of life to people living with dementia, and nursing assistant, recreation workers, dietary staff, housekeepers, nurses, physicians, and all other departments at Coler, demonstrated

a caring, compassion and willingness to learn new approaches that was exemplary.

Coler now joins a growing number of homes in the metropolitan area, and across the country, that are turning to a comfort approach for caring for people with advanced dementia. CaringKind is proud to have assisted Coler from the beginning of their efforts, and we look forward to more work together in the future.



Self-care is Good Care



MEREDITH WONG
 Manager of connect2culture®
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Caring for a family member living with dementia can be emotionally and physically draining. Caregivers rarely identify as caregivers and often don’t recognize that they too need care and support. Also, caregivers can become lost in the demands and responsibilities of caring for someone else so intensely that they neglect their own well-being.

Several opportunities have been created by cultural organizations in New York City – Ailey Arts in Education’s AileyDance Workshops for Caregivers, The Rubin

Museum of Art’s Empowering Caregivers: Mindful Tours, Conversation, and Community, and the Intrepid Sea, Air & Space Museum’s Caregiver Appreciation events. These pilot programs, offered in partnership with CaringKind’s connect2culture program, are initiatives that address the need for engaging cultural activities where caregivers can enjoy themselves, connect with others in similar circumstances, and re-energize body, mind, and spirit. Led by teaching artists and instructors who have been trained by connect2culture staff, these programs encourage caregivers to focus on their emotional and physical health. Free for all participants, AileyDance Workshops, Empowering Caregivers and the Caregiver Appreciation programs provide a necessary break, building

connect2culture

informal support networks and enduring friendships.

Recognition of the need for these programs continues to develop as connect2culture reaches out to cultural organizations across the five boroughs. For additional information about these and other programs, please go to our website at caringkindnyc.org/connect2culture or call our Helpline at 646-744-2900.



The Journey of Dementia Caregiving



SERENE NIE
Social Work Supervisor
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The usual journey of dementia caregiving is not short, and it is filled with an incredible amount of uncertainty. How are we to anticipate the next step of our journey?

Social Work Services at CaringKind helps caregivers through their journeys and assists in identifying and choosing different care options.

When Marc first came to CaringKind, he was torn between his caregiving role and his career in Florida. His mother was in the middle stage of dementia and his father was too exhausted to manage her care. Marc eventually put his career on hold and relocated to New York. Marc soon came to realize just how much he had to learn about caregiving. It was a difficult situation. His father did not see the need for extra help; his mother resists the care; he needed to start Medicaid

planning to pay for the long term care. Marc was overwhelmed, overworked, and had no social outlet or respite.

Caregivers ride a roller coaster of emotions while caregiving.

Caregivers ride a roller coaster of emotions while caregiving. They doubt their ability to adequately care for the person with dementia and ask themselves all kinds of questions like, “Am I doing the right thing?” “How much is too much?” “Where do I begin?” “What else should I be doing?” Marc was no different.

From Marc’s first call onward, he was reminded that CaringKind is part of the team. No one should walk this journey alone! Meeting with a social worker has so many benefits for the caregiver and person with Alzheimer’s or dementia. Our professionally trained social workers help caregivers process what is happening and begin to make sense of the confusion and loss. A few sessions may be required to

develop a care plan. Like most caregivers, Marc was hesitant to open up about his situation and stress. But in the end, Marc came to value this opportunity. After his care consultation session with a social worker, he was filled with hope and tools that enabled him to take better care of his mom and himself.

Through his care consultation sessions with a social worker, Marc found support in our education meetings, support groups, and in the family caregiver workshop trainings. He finally felt confident enough to care for his mom. And, he knows that if he needs anything at all, he knows CaringKind is a phone call away.

There is an ancient Chinese saying taken from a war strategy, “知己知彼” which translates to “know yourself and know your enemy.” To provide the gold standard of care for you and the person with Alzheimer’s you need education and support. You need to understand yourself, this terrible disease, and the plans you need to put in place.

We want to be a part of your journey. We are on your team. Feel free to give us a ring at 646-744-2900.

Save-The-Date

CaringKind's Annual Research Meeting

Innovative Approaches in Research

Monday, October 28th at 6:00 p.m.

Formal invitation to follow!

Stay tuned for updates: www.caringkindnyc.org/annual



Caring for the Caregiver

By Dasha Kiper

*Consulting Clinical Supervisor,
Support Groups*

When Carol, a young woman caring for a mother with Alzheimer's, said goodbye to her group, she thanked everyone and then added: "I want you to know, this support group saved my life."

How can a bi-monthly meeting, where people gather to talk about the hardships of day-to-day caregiving, have such a profound effect? Do the meetings slow down the progress of the disease? Do they fix what is maddening or devastating about it? Of course not. But the group members knew what Carol meant. It was true for them as well.

Like many caregivers, Carol felt overwhelmed by the logistic and emotional demands of the disease. Her strong, capable mother, whom she had always leaned on, had gradually become combative and paranoid, exhibiting mood swings that never ceased to stun her daughter. Dealing with her mother's decline changed Carol as well. She became anxious, always on edge, snapping at people, especially her mother, which only made her feel worse. Her siblings were not around much, and her friends didn't really understand what she was going through. She felt completely alone.

As with many caregivers, it did not occur to Carol that she might need support. Only after she joined a group did she realize what had been missing in her life – namely, a consistent level of both emotional support by people who "get it," who know firsthand what caring for parents or spouses with dementia truly entails.

CaringKind groups are unique. They are not drop-in groups. Members make a firm commitment to be there for each other, and all are invested in each other's lives. They bear witness to their own pain and to the pain of others. They admit things they might not tell their closest friends, and they provide the understanding and compassion that caregivers do not find at home. Sharing their stories—their concerns, doubts, conflicts, frustrations, fear, and guilt—group members give each other permission to grieve and even to fall apart.

More than anything, support groups are a shield against the loneliness that engulfs most caregivers. A sense of isolation does not just feel bad, it also elevates stress, increases depression, exacerbates chronic health conditions, decreases motivation for self-care, and makes self-regulation and self-control harder to sustain. This is particularly harmful for those caregivers who feel their own lives are unraveling.

When Carol said that the group saved her life, she meant that it provided the emotional support that gave her both the strength to endure and the willingness to have a life away from her mother. For the first time since her mother fell ill, she was able to think of herself not just as a caregiver. With the group's encouragement, she asked herself what she needed, what was meaningful to her. Being kinder to herself, Carol was better able to be kind to her mom.

For someone taking care of a person with an incurable neuro-degenerative disease, a support group plays an indispensable role. By helping to maintain a quality of life for one person, it assures the well-being of both.

Leading a Support Group for Alzheimer's and Dementia Caregivers

Are you a former caregiver or mental health professional, interested in volunteering your time to help dementia caregivers?

Caringkind offers free, extensive 4-day training to become a support group leader.



If you would like to find out more about our training to become a support group leader please contact Dasha Kiper, Consulting Clinical Supervisor at dkiper@caringkindnyc.org or 646-744-2917.

Our next session begins November 1.

What to Consider After a Diagnosis of Alzheimer's Disease



PAULA RICE
Manager of African American Outreach
price@caringkindnyc.org

Many caregivers are at a loss after a family member is given a diagnosis of Alzheimer's disease or a related dementia. Every person with dementia's situation is

unique; there is no standardized care plan. So, what are the family's care options?

When I was a caregiver for my mom, I sought out the services of CaringKind (formerly the Alzheimer's Association, NYC Chapter) to determine the best care options for her. We settled on the Adult Day Care Model. This model is a structured program that provides functionally impaired adults with socialization, supervision, personal care and nutrition in a protective setting. Arts and crafts,

cognitive stimulation, exercise and music are some of the activities offered. Breakfast and lunch are served as well and many offer transportation services. My mom thrived in this environment and it also offered respite for me.

I encourage you to contact CaringKind's Helpline and speak to one of our Social Workers to help determine the appropriate care plan for your family. You can reach us at 646-744-2900, anytime of the day or night.

Chinese Advisory Board



WEIJING SHI
Manager of Chinese Outreach
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The first of CaringKind's Chinese Advisory Board meetings was held on Thursday, June 27, at the CaringKind office. The purpose of the advisory board is to have a variety of Chinese community leaders, partners and professionals provide external advice, consultation and involvement in the CaringKind Chinese Outreach Program. These leaders include representatives from different community senior services, faith-based organizations, hospitals, health care and

home care organizations, nursing and social work schools, and family caregiver representatives.

The Board will advise on Chinese Alzheimer's community issues, caregiver support and engagement, information, unmet needs, and programing and planning, in order to increase awareness

of dementia and better promote CaringKind's Chinese programs and services. Together we hope to improve the quality of care for Chinese individuals and families affected by Alzheimer's disease and related dementias. The Advisory Board members will meet on the fourth Thursday of every four months.



David Hyde Pierce, Ron Rifkin, Debra Monk, Dr. Max Gomez, Wendy Dessy, Victor Garber

2019 Forget-Me-Not Gala

The 2019 Forget-Me-Not Gala took place on Monday, June 3rd at the iconic Pierre Hotel. Raising nearly \$1 million to support the critical programs and services of CaringKind, the event was a true success. We would like to thank our Board of Directors and the generous support of our sponsors and attendees. And a special thank you to actor, Ron Rifkin, for emceeding the event.

Safety First



ELIZABETH BRAVO SANTIAGO
 Director of Wanderer's Safety Program
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Six out of ten persons with Alzheimer's will wander away from home and become lost. Wandering can be dangerous and life-threatening.

CaringKind offers a low-tech identification bracelet that saves lives! In collaboration with the New York City Police Department and the MedicAlert Foundation, CaringKind MedicAlertNYC Wanderers Safety Program is a 24-hour nationwide emergency response service for individuals with Alzheimer's or dementia who wander or have a medical emergency.

When a Person with Alzheimer's Disease is Missing:

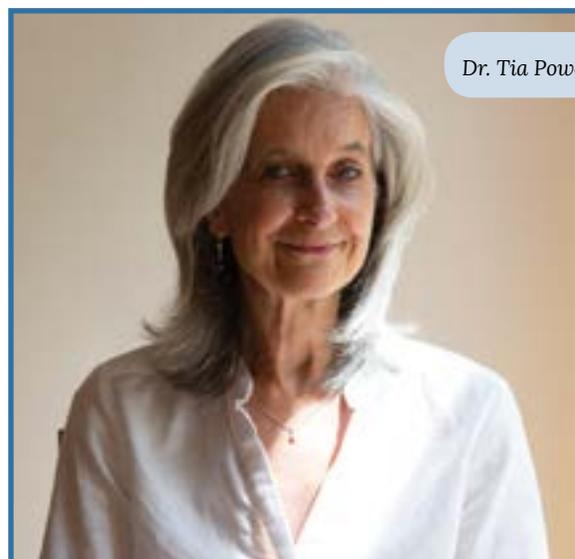
- ✦ Begin to search the immediate area.
- ✦ If the person is not located quickly dial 911. Inform the operator if the person has diagnosis of Alzheimer's and you believe they have wandered.
- ✦ The 911 operator will begin to ask you questions. You are now considered the reporter. This can be a very emotional and trying time but try to respond to the operator's questions to the best of your ability. The more detail you provide, the easier it will be for the police to locate the missing person.
- ✦ It's important that you remain on the site where the person went missing until the police arrive.
- ✦ When the police arrive, they will begin to ask questions like:
 - What is the missing person's name and do they have a nickname?
 - Do you have a current photo?
 - What medical conditions does the person have?
 - When was the person last seen?
 - Was the missing person's I.D. left behind?
- ✦ The police may ask for a garment that belongs to the missing person so they can use it if they choose to include a K-9 dog in the search.
- ✦ Provide the police officer with MedicAlert 24-Hour Emergency Line 1-800-625-3780 so they can call in the report as soon as possible. This applies even if the person is not currently enrolled in the MedicAlert Wanderers Safety Program.
- ✦ Police officers will begin patrolling the streets and surrounding area.
- ✦ Police officers may return to the reporter's home to update the caregiver with any news. With permission from the family a missing person bulletin will be e-mailed and faxed to, Hospitals, Emergency Rooms, Admitting Departments and other local agencies within the 5 boroughs.
- ✦ Once the incident report is called into MedicAlert they will generate a Missing Person Incident Report and contact CaringKind. We will assist by reaching out to the family to provide emotional support.
- ✦ We are always available to assist caregivers, providing support during the period when a person with dementia is missing, and afterwards to provide guidance and care planning to ensure the safety of the person with Alzheimer's disease or a related dementia.

Lorraine Halis Lecture

This spring, nearly 200 people gathered at the CaringKind office for our annual Lorraine Halis Lecture on the Arts & Science of Caregiving. The program was entitled "Dementia Reimagined: Building a Life of Joy and Dignity from Beginning to End," and was hosted by our guest speaker and bioethicist, Dr. Tia Powell. In conversations with Jed Levine, CaringKind's President and CEO, Dr. Powell discussed the current state of dementia research and explained how, given that a cure for dementia is elusive, we should focus more effort and appreciation on providing good care to those who have dementia. Lastly, Dr. Powell also offered advice to attendees on how to keep life meaningful and even joyful.

Our feedback survey revealed that 97% of participants reported that the lecture provided them with information they can use and 97% would recommend it to others. You can view the full event at caringkindnyc.org/caregivinglecture.

Please be sure to check out our Education calendar in this issue on page 14 to see our upcoming seminars.



Dr. Tia Powell.

Monthly Education Meetings

Meeting topics change monthly.
All meetings from 6:00 – 8:00 p.m.

Monday, August 12

Bathing without a Battle

- Learn why bathing is such an issue for people with dementia.
- Discover new strategies to make bathing more palatable for the person for whom you provide care.
- Ask questions of a Dementia Care Trainer experienced in bathing issues.

Speaker: **Nancy Hendley**, *Dementia Care Trainer, CaringKind*

Monday, September 9

Placing Your Relative in a Nursing Home

- Paying for nursing home care.
- How to ease the transition for both the person and the caregiver.
- How to be a successful advocate for a nursing home resident.

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

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:

Manhattan - Thursdays, 5:30 - 7:00 pm
August 1, September 5, October 3

Family Caregiver Workshops

During this 10-hour workshop series, caregivers learn to view the world from the perspective of the person with dementia. Topics covered include: communication, managing behavior and self care. Attendance is required at all workshops in a series.

Upcoming Dates in English – In Manhattan – Evenings:

August 2, 9, 16, 23,
September 5, 12, 19, 26th

Upcoming Dates in Spanish – In Manhattan

Mid-mornings:
September 9, 16, 23, 30

Upcoming Dates in Chinese – In Queens - Afternoons:

August 1, 8, 15, 22
October 18, 25, Nov. 1, 8

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:

August 20	5:00 - 7:00 pm	Brooklyn
August 21	5:30 - 7:30 pm	Manhattan
Sept. 13	12:00 - 2:00 pm	Manhattan
Sept. 17	2:00 - 4:00 pm	Brooklyn
Sept. 18	5:30 - 7:30 pm	Manhattan
Oct. 11	12:00 - 2:00 pm	Manhattan
Oct. 16	5:30 - 7:30 pm	Manhattan
Oct. 22	6:00 - 8:00 pm	Brooklyn

Upcoming Date in Spanish

Sept. 6 11:00 am - 1:00 pm Manhattan

Upcoming Date in Chinese (Cantonese)

August 4 1:00 - 4:00 pm Manhattan

Legal & Financial Seminar

An attorney specializing in elder law discusses important topics caregivers should understand before meeting with an attorney, including: power of attorney, guardianship, Medicaid eligibility, long-term care insurance, healthcare proxy, and more.

Prior attendance of an Understanding Dementia seminar is recommended.

Upcoming Dates in English:

Manhattan
August 5 12:00 - 1:30 pm
August 19 5:30 - 7:00 pm
Sept. 9 12:00 - 1:30 pm
Sept. 16 5:30 - 7:00 pm
Oct. 7 12:00 - 1:30 pm
Oct. 21 5:30 - 7:00 pm

Dates in Chinese (Cantonese):

Manhattan
Sept. 18 1:00 - 3:00 pm

Seminars for Professionals

Understanding Dementia for Professionals:

The Seminars are free of charge. Two (2) Social Work Continuing Education units are available for a fee.

Manhattan
Sept. 24 3:00-6:00 pm

To register, please call our 24-hour Helpline at 646-744-2900

or visit www.caringkindnyc.org.

Registration is required. Space is limited.

All meetings are free of charge and subject to change.

Location information provided upon registration.

We thank our community partners for providing meeting space:

Hand in Hand Together
Homecare
Heights & Hills
Queens Library
Visiting Nurse Service of New York – Chinatown
NNORC

caringkind chronicles

Writer: Jennifer Camper Artist: Ivan Velez

Story 2 Episode 3 Previous Stories: caringkindnyc.org/comic



CaringKind provides free programs and services for people with Alzheimer's and dementia and for their caregivers. 24-hour Helpline: 646-744-2900 ~ www.caringkindnyc.org

**LACE UP
YOUR
SNEAKERS...**

**...AND
WALK
WITH US!**

BROOKLYN
Sunday
Sept. 22, 9am
Coney Island
Boardwalk

MANHATTAN
Sunday
Oct. 13, 9am
Riverside Park

New Entrance:
103rd St. &
Riverside Drive

caringkind
Alzheimer's
Walk

SIGN UP TODAY!

caringkindnyc.org/walk

24-hour Helpline: 646-744-2900

walk@caringkindnyc.org

