Caringkind The Heart of Alzheimer's Caregiving

Issue 3, 2021

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You Gave This Family Time to Get Organized

Caregiver D'Ambrose Boyd and his mother, Wilma

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

You Gave This Family Time to Get Organized Caregiver D'Ambrose Boyd and his mother, Wilma

D'Ambrose noticed personality changes

"My mom was changing in ways I didn't know how to handle and that frustrated me. She was getting aggressive, calling me repeatedly at work, and calling the police. I had my cousin watching her while I was at work.

One day, she was out in the front yard and began yelling for the police. An ambulance was called and once she got in, she calmed down. But that's the incident when I knew we needed professional help.

A valuable connection

Keith Amparado – a longtime volunteer at CaringKind – told me about CaringKind. I signed up for the legal/financial training and estate planning classes. Talking with social worker Nansi Rivas about mom was a really big deal for me. I started crying! I didn't realize how much I needed that support. I felt like I was finally talking to someone who really understood our situation.

A social worker to the rescue

Ms. Rivas helped me feel like it was OK to feel what I was feeling. And she helped me identify an agency that could provide the home health aides we needed when I wasn't at home. And – this is important – she helped me navigate the process of hiring and paying for a home health aide in a way that was sustainable for us. The respite grants we qualified for were transformational – they gave us the financial breathing room we needed to plan for the future.

Even the education classes were a kind of emotional support. While the main objective of the classes was information, the questions from the other participants provided insight into the lives of other families. It made me feel less alone and that we're all just doing our best to provide for our loved ones.

In her career (and life in general), mom was a mover and shaker. She worked for the City of New York as Director of the Crime Advocates Program. To this day, a family she helped visits her each year to express their gratitude. I am so proud of her.

A family in better shape

I understand their gratitude because that's what I feel for CaringKind. Because of the support we've gotten, our family is in better shape. My mom knows that she is being taken care of and that she's loved."





Message from Eleonora With Your Help, CaringKind Receives \$1 Million Award to Develop New Services!

by Eleonora Tornatore-Mikesh, CaringKind President & CEO

In July, CaringKind received a prestigious, three-year, \$1 million award from the Administration for Community Living, a department of Health and Human Services.

This project brings new services to New York City residents affected by Alzheimer's or dementia living at home. These awards pilot new programs to fill gaps in services for special populations including family caregivers, people with Alzheimer's disease or related dementias who live alone, and individuals living with intellectual and developmental disabilities who are at risk of developing a dementia.



Stephani Shivers

Stephani Shivers, CaringKind's new Chief Innovation Officer, will lead the initiative. According to Stephani, "*The CaringKind Connects* project includes a suite of new, innovative early-stage programs, as well as individualized services for family caregivers with training for today's challenges as well as preparations for the future. Evidencebased interventions must be included in the project, and incorporating these new programs into CaringKind's portfolio will only help us better serve the families who seek our services."

Our initiative includes:

REACH-II

The REACH-II program helps caregivers to manage stress, deal with distressing

behaviors, develop formal and informal support networks, while improving caregiver health and wellbeing. REACH provides assessment, education, skills training, referrals, problem-solving strategies, and support around 9 topics: Home Safety, Using Social Support, Managing Stress, Pleasant Things for You, Healthy Living, Understanding Your Feelings, Skillful Communication, Relating Memory Problems to Behaviors, and Legal and Medical Information.

Cognitive Stimulation Therapy (CST)

CST is an evidence-based intervention for people with mild to moderate dementia, developed in the U.K. and now widely used around the world. A7-week, 14 session small group virtual or in-person meeting offers engagement and discussion on specific themes and draws on reality orientation, reminiscence therapy, validation therapy and multisensory stimulation.

SHARE

SHARE is an evidence-based care planning and counseling program for people living with early-stage dementia and their caregivers. SHARE stands for: Support care partners and help them communicate effectively and plan for the future; promote *Health* and well-being and decrease stress; encourage participation in fulfilling *Activities*; learn about available *Resources* that reflect care partners' values and preferences; provide *Education* about dementia and how to manage changes that lie ahead.

To Whom I May Concern®

To Whom I May Concern® is an interactive reader's theater program in which people in the early stages of dementia create a script of their own stories and experiences, expressing their fear, anger, frustration, hope and determination — often with humor and love. Scripts are then performed by group members to family members, friends and invited guests with a talk back session for a transformational experience.

These programs won't be ready for participants until 2022, so please don't call the Helpline yet. We'll announce the launch of these programs by way of this newsletter, email, and social media. Stay tuned for more information!

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Do you have a parent diagnosed with an inheritable type of dementia?

We want to understand the impact on children who are now 18 or older.

If you are interested in talking about your experience please contact:

Caroline Gelman, Ph.D., Associate Professor of Social Work at Hunter College, cgelman@hunter.cuny.edu CUNY

CUNY University Integra Protocol: 2021-0020 Approved: 04/26/2021 Expires: 04/26/2022



The FIRST EVER Anti-Viral Clinical Trial for Alzheimer's Disease

This research is funded by the National Institutes of Health (NIH)

Viruses may cause or contribute to the pathology of Alzheimer's disease. This research treatment study at the **MEMORY DISORDERS CLINIC** is the first-ever clinical

is the first-ever clinical trial to address this hypothesis. This study includes:

- Brain imaging
- Clinical assessments
- Anti-viral research treatment with pills



1 IRB Approved

/2021 -> 8/6/2022

CONTACT US: 646.774.8638 40 Haven Avenue New York, NY 10032

With Your Support, We Trained Almost 300 Professional Caregivers!

We train professional caregivers to care for people with dementia. Trainings are a 6-week commitment. Since January 2020, we've successfully graduated 273 professional caregivers (for example, home health aides). We're proud of our graduates. And we're grateful for your support, which makes these achievements possible:

• **273 individuals graduated** training. Graduates attended training in Spanish (119), Chinese (84), and English (70).

• **95% satisfaction** with training content and instructor.

• Our graduates are more confident in dementia caregiving. Pre- and posttraining surveys revealed that our graduates' confidence in dementia caregiving rose significantly from 3.8 to 4.4 on a 5-point scale.

• 98% of our graduates reported increased use of at least one skill.

For example, as a result of the training, our graduates now:

- ▶ approach a person with dementia slowly more often
- ▶ sit at eye level more often when providing care
- agree with what a person with dementia says, whether they are right or wrong
- use short sentences more often when speaking with a person with dementia
- use sounds, smells, and touch more often when engaging the person with dementia
- calm themselves more often in order to provide good care.

We're Walking With You



Every fall, we come together as a community in honor of everyone affected by Alzheimer's and dementia: Caregivers. People with the disease. And people we've lost. This past year has been especially difficult for all of us. For families affected by Alzheimer's, life has been even more challenging. That why it's so important for us to come together at our Alzheimer's Walks.

At the Walks, you will be able to honor a loved one at our Memory Wall by writing a message or attaching a photo. You will hear words of inspiration from fellow

September 26 Brooklyn Coney Island Boardwalk caregivers who know your struggle. And you will see – in person – friends from past Walks who you weren't able to see last year. We'll even see some inspiring performances. After all, our Manhattan Walk will be at the **Naumburg Bandshell in Central Park** this year – and that calls for music!

This year is especially meaningful for the Patricof family, a CaringKind family who experienced their own loss this year. As a result, the Patricof family is making a special effort this year to help CaringKind reach our fundraising goals in support

October 10 Manhattan Central Park Bandshell of families affected by Alzheimer's and dementia. In recognition of this incredible generosity, you may see reference to the CaringKind Alzheimer's Walk in memory of Susan Patricof.

To honor a loved one, please register for the Walk at caringkindnyc.org/walk



CaringKind's

Free Live Webinars in **September and October**

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

September

Understanding Dementia Understanding Dementia

Sept. 10: 10:00 am-12:00 pm Oct. 18: 10:00 am-12:30 pm Sept. 21: 5:30-7:30 pm Sept. 27: 5:30-7:30 pm

October

Oct. 19: 5:30-7:30 pm In Chinese: Oct. 15: 10:00 am-12:30 pm

Legal and Financial

Sept. 13: 12:00 -1:30 pm Sept. 20: 5:30-7:00 pm

Medicaid Home Care

Sept. 2: 5:30-7:00 pm

Monthly

Education Meeting Placing Your Relative in a Nursing Home Sept. 13: 6:00-8:00 pm

Legal and Financial

Oct. 4: 12:00-1:30 pm Oct. 18: 5:30-7:00 pm

Medicaid Home Care

Oct. 7: 5:30-7:00 pm

Monthly **Education Meeting** Bathing without a Battle Oct. 18: 6:00-8:00 pm

Training

Understanding Dementia for Professionals

Sept. 28: 2:00 -4:00 pm



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

Ways to Give

Giving by Check

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

New York, NY 10017

Online/Credit Card

Visit www.caringkindnyc.org and click on Donate or call 646-744-2908. We accept MasterCard, Visa, and American Express.

Appreciated Securities

Gifts such as stocks or bonds may offer substantial tax advantages. Please speak to vour tax advisor.

Bequests

By remembering CaringKind in your will, you can have a significant impact on improving the quality of care for those affected by Alzheimer's disease. Your bequest may have estate tax planning benefits as well. The following is sample bequest language for discussion with your attorney:

I, _____ (first and last name, city, state, zip), give, devise and bequeath to CaringKind (or Alzheimer's Disease and Related Disorders, New York City, Inc.) with offices located at 360 Lexington Avenue, 3rd Floor, New York, New York 10017, (insert written amount of gift, percentage of the estate, or residuary of estate, or description of property) to be used for (insert "its unrestricted use" or name of CaringKind program).

Life Insurance and Retirement Plans CaringKind can be named a beneficiary of your retirement plan or insurance policy. Donor Advised Funds

If you have established a donor advised fund through another organization (e.g., community foundation, investment firm) you may recommend the award of a grant to CaringKind. Please check the guidelines pertaining to your donor advised fund.

Corporate Giving

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

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

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

OUR MISSION

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



Movement Speaks[®]

English Workshops: First Tuesday of Every Month October 5, 2021 – March 1, 2022

Spanish Workshops: Third Tuesday of Every Month October 19, 2021 – March 15, 2022

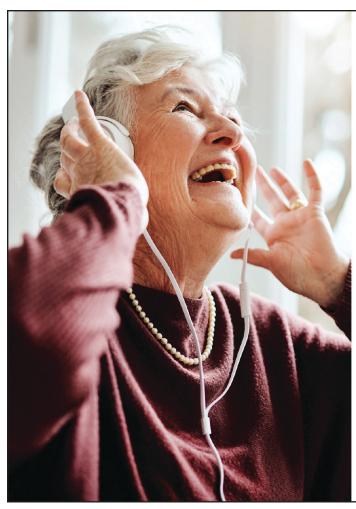
Connect2culture partners with Dances for a Variable Population (DVP) to offer this interactive movement program to individuals with dementia and their care partners. This monthly series of online workshops are offered in English and Spanish over the Zoom platform, facilitated by DVP teaching artists.

Orpheus Reflections[™]

Tuesday, October 12, 2-3PM

Musicians from the Orpheus Chamber Orchestra will present this interactive program designed to give individuals living with dementia and their caregivers an opportunity to participate in intimate performances and socialize with Orpheus musicians in comfortable, accessible settings. The performance will include music composed by Spanish and Latino composers.

To register for programs or for more information, call CaringKind's Helpline at 646-744-2900. Registration for programs listed will open September 20.





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Research Trial of Anti-viral Medication for Mild Cognitive Impairment

Viruses may cause or contribute to the pathology of Mild Cognitive Impairment (MCI). This research treatment study at the New York State Psychiatric Institute will address this hypothesis.

This study includes:

- Brain imaging
- Clinical assessments
- Anti-viral research treatment with pills
- This is a new use of this medication



PI IRB Approved

/27/2021 -> 11/22/2021

Contact us to schedule a screening: 646.774.8638

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