caringkind The Heart of Alzheimer's Caregiving

Issue 1, 2022

You were there for this caregiver.

Now she's here for you.

Marcia Henne, MAP Program Manager, with a photo of her mother.

Also Inside: President's Message MAP Program Fundraising Highlights



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Issue 1, 2022 CaringKind Helpline: 646-744-2900 caringkindnyc.org 360 Lexington Avenue, 3rd Floor New York, New York 10017

You Were There For This Caregiver. Now she's here for you.

Marcia Henne, holding a photograph of her mother, Maria Clara Avellaneda.

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A Few Odd Stories

"My mom was living alone and she started telling us stories like how she got lost in the neighborhood and had to call a cab to find her way back home. My sisters and I thought that these stories were a littleA odd, but not alarming. Then she started getting a little paranoid. She said that a thief was coming into the apartment and taking things, like food and jewelry. She was so sincere in her anxiety that we actually considered installing cameras to see if someone actually was entering her apartment! We didn't realize that she was showing common signs of Alzheimer's or dementia.

Something Had to be Done

Eventually, her behavior became too much of a concern to ignore – meals left out for days, repetitive questions, and more. She insisted that she was fine, but we knew something was wrong. And a trip to the doctor confirmed it. At the same time, I felt overwhelmed by my anxiety about her well-being, and stressed by the increasing conflict between us sisters about her care.

I Reached Out for Support

One day, I just started researching support for Alzheimer's caregivers and I learned about CaringKind's support groups. That group became a gateway to CaringKind services in general and I jumped in with both feet. My mother was big on volunteering, so that's what I did – I volunteered for everything I could. When my mom started wandering, I knew to enroll her in the Wanderer's Safety Program. These programs helped my family, and I couldn't be more grateful.

An End, But Also a Beginning

My mother passed away from Alzheimer's disease in 2010. But instead of ending my relationship with CaringKind, I found my calling. Fast forward 12 years, and I am now serving as Program Manager of the MAP Program connecting experienced caregivers with people newly diagnosed with dementia and their care partners. (*Read about MAP on Page 2.*)

It's incredibly meaningful for me to be able to leverage my personal caregiving experience in service of this vital program to help improve the quality of life for people with dementia and their care partners. Stigma is still an issue for those affected by Alzheimer's. To help reduce stigma so that there's one less hurdle to a life of dignity for people in this community is an honor for me and a tribute to my mom.

Message from Eleonora Sharing Gratitude and Purpose

by Eleonora Tornatore-Mikesh, CaringKind President & CEO



Each day I am blessed with an email, a handwritten note, or a phone call from family caregivers and people living with dementia

sharing how we have been a key part of their journey after cognitive decline symptoms or a formal diagnosis of Alzheimer's Disease or dementia. At Caringkind we strive to support family caregivers and persons with the disease through our boutique programming.

One of the highlights of my day is receiving confirmation that our mission and daily work provides concrete relief and comfort to families. I thought I would share a special note that illustrates the work of CaringKind and the collective relationships families have with multiple staff at CaringKind as they travel many years of uncertainty and hard prognosis. Thank you to this caregiver for allowing me to share what our work meant to her. Her words fuel our mission to grow and provide more services to this community. She is thanking us, but really, we are grateful to her for sharing her story. Our caregivers are strong, relentless advocates for people living with this disease. We stand by you as relentless advocates, raising funds and awareness until one day we have a cure or treatment.

"My heart is heavy upon sharing the news with you that my husband passed away on February 1, 2022. CaringKind has been present in our lives since my husband was first diagnosed with 'dementia associated with Alzheimer's type disease' in the fall of 2013. The first call I made was to the hotline and thus began our journey with the support of CaringKind. I attended each of the education workshops offered, some more than once; I joined a CaringKind support group led by Dasha Kipper, who knows my story well; and I attended the CaringKind lectures and panel discussions. The panel discussion with Alex Kates Shulman about her book, "To Love What Is" and then reading the book inspired me to love what is and it gave me strength to find the joy in the small moments, and to focus on the 'can-dos' and not on the 'no longer can do.'

At the April 2018 Loraine Halis Lecture on the Art and Science of Caregiving, I heard Meredith Wong speak about CaringKind's connect2culture program. For all that CaringKind has offered to me, a caregiver spouse, for all that I have learned through your organization, and all the resources that have been made available to me, I thank you from the bottom of my heart. I don't know how I would have survived this journey without you!"

For us it is a pleasure to serve this community and welcome you to share your stories as well.

Mentors for Caregivers: The MAP Program

MAP (Memory Advocate Peers) is a pilot program at CaringKind that will help a person living with dementia and their support partner. The program will connect two people (the person living with dementia and their support partner) with a former caregiver/support partner who will be trained to provide emotional support, empathy, and information on additional resources. This former caregiver will be a MAP volunteer mentor. The program also looks to increase participation in clinical trials.

Former caregivers/support partners can speak from experience. The goal of MAP is to leverage that hard-won experience in a positive way to help people currently affected by dementia and their support partner. Through MAP, those affected by dementia will benefit from the experience of a former caregiver/support partner. Former caregivers will enjoy the satisfaction of helping others and having a greater sense of meaning and purpose in life.

This program is for people in the early stage of dementia and their support partners. MAP volunteer mentors will be recruited by CaringKind. People living with dementia and their support partners will be referred to CaringKind by NYU, Montefiore, and Bellevue Hospitals. Once the participants are identified, MAP will pair the mentor with the person living with dementia and their support partner based on a set of screening criteria.

The first cohort of mentors have been recruited and their training is scheduled to begin mid-March. Once the assignments are made, mentors make a 12-month commitment.

Over the course of 12 months, mentors will report their activities to MAP. Likewise,



MAP will gather information from the person living with dementia and their support partner through surveys on the usefulness of the relationship. The goal of the 12-month mentor commitment is to help a person living with dementia and their support partner build a strong foundation of support from a variety of sources.

To be eligible to serve as a volunteer mentor, caregivers must wait a minimum of 12 months after the completion of their caregiving journey.

For more information, please contact Marcia Henne at mhenne@cknyc.org.

Generous Donors Provide Essential Services

by Carol Berne, Senior VP of Development

I wish to express deep appreciation to the donor community who, over the last year, has helped us not only sustain our work but start new initiatives. CaringKind is reliant on donations – both large and small – from foundations, corporations and people like you – to support our helpline, social work counseling, education and training, support groups, wanderer's safety program, connect2culture, and a host of other programs, offered free of charge, that makes it possible for an individual living with dementia and their care partner to have a better quality of life. Ensuring good care is the hallmark of CaringKind.

Notable fundraising highlights include:

• Our **2021 Year End Campaign**, as of February 22, 2022 has raised \$600,947, and counting!

• Among the many foundations providing leadership support are **The Helen Hoffritz Charitable Trust**, funding our Wanderer's Safety Program and the Special Assistance Fund. **The Sephardic Foundation on Aging** launched our Jewish Outreach and Social Work program and now supports its expansion. **Jarvie Commonweal Service** funds our work in the Chinese-speaking community, **The Harry and Jeanette Weinberg Foundation** funds our Latino Outreach Manager, and the **Andrew W. Mellon Foundation's** generosity is broadening our connect2culture program to reach diverse communities. These grants ensure that our programs are accessible to everyone in the community who needs our help.

• Our two Virtual Galas, together, raised \$1,762,000

Please mark your calendar for our Loraine Halis Lecture on the Art and Science of Caregiving, to be held onsite and virtually, on Tuesday, April 5, at 6PM at CaringKind. This year's program, Finding Comfort: Living with Advanced Dementia in Residential Care, marks ten years since CaringKind launched its dementiacapable palliative care work, advancing the way care is provided to persons living with advanced dementia in residential care. We will share what we have learned over the past decade, and celebrate our newly published Guide, on which the Lecture is based. To register, please call our helpline at 646-744-2900, or visit www.caringkindnyc.org/caregivinglecture.



And, on Monday evening, June 6, we return to the Pierre for our first in-person Forget-Me-Not Gala in two years. Please join Jon Henes, Gala Chair, David Hyde Pierce, Gala Emcee, and honorees Marshall Leonard, James Lapine, and Nick Buettner. For tickets and sponsor information, please visit: www.caringkindnyc.org/gala.

We continually hear from clients how helpful CaringKind has been for them, especially over the last two years as they faced greater isolation, loneliness, and depression. Please accept our deep gratitude — because of you, our doors have remained open (virtually) to provide support, comfort, and a means to engage with others. Thank you.



Upcoming Events at CaringKind



Loraine Halis Lecture on the Art and Science of Caregiving Finding Comfort: Living with Advanced Dementia in Residential Care Tuesday, April 5, 6 pm at CaringKind and available virtually



Forget-Me-Not Gala Monday, June 6, the Pierre



CaringKind Walk September 25, Coney Island Boardwalk October 23, Central Park More information: CaringKind Helpline: 646-744-2900 caringkindnyc.org

CaringKind's

Free Live Webinars in **April and May**

Webinars are at Eastern Time, and in English unless otherwise specified.

April

May

May 2

May 16

May 5

Understanding Dementia April 8 10 am - 12 pm April 19 5:30 - 7:30 pm

May 13 May 17

Understanding Dementia 10 am - Noon 5:30 - 7:30 pm

12:00 - 1:30 pm

5:30 - 7:00 pm

5:30 - 7:00 pm

Legal and Financial

Medicaid Home Care

Legal and Financial

April 4 12 - 1:30 pm April 18 5:30 - 7:30 pm In Chinese (Cantonese):

April 5 10 am - Noon

Medicaid Home Care

Apr₇ 5:30 - 7:00 pm

Monthly

Education Meeting Lewy Body Dementia: One of the Most Common Diseases You've Never Heard Of April 11: 6:00 - 8:00 pm

In Chinese (Mandarin) 4 days: May 3, 10, 17, 24 Monthly

Family Caregiver Workshop

Education Meeting Topic TBD May 14: 6:00 - 8:00 pm

Chinese Music Workshops (in Mandarin) 1:30-2:45pm April 19 (and every 3rd Tuesday of the month) Flushing Town Hall, Flushing, NY

Training

Understanding Dementia for Professionals April 26 2:00-4:00 pm

Register by calling the CaringKind Helpline: 646-744-2900

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. We accept MasterCard, Visa, and American Express. **Appreciated Securities** Gifts such as stocks or bonds may offer substantial tax advantages. Please speak to vour 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@cknyc.org if you would like additional information.

OUR MISSION

The mission of CaringKind is to create, deliver, and promote comprehensive and compassionate care and support services for individuals and families affected by Alzheimer's disease and related dementias, and to eliminate Alzheimer's disease through the advancement of research. We achieve our mission by providing programs and services for individuals with dementia, their family and professional caregivers; increasing public awareness; collaborating with research centers; and informing public policy through advocacy.