

You Connected This Caregiver to the Community She Needed

"Now I believe that everything is manageable."

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Connecting Caregivers with MAP
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Issue 2, 2021

caringkind

The Heart of Alzheimer's Caregiving

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

You Connected This Caregiver to the Community She Needed Ellen Lebowitz's Something was wrong. **Caregiver Story**

"My mother, Ruth, has been living in a nursing home with Alzheimer's for five years and I see her twice a week. It's just devastating.

I realized that something was wrong when she was in assisted living. She started experiencing sundowning, and her personality changed. As a friend once told me, "Meet your new mother." And now I just try to offer unconditional love and understanding. The changes she's gone through are staggering.

She wasn't sleeping, she was trying to leave the building, she started calling the police, and became aggressive with the nursing home staff. I had to visit morning, noon, and night because of her behavior.

But it also became clear that she needed touch she needed someone to hold and kiss. The first time I touched her, she screamed. But then she grabbed my hand and kissed me. And it's kind of odd, because growing up, she was not that affectionate. I guess you have to find the humor in these situations wherever you can find it!"

Ellen looked for help...

"Still, I was very confused. I had no idea what to do. I was doing a lot of research, but it wasn't helping - I couldn't get enough information. I started visiting different organizations for support, but every place felt sterile and it didn't feel like anyone really cared."

And - thanks to you - she found help.

"Then I discovered CaringKind. I remember signing up to attend CaringKind's annual meeting presenting the latest research on Alzheimer's. When I arrived, the line went around the building, and I burst into tears! All these people were there for the same reason! I stopped feeling so incredibly alone. To say I was impressed would be an understatement. I felt tremendous relief.

And now I believe that everything is manageable.

Having the right support makes all the difference. I read everything I can, and I go to every CaringKind event there is. And if sharing my story helps someone else, then I'm glad."

"Now I believe that everything is manageable."

You can hear the full interview on Caregiver/Storyteller, CaringKind's award-winning podcast. [Episode 8: If I Had Only Known]

MAPHABIT

Because of your support, we're able to study a new tactic to improve health outcomes for caregivers and care recipients.



MapHabit™ is a visual mapping system built to promote independence and improve quality of life for individuals living with Alzheimer's Disease and related dementias, their caregivers, and family members. The mobile software provides behavior prompts with customizable picture and keyword visual maps to assist memory-impaired people with accomplishing activities of daily living. The tool provides benefits such as increasing quality of care, improving caregiving staff satisfaction and retention, and offering a hybrid-care model to improve the bottom

line while also providing a key competitive advantage.

"CaringKind is the ideal partner for testing the efficacy of our visual mapping project," said MapHabit CEO, Matt Golden. "Their community of caregivers is so large and engaged, we've been able to recruit study participants in a fraction of the time it normally takes."

"Our partnership with MapHabit may reveal a new, evidence-based strategy for making life easier for care partners and improving the quality of life for the person in their care," says Eleonora Tornatore-Mikesh. "That's a win-win for everyone, and it's why I'm so excited about our partnership with MapHabit."

Thirty participants will be enrolled in the study, which will take about three months to complete. Stay tuned for results later this summer.

To learn more, visit: https://www.caringkindnyc.org/maphabit/

Eleonora's Message

by Eleonora Tornatore-Mikesh CaringKind President & CEO

As the world regains a sense of normalcy, we realize that the virtual part of our work – once thought to be a temporary solution – has become



an increasingly important part of our post-pandemic life. We look forward to resuming in-person support while we expand our efforts to help even more people, virtually.



The pandemic has forced us to look at our work through a new lens, and we now see a need for not only virtual flexibility, but also innovation. As such, we are excited to announce additional programs, services, and projects that will help more families and people with dementia in New York City and beyond. Take a look at the articles in this newsletter as good examples of our new efforts!

While Alzheimer's and dementia care can be challenging and exhausting, there is hope that there will soon be effective treatments. Until then, expert caregiving is the best medicine. Check back with us over the summer as we announce a menu of new, evidence-based interventions designed to improve the quality of life for people with dementia and caregivers!

Our innovation is only possible with your support. Please help us continue to innovate by walking with us in Central Park on October 10th! Thank you!

The CaringKind Alzheimer's Walk will be Moving to Central Park

Dr. Alisa Kauffman is our official Chair for 2021.

Walk season has begun! To acknowledge the outsized impact that Alzheimer's has on women, we launched Walk on Mother's Day with a video to help everyone get warmed up for walking! To see the video, please go online to: caringkindnyc.org/walk.

We're thrilled to announce that the Manhattan Walk on October 10 will



take place at the Naumburg Bandshell in Central Park! The Brooklyn Walk on September 26 will take place at its usual location on the Coney Island Boardwalk.

We're also happy to announce that Dr. Alisa Kauffman is serving as the Chair of the 2021 Walk! Dr. Kauffman is a dentist who specializes



in serving patients with Alzheimer's and dementia. Her practice is called Geriatric House Call Dentistry. Welcome, Dr. Kauffman!



CaringKind Walks

Brooklyn at Coney Island: September 26 Manhattan at Central Park: October 10



MAP: Memory Advocate Peers

With your help we're incubating a new project to connect new caregivers with experienced caregivers.

It's called "Memory Advocate Peers" or MAP. Co-founded by Jim and Geri Taylor and Sarah Walter, the project is a peer-to-peer effort to bring guidance to individuals newly diagnosed with dementia and their care partners.



Jim and Geri Taylor

MAP will help them find online and local resources, provide supplemental information about their disease, give assistance in finding a clinical trial, and provide a trusted friend with whom to speak about their challenges with this new development in their lives.

MAP will recruit and train up to 25 advocates and provide support to 50 clients and care partners and include individuals from culturally diverse communities from the very beginning. A research study is embedded within the program to evaluate feasibility, as

well as participant quality of life, health resource use, and impact on psychological wellbeing.

Because of your financial support, CaringKind is able to serve as fiscal sponsor for this exciting pilot project!



TOP 10 REASONS PEOPLE CALL OUR HELPLINE

- 10. My loved one is wandering. Can you help?
 - 9. How do I pay for a Home Health Aide?
 - 8. How do I find and hire a Home Health Aide?
 - 7. How do I attend one of your special events?
 - 6. How do I join a CaringKind support group?
 - 5. I am stressed out and I need to vent can you talk to me?
 - 4. How do I plan for the future? I'm at a loss.
 - 3. My family needs some general information.
 - 2. I need specialized training can you help?
 - 1. Can you register me for one of your seminars?



We answer a lot more questions than just these.



If you have
a question,
call our
Helpline at
646-744-2900.



Free Live Webinars in July and August

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

July

July 9: 10:00 am-12:00 pm July 20: 5:30-7:30 pm

In Chinese:

July 11: 2:00-4:00 pm

Legal and Financial

July 12: 12:00 -1:30 pm July 19: 5:30-7:00 pm

Medicaid Home Care

July 1: 5:30-7:00 pm

Monthly **Education Meeting**

Topic TBD

July 12: 6:00-8:00 pm

August

Understanding Dementia Understanding Dementia

August 13: 10:00 am-12:00 pm August 17: 5:30-7:30 pm

Legal and Financial

August 2: 12:00-1:30 pm August 16: 5:30-7:00 pm

Medicaid Home Care

August 5: 5:30-7:00 pm

Monthly **Education Meeting**

Topic: Estate Planning

August 9: 6:00-8:00 pm

Training

Family Caregiver Workshop Training

In Spanish:

July 12, 19, 26, Aug 2 10:00 am-1:00 pm

In Chinese:

July 30, Aug 6, 13, 20 10:00 am-1:00 pm

In English:

August 4, 11, 18, 25

1:00-4:00 pm

Dementia Care Training for Professional Caregivers

In English:

July 6 - August 5 10:00 am - 1:00 pm

In Chinese:

July 21 - September 1 9:00 am - 1:30 pm

In Spanish:

July 13 - August 12, 10:00 am - 1:00 pm

In Spanish:

August 25 - September 24, 2:00 - 5:00 pm

Register by calling our 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 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

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.



CaringKind 2021 Forget-Me-Not-Gala

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