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The Heart of Alzheimer's Caregiving



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Development Update p. 12



Early-Stage Services p. 13



Athletes To End Alzheimer's p. 14

- 4 President's Message
- 5 Program Development
- 6 Spreading the Word
- 7 Dear Helpline
- 8 Education and Training
- 9 Research
- 10 Community Building
- 11 Support Services
- 12 Development Update
- 13 Early-Stage Services
- 14 Athletes To End Alzheimer's
- 16 Caregiver Champions
- 18 Jewish Outreach
- 19 To Whom I May Concern®
- 20 Memory Advocate Peers (MAP)
- 22 CaringKind In The News
- 24 Notes from the President Emeritus
- 25 Social Engagement
- 27 Education and Training Seminars

Leading with Vision: Your Trusted Partner in Care

Dear Friends and Supporters of CaringKind, As we journey through this year with unwavering commitment and compassionate service, I am filled with a profound sense of gratitude and optimism. At CaringKind, our mission is not just about providing care, but about providing support, understanding, and empowerment for those affected by Alzheimer's and dementia-related illnesses.

Each day, I am inspired by the resilience and strength I witness in our community - the families bravely navigating these challenging waters, the caregivers giving their all, and the volunteers whose generosity knows no bounds. Your dedication is the heartbeat of CaringKind, pulsating with hope and love, driving us forward.

Each day I learn from our family caregivers and persons with dementia about how our programs have become a lighthouse for them. It is such a privilege to serve in my role and be part of the family's journey when human support and connection are needed.

We have renewed our pledge to be a beacon of light in the darkness that often surrounds Alzheimer's and dementia. We

are committed to expanding our reach, enhancing our programs, and continuously evolving to meet the changing needs of our community. Together, we will break barriers, build bridges of understanding, and provide a sanctuary of care and compassion.

As I reflect on our past achievements and look forward to future endeavors, I am reminded of the power of unity. It is in our togetherness that we find the strength to face challenges and the courage to continue our vital work. Let us embark on this journey with renewed vigor, bound by our shared mission to make a meaningful difference in the lives we touch.

Thank you for being an integral part of the CaringKind family. Your support fuels our mission, your voices amplify



ELEONORA TORNATORE-MIKESH
President and Chief Executive Officer
etornatore@cknyc.org

our advocacy, and your stories inspire our spirit. Here's to impactful work, to heartwarming connections, and to transformative experiences. You have my full commitment that we will continue to create new supportive programs as we know this disease impacts the entire family and community.

With my deepest appreciation and unwavering hope,

Eleonora Tornatore-Mikesh

President and CEO, CaringKind

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/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.

Life Insurance and Retirement Plans

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

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).



caringkindnyc.org/waystogive

*Thank you!
100% of your donation supports individuals and families affected by an Alzheimer's or dementia diagnosis.*

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.

A Hopeful Horizon: Pioneering Progress



STEPHANI SHIVERS, MEd, ORT/L
 Chief Innovation Officer and
 VP of Program Development
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I don't like math. I really struggled in high school passing algebra and geometry, because the concepts, formulas, and symbols were too abstract. What's funny to me about the fact that I don't like math, is that recently one math concept keeps circling around in my head. As I think about our field of dementia care and treatment, and where we are in this moment, the math concept of inflection point seems very fitting.

Merriam-Webster, aka my favorite math teacher, describes the inflection point as: "a moment when significant change occurs or may occur." It's like a situation when you find yourself driving in the wrong direction on a road and you come to an intersection where you can't turn around... and another intersection and you can't turn around... and another intersection and you can't turn around. Emotions of frustration, anger, despair, and resignation set in. And suddenly (finally) the whole road turns and heads back into the direction that you want to go!



In our 45-year history at CaringKind, we have been diligently working with families in what has often felt like a hopeless situation. But now, we're at the inflection point. For the first time in the history of Alzheimer's disease, we are in a new era. We are now witnessing research discoveries, disease modifying treatments, blood tests and better scans for early diagnosis, and new care and support services that will be covered under Medicare in the future.

We're at the inflection point and the horizon is different. The situation we are seeing is moving in a direction from hopeless to hopeful. No, we don't have a cure... yet. But we are definitely on the upswing. Hope feels palpable, and it is propelling us forward in new ways.

CaringKind has always been a pioneer and our work over the past three years is helping push the upward curve.

Our ten new multi-lingual, virtual and in-person services are equipping family care partners with emotional support, strength, and caregiving skills. Individuals diagnosed with MCI or early-stage dementia are being empowered with their peers to engage, share their experiences, and live their best lives. Being a trusted partner and lifeline for caregivers drives us to innovate new and better ways to meet people's needs.

I may not like math, but I love pioneering progress so that significant change may occur.

Our team at CaringKind is grateful to be standing with our families at this inflection point in history. Significant change has, is and will continue to occur in the dementia care field. The hopeless horizon is beginning to brighten, and while it does,

we will stay steadfast to be the caring, kind, and hopeful lifeline for those we have the privilege to serve.

The groups I have had the great pleasure of being a part of have been a lifeline for me.

I have close family, and many dear friends, all of whom love me and who try to take care of me.

Yet, there is something so vital, so special about these groups: the smart, knowledgeable and compassionate leaders; the vital interactions with fellow Alzheimer's "diagnosisees"; the immeasurable value of being truly gotten.

Clearly, I can't recommend these groups and CaringKind highly enough.

— Early-Stage program participant

Uniting Voices: The Power of Awareness



COURTNEY DAWSON

Director of Marketing, Communications,
and Development
cdawson@cknyc.org

In the quiet, yet profound journey many of you embark upon while caring for individuals with Alzheimer's and other cognitive changes, your stories demand to be told. As the Director of Marketing, Communications and Development at CaringKind, and as someone who has personally walked this path, I have witnessed the transformative power of sharing these experiences. It's not just about media coverage; it's about enlightening, empowering, and uniting a community often shadowed by the complexities of dementia.

The Importance of Visibility

Alzheimer's and related dementia often come with a heavy cloak of misconceptions and stigma. By bringing our stories to the forefront of public consciousness, we challenge these misunderstandings, and build a more informed and compassionate society. Every news feature, article, and

interview shine a light on the daily realities faced by many, helping to dissolve the isolation many of us feel. This visibility is essential. It fosters a deeper empathy and understanding while galvanizing public and private support for research, care, and advocacy.

Spreading the Word: Creating A Ripple Effect of Support

Awareness is the cornerstone of hope. When CaringKind's initiatives and stories are shared, we reach hearts and minds far beyond our immediate community. This exposure helps us connect with individuals and organizations who can join us in our mission. It brings more volunteers, more funding, and, importantly, reaches more individuals and families who can benefit from our support and resources. Every article and media appearance creates a ripple of understanding and compassion, building a network of care and support that no one should have to navigate alone.

Empowerment Through Knowledge

Our commitment to transparency and communication is not just about sharing what we do; it's about empowering you with knowledge. Whether it's understanding the latest in dementia research, navigating caregiving challenges, or learning about



new resources, being informed is a form of support. Through our presence in the media, we strive to be your Trusted Partner throughout your journey.

A Call to Action: Join Us in Sharing Your Story

Your experiences, challenges, and triumphs have the power to inspire and create change. If you or someone you know has been impacted by Alzheimer's or other cognitive changes, your story is invaluable. By sharing your journey with us, you contribute to a greater understanding and a stronger, more connected community. Your voice matters and can illuminate the path for others, providing comfort and guidance to those who may feel alone.

Together, we can build a future where every individual affected by dementia feels understood, supported, and connected. Your story is the light that guides us all towards a world filled with compassion, understanding, and hope.



“ I recently moved back in with my parents to help my mom care for my dad. My dad was recently diagnosed with Alzheimer’s disease. Most of my friends are busy with their families. I cannot talk to them about this. How can I cope with all these new changes in my life?

— Dani



STEPHANIE ARAGON
Navigator and Director of Helpline Services
helpline@cknyc.org

Dear Dani,

I’m glad you took the first step and reached out to CaringKind. We will be your trusted partner throughout your caregiving journey.

Some caregivers, like you, feel alone in their new role as caregiver. I encourage you to join one of our support groups. Meeting with people, either in-person or virtually, will make you feel less alone. In these groups you will be able to discuss what you are experiencing in your new role and share the feelings you can’t share with your friends.

If a group setting is not your preference, you may want to consider a one-on-one dementia consultation and/or joining our Coaching program. Our Coaching program empowers family members with the caregiving skills they need to adjust to their role as a caregiver. Sessions focus on managing stress, communication, behaviors, and home safety. Our dementia specialists use best practice techniques and research-based tools during the private in-person or virtual coaching sessions.

Dani, remember to take care of yourself first. Carve out some time for self-care.

The social engagement section of our website lists events, some for caregivers only and others for both the caregiver and person living with dementia.

Visit our social engagement calendar for detailed information:
caringkindnyc.org/socialengagement

If you are interested in enrolling in any of CaringKind’s programs or are looking for a listening ear, call the Helpline at 646-744-2900 email us at: helpline@cknyc.org or by complete this online form: caringkindnyc.org/contact

A Night To Remember: The CaringKind Forget-Me-Not Gala

We are overjoyed to share that our **Forget-Me-Not Gala** was a monumental success, raising an incredible \$1.4 million! This remarkable achievement is a testament to the power of community and the extraordinary generosity of our sponsors.

To our amazing sponsors: your dedication and support have made a world of difference. Your commitment extends beyond mere contributions; it is a lifeline for every individual and family navigating the challenges of Alzheimer’s and related dementias. Your support empowers us to provide essential care, resources, and hope to those who need it most.

Thank you for standing with us, for believing in our mission, and for continuing to make such a profound impact.



LEGACY
Elaine Thomas and Joseph Healey

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 Sandra Baron and Gregory Diskant Pam and Jon Henes
KIRKLAND & ELLIS

VIP COCKTAIL RECEPTION **MEDIA**

Thank you to all our generous Sponsors!

Empowering Through Knowledge: Innovations in Education and Training



MICHELE PISKIN
VP of Residential and LTC Division
and Development
mpiskin@cknyc.org

Education is our most powerful tool, a light in the often-challenging journey of dementia caregiving. I am continually inspired by the resilience and compassion that emerge from our community. At CaringKind, we don't just share knowledge, we build bridges of understanding that can transform lives.

Our goal is to empower individuals with knowledge and skills that can enhance their caregiving journey and improve the overall well-being of the caregiver and the person living with a dementia diagnosis.

At CaringKind, we understand the challenges and complexities of caregiving for individuals with a memory loss diagnosis and we are here to provide the necessary support and education to help caregivers navigate this journey with confidence and compassion.

Each workshop, seminar, and resource we offer at CaringKind is more than just education — it's a pathway to understanding, a source of support, and a beacon of hope for countless individuals and families.

As we navigate the intricate journey of caregiving, it's essential to remember the power of understanding, empathy, and education. At CaringKind, we believe that every person touched by dementia has a unique story, and each of these stories holds profound significance.

In the sphere of caregiving, knowledge is more than just power — it's a lifeline.

Our commitment to education aims to illuminate the path for caregivers, providing them with the tools and understanding necessary to navigate the challenges of dementia. We don't just offer information; we offer a compass for the heart and mind.

Yet, the essence of our mission transcends the boundaries of practical knowledge. It's about cultivating a community where empathy flourishes. When we understand the experiences of those living with dementia, our actions become more compassionate, and our support more meaningful.

As we continue our work, remember that each workshop, seminar, and resource we offer at CaringKind is more than just education — it's a pathway to understanding, a source of support, and a beacon of hope for countless individuals and families.

Your involvement and support fuel this mission, igniting a community where empathy and knowledge create a nurturing environment for all affected by dementia.

Thank you for being an integral part of this journey.

Please find more information about our
Education and Training Programs
on page 27.

**CaringKind and
MedicAlert®
NYC Wanderer's Safety
Program
are here to help.**



A 24-hour nationwide emergency response service providing assistance for finding persons diagnosed with Alzheimer's disease or related dementias who wander locally or far from home, or have a medical emergency.

**To Enroll
Call CaringKind:
646-744-2900**

**Or Visit Our Website:
[www.caringkindnyc.org/
wandersafety](http://www.caringkindnyc.org/wandersafety)**

**CaringKind Needs You!
If you are interested in
Volunteering for
CaringKind,
please call our
Helpline
646-744-2900**

Making an Impact: Updates from Evaluation and Research



EDWARD CISEK, PhD

Chief Research, Grants,
and Evaluation Officer
ecisek@cknyc.org

Former New York City Mayor Ed Koch used to ask “How’m I doin’?”

Likewise, we use feedback surveys to find out how our programs and services are doing. Your responses — be they positive or negative — are essential to help us improve our current programs and shape new ones.

Feedback survey questions come in all shapes and sizes: true/false, multiple choice, rankings, and more. While they are all important, my favorite questions are the ones that allow people to answer with their own words.

Your words speak to the heart of what we try to accomplish here at CaringKind.

Here are some of my favorite quotes from last year. Words like these keep us going at CaringKind. Good or bad, please continue to let us know... “how’re we doin’?”

Let us know how we're doing!

Call our Helpline at
646-744-2900

Email us at
helpline@cknyc.org

Join us on Social Media:

 @caringkindnyc

From Participants of Early-Stage Services

“The groups I have had the great pleasure of being a part of have been a lifeline for me. I have close family, and many dear friends, all of whom love me and who try to take care of me. Yet, there is something so vital, so special about these groups: the smart, knowledgeable, and compassionate leaders; the vital interactions with fellow Alzheimer’s “diagnoses”; and the immeasurable value of being truly “gotten”. Clearly, I can’t recommend these groups and this organization highly enough.”

“I’m happy to be able to participate with those having many of the same problems I am experiencing. I don’t feel so isolated!!!!”

“I find it immensely helpful to know that each of us in the group has similar challenges and limitations to those I’m experiencing. What a real blessing and gift to have the opportunity to be in a group meeting where everyone has my problems! It’s GREAT not to be alone, and I don’t mean “living alone”...I mean that it’s great to discuss and share our mental processes, and our coping mechanisms. And you’ve helped us to keep setting goals for our thought processes and capacities. You remind us to take care of ourselves, and to stay active in every way, so that we can keep our brains active.”

From Participants of Care Partner Programs

“The education piece has been big for me and helped me to know more about what lies ahead.”

“This group helped me change my resentment to appreciation towards my mom.”

*“Looking at your faces I watched frustration turned into smiles.”
“To have support with strangers to listen to me and not criticize me is huge.”*

“We are in a good place to take on whatever is going to happen.”

Embracing Inclusivity and Equity: A Journey Together



WEIJING SHI, MSW
VP of Community Building
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At CaringKind, our commitment to diversity, equity, and inclusion (DEI) remains at the core of everything we do.

This journey, while challenging, is one of the most rewarding paths we can walk together.

Diversity in our community is a beautiful mosaic – a rich tapestry of backgrounds, experiences, and perspectives. It is not just a concept, but the very essence that makes us stronger and more resilient. In our daily endeavors, we strive to ensure that every voice is not only heard but valued.

This commitment is not just about recognizing differences but celebrating them.

Equity is our steadfast promise. It means providing resources and opportunities tailored to the individual needs of our community members. We understand that equality is about fairness, but equity is about justice – giving everyone what they need to thrive. Our mission is to bridge gaps and remove barriers, creating an environment where everyone has the chance to succeed.

Inclusion, the heartbeat of our culture, is about creating a space where everyone feels a sense of belonging. It's about building an environment where differences are not just accepted, but embraced. At

CaringKind, we don't just open doors; we invite people in, offering a seat at the table for all. We are continually learning and evolving, ensuring that our practices and policies reflect the diverse needs of our community.

Alzheimer's and cognitive disorders occur regardless of culture, race, ethnicity, language, socio-economic status, gender, sexual orientation, or geography. To achieve our DEI goals, we will ensure families have access to dementia-friendly community programs in addition to inclusive services that honor diverse backgrounds, experiences, preferences, cultures, and languages.

We will cultivate relationships with community stakeholders and service providers to increase direct connections with individuals needing services, especially within special and under-served populations; expand best practice and evidence informed, culturally sensitive and or language specific services to increase service access by families impacted by Alzheimer's and cognitive disorders; amplify and expand dementia friendly education for community

members, organizations, businesses, and cultural institutions; promote social and meaningful peer to peer engagement opportunities to improve quality of life, decrease burden and social isolation, and increase connection to CaringKind's continuum of services.

As we move forward, let us remember that the journey towards diversity, equity, and inclusion is ongoing. It requires patience, understanding, and most importantly, action. Each step we take, no matter how small, moves us closer to a world where everyone is respected and valued for who they are.

I invite you all to join us in this journey. Share your ideas, participate in our initiatives, and help us build a community where diversity, equity, and inclusion are not just words, but the pillars of our collective strength.

Together, we can make a difference. Together, we can create a world that is caring, kind, and inclusive for all.



Strengthening Support: Enhancing Care Partner Support



SUSANNE BENGTSSON, LMSW
 VP of Family Supports
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New Program in 2023 – Partnering Together Workshop

Last year saw the inception of a new program offering at CaringKind, **Partnering Together**, a 10-week workshop and support group for care partners of people living with dementia. The workshop focuses on the Eight Central Needs of care partners:



1. Tell & retell your story
2. Educate yourself
3. Adapt to changing relationships
4. Grieve your losses
5. Take care of yourself
6. Ask for and accept help from others
7. Prepare for what's ahead
8. Explore existential & spiritual questions to find meaning

Partnering Together is based on work by Edward G. Shaw, MD, MA, professor of gerontology and geriatric medicine and a founding director of the Memory Counseling Program at Wake Forest Baptist Health, and Alan D. Wolfelt, Founder and

Director of the Center for Loss and Life Transition.

Dr. Shaw was chair of radiation oncology at Wake Forest Baptist when his late wife Rebecca was diagnosed with early-onset Alzheimer's disease. The diagnosis spurred him to shift careers, earn a master's degree in counseling at Wake Forest University and launch the program at the Sticht Center for Healthy Aging and Alzheimer's Prevention in 2011.

According to Dr. Shaw, care partner support groups are helpful because they:

- Introduce members to a community of others who have similar experiences, thoughts and feelings
- Counter the sense of loneliness and isolation that many care partners experience
- Provide emotional, physical, and spiritual support in a safe, non-judgmental environment
- Allow members to explore their many thoughts and feelings about caregiving in ways that help them be compassionate with themselves
- Encourage members to not only receive support and understanding for themselves but also to provide the same to others
- Offer opportunities to learn new ways of approaching problems and challenges
- Help care partners trust their fellow human beings and bond again in what for many feels like an unsafe, uncaring world
- Give members a forum to ask questions and search for meaning



- Provide a supportive environment that can reawaken their zest for life and give them hope for the future

At CaringKind we offer the Partnering Together workshop in-person, virtually, and also in Spanish language, several times per year. Graduates of the 10-week workshop get the opportunity to join an ongoing maintenance/support group following completion.

C

Caregiver
Storyteller

caringkind The Heart of
Alzheimer's Caregiving

New Episodes!
Caregiver Storyteller

*The award-winning
CaringKind Podcast*

This heartfelt
storytelling podcast
delves into the diverse
world of Alzheimer's and
dementia caregiving.

www.caringkindnyc.org/podcast

Building Bridges: Forging New Partnerships



ANDREA TALLENT SPIVAK
VP of Development and Strategic Alliances
aspivak@cknyc.org

I joined the CaringKind team on January 9, 2023, to oversee the Development Department and all fundraising efforts. I had known of CaringKind for years and had supported the organization personally as a volunteer and a donor in the past. Additionally, I have family members who have participated in the invaluable, life-changing Cognitive Stimulation Therapy (CST) that CaringKind pioneers, and when the opportunity was presented to devote 100% of my professional attention to a cause and organization that I am so deeply passionate about, I didn't have to think twice. And what a year it has been!

The philosopher Nietzsche proclaimed, "Become who you are". I can say I have found my true passion, purpose and people within our transformational office at 360 Lexington Avenue. My *why* is amplified when I have the true blessing of meeting with our CaringKind clients (with whom we are fortunate to be trusted partners in their Alzheimer's and related dementias journey), and our dynamic CaringKind team which truly proves to be a professional family.

We know who we are at CaringKind – the TRUSTED PARTNER and CARE behind an Alzheimer's and related dementias diagnosis. We believe in the POWER of caregiving, have served hundreds of thousands of clients in the NYC area over the past 45 years and seek a world where everyone dealing with Alzheimer's disease

and related dementias has the support they need, when they need it, where they need it.

As we proudly celebrate the 45th anniversary of CaringKind this year, we embark on a well-planned 3-year strategic plan embracing who we are as an organization and igniting the immense growth we can achieve and lives we can help by forging new partnerships.

According to the National Council on Aging, over 11 million people in the U.S. act as unpaid caregivers for the nearly 7 million members of their family and friends with Alzheimer's disease and related dementias. Out of the 11 million people across the United States, 1 million people reside in New York. The need for CaringKind programs and services is greater than ever and we are well positioned with a laser-focused plan to help them.

In addition to the legacy year-long fundraising initiatives CaringKind has in place, including our annual Forget-Me-Not Gala (this year on Monday, June 3rd at Cipriani 42nd Street), our Athletes to End Alzheimer's events (including the Walk, Marathon, Half Marathon and TD Boro Bike Tour), and our Spring and Year end campaigns, we also launched several new events including Caring to Remember. CaringKind hosted the 7th Annual Caring to Remember benefit which welcomed over 400 leaders throughout New York City's real estate industry and raised over \$450,000 to see a world without Alzheimer's and related dementias.

We recognize at CaringKind that together is better, and we want to continue partnering with other Alzheimer's and related dementia charities who are leaders in their area of expertise.

Through the real estate industry, CaringKind was honored to receive the 2023 BOMA Civic Betterment Award which recognizes organizations in New York City who have made major contributions to help make the city a better place to live, work and play. We accepted the award in front of over 700 leaders throughout the real estate industry, some of whom have already become CaringKind clients given the immense need for the caregiving support services we provide.

This past year, we have expanded our professional education offerings, including corporate dementia education programs, and are rolling out for organizations, including NYU, Audible and International Union of Operating Engineers Local Union 94 to name a few.

The impact of Alzheimer's and related dementia caregiving on the workforce is undeniable. According to AARP, in 2021 alone, family caregivers provided 36 billion hours of unpaid care worth \$600 billion. The average caregiver provides over 31 hours of unpaid care per week.

In summary, our expanded reach and increased growth potential is exponential. Thank you for being a supporter of our work and our mission. I can only imagine how many people reading the pages of this newsletter have been or know someone whose lives have been changed because of an Alzheimer's or related dementias diagnosis. WE SEE YOU and YOU ARE NOT ALONE. We are here for you, we want to connect with you and until there is a cure, you will always have care and support. That is CaringKind.

To Donate, please visit:
[caringkindnyc.org/
waystogive](https://caringkindnyc.org/waystogive)



Empowering Journeys: CaringKind's Innovative Approach to Early-Stage and Engagement Services



OLIVIA COHEN, MS, MT-BC, LCAT, CDP
 Director of Early-Stage and
 Engagement Services
ocohen@cknyc.org

Dementia Care and Transformation Through Connection

Navigating the intricate journey of life amid -stage cognitive changes and memory loss, whether from Alzheimer's or another form of dementia, can be a daunting task. Amid the maze of doctor appointments, tests, reminders, and the pursuit of maintaining a sense of normalcy; the pursuit of joy, engagement, and connection often takes a backseat.

Recognizing the need for individuals living with dementia to connect with others sharing similar experiences, CaringKind's Early-Stage & Engagement Services stands committed to providing opportunities for meaningful, impactful, and transformative engagement across a continuum of services. Our Early-Stage programs are pioneering innovative methods that empower the individual to be in the driver seat of their own experience. We offer evidence-based programs, sensitively and intentionally targeted towards enhancing and enriching the lives of those with cognitive changes.



these programs either in-person at our CaringKind office, steps away from Grand Central station, or as easily as logging on to their computers (from anywhere in the world!) in the comfort of their own homes.

Cognitive Stimulation Therapy (CST) is an evidence-based program designed to stimulate and sustain current cognitive functioning while engaging various aspects of individuals' minds. Originating in England over two decades ago, CST has shown improvements in cognitive function, mood, communication, social engagement, and overall quality of life.

Journey Together offers a supportive environment for individuals adjusting to life with memory and/or cognitive changes. Group members engage in meaningful discussions that revolve around comprehending, embracing, and learning to coexist with their diagnosis. The sessions seamlessly blend mind, body, and soul-enriching activities, exploring topics such as Living with Change, Connecting with Community, Understanding Dementia, Nurturing Relationships, Grief and Loss, Self-care, and the empowering act of "Sharing Your Story."

Since sharing one's story is so powerful, **To Whom I May Concern**® is an interactive theater program designed to amplify the voices of people with early-stage dementia or Mild Cognitive Impairments. Through small 'sharing groups' and supportive conversations led by trained facilitators, group members can share their own stories. From these collective stories, a script is created, and group members perform it in a reader's theater style event for family members, peers, friends, care partners, and professionals. Following the performance, there is a Q&A and

talk-back session that often reveals the program's transformational impact on both participants and audience members who witness those with cognitive changes tell their stories of fear, anger, frustration, hope, and determination with humor and love.

Social integration becomes a vital component in promoting mental and emotional well-being. Our social engagement programs aim to foster relationships between both individuals with dementia and their care partners.

360 Meet Ups orchestrate social gatherings for individuals and their care partners to come together and meet other members from the CaringKind community. These can take place at a coffee shop before a **connect2culture**® program or after an engaging workshop at CaringKind on 360 Lexington Ave. And for our sports enthusiasts, **connect2baseball** aims to knock it out of the park with fun and fond discussions on their shared love for the game.

As virtual and in-person group offerings expand, our outreach continues to grow. Collaborating closely with our clients to deliver top-notch programming places us in the co-pilot seat, actively engaged and accompanying them throughout their journey.

For more information about our
 Early-Stage & Engagement Services,
 please call our
 Helpline: 646-744-2900
 or visit:
caringkindnyc.org/earlystage

Steps of Hope: Uniting Our Community in the CaringKind New York City Alzheimer's Walk



SAMANTHA VACCARO
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The CaringKind New York City Alzheimer's Walk on October 22, 2023 was a true Community Day filled with love, empowerment, and support. Caregivers, families, and those living with Alzheimer's and dementia from all five boroughs came together to raise awareness for the cause in a way New York City has never seen before. Walkers enjoyed an interactive health fair, brought to them by our sponsors, that included screening for medical trials, a caregiver relaxation station, hearing testing, educational activities, and paw therapy!

It was a day that radiated strong positive energy throughout Central Park and saw over **1,000 walkers** joining in to support the CaringKind mission; to provide programs, services, and resources free of cost to those affected by Alzheimer's disease.

It is such a defining moment to stand on stage at the Bandshell and look out to a sea of orange, and witness



the community coming together to remember those lost to the disease, and see others coming together in honor of a loved one currently living with Alzheimer's and dementia, and to honor their caregivers. CaringKind is proud to be New York City's largest support group and that energy was felt throughout Central Park on a sunny day, October 22, 2023.

Honored at the 35th Annual CaringKind New York City Alzheimer's Walk were Anne Sansevero, Dr. Anderson Torres, Dr. Jahar, Pauline Yeung & Judith Grimaldi, and the NYPD Canine Unit, all of which have dedicated themselves to helping those affected by Alzheimer's and dementia.

Thank you to our supporters, including our emcees, WABC-TV's Bill Ritter and Mike Marza, and all our sponsors.

Together We Move Mountains: Join our Journey of Hope and Endurance

In the face of Alzheimer's and related dementias, every step we take, every pedal we push, every stride we run is more than just physical movement — it's a powerful statement of solidarity, hope, and resilience. At CaringKind, we believe in harnessing the energy of community engagement to make a tangible impact. We invite you and the entirety of our community to join us in our exciting athletic initiatives, where your participation truly makes a difference.

The CaringKind New York City Alzheimer's Walk: A Step Towards Change

Our annual Alzheimer's Walk is not just a Walk; it's a symbol of our collective journey. It's where caregivers, families, and those living with Alzheimer's and related dementia come together to share stories, support each other, and walk as one. This event is a cornerstone of our

community engagement, providing a space for connection, awareness, and hope.

Join us for The CaringKind New York City Alzheimer's Walk on Saturday, October 19. Register here: [CKWALK.ORG](https://ckwalk.org)

Athletes to End Alzheimer's: Be the Hero in Our Story

Join our Athletes to End Alzheimer's Team, where your passion for sports meets your commitment to our cause. Whether it's running, cycling, or any form of athleticism, your participation helps bring better care and understanding.

NYC Half Marathon: Lace up your running shoes and hit the pavement of New York City. Experience the exhilaration of the NYC Half Marathon while championing our cause. Every mile you conquer brings us closer to our goal.

TD 5 Boro Bike Tour: Gear up for the ride of a lifetime in the TD 5 Boro Bike Tour. Pedal through the heart of NYC, across the five boroughs, over bridges, and finish strong, knowing that each turn of the wheel is a cycle of hope for those affected by Alzheimer's and dementia.

NYC Marathon: Challenge yourself in the ultimate test of endurance by joining us in the iconic NYC Marathon. Run through the vibrant streets of the city, fueled by the cheers of supporters and the knowledge that with every step, you're advocating for a cause that touches millions.

Why Your Participation Matters

Engaging in these events is more than only physical activity; it's a commitment to our mission. You're not just an athlete; you're a beacon of hope, an ambassador of awareness, and a warrior in the fight against Alzheimer's and dementia. Your

participation helps raise crucial funds that enable us to provide invaluable resources, support, and care to those in need.

How to Join: Signing Up is Easy

1. Visit our website at: caringkindnyc.org/athletes and choose the event that most resonates with you.
2. Register to be part of the CaringKind team.
3. Start training, fundraising, and spreading the word.

You're not alone in this journey and we are here to support you every step of the way with training tips, fundraising resources, and an entire community cheering for you.

Your Impact

Your involvement goes beyond the physical challenges; it's about the lives you touch and the difference you make. By joining our Team, you become a vital part of a community that believes in strength, hope, and the power to make a change.

Let's lace up, gear up, and step up together in the fight against Alzheimer's and dementia. Your participation is not just a personal achievement; it's a triumph for our entire community.

Thank You to Our 2023 Walk Sponsors!



Join us for the 2024 CaringKind New York City Alzheimer's Walk
Saturday, October 19
Register: CKWALK.ORG





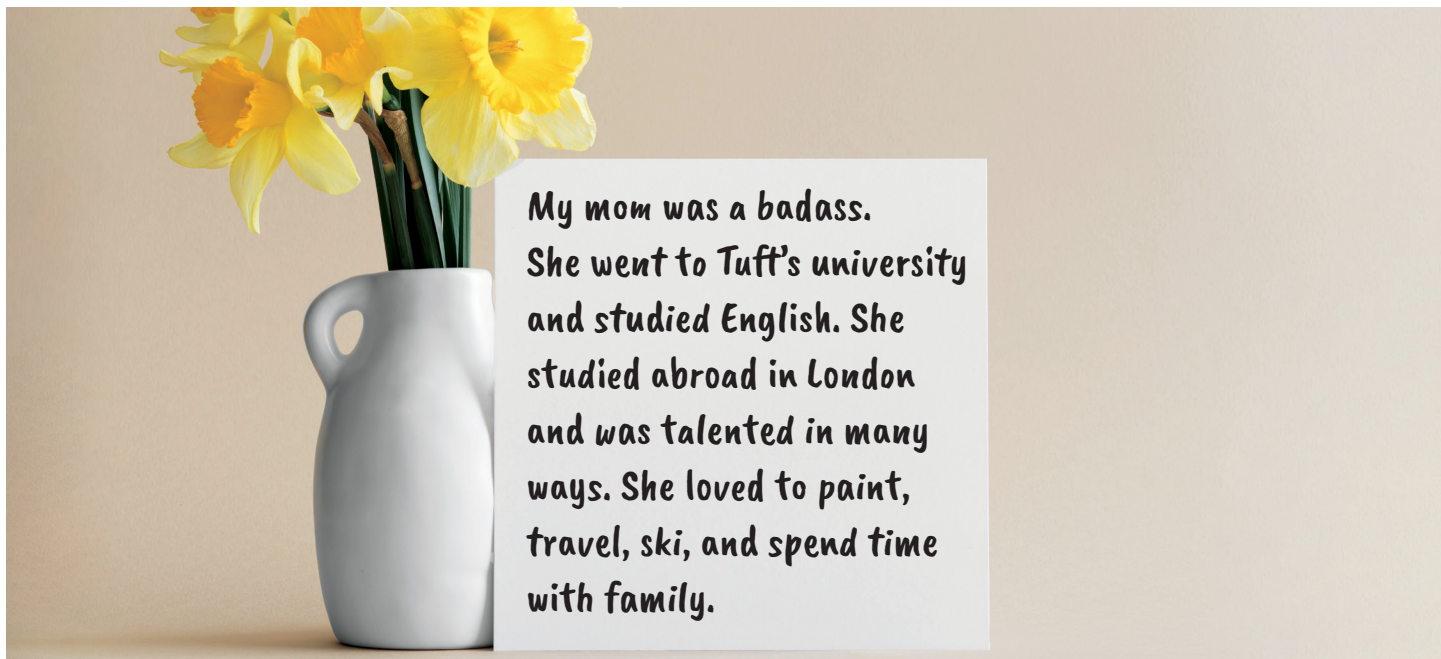
CaringKind's Caregiver Champions are devoted and empathetic individuals who form the bedrock of our efforts to aid those impacted by Alzheimer's and other dementia.

We recognize the resilience, compassion, and sacrifice caregiving entails and these dedicated individuals merit exceptional acknowledgment.

For more information, or to nominate a Caregiver Champion: ckchampion.org



Letter from Esther Blair Schiffman



My mom was a badass. She went to Tuff's university and studied English. She studied abroad in London and was talented in many ways. She loved to paint, travel, ski, and spend time with family.

She worked for Coca-cola, collaborating with people in the Olympics like Katarina Vik, Bruce, now Kaitlyn Jenner, talented artists like Elton John and Paula Abdul. She worked at IBM too. She did PR and advertising and was an amazing writer. Everyone loved her and she even played the guitar. She also was on the team that launched the famous cabbage patch doll! She always did amazing work, succeeded when putting her mind to something, and I know that there's a lot of her in me.

Now my mom is on hospice, she's only 64. My mom got diagnosed with Alzheimer's when I was only in 8th grade. All I knew was that she forgot things. Growing up, me and my brother didn't have a lot of emotional support. My dad worked a lot and my mom was not paying attention to

us because of this disease. It made things difficult for my dad and my family.

When I went off to college, I didn't see her a lot, and when I did go home, the progression of the disease would get worse and worse. This was hard for me. Things got out of hand at home and I didn't see myself getting a full-time job when I graduated from college.

I decided I needed to come home and help support my mom and dad. I fired the aide that was not doing a good job. I deep cleaned the house — really deep cleaned the house. There were papers that were left in drawers from 2001, expired food in the pantry, clutter everywhere. I knew my mom would want me to take care of things because she wasn't able, and my dad didn't

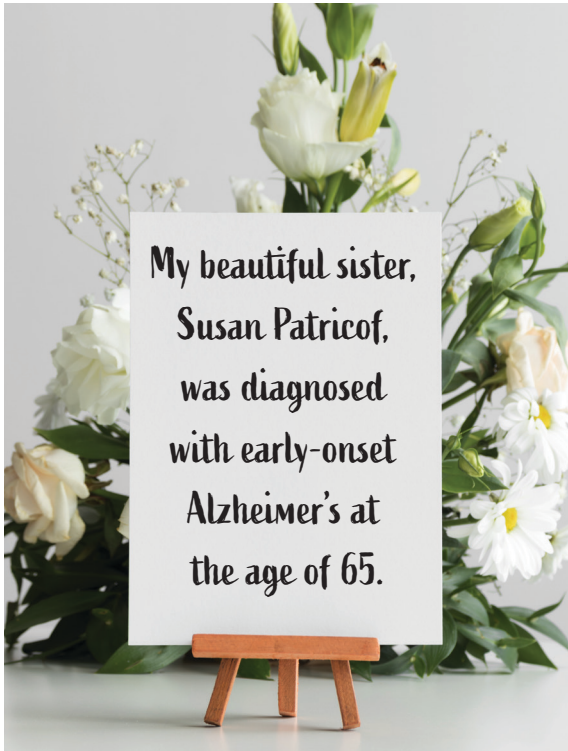
have the time or energy to do it.

I hired new care, worked with my mom, and tried to have a life, but it was hard. I traveled as much as I could and worked when I had the opportunity. I was only 22. I knew that the only way for my family to be OKAY, was if I stepped up. And that's what I did. I knew that if I didn't, things would just get worse later.

We are still figuring it out. I am proud of my mom and who she was. I hope she is proud of me too. Alzheimer's sucks. I love my mom, and I hope all the sacrifices I've had to make have been worth it to make sure she's comfortable.

Esther Blair Schiffman

Letter from Amy Hatkoff



created a disco in the kitchen and played my sister's favorite music to which family and caregivers danced!!

One of my biggest takeaways from the years I spent helping Susan was realizing that we are so much more than our minds. Even as she began to "lose her words," I could always find her heart. The glint in her eyes and her body language spoke volumes. I was able to communicate with her in ways that transcended the usual day-to-day talk. It seemed that the more she felt seen, the more she could hold onto herself.

"The more of me you see, the more myself I can be."

A generous and accomplished philanthropist and advocate for women and children throughout the world, she tirelessly improved the lives and championed the rights of so many.

Susan lived with this illness for 12 years. During those years, I moved from home in Florida back to New York City to be with her and to help my family with her care. I recently learned that I was one of 11 million Americans to do so. My role was to make Susan's days as pleasant, stimulating, and enjoyable as possible. We took art classes, walks in the park, visited the Botanical Gardens, went for music lessons, ballet classes, and walked through museums. Susan and I even flew to Prague to visit her son who was making a film.

We set up frequent visits with the children in our family, all of whom were so understanding, gentle, and loving. We had a steady stream of family and friends for meals and other occasions. We even

When speaking became increasingly difficult, Susan could still make her presence known. Her smile could light us up and fill a room. Her compassion was palpable. Despite the loss of many abilities, her grace, elegance, and concern for others were still present.

I heard actor Bryan Cranston explain the shift in his understanding of his mother's experience of Alzheimer's. He shared that once he was able to let go of the relationship he had with his mother in the past, and instead began to meet her where she was in the present without judgment, everything changed for the better and they forged a new connection.

We were blessed to be able to keep Susan at home. Families can feel so vulnerable when a loved one is diagnosed with Alzheimer's. The incredibly difficult terrain of loving, caring for and living with someone who has a challenging condition can be overwhelming. I am amazed by

individuals and families who are able to support a loved one on their own.

It was a gift to discover CaringKind. The staff and their caregivers helped us navigate the rocky waters of this challenging illness. They were available to answer all our questions, provide resources and meet our varied needs. Ultimately, they provided care for my sister around the clock. They were our angels and guiding lights. Their services were invaluable.

It was so uplifting to witness the level of care they provided for Susan, as well as the entire family. It felt as if we were experiencing the best of humanity. The patience, devotion and respectful approach of the caregivers made all the difference. My eternal thanks to them for being on this journey with us.

The focus of my work has been to translate the science on what babies need for optimal growth in every area of development. Modern technology can now see the impact that various interactions have on different areas of the brain. The findings show that warm, loving, soothing interactions build a baby's best brain and can actually help the brain grow larger. Just being with a parent stimulates brain connections. I hope this information about the profound and powerful impact of nurturing on babies' development can open the door to research on how nurturing interactions might benefit adults with Alzheimer's.

It is my hope and prayer that we can join forces and continue to move forward together, sharing our stories, and learning from and supporting one another in conquering the growing challenge of Alzheimer's.

Amy Hatkoff

Together in Support: The Power of Community



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CaringKind's Jewish outreach and culturally competent services continue to grow as we proactively anticipate and respond to emerging needs of the community. We customize evidence-based interventions to be culturally attuned and develop our own supplementary programs designed to address unique needs of this population impacted by dementia through a lens of Jewish affiliation and/or practice.

While holiday celebrations often increase caregiver stress, the nature of what observance entails, and the relative value placed upon remembering our past is rooted in the Jewish experience. With that in mind, we developed and virtually delivered educational webinars entitled *Caring for the Caregiver: Passover Edition* and *Caring for the Caregiver: High Holidays*. Both workshops give participants guidance on how to make their holidays dementia-friendly while also making sure caregivers invest time in self-care.

Jewish dementia care partners and Jewish people living with dementia have had to contend with ongoing tragic events and ongoing news cycle coverage connected to the October 7 massacre in Israel and the

related war in the region. In response to this reality, we developed a virtual educational webinar entitled *Being a Responsive Caregiver While Israel is at War*, where we provided trauma-informed guidance on dementia care as well as support for the caregiver impacted by traumatic events. A separate educational seminar entitled *Caring for People Living with both Dementia and Holocaust-related Trauma* planned initially in honor of International Holocaust Remembrance Day, has become all that much more relevant given surging antisemitism being perpetrated around the world since October 7.

We continue to strengthen our partnership with and presence at Sephardic Bikur Holim (SBH) in Brooklyn, which has an older adult center (OAC) serving local Jewish community members. While collaboration has existed for some time, we have furthered it and now offer an intervention known as Cognitive Stimulation Therapy (CST) to a subset of their OAC participants living with dementia. These in-person groups are being co-facilitated by professionals from CaringKind and SBH, utilizing an evidence-based curriculum that has been adapted to be culturally sensitive including topics of Jewish interest.

At SBH's OAC, we celebrated Purim with a highly interactive Jazz concert with musicians schooled in how to engage folks in ways that are more accessible. Doing so enabled community members to join together in a dementia-friendly space to sing and dance to their favorite songs as well as to reminisce about their associations to them.

Our deepening partnership with the Museum at Eldridge Street has consisted of tours of the historic Lower East Side synagogue (and now museum) in conjunction with intimate, participation-encouraged reflection. Topic including a historical review, focused on Christmas

music written by Jewish composers from the Lower East Side (i.e. George Gershwin and Irving Berlin), and in honor of the Channukah season a discussion around, and walk-through of, their Menorah collection. These gatherings provided participants the opportunity to enjoy beautiful music, reminisce on their own experiences, and share opinions on the merits of tradition as compared to innovation.

We seek to increase care partner knowledge of dementia and comfort by utilizing skills to effectively impact those they care for by hosting educational programs in the community in group settings as well as by coaching and guiding care partners on an individual basis.

We facilitate an ongoing Orthodox Adult Child Caregiver Support Group that serves adult children from a diverse array of Jewish communities, including participants Zooming in from Israel.

We provide Jewish individual care partners with care consultations as well as a series of one-on-one coaching sessions utilizing the evidence-based program known as REACH (Resources for Enhancing Alzheimer's Caregiver Health). We collaborate with community partners to provide in-person REACH services at satellite locations and via combined in-person and virtual visits in conjunction with our community partners.

We look forward to expanding our presence and connection with other community-based organizations to help bring education, emotional support, and guidance to those in need in a way that works best for those we are looking to serve. Stay tuned for exciting developments going forward!

Inspirational Storytelling



RICHELLE MATARAZZO, MSW
 Navigator and Program Specialist
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In August, CaringKind proudly presented the storytelling production **To Whom I May Concern®** featuring a lineup of inspirational individuals living bravely beyond their diagnosis of Mild Cognitive Impairment (MCI), Alzheimer's, and other forms of dementia.

The remarkable cast shared a theater-style script crafted from their diverse tales of courage, sadness, insight, humor and love. After the presentation, the audience was

asked to write down what living with MCI, Alzheimer's disease or another dementia would be like for them. Surveys showed the four most common words were:

Hope, Brave, Courage, Adaptability

It was a sharp contrast to the most common words written down *before* the presentation:

Confused, Sad, Fear, Frustration

Before the presentation, they hadn't yet heard Alan speak about his love for the ukulele and listen to him play during the performance, with the support of his loving wife. They hadn't yet learned about Paula's best friend, the "ultra-calendar," that helped her to organize her life and maintain some new normalcy with her everyday activities. The program gave the storytellers the power to tell of their own

experience and audience members were able to gain a new perspective on what it was like living with cognitive changes.

To Whom I May Concern® is a supportive small group program for people with dementia living with similar memory and/or cognitive changes. A trained facilitator guides the group to share their experiences and stories. A creative script is then crafted and shared with invited friends, family and professionals.

You can personally experience the impact of these events through the video recordings on our website: www.caringkindnyc.org/twimc

The CareLink360™ Digital Health Companion™

How do we demonstrate how much we care for our loved ones if we are not able to physically be with them?

Video chat products like Zoom and Facetime are helpful for some, but they sadly do not work if our loved ones are not comfortable with technology and apps.



Help is on the way with the CareLink360™ Digital Health Companion™.

CareLink360™ was specifically designed to make the "simple act of caring" possible by actually being simple enough to use for people who are not proficient with technology.

The CareLink360™ Digital Health Companion™ offers "Virtual Social Therapy®" through video chats along with photo and video sharing.

It acts as a simple platform to deliver curated music therapy, physical fitness

coaching, speech therapy, counseling, spiritual support, and cognitive puzzles.

This is a safe, secure device that is not run over the internet, so the only people who can communicate on it are the device owners and those set up on the device as their care circle or care team.

For the Digital Health Companion™ user, the device has a 15 inch screen and internal speakers that are enhanced for those with visual or hearing impairment.

There are no passwords or links to remember and if the user cannot remember the name of the person they wish to connect to, they just see the face, and tap on it to connect. It is that easy.

On the other side, the care circle members have a "companion app" that works from any smart phone making it easy to connect to their loved ones or receive video calls, just like they would on Facetime, wherever they are.

Paid Advertisement



The uses of the CareLink360™ are vast, but it all boils down to three little words — Simple, Safe, and Social.

To learn more, contact Dave Duplay at DDuplayMyCareLink360.com or check out our website at: <https://mycarelink360.com/>



Bridging Communities: The Memory Advocate Peers Program (MAP) at CaringKind



MARCIA HENNE
MAP Program Manager
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Launched nearly two years ago, the Memory Advocate Peers Program (MAP) at CaringKind has evolved into a dynamic support system for those grappling with Mild Cognitive Impairment (MCI) or dementia, with a distinctive focus on breaking barriers within the Latino and African American underserved communities.

MAP operates as a support program that thoughtfully pairs recently diagnosed individuals and their care partners (dyads) with trained volunteers, or mentors, who bring invaluable prior experience in caring for someone living with dementia. These mentors serve as empathetic guides, fostering a sense of understanding, education, and empowerment within the MAP community.

The program's core objective is to enhance the experience of the dyads after the diagnosis. This multifaceted approach involves connecting clients to community resources, providing a robust foundation of support.



participation in clinical trials, contributing to advancements in dementia research while concurrently offering much-needed emotional support.

Since the program launched, we have had more than 20 dyads enroll in the program. The dyads have told us that they look forward to meeting with their mentor, as they have built trust, they know one another and truly enjoy having someone “on their side”, knowing what they are going through.

Upon completion of the 12-month program, these persons with dementia and their care partners frequently ask me if there is a MAP 2, or how they can continue to engage with MAP as their experience has been so positive with the mentor and all the CaringKind services.

The dyads are not only creating a bond with their mentor and being emotionally supported by them, but they feel fully supported in living with a positive quality of life, engaging in social events, being validated and heard, and feeling empowered and prepared to forge forward with a long-term plan.

All MAP mentors have received training at CaringKind and we have a great group of individuals hailing from New York to Florida and Arizona! Yes, we do accept volunteer mentors nationwide!

Just this past summer, we had a Mentor Appreciation Dinner to acknowledge and thank our mentors for the amazing “work” they do with the dyads.

The mentor's contribution is not just “work”. It comes from a place of love. It comes from wanting to “give back”, it

It is so important that programs serving people living with dementia are developed in partnership with community members, and MAP is involving the communities most impacted by Alzheimer's and related disorders.

— Sarah Walter
MAP Co-Founder and Researcher

comes from not wanting anyone else to have to go through this alone, not knowing where to turn.

So, although it may be called or seen as work, it is priceless hours that they give to someone in need. That is love and commitment. One of the mottos that I have for the MAP mentors is: if we ever find ourselves not knowing an answer, just fall back on what we are good at, and that is Patience, Love and Kindness!

I am a former caregiver. I cared for my mother who was diagnosed with Alzheimer's disease. After many years of providing care for her, I came to CaringKind looking to volunteer because I too wanted to give back, wanted to share the skills I learned while being a caregiver, and mostly I wanted to help another caregiver not feel alone. If MAP had been around back then, I surely would have become a mentor.

MAP's commitment extends beyond the mainstream dementia community. The program identifies and addresses the unique challenges faced by the Latino and African American populations, acknowledging the barriers stemming from socioeconomic disparities, cultural differences, and a lack of trust in medical institutions. To tackle these challenges head-on, MAP has initiated an African


American Community Advisory Board. This board serves as a vital platform for community members to share insights, build trust, and foster understanding to dismantle barriers.

MAP envisions itself as more than a service provider – like CaringKind, it aspires to be a trusted partner within the dementia community. By actively engaging with underserved communities and involving them in the decision-making process, MAP aims to tailor its services to address specific cultural and socioeconomic factors influencing the early intervention decision-making process.

In conclusion, the Memory Advocate Peers Program stands as a testament to inclusivity and community-driven initiatives. As it looks toward the future, MAP at CaringKind is poised to be a beacon of support, understanding, and empowerment for all individuals facing the challenges of dementia, irrespective of cultural or socioeconomic backgrounds.

To learn more about the MAP program, please contact:

Marcia Henne,
MAP Program Manager
Phone: 646-744-2937
Email: mhenne@cknyc.org



8th Annual

CARING TO REMEMBER

Changing the World of Alzheimer's and Dementia

Wednesday, September 18
5:30 - 8:30pm

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10 Desbrosses Street, New York, NY 10013

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FRANCES GRAHAM
Senior Managing Director
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Andrea Tallent Spivak at aspivak@cknyc.org

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To Whom I May Concern®: Coping with Alzheimer's, One Tale at a Time

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Our Town

Upper East Side Newsletter

June 11, 2024

BY CHIA-TIEN NICOLE CHEN

On a Friday afternoon this April, Michael Pollack, a 73-year-old man with close-cropped white hair and rounded glasses, sat in a director's chair in front of a packed room in a Midtown office building.

"My memory's not so good," he said steadily into a headset microphone. "I've really become self-conscious about it. Actually, I'm a bit embarrassed. If I could just get across to them — my family, my friends, the people I live with, the people who try to help me. If I could just let them know what it's like to be me these days."

Pollack, who has Alzheimer's, was one of four people that afternoon who spoke about living with dementia. Through reading aloud letters addressed to people in their lives, they laid bare the ways in which dementia had set into and fundamentally reordered their everyday lives — and even their senses of self.

A storytelling series gives the stage to people living with dementia, who tell their stories, in all their complexity, in their own words.

They were taking part in an international storytelling program called *To Whom I May Concern*®, locally organized by the Alzheimer's care nonprofit, CaringKind. The storytellers, all diagnosed with some form of dementia or mild cognitive impairment, take part in weekly group sharing sessions, in which they work with facilitators to turn their stories into a script. They then perform the script to an audience of family, friends and healthcare professionals.

The performances are a look into the interior lives of those living with dementia, and in particular, Alzheimer's, a progressive disease whose defining effect is, as Pollack puts it, "a diminishing" of selfhood. In its middle to late stages, most lose their speech completely; the experience of living with the condition becomes unspeakable, and to outsiders, unknowable.

To Whom I May Concern® is a way for patients, who may otherwise be inclined to keep their diagnoses close to their chest, to narrate, on their own terms, the experience of living with dementia and cognitive impairment. There's the mourning of everyday things: small blips in memory, directions that had previously been ingrained. The everyday losses amount to monumental ones: careers and family roles, selves they were before.

Adrienne Viscio, a former special education teacher, read a letter addressed to her students during the April performance: "It dawned on me that if I were to take the same evaluations of learning disabilities that I was giving you, my own performance would have been dismal. The symptoms were subtle until they weren't. I stood confidently in front of you teaching from my notes, while I held on to them for dear

life," she said between long breaths. "Not a day goes by that I don't think of you and mourn the loss of what was so much more than a career."

Detailing these losses so vulnerably, in front of an audience of caregivers and loved ones, seems not just to be about the grieving of former selves, but also the acceptance of a new reality shaped by dementia.

Speaker Ronnie Sholom read a letter addressed to his wife, describing a former self who was always moving a few steps ahead of her. Illness has slowed him down. "Maybe slow is what I needed. When I began to lose my balance, you stood strong. When I looked for more things to do, you filled my day," he said. "I am seeing and appreciating everything around me one step at a time. I live in the present."

A month after the event, Our Town interviewed Pollack over a Zoom call. He spoke from a couch in his Tribeca home, wearing an orange baseball cap with the CaringKind logo. "Alzheimer's is a forest and we are all trees and each of us is affected and afflicted in our own way," he said. "But you spend time with the other trees and you get to know people. There's no judgment, whatever goes on."

As a wry, confident speaker who initially tested well on cognitive evaluation exams, it took Pollack years of doctors' visits and several hospitals in New York before he was officially diagnosed. "I present well. Even now I'm present. I'm engaging. I'm funny," he explained.

Pollack is a proponent of talking about the disease and advocating for oneself: He's participated in four *To Whom I May Concern*® performances, and wears his

CaringKind hat while walking outside, eager to talk with strangers about Alzheimer’s.

“While I’m losing my mind, I’m trying to help change minds,” he said. He is frank about the disease’s impact on his life: “I am afflicted and everyone else in my life is affected... I am not exactly who I used to be.” But, he continued, “I can have hard conversations because I’m not giving up and I’m not surrendering. I’m fighting.”

For Pollack, telling his story is also a vital tool for piercing through the stigma that hangs around dementia and other cognitive disorders — a dark cloud heavy with fear, fatalism, and eventually, dehumanization.

The mission takes on a particular urgency in healthcare settings: a 2021 AARP study found notable discrepancies between the perceptions of average adults and healthcare providers regarding dementia and cognitive impairment. Healthcare providers tended to overestimate how negatively their patients feel about dementia, and some were less willing to tell their patients about a diagnosis.

Medical students and healthcare professionals have attended previous “To Whom I May Concern” events. Before the performance, the audience completed a word association exercise. “The first three words before the program, people think, you know, ‘hopeless,’ ‘sad,’ ‘depressed,’” said CaringKind president Eleonora Tornatore-Mikesh. “And then after the program, people’s words changed to ‘hopeful,’ ‘community,’ ‘love.’”

Pollack recalled performing for a group of geriatric palliative care providers — “I’d say the hardest job there is because you



Photo: Gary Tomei (from left), Ronnie Sholom, Adrienne Viscio and Michael Pollack speak at CaringKind headquarters on April 19, during a “To Whom I May Concern®” storytelling event.

lose every one of your patients eventually,” he said. You gird yourself because on an emotional level, that’s a really hard thing to come to work to do.” By Pollack’s telling, however, everyone in the room cried, including the performers. “Getting to be able to break through that wall and open their hearts a little for us was amazing,” he said.

Last year, Leqembi, the first and only commercially available drug treatment for early-stage Alzheimer’s, was put on the U.S. market. Researchers told Reuters that its adoption has been slow, in part due to healthcare providers’ skepticism and “therapeutic nihilism.” Pollack is one of several thousand Americans who receives infusions of the drug, which may slow the disease’s progression. “There are treatments now. I’d say 10 years ago, I couldn’t make that statement. ... I believe in my lifetime, there’ll be a cure for this,” he asserted.

In the meantime, he wants people who suspect they may have dementia to know there are resources. There is a community. “Do not question,” he emphasized. “If you have concerns, go seek help. Go to CaringKind. They’re there to help. The worst thing about this illness is that it drives people away from people. Aging is its own challenge. And this is icing on that cake. It’s a bitter icing. But don’t isolate.”

For more information about
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Treatment Updates



JED A. LEVINE
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Occasionally, we re-visit articles from our archives that are still relevant, but need updating to be current. This inaugural column from Jed Levine originally appeared in the CaringKind Newsletter from Summer 2012, and has been revised to reflect current knowledge.

Treatment. When we have a disease, we want a treatment. For most of us that means a pill, potion, lotion, drops, surgery, a procedure, or other medical intervention. In the world of Alzheimer's disease, the pharmacological options are limited. The current medical treatment scenario is both "good" news and "not so good" news.

The "good" news is that back in 2012 we could talk about medical treatment. That had only been the case for less than twenty years.

The "not so good" news is that the treatment was not so good. It didn't modify the disease or slow down the rate of decline. It did, in some cases, modify the symptoms for a period, but did not alter the underlying biological process of the disease. However, in the absence of anything better it was good enough to warrant a trial. We still needed to invest in research and to find a better way.

In 2024 things have advanced remarkably, three drugs have been approved for the treatment of Mild Cognitive Impairment and early-stage Alzheimer's disease. The

first, Aducanamab, is no longer available, Lecanemab was approved in 2023, and most recently Donanemab was approved in July, 2024. These are the first disease modifying drugs to be approved by the FDA, that meaningfully eliminate amyloid from the brain and slow the cognitive and functional decline of dementia. They are a reason to celebrate.

However, be aware: they are administered by IV infusion, require PET scans or other tests to establish the presence of amyloid in the brain and regular MRI's to detect potentially dangerous swelling or bleeding in the brain, a possible side effect. And they are expensive. Even with Medicare and Medicaid's approval to pay for them, the cost might be prohibitive for some, depending on what kind of secondary insurance they have.

Most importantly, only individuals in the very earliest stages of Alzheimer's or its pre-cursor, MCI, meet the diagnostic criteria to take this new class of drugs. We are optimistic that advances in diagnostics will lead to more accurate and earlier diagnoses. However, that still leaves millions of Americans who are in the more advanced stages of the disease ineligible for treatment by these drugs. It is also important to note that people living with non-Alzheimer's dementia are not eligible to take these medications. We are optimistic that advances in diagnostics will lead to more accurate and earlier diagnoses.

There is another category of treatment that can improve the quality of life for the person living with Alzheimer's Disease and their caregivers. Music, art, poetry, movement, reminiscence, pets, children, sensory stimulation, are life-affirming, anxiety and depression reducing activities.



At the 10th Annual Barry Reisberg award presentation lecture in 2012 given by Hearthstone Alzheimer's Care, (no longer operating), the late Linda Buettner, Ph.D., showed a video of a woman in a wheelchair enjoying a ride in a wheelchair bike with a staff member. Her sense of freedom, her joy at moving through space in a way that she hadn't in years was infectious. She was fully in the moment, and fully alive. It was the result of a "non-pharmacological" or psycho-social approaches to care. And I know they work.

From the time I supervised the first day treatment center for persons with dementia in New York City, in 1979, I knew that I could reach people with Alzheimer's Disease through these kinds of programs. We moved together, prepared food together, painted and drew together, sang and laughed together. Did we slow the progression of the disease? Probably not. Did we cure the disease? Of course not. But, we were able to engage individuals who had been written off; and gave them hope, laughter, joy, and the opportunity to feel the full range of human emotions. The participants connected to each other and to the staff. There were times when you couldn't tell who had Alzheimer's in that room.

Many have studied the profound and positive impact of the psycho-social and creative approaches; Ladislav Volicer, Linda Teri, Barry Reisberg, Ann Bastings, Cameron Camp and John Zeisel.

Power of Connection: Meaningful Moments for People with Dementia and Their Care Partners

Consistently the data tells us that quality of life improves, falls are reduced, people take less psychiatric medication, and the individual is more “cooperative” with activities of daily living.

I had the moving experience of attending the premiere of *Alive Inside* at the Rubin Museum (in 2012). In this documentary, we see people with advanced dementia put on headphones connected to an iPod that has been specially prepared with “their” music, be it The Bee Gees, Gospel, Country Western or Opera. These formerly withdrawn, mute individuals come amazingly to life. Eyes open up, silenced voices sing, contracted arms move; they are re-awakened. The music was there all the time, it just had to be accessed. Thanks to the creativity and tireless persistence of Dan Cohen, (former) director of the Music and Memory Project, more and more nursing home residents are able to take advantage of this program. For more information, search online for “Alive Inside” or Music and Memory.

Until we find a more meaningful medical treatment for all affected by the disease, let’s not forget the power of the psychosocial and creative arts approaches. After a lifetime of believing in the power of the arts and activities that speak to the residual strengths of the person with Alzheimer’s, I am delighted that CaringKind is significantly engaged in the world of art, music and culture, with our connect2culture® program.

To learn more about these and other programs at CaringKind, please call our Helpline at 646-744-2900 or visit www.caringkindnyc.org
We are here to help.



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Dementia can be isolating, bringing about feelings of loneliness and frustration for both individuals living with dementia and their devoted caregivers. Finding ways to foster a sense of connection is crucial for everyone involved.

Our **connect2culture®** program engages people with dementia and their caregivers through cultural experiences. These programs provide opportunities for meaningful interactions, enhancing the quality of life for both parties.



A garden walk can prompt discussions about favorite plants and past experiences with nature. Attending a music performance or dance workshop can evoke emotions and memories tied to specific songs or dances.



When individuals with dementia and their care partners participate in programs together it can strengthen bonds, encourage collaboration and communication, and provide a sense of normalcy. Our **Connect2Baseball** program allows clients and care partners to share their love of the game, a favorite pastime for many.

Shared experiences provide a sense of purpose and joy, crucial for mental and emotional well-being. It reminds participants that despite dementia’s challenges, there is still much to appreciate and enjoy. Together, these efforts create a holistic approach to dementia care, enriching the lives of both individuals with dementia and their caregivers. Visit our Community Engagement Calendar for program schedules.

For more information about connect2culture® programs, visit: www.caringkindnyc.org/socialengagement or call our Helpline: 646-744-2900



Alzheimer's Disease

Green Tea and Resveratrol Reduce Alzheimer's Plaques in Lab Tests

Using a 3D neural tissue model, Tufts researchers find the compounds diminish amyloid plaques with no side effects.

by Taylor McNeil
November 1, 2022

Alzheimer's disease is the sixth leading cause of death in the United States, affecting more than 6 million Americans, and its incidence is expected to rise in the coming decades.

The cause of the disease in its most common form, which is not genetically based, is not well understood. This makes treatment difficult, but progress is being made. Using a 3D model of living human brain cells, Tufts researchers earlier this year showed that the common herpes virus could induce plaques in the brain associated with Alzheimer's disease.

Now, Tufts researchers are working to understand what might slow progression of the disease. They have tested 21 different compounds in Alzheimer's-afflicted neural cells in the lab, measuring the compounds' effect on the growth of sticky beta amyloid plaques. These plaques develop in the brains of people with Alzheimer's.

The researchers found that two common compounds—green tea catechins and resveratrol, found in red wine and other foods—reduced the formation of plaques in those neural cells. And they did so with few or no side effects. The researchers reported their findings in the journal *Free Radical Biology and Medicine*.

Some of the 21 compounds tested reduced the disease progression by acting as anti-viral agents—slowing Alzheimer's induced by the herpes virus. But finding a compound "that could diminish the plaques regardless of the virus component would be ideal, because that would show that regardless of the cause of Alzheimer's, you might still see some kind of improvement," says Dana Cairns, GBS12. Cairns is a research associate in the Kaplan Lab in the School of Engineering and led the research.

The initial screening was done in simpler models, and compounds that had a positive effect were then tested in the 3D neural tissue model. That model is created

using a nonreactive silk sponge seeded with human skin cells that, through genetic reprogramming, are converted into neural stem cell progenitors. Those cells grow and populate the sponge, "which allows for 3D network formation of neurons similar to what you'd see in the human brain," Cairns says.

The initial screen found five compounds had "really robust prevention of these plaques," she says. In addition to the green tea compounds and resveratrol, they found curcumin from turmeric, the diabetic medication Metformin, and a compound called citicoline prevented plaques from forming and did not have anti-viral effects.

"We hoped to find compounds that would be harmless and show some level of efficacy," she said. Green tea compounds and resveratrol met that standard. "We got lucky that some of these showed some pretty strong efficacy," Cairns said. "In the case of these compounds that passed the screening, they had virtually no plaques visible after about a week."

Green tea catechins—molecules in the tea leaves that have an antioxidant effect—have been explored as a potential treatment for cancers, and resveratrol has been tested for anti-aging properties.

Cairns cautioned that seeing effects in the lab "doesn't always necessarily translate to what you might see in a patient." Some compounds do not cross the blood-brain barrier, which would be essential in the case of Alzheimer's, and some have low bioavailability, meaning they are not readily absorbed into the body or bloodstream.

Still, the discovery is significant because there is no cure for Alzheimer's or a way to prevent its progression, aside from several potential drugs developed by pharmaceutical companies that are still in trials, Cairns says. Compounds like these two that show some efficacy and are known to be safe and easily accessible could be

taken as a supplement or consumed as part of one's diet, she adds.

"For example, natural sources of resveratrol include red wine, certain fruits such as grapes, blueberries, and cranberries, peanuts, pistachios, and cocoa," says Cairns. "While it is empowering to be able to take measures like these to potentially prevent neurodegeneration in the future, it is also important to consult with your health-care provider before making any major changes to your diet."

Looking ahead, a potential area of research for researchers and pharmaceutical companies would be to take the beneficial properties of these compounds and "try to enhance them to make them more bioavailable or make them penetrate the blood-brain barrier a bit better," Cairns says.

In addition to Cairns, other co-authors of the journal article include Isabella A. Silveira, E21, and Adam Mullis, a postdoctoral scholar at Tufts, along with David Kaplan, Stern Family Professor of Engineering and chair of the Department of Biomedical Engineering.

For full article; see:

Tufts University
Green Tea and Resveratrol Reduce Alzheimer's Plaques in Lab Tests

<https://now.tufts.edu/2022/11/01/green-tea-and-resveratrol-reduce-alzheimers-plaques-lab-tests>

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To register, call our Helpline at 646-744-2900, or register online at the links below.
All meetings are free of charge and subject to change.

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

- Provides information on Alzheimer's disease and other types of dementias.
- Discuss the different stages of the disease and what to expect.
- Include an overview of our programs and services and other available resources.
- Teach you how to more effectively support people with dementia and their caregivers.

Online Live Webinars

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Register by calling our Helpline: 646-744-2900
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An attorney specializing in Elder Law will discuss important topics that Alzheimer's and dementia caregivers should understand before meeting with a personal attorney.

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Prior attendance at an Understanding Dementia seminar is recommended.

Online Live Webinars

In English, Spanish, and Chinese.

Register by calling our Helpline: 646-744-2900
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Medicaid Home Care Seminar: A Practical Guide to the System

Alzheimer's and dementia caregivers are guided through the application process for Medicaid home care service. Prior attendance at a Legal & Financial Seminar is required.

Prior attendance at an Understanding Dementia seminar is recommended.

Online Live Webinars

In English, Spanish, and Chinese.

Register by calling our Helpline: 646-744-2900
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Seminar topics change monthly and are in English.

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Social Engagement

Engaging people with dementia and their caregivers through cultural experiences.

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Meeting topics vary. Two (2) Social Work Continuing Education units are available for a fee

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