

caringkind

The Heart of Alzheimer's Caregiving

**2018
Year In
Review**



Volume One 2019

- You're invited to the Loraine Halis Lecture on the Art and Science of Caregiving, page 15.

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New Chinese Website p. 9



Athletes To End Alzheimer's® p. 11



Ways To Give p. 13

- 4** President's Message
- 5** Dear Helpline
- 6** Education
- 7** Social Work
- 8** Training
- 10** connect2culture®
- 11** Athletes To End Alzheimer's®
- 12** Development Update
- 13** Ways to Give
- 14** Support Groups
- 15** Loraine Halis Lecture Invitation
- 16** Wanderer's Safety Program
- 17** CaringKind In The News
- 20** Education and Events Calendar
- 22** In My Opinion
- 23** CaringKind Chronicles

Dear Readers,

A client recently took the time to let me know how much our programs and services mean to her. "My reason for writing this letter is to say "thank you" to CaringKind in general as well as to support group leader Mike Koski in particular. As I am certain you have heard countless times before, having a parent with dementia is a nightmare, and as nightmarish as my experience has been, I know for certain that I could not have coped as well as I did without the support of the CaringKind Support Group and without our facilitator who provided a safe space to openly speak about the most difficult of feelings."

This letter, and the countless others that I receive, reinforces our commitment to our core mission: providing programs and services for individuals and families affected by a diagnosis of Alzheimer's or a related dementia. And, as we work hard to ensure that we have the resources to continue to meet the increasing demand for our services, we are grateful to the individuals, foundations and corporate supporters who are making it possible to sustain our work and to grow to meet an exponentially increasing demand.

We thank the PARC Foundation, the William Randolph Hearst Foundation, and the Andrew W. Mellon Foundation for renewed and generous funding to support specific programs. These gifts from prestigious funders are a reflection of the esteem in which CaringKind is held and the belief in our work and our ability to deliver quality services. Yet, they are only a part of the solution.

As 2019 begins, I am particularly grateful for two things. First, the dedicated work of our outstanding staff who work tirelessly to meet the needs of our community, making themselves available seven days a week to ensure that every client is served. Second, I am grateful to the many clients and supporters who express their thanks with generous contributions to

sustain us and to ensure that others, less fortunate than themselves, can access our programs.

We need their help and yours. CaringKind is over 95% privately funded and, as the aging population grows and more New Yorkers will need our help, the increase of families affected by a dementia diagnosis will become increasingly a community problem. We all have a role to play.

If you have been helped by one of our services, spoken to one of the social workers, called the Helpline, had your relative located through our MedicAlert Wanderer's Safety Program, attended an education meeting, Family Caregiver Workshop or support group, learned about Palliative Care for persons with dementia, or spent time in one of our cultural arts programs, please consider making a gift. And if you can, schedule a gift through your bank or company. Monthly gifts are an easy, affordable way to express your appreciation and ensure that we are here for the community when they need us. And, we know they will. (To make a monthly gift, please visit caringkindnyc.org, click on "donate", and choose "once a month".)

I look forward to seeing you at CaringKind on Wednesday, May 1st for the Lorraine



JED A. LEVINE
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Halis Lecture on the Art and Science of Caregiving with guest Tia Powell, MD, Director of the Montefiore Einstein Center for Bioethics, and author of "Dementia Reimagined: Building a Life of Joy and Dignity from Beginning to End." Dr. Powell is an extraordinary speaker and has much to share with us about the challenges and potential in caregiving.

On behalf of our staff and our Board, I wish you good health, prosperity and peace in 2019. Until there is a cure, prevention or way of slowing down dementia, CaringKind is here for you. With your help, we can ensure that future generations have the resources they need.

P.S. Next newsletter I will report on my fascinating and eye-opening trip to Shenzhen China, leading a team of CaringKind staff that was invited to bring our model of care and support to over 150 Chinese health care professionals.

“My husband was a supervisor at his firm. Recently, they convinced him to retire. Now, he is restless and gets up early everyday thinking he has to get ready for work. He is in an early stage of dementia and I don't think that he would be comfortable in a senior center considering his educational and professional background.”

“I find myself worn out and short tempered; I am short-changing everybody. I run over to my parents' apartment on many occasions which makes me constantly late for work. My thirteen-year-old daughter is sullen and resentful, yet I have little time and patience for her needs.”

“My mother refuses to take a bath or even change her underwear except for the times that we have a medical appointment and I say we must see the doctor.”

“We didn't know why my father was acting so secretive and making excuses for us not to visit. Recently, I found out he sent two sets of checks to each of the people to whom my mother had made bequests in her will. I was venting to a friend of mine, whose mother had died six months before from Alzheimer's, and she said, “That's Alzheimer's!” No one to

whom I had been complaining for months, not even my former classmate who is a psychiatrist, made that suggestion. I don't know where to begin.”



Those are some examples of the 10,000 calls that the Helpline responded to in 2018. There is a common, underlying theme to most Helpline calls: I don't know what to do. Helpline Specialists often speak to a family member who has the caregiving role thrust upon him or



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her. He or she may go through myriad emotions: fear, resentment, anger, helplessness and loneliness, to name a few.

No one should ever have to be alone throughout the caregiving journey. CaringKind is here for you. Helpline Specialists gently ask a few questions to get a better understanding of your current situation. They will ascertain what is needed, for example, a diagnosis, a home health aide, or an adult day care center. The issue might concern the behavior of the person with dementia who already has a diagnosis. Now he is up at night keeping the whole family awake. Other situations may concern refusal to bathe or eat. The person might have gotten out of the house and wandered off. The difficulty might involve temper tantrums, or inappropriate sexual behavior. Perhaps the caregiver just needs to talk about the stress he or she is under, which might be related to being a member of the sandwich generation caught between the needs of her children and her parent. No matter what the need is, CaringKind is here to offer support. Reach out to us anytime of day or night at 646-744-2900 or helpline@caringkindnyc.org.



The Year in Review



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2018 was an exciting year for caregiver education at CaringKind.

In March, we learned about how faith and spirituality can provide comfort to people with dementia and their caregivers at our annual Keeping Faith in Mind conference.

In April, over 200 family and professional caregivers learned about the latest caregiving innovations at our second annual Technology and Caregiving Fair.

Also in April, our Loraine Halis Lecture on the Arts and Science of Caregiving took us into one artist's perspective on dementia. The video recording is available on our website.

Our Annual Meeting, held in October, focused on the role of nutrition and sleep on brain health. Check our website for a recording of this too.

In December, we partnered with the NYU Alzheimer's Disease and Related Dementias Family Support Program to present 3 special topics: respite, support groups, and enhancing communication with people with dementia.

It was also a busy year for our "standards," like the Understanding Dementia and Legal and Financial seminars. In fact, we welcomed over 1,200 people from NYC and beyond to 130 meetings! These meetings were offered in English, Spanish, Mandarin, and Cantonese.

Our Monthly Monday Night meetings continue to be a hit. Our 2018 schedule featured diverse topics such as: Lewy Body and frontotemporal dementias, meaningful activities, communication, care planning, and Music & Memory®.

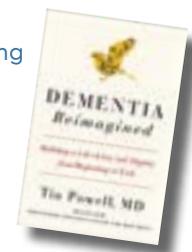
Thanks to feedback from our attendees, we know that we deliver quality as well as quantity. For example, surveys from two of our most common meetings indicate that 98% of caregivers were satisfied (see the graph below).

While continuing our regularly scheduled meetings, we're excited about upcoming meetings in 2019.

Our 2019 Loraine Halis Lecture on the Arts and Sciences of Caregiving will feature Dr. Tia Powell, a leading bioethicist and

psychiatrist, who, in her latest book *Dementia Reimagined*, calls for a true appreciation of providing care, as no sign of a cure is in sight.

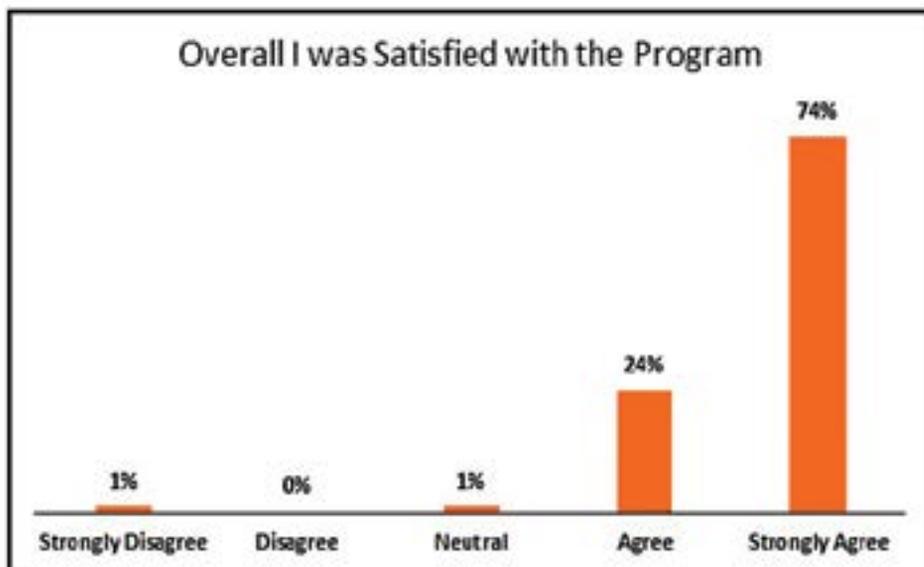
Dr. Powell will be signing copies of her book, *Dementia Reimagined* at the Loraine Halis lecture on May 1. See page 15 for invitation.



Together with NYU, we plan to offer presentations on adult day care and respite, the role of music in dementia caregiving, and more.

And, for all our tech-savvy clients, our third annual Technology and Caregiving Fair will take place on April 29. Stay tuned for more details!

Please be sure to check the Education and Events calendar in each issue for the latest offerings (pages 20-21 in this issue). And, most people hear about our meetings by word of mouth, so please spread the word!



How Social Workers Can Help



RITA GREENFIELD

Social Worker

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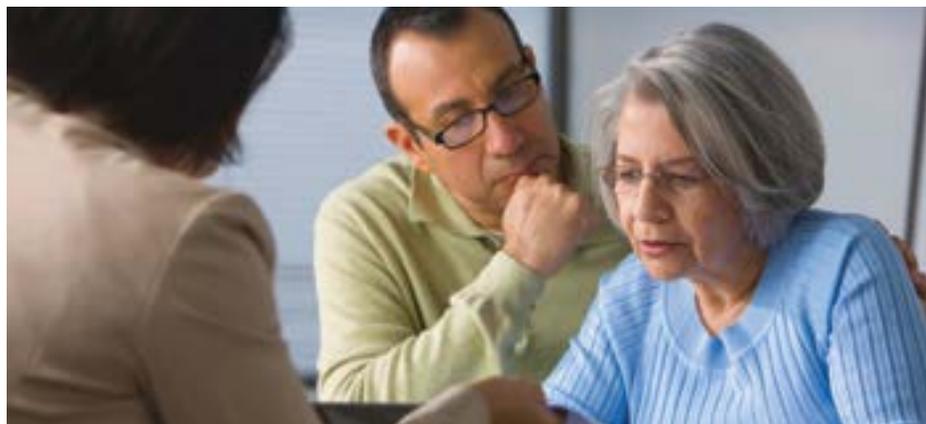
During calendar year 2018, the Social Work Services department conducted 1,800 client consultations. Most of these consultations were with family members or close friends of individuals with Alzheimer's disease or a related dementia. Some of our clients have been caregivers for years, while others are just starting their journey. Although our clients come from varied backgrounds, and every caregiving situation is unique, there are some common themes among our conversations with clients.

Oftentimes, a family member or close friend contacts CaringKind because they just learned that someone they care about has been diagnosed with Alzheimer's disease or a related dementia. To many people this is frightening news. They call CaringKind and ask to speak with a social worker because they want to talk about the significance of a diagnosis and to plan for the future. CaringKind social workers are able to talk to caregivers about practical matters such as the impact of a diagnosis of Alzheimer's disease on daily functioning. We are able to spend more time speaking with family caregivers than a doctor's schedule typically allows. By providing family caregivers with time and a safe space to ask questions, the planning process can begin.

Family caregivers also call CaringKind when the person they are concerned

about appears to need additional help. In many cases the caregiver has noticed new behaviors or symptoms that need attention, but they are not exactly sure of the type of assistance that is needed. In these cases, a CaringKind social worker can help the person assess the situation and identify the type of additional care that is helpful. Social workers can explain the different types of home care available, where to find home care workers, how to introduce a home care worker, and how to pay for home care. They can also discuss what types of institutional care are available and when it may be appropriate to consider this option.

Due to the high cost of providing ongoing care, many family caregivers eventually speak with a CaringKind social worker in order to learn about Community and Institutional Medicaid. A CaringKind social worker can provide family members with an overview of how Medicaid works including how to qualify for it financially, where to go for help in applying for Medicaid, and how a pooled income trust works. Of course, it is always advisable for caregivers to attend one of our Legal & Financial seminars. But, when that is not possible, or the family caregiver has unanswered questions, a CaringKind social worker can help.



Perhaps the most common theme our social workers discuss with family members is the stress associated with caregiving. Many family caregivers seek out our social workers because they know they can talk to them honestly about their experiences. Others may feel resentful of their situation, or financially burdened. And other family caregivers are grieving the gradual loss of the person with dementia.

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

Whatever your reason for wanting to speak with a CaringKind social worker, please know that we are available to assist you through your journey. Just contact the CaringKind Helpline at 646-744-2900 and ask to speak with a social worker.

CaringKind Offers Practical Training for Family and Professional Caregivers



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Over the past year, CaringKind's training department has trained 500 family members, friends and professional caregivers, whose difficult jobs were made easier with their new skills and resources. The Family Caregiver Workshop is a 10-hr training where family and friends assisting a person with dementia learn how best to communicate with person with dementia and manage challenging behaviors that may arise over the course of the person's illness. In addition to building knowledge, participants are connected to other CaringKind services to ensure they are receiving the support they need to tackle the difficult job of caregiving. The Dementia Care Training for Professional Caregivers (DCTPC) is a 45-hr training for home health aides, certified nursing assistants, personal companions and other paid caregivers. Through this program, participants build on their knowledge of dementia and grow their professional skill set to better care for clients with Alzheimer's or dementia.

Many that register for CaringKind's Family Caregiver Workshop, do so with the intention of learning how to better manage one or two challenging behaviors that the person with dementia may demonstrate. Most people with dementia experience a range of mild behavioral changes, such as repetition or eating without utensils. However, at some point, more severe behavioral changes may manifest, such as wandering or engaging in instances of physical aggression. At the beginning of a workshop, participants are often so overwhelmed and distraught they express the desire for a quick solution - an intervention that will immediately

put a stop to the behavior. However, the workshop builds on the concept that the behaviors people with dementia exhibit change throughout the course of the person's illness. We promote the concept of behavioral management as a method to lessen the negative impact these difficult behaviors can have on caregivers.

In a recent Family Caregiver Workshop, the daughter and primary caregiver of a Mother with Alzheimer's disease expressed the changes in her mother's behavior were "tearing her family apart." Once a week, she and her siblings connected by gathering for a pot luck. Unlike before, now their Mother began having difficulties staying seated during the meal, couldn't tolerate socializing with her family, and would become agitated, grasp at food on other people's plates and began raising her voice and requesting that everyone leave. This behavior continued over the course of several months so that family pot luck dinners were no longer possible.

After the daughter's time in the workshop and practicing the techniques in communication portion of the workshop, she then became able to coach her family on how best to speak to her mother and how to include her in this bonding time. Family members had conversation that relied on the person with dementia's long term-memory and made it a point to speak one at a time so as not to overwhelm their Mother. They never corrected her if she did something a bit differently. During the daughter's last session, she expressed how the workshop gave her back family dinners in such a meaningful way that made not only her family happy but made her mother feel included again.

One of the concepts discussed in the Dementia Care Training Program for Professional Caregivers (DCTPC) is the importance of learning the background and preferences of the person you are helping. Often, people with more progressed dementia cannot self-report information about their history or

preferences. Professional caregivers must turn to other resources to piece together the person with dementia's preferences, what they find meaningful and comforting. A recent DCTPC participant expressed her concern over being able to assist her new client who seemingly had very little language available. Over the course of several weeks, she had only heard her client speak a handful of times.

As the training progressed, she was encouraged to interview all the visitors her client received and fill out the questionnaire provided to her during training. This questionnaire encourages participants to discover more about the person with dementia - their work and family histories, hobbies, past daily routines as well as how their preferences may have changed or been impacted by their illness. Armed with information about her client's history, she began to bring up topics her client was familiar with, specifically baseball which she discovered had been her client's life-long hobby. After a few attempts, her client began responding to her inquiries regarding baseball players and their histories. The caregiver noticed that once her client began speaking, he was able to articulate thoughts not only about baseball but other topics and preferences as well, including his grandchildren, what he preferred to eat and when he would like to go for a walk. She noticed that in order to begin interacting with her client, she needed to begin a conversation about his topic of interests. The caregiver expressed how her confidence and expertise had grown over her time in the program.

As you can see, our training programs help you understand and navigate the challenges of Alzheimer's disease and caregiving. We provide knowledge and skills to help you more successfully care for someone with dementia and take care of yourself. If you would like to register for any of our free training programs, please contact our 24-Hour Helpline at 646-744-2945.

**CaringKind
launches a
new website for
Chinese-speaking
clients!**



www.caringkindnyc.org/Chinese



**Programs and Services
Support Group information
Chinese Newsletters
Upcoming Services and Projects
Events and Activities**

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For more information visit:
<https://paidfamilyleave.ny.gov/>



connect2culture®: Your Link to Cultural Engagement



MEREDITH WONG
Manager of connect2culture®
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The year 2018 was one of partnerships, education, and exciting new expansion for connect2culture®. It was a time of discovery for families who chose from various programs offering creative and engaging opportunities for social connection, creative stimulation, and joy. Connect2culture explored caregiver-only pilot programs, and by the end of 2018, had 18 cultural partners including botanical gardens, art and history museums, and performing arts organizations. In becoming cultural partners, organizations served caregivers and people living with dementia through interactions from trained staff, creating a welcoming and safe environment and facilitating creative and innovative programs.



With Music in Mind® was the first partnership pilot program, initiated with Orpheus Chamber Orchestra, an orchestra internationally recognized for high-level performances without a conductor. The program offered families an enjoyable music program in two of CaringKind's partner organizations, Hebrew Home at Riverdale and the Brooklyn Museum, followed by a chance to socialize with the performers over

light refreshments. Families and staff were treated to a music selection that inspired some to dance, move, and sing while lifting spirits and strengthening connections.

A well-received short film produced about With Music in Mind® is screened during trainings to illustrate how music engages families and offers respite. In the film, family caregivers and the individual with dementia movingly speak about music's positive impact on themselves as well as their family member living with the disease. Music allows for a shared cultural experience, stimulates emotional connections to memories, and encourages movement and social engagement. Through a generous multi-year grant from the Andrew W. Mellon Foundation, connect2culture continues to explore other opportunities for families to connect through music and the performing arts in partnerships with the Alvin Ailey Dance Foundation and with The New York Pops in 2019.



A second partnership, with the New York Botanical Garden (NYBG) in the Bronx, enabled connect2culture to pilot the Along the Garden Path® program. Participants took a guided walk through the gardens, smelled the fragrances and felt the textures of herbs and seasonal plants in the sensory garden. And, they became caregivers themselves by planting bulbs in flower pots to care for

at home. This program culminated in the production of a program guide of the same name, now a resource of seasonal ideas for horticultural venues to do with families in their communities.



Photo: Rubin Museum

A new initiative for connect2culture is to encourage cultural institutions to create caregiver-only programs. Recognizing that caregivers need time to practice self-care, connect2culture piloted a program with The Rubin Museum of Art in downtown Manhattan. The Rubin Museum's collection of Himalayan art and contemporary installations facilitate thought-provoking conversations in their galleries. Caregivers use this time to meet other caregivers, explore their own ideas of life cycles through art, and enjoy time to themselves.

Connect2culture thanks families for their support and participation in its cultural partners' programs, and continues to look for opportunities to expand its roster in 2019.



Seize an Opportunity of a Lifetime



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In 1996, I was fresh out of college when a friend asked me to ride my beat-up bike 250 miles, from Philadelphia to Washington, DC, to raise money and awareness for HIV/AIDS. Always up for an adventure, I enthusiastically and confidently agreed! In the next breath, when he informed me that I had to raise \$1,600 for the privilege, I was less confident. At the time, I was burdened with more than \$30,000 in student loans and working for a nonprofit earning \$18,000 a year. I didn't want to trouble my working-class family, my friends had no money to spare, and I didn't know a single wealthy person. Turns out, I had nothing to worry about! When I wrote a letter to everyone I knew about the challenge I was taking on, I was stunned at the response – people were so enthusiastic

about my endeavor and I exceeded my fundraising goal within just a few weeks! On race day, I crested every hill between Philadelphia and DC with pride. (And believe me - there are more hills between those two cities than you realize.)

Twenty years later, I've come full circle. As the Director of Community Engagement for CaringKind, it's now my job to help people seize an opportunity of a lifetime by challenging themselves to complete a feat of endurance while supporting a noble cause – helping people with Alzheimer's and dementia and their caregivers. I'm thrilled to announce registration is now open for the United Airlines NYC Half Marathon, the TD Five Boro Bike Tour, and the Lifetime NYC Triathlon! With professional coaching support from Enhance Sports and Empire Tri Club, the members of our Athletes to End Alzheimer's® team are prepared to meet and exceed their personal best.

So, as we usher in the new year, are you looking for another good reason to get in shape? Do you need a little extra motivation to hold you accountable? Maybe you're looking for a new way to



help combat Alzheimer's and dementia. No matter the reason, the Athletes to End Alzheimer's team is waiting for you. The number of entries that we have in these events is limited, so if you're interested in participating, now is the time to act!

Please feel free to call me anytime with questions at 646-744-2955. You can also reach me by email at cdoucette@caringkindnyc.org. I look forward to hearing from you!



ATEA Upcoming Events

United Airlines NYC Half Marathon – March 17, 2019

TD Five Boro Bike Tour – May 5, 2019

Panasonic New York City Triathlon – July 21, 2019

To meet our athletes and coaches, go to caringkindnyc.org/athletes

caringkind
Athletes To End
Alzheimer's®

Support Our Growth in 2019



CAROL BERNE

Senior Vice President of Development
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Now marking the fourth year of our transition to CaringKind, we continue to build much-needed awareness and funds for our essential programs and services to help families affected by dementia. Our Year-End Campaign, launched in November 2018, has raised over \$600,000 to date from 613 individuals and families. With the campaign ending on February 28th, we anticipate reaching close to \$700,000. These funds will help ensure our programs remain free of charge for all those in need. Thank you to each one of you!

With many charitable organizations focused on Alzheimer's and dementia, all competing for the same charitable dollars, we are honored to be recognized by two

of New York City's leading foundations with significant multi-year support. The Andrew W. Mellon Foundation is funding the expansion of our connect2culture program. We aim to broaden the diversity and reach of our cultural partners, ensuring that our clients have access to the richness of the arts, closer to where they live. And over the next three years, we will be training administrative staff and artists from Alvin Ailey Dance Foundation and The New York Pops, bringing the joy of music and dance to individuals with dementia and their caregivers.

Support from the William Randolph Hearst Foundation will provide training to hundreds of home care workers to be skilled in good dementia care, at a time when there could not be greater need. Our Dementia Care Training for Professional Caregivers is evidence-based, incorporates adult learning, and has a nationwide reputation. Graduates are employed by home care agencies, nursing homes or assisted living facilities, or work independently and register at our job-matching site, TogetherWeCare.com which matches our graduates with



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.

families seeking aides with expertise in dementia care.

In closing, I would like to thank our friends who have included CaringKind in their estate or financial plans. If you have already left us in your will, or are planning to do so, please be sure the name is listed as CaringKind, or our corporate name of more than 40 years, Alzheimers Disease and Related Disorders, New York City Inc. We are located at 360 Lexington Avenue, 3rd Floor, New York, New York 10017. Our Tax ID is 13-3277408.

As always, please contact me if you have any questions, would like to support a program or service that has been especially meaningful to you, or recognize a staff member for the help they gave.

I can be reached at 646-744-2905 or cberne@caringkindnyc.org. With 98% of our operating budget raised by private philanthropic support, your gifts ensure that we are here for you or someone you know, providing the gold standard of dementia care, today and tomorrow.

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
- Bright Focus Foundation



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 646-744-2900.
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.



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.



Life Insurance and Retirement Plans

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



Corporate Giving

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



Monthly Giving

By giving to CaringKind each month, you'll join a community committed to providing the gold standard of dementia care for all New Yorkers.



Tribute Gifts and Campaigns

Honor a loved one, or someone special in your life, or give back for the help that you received by a caring professional at CaringKind.

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

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.

Please contact
Carol Berne at
646-744-2905 or
cberne@caringkindnyc.org
if you would like
additional information.

Caring for the Caregiver

By Dasha Kiper

Consulting Clinical Supervisor,
Support Groups

At CaringKind, we make sure that spouses and adult children of people afflicted by Alzheimer's and related dementias have a safe place to go where they can freely discuss their concerns with the people who understand them best: other caregivers. Because we recognize that the complicated nature of the disease often pushes caregivers to their limits while exposing old wounds in family dynamics, it is essential that support groups are led by highly skilled and knowledgeable group leaders.

Such leaders are not made overnight. Unlike other organizations, CaringKind spends days, rather than hours, informing trainees about the unique emotional challenges presented by the disease, and providing the clinical tools necessary to create a cohesive and emotionally supportive environment for caregivers who may be at the end of their rope.

"On the first day of training, I quietly said to myself, 'Yes! This is it!' The course was loving, warm, welcoming, compassionate,

instructive, informative, and yes—supporting. I am extremely thankful that I was given the tools, skills, and understanding to be an effective support group leader—to constructively, compassionately, and safely support caregivers, who might be feeling hopeless, disillusioned, frightened and saddened to their core."

Joko Gilbert

Because the frustrating, contradictory, maddening nature of this illness makes so many caregivers feel their own minds unraveling even faster than their person's their caring for, we often hear caregivers say, "People keep asking me about my husband. It's always, 'How is Frank?' Let me tell you something, Frank is fine. It's me, it's all of us, who are going crazy." Yes, taking care of spouses and parents with dementia takes its toll on caregivers' sanity, identity, and even their ability to care for themselves.

Given what is at stake, the CaringKind Model recognizes that caring for the support group leader does not end after training. Therefore, CaringKind offers supervision sessions for over 80 support group leaders throughout the five boroughs. Being in direct contact

with people experiencing and expressing anger, frustration, confusion, grief, and despair requires leaders to process difficult emotions. Supervision enables leaders to receive support and guidance from their peers and refine their clinical skills while creating a sense of community that helps our very best leaders stay engaged.

"Monthly supervision has provided me with a safe place to share my experiences and to receive support from fellow group leaders. I could not do this work without having a place to honestly share my experiences and get helpful feedback from my peers and my supervision group leader. I, and, therefore, my group profit from such support."

Mike Koski

The CaringKind model works. By investing in our support group leaders, we support the caregivers who come to us for help. Caregivers often say that support groups have saved their lives, their relationships, and their identities, while also imparting a sense of home. Creating such an environment takes time, it takes lengthy training, and it takes supervision. And, it is worth every drop of effort we put into it.



Rabbi Posner and Senior Rabbi Joshua Davidson.



Posner Family: (from left) Lionel and Rachel, Sylvia and David, Courtney and Raphael.

CaringKind is grateful to **The Posner Family and The Temple Emanu-El Community**

for the generous memorial gifts made in memory of Senior Rabbi Emeritus,

Dr. David M. Posner

of Temple Emanu-El in Manhattan.

They are a reflection of his love, his work as a humanitarian and spiritual leader and his nurturing spirit, which exemplified what it means to be caring and kind.

We are honored to receive these gifts which support our free programs for families caring for a relative with Alzheimer's and related disorders.

Invites you to the

Lorraine Halis Lecture on the Art & Science of Caregiving

Dementia Reimagined: Building a Life of Joy and Dignity from Beginning to End

A conversation with Tia Powell, MD

While hoping for rapid development of effective therapies, we now recognize that these are far off in the future. Tia Powell, physician and bioethicist, supports the important shift from cure to care. During this conversation with Dr. Powell, we will uncover a "genuine appreciation of care – what we can do for those who have dementia, and for their caregivers, and how to keep life meaningful and even joyful."

Wednesday, May 1, 2019

Check in: 5:30pm ~ Program: 6:00pm

CaringKind 
360 Lexington Ave, 3rd Floor, NYC

RSVP: 646-744-2900, or email: helpline@caringkindnyc.org
www.caringkindnyc.org/caregivinglecture

Dr. Powell will be signing copies of her book, Dementia Reimagined.



Speaker:

Dr. Tia Powell is Director of the Montefiore Einstein Center for Bioethics and the Einstein Cardozo Master of Science in Bioethics program, and a Professor of Epidemiology and Psychiatry at Albert Einstein College of Medicine. She is a board-certified psychiatrist and Fellow of the New York Academy of Medicine, the American Psychiatric Association, and the Hastings Center. She lives in New York City with her husband.

Jed A. Levine, moderator, CaringKind's President and CEO.

This event is free of charge, and open to the public. Registration is required.

Helping Caregivers Care with Confidence



ELIZABETH BRAVO SANTIAGO
Director of Wanderer's Safety Program
esantiago@caringkindnyc.org

60% of persons with dementia are at risk of wandering or becoming lost. Or six out of ten people with Alzheimer's will wander.

Wandering can be dangerous and even life threatening. This is a terrifying reality for both the person with dementia and their caregiver. But CaringKind provides solutions to help caregivers care with confidence. One such solution is our MedicAlert® NYC Wanderer's Safety program. When a person with dementia goes missing, this service activates a community support network which includes law enforcement agencies. CaringKind and this network work together to help reunite the person who wandered with the caregiver or a family member.

We are proud to announce that in 2018 an additional 1,400 people with dementia were enrolled into the MedicAlert® NYC Wanderers Safety Program, bringing the grand total enrolled to 30,400. This would not have been possible without the support of caregivers, social workers, nursing home directors, manage care providers and the New York City Police Department.

For the many families and care providers

who are still not sure if you should enroll someone, here is something for you to think about. MedicAlert NYC Wanderers Safety Program assist in many ways, especially when a person is reported missing by their caregiver or when a person is found and not reported missing. CaringKind MedicAlert NYC Wanderers Safety Program is a very prompt, simple and effective system for communicating pertinent information concerning the member medical conditions, critical medications, and contact information during an incident.

As CaringKind MedicAlert NYC Wanderers Safety Program director, it's my responsibility to work in collaboration with emergency room doctors and the police department whenever a person is reported missing or found.

Over the holidays I received a call from MedicAlert emergency Response Team notifying me Mr. Brown was found wandering approximately 15 miles from his home and the police were escorting him to a local hospital.

Because Mr. Brown had on his identification bracelet the police were able to call MedicAlert 24 Hour-Emergency Line and immediately request Mr. Browns medical conditions, critical medications and his primary and additional contacts; so that they can provide this crucial information to the emergency room doctor upon arrival to the emergency room.

The MedicAlert Emergency Response Team initiated a call to Mr. Browns primary and additional contact, listed on his application. When MedicAlert called Mr. Browns primary caregiver the phone numbers which were listed have been

disconnected. They proceeded to call his daughter who was listed as a second contact, and the two phone numbers we had listed for her were also non-working numbers.

MedicAlert called the third contact who was listed as a cousin. Finally, the telephone rang, and the cousin answered. They were finally able to speak to the cousin and inform them Mr. Brown was found wandering and is being transported to a hospital. At that point MedicAlert placed a three-way call with the police officer and find out which hospital they were transporting Mr. Brown.

It is very important that our members information remains current in our database. Not having updated information can be detrimental toward the members emergency medical care. To all our caregivers of new and longstanding members, it is important for you to remember to provide you with exceptional service we need your support in keeping us informed with any changes that occur concerning your membership.

To update your records please call 1-888-572-8566. If you would like to enroll someone in to the Wanderers Safety Program you can do so by visiting our web-site at www.caringkindnyc.org or call 646-744-2918.



As 2018 ended, Jed A. Levine featured his late-December "Care Chronicle" column on the year ahead. He offered solutions to common caregiver pitfalls that might help eliminate as much stress as possible in 2019. Jed wrote, "At CaringKind, we like to say, 'If you've seen one case of Alzheimer's, you've seen one case of Alzheimer's.' But we also know that caregivers share some universal experiences along their Alzheimer's journey. With a new year on the horizon, it's important to remember common caregiver pitfalls and consider new approaches to those problems." For example, Jed continued, "**Pitfall: Your mom has, once again, accused you of hiding the remote control. You insist you haven't and go back and forth until she's worked up and you're exhausted. New Approach: Instead of arguing with her, tell her you're sorry and must have hidden it without realizing, and move on. The issue is a small one. By keeping the peace, you'll keep the arguing and stress levels to a minimum.**"



In keeping with the spirit of the season, Jed focused his November "Care Chronicle" column on gift giving, breaking down some thoughtful, personal, and practical ways to spread holiday cheer to people with Alzheimer's and those who care for them. His top gift ideas included a personalized scrapbook, music, movies and, for the caregiver, offering to help them with their caregiving duties. Don't forget, these suggestions also work throughout the year for birthdays!

Also, in November, USA Today's special supplement, an Alzheimer's and caregiving insert which ran in several major media markets across the country, included two articles by Jed. In the first article, "6 Tips for Celebrating the Holidays with Friends and Family Living With Alzheimer's," Jed discussed ways to make the holidays less stressful for caregivers and more inclusive for people with dementia, ways to simplify

traditions, and how practical gifts can bring comfort and joy to the Alzheimer's community. In the next piece, titled "A Lifeline of Support to Help You Through the Caregiving Process," Jed advised people dealing with Alzheimer's can fight loneliness and isolation.

Concluding November, CaringKind was one of the recipients of Van Dyk Health Care's "When Broadway Goes Dark, Van Dyk Goes Live" benefit concert featuring talented Broadway stars Catherine Brunell, Major Attaway, Natalie Cortez, and James Moyer. CaringKind was featured in over 20 New York City and New Jersey calendar listings promoting the event.

The North Carolina based newspaper, Richland Source, featured Jed in the December 25 article, "Finances, not lack of services, major factor for Richland County's aging residents." Reporter Noah Jones attended Jed's lecture at the The Atlantic's New Old Age Summit in NYC this October at which Jed discussed topics including the importance of serving diverse populations within the Alzheimer's community.

And CaringKind's important education meetings continue to be featured in local newspapers and news sites in the Tri-State area, helping us raise awareness about our programs and how the community can access them. Keep on reading!



Interested in advertising in the CaringKind Newsletter?

For rates and more information, please contact Danielle Bruzese at dbruzese@caringkindnyc.org

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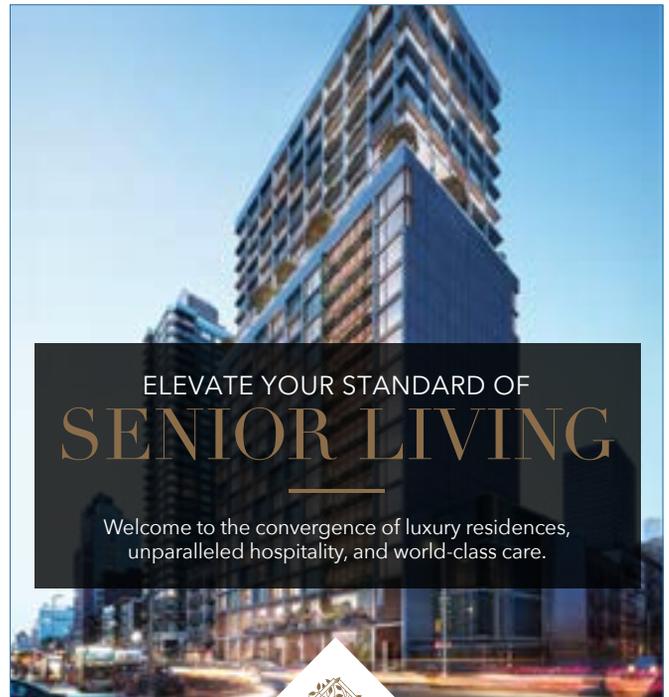
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Understanding Dementia Seminar: What You Need to Know and Where to Go

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

Upcoming Dates in English:

February 19	5:00 - 7:00 p.m.	Brooklyn
February 20	5:30 - 7:30 p.m.	Manhattan
March 8	12:00 - 2:00 p.m.	Manhattan
March 19	2:00 - 4:00 p.m.	Brooklyn
March 20	5:30 - 7:30 p.m.	Manhattan
April 12	12:00 - 2:00 p.m.	Manhattan
April 16	5:00 - 7:00 p.m.	Brooklyn
April 17	5:30 - 7:30 p.m.	Manhattan

Upcoming Date in Spanish

March 1	11:00 a.m. - 1:00 p.m.	Manhattan
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Upcoming Date in Chinese

Please call 646-744-2900 for upcoming dates.

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

Legal & Financial Seminar

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

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

Upcoming Dates in English:

Manhattan	
February 25	5:30 - 7:00 p.m.
March 4	12:00 - 1:30 p.m.
March 18	5:30 - 7:00 p.m.
April 1	12:00 - 1:30 p.m.
April 15	5:30 - 7:00 p.m.

Seminars for Professionals

Understanding Dementia for Professionals:

Contact our 24-hour Helpline at 646-744-2900 for upcoming dates.

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

Medicaid Home Care Seminar: A Practical Guide to the System

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

Upcoming Dates in English:

March 7	5:30 - 7:00 p.m.	Manhattan
April 4	5:30 - 7:00 p.m.	Manhattan



Follow CaringKind on Social Media!

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Monthly Education Meetings

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

Monday, March 11

Planning Ahead for When Hospice Can Help: Why it Doesn't Mean "Giving Up"

- What services are provided by hospice.
- How hospice can bring greater comfort.
- When to know if hospice might be appropriate.

Speakers:

Ann Wyatt, *Consultant, Palliative & Residential Care, Caringkind*
Sophie Ostergren,
LMSW, ACHP-SW Calvary Hospital Hospice

Monday, April 8

Creating a sense of purpose: Meaningful Activities for a Person with Dementia

- Finding areas of interest
- Determining a person's remaining strengths
- Proceeding and Assessing

Speaker:

Nancy Hendley, *Dementia Care Trainer*

Family Caregiver Workshops

During this 10-hour workshop series, caregivers learn to view the world from the perspective of the person with dementia. They also learn how to communicate more effectively with the person for whom they are caring and receive new insights on how to manage the challenging behaviors often associated with Alzheimer's disease, as well as the importance of self-care. Attendance is required at all workshops in a series.

Upcoming Dates in English – In Manhattan:

February 28, March 7, 14, 21	Afternoons
April 11, 18, 25, May 2	Afternoons

Upcoming Dates in Spanish – In Manhattan:

February 25, March 4, 11, 18	Evenings
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Upcoming Dates in Chinese – In Manhattan:

March 6, 13, 20, 27	Afternoons
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connect2culture



WE SING!

We invite caregivers and individuals with memory loss to lend your voice to some American Songbook standards and more. No experience necessary.

Upcoming Dates in English:

Manhattan

March 15 10:30 a.m. - 12:30 p.m.

April 12 10:30 a.m. - 12:30 p.m.

**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.

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
- Hand in Hand Together Homecare

Advocating for Professional Caregivers



LOU-ELLEN BARKAN
Founding Director
lbarkan@caringkindnyc.org

Just before dawn, Rosa Gonzales arrives at her job as a home health aide caring for an 85-year-old widow with Alzheimer’s disease. She will spend the next twelve hours keeping her client safe, occupied, clean and fed until a family member takes over. Sometime during the day, her client’s daughter will call to see how things are going.

“Fine.” Rosa says. “She ate well and had a nice sponge bath.” Rosa always reports that things are going well. Even on the days when Mrs. Rogers is yelling at her or accusing her of theft or crying because she wants her husband to come home from work.

Notwithstanding the challenging work, the absence of supervision, an annual salary ranging between \$15,000 and \$23,500, no medical benefits, minimal or no training and no job security,

home health aides are among the five fastest growing job categories. This is primarily driven by a rapidly growing population of aging baby boomers, many of whom will eventually need assistance to perform the simplest activities of daily living; eating, bathing, toileting and dressing. Today, this assistance is provided primarily by home health aides, like Rosa, who are recent immigrants. As the aging population grows, Americans will be increasingly dependent on this immigrant population to meet our needs for home care. This should be an important concern as we consider immigration policy.

In 2016, the Bureau of Labor Statistics reported that there were 911,000 home health aides in the country. By 2026, we will need 1,337,000 aides to meet the demand; an increase of 46.7 percent. In the future, as in the past, most are likely to be immigrants attempting to break into the workforce by doing a job with low pay but few educational requirements.

Advocates for the aging community make the case that a deficit of home care workers will have the unintended consequence of reducing the tax revenue

needed to pay for entitlement and health care programs. They project that thirty million baby boomers will live to eighty-five or older, at which time many will require full-time care for the rest of their lives. Without home health aides able to provide that care, family members will be forced to quit their jobs to provide care. This will dramatically reduce the tax base at the same time more tax dollars are needed to support greater use of government funded programs.

Many families prefer to keep their relatives at home until the end of life cared for by a family member with the assistance of a home health aide. But to achieve this, we will need a healthy flow of immigrants. Otherwise, it will be impossible to deliver the number of aides we need in 2019 and beyond.

As baby boomers age and government debates the economy, employment, immigration and health care policies, the need for an adequate supply of home health aides should be a critical issue for consideration. It is up to us, the voters, to ensure that we consider this issue when casting our votes.

Rosa Gonzales is a pseudonym.



Dealing with the pressures of adolescence is hard enough, but losing a parent to a degenerative mental illness and witnessing the effect on everyone in the family can be overwhelming.

The grief, frustration, and loneliness attending the disease makes its way into school and friendships.

A dementia support group provides a safe, non-judgmental place for young people to process and share feelings with those who truly understand what they're going through.

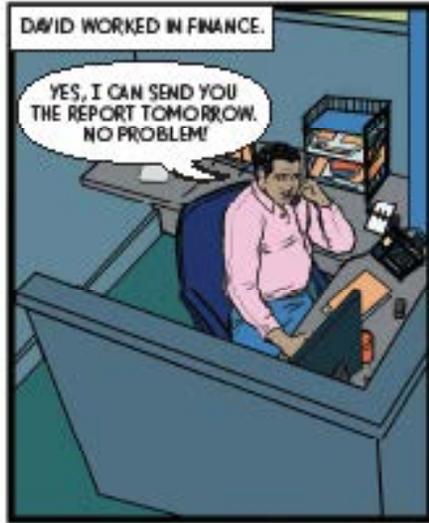
For more information about Support Groups, call our 24-hr Helpline at 646-744-2900.



caringkind chronicles

Writer: Jennifer Camper Artist: Ivan Velez

Story 2 Episode 1 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

Programs and Services

- 24-hour Helpline at 646-744-2900
- Social Work Services
- Support Groups
- MedicAlert® NYC Wanderer's Safety Program
- Diversity & Outreach
- connect2culture®

Education and Training

- Understanding Dementia for Caregivers & Professionals
- Dementia Care Training for Professional Caregivers
- Monthly Education Meeting
- Legal & Financial Seminar
- Medicaid Home Care Seminar
- Placing Your Relative in a Nursing Home Seminar
- Family Caregiver Workshop

