

caringkind

The Heart of Alzheimer's Caregiving



Issue Two 2020

Read about CaringKind and COVID-19 on page 6.

Not pictured: Susan Strassberger, Marlene Wong, Willima Senders, Andy To, Robert Sakowitz, Wing Luo, Carol Royce, Ron Bucci, and more.



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SUNDAY, OCTOBER 11, 2020



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Dear Reader,

Greetings from NYC, and thanks for the warm welcome back! As I look out of my new office window I see a different NYC today. I see a city that is quiet and sleepy; ironic for a place that is known as "the city that never sleeps." COVID-19 has changed our city and our world, but here at CaringKind, even though so much has changed, our mission remains the same. We still need to support people with this disease, their families, and their caregivers, and help them cope through each day.



ELEONORA TORNATORE-MIKESH

President & CEO

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Indeed, the need is greater than ever. Add the new coronavirus to this already stressful situation and what do you see? Our helpline calls are longer and more complex. Family caregivers are trapped at home, with no break from caregiving. Support Groups are providing desperately needed comfort and connection. Education meetings are reaching more individuals across the city and beyond.

We are proud of the diversity work that we have done for over 30 years in the Latino, African American, and Chinese communities and today these populations are struggling, as they are disproportionately affected by the virus. We are finding new ways to reach out virtually until we can resume face-to-face programming in the office and in the community. The social work and education department is one that has shaped my career and provided a pathway to hope for so many families. The MedicAlert® NYC Wanderer's Safety Program continues to enroll people in the program and respond to cases of missing and found individuals.

Looking ahead, what do I see? I see that the way we deliver programs today may seem different as we pivot to virtual and online platforms, but our relationship with families remains as strong as ever. Our programs and events will expand to new areas of research, brain health, and caregiver wellness, and be ever more

inclusive. We have expanded our reach and we are creating more opportunities to strengthen our position as leaders in the dementia care world.

I am working hard with our amazing staff and volunteers to build new sources of support. I am thrilled to welcome the newest members of our Board of Directors, who bring new energy and renewed commitment to our cause. We cannot do this alone. Please consider supporting our 2020 Forget-Me-Not Gala, which will honor our own Jed Levine for his thirty plus years of leadership and will celebrate our connect2culture program. Or create a walk team for our first virtual CaringKind Walk on October 11. Or join your fellow caregivers and become a member of our exclusive Caregiver Champions campaign! (See page 9.)

There are many ways to support CaringKind and we are so grateful to all our friends, donors, and supporters.

I look forward to working with all of you and serving this community.

Introducing

Eleonora C. Tornatore-Mikesh,
*CaringKind's new President and
Chief Executive Officer*

Returning to CaringKind is like coming home for Mrs. Tornatore-Mikesh. After graduating from college, she trained as a specialist in aging and dementia at CaringKind, working as a research associate for two years on a New York State Department of Health grant.

Mrs. Tornatore-Mikesh credits her knowledge and expertise to the training she received at CaringKind, "Without the foundation of learning I gained almost 25 years ago at CaringKind, I would not have become an expert in aging and Alzheimer's disease in long-term care."

Mrs. Tornatore-Mikesh then moved to Connecticut and spent almost 14 years at a premier assisted living community as the executive director. More recently, Mrs. Tornatore-Mikesh was the CEO of the Alzheimer's Association's Connecticut Chapter.

Eleonora's experience, passion, and drive will help to ensure that all dementia caregivers in New York City get the support they need, especially during the COVID-19 pandemic and in the future.

Helpline – Supporting Caregivers Through COVID-19 and Beyond



STEPHANIE ARAGON

Director of Helpline
helpline@cknyc.org

Many caregivers, like you, are facing a constant struggle to both care for their family and work from home during this pandemic. What used to be a quick call to learn about the programs and services CaringKind offers is now an intense call that requires creative thinking to help solve the complex issues that have surfaced due to COVID-19. Caregivers that live out of state are now calling for support; not only have we heard from people in Chicago and California, caregivers are calling in from as far away as China and Edinburgh.

Since mid-March, helpline specialists have been working remotely and honing in on the training they received prior

to answering calls. As part of their orientation, helpline specialists participate in all education and training programs offered by CaringKind. Now that we are working from home, we often call one another or send group emails for help thinking outside of the box. Most members of the CaringKind staff have 15-plus years of dementia experience. I, personally, have learned a great deal about activities and behaviors from our training team.

Below are examples of what caregivers have said to helpline specialists during the pandemic:

- My father keeps taking off his mask.
- The day program my wife attends closed.
- He won't wash his hands.
- The aide stopped coming.
- My mother doesn't understand why we can't go out.
- I don't know what to do to keep my spouse engaged.

I answered a call from a daughter who was at her wits' end because she could not get her mom to wash her hands. She was terrified that her mother would contract the coronavirus. Luckily, I had just watched a video on our website that offered the suggestion of having mom "wash socks" in lieu of washing her hands.

Another call was from a woman whose partner not only wanted to go out, but he didn't want to wear a mask. I originally was going to direct her to the COVID-19 Tips and Resources section of our website, but they didn't have access to the internet. As we spoke further, I learned that her partner was an artist and that she had some of his art supplies in a closet. I suggested she take out the art supplies and let her partner relive his artistic days.



In the past, calls came into CaringKind's Helpline office; an environment where helpline specialists could walk into their colleagues' workspace to lean on each other for support. Since we have adapted to virtual operations, our support systems still remain strong and we are still there for each other while distancing. The Helpline is a special place within CaringKind not only for the dementia specialists who work with each other, but as a vital resource to all dementia caregivers.



For information,
help, and support,
call the
CaringKind Helpline
646-744-2900

A Lifeline During COVID-19: Virtual Support Groups

By Dasha Kiper

Consulting Clinical Supervisor,
Support Groups

Like so many programs at CaringKind, support groups had to shift from meeting in person (as they have for over 30 years) to meeting virtually on Zoom or over the phone. Support group leaders accepted this change graciously, but, of course, there were concerns. Would clients feel supported without the comfort of their leaders and their fellow members nearby? Would leaders be able to direct the flow of conversation without benefiting from their members' physical presence? Could they handle the glitches and the distraction of technology? Finally, could a safe environment be sustained without sharing the same space as their members?



Despite these challenges, our leaders adapted quickly and many were gratified to see their groups become richer and their members grow closer. The stress of caregiving during the epidemic and the isolation that comes with social distancing have only reinvigorated the members' eagerness to connect to, and gain comfort from, each other.

My group has been a lifeline for me for years. I shudder to think how I would have gotten through the current crisis without the group. Each caregiver's situation is unique,

but we have come to know each other well and consistently offer commiseration and practical and emotional tips. I look forward to the day when we can again meet physically and give each other a personal, not a virtual, hug. In the meantime, the Zoom meetings are a bright spot in a dark time.

Along with COVID-19 has come increased stress, helplessness, and conflicted feelings about one's role as a caregiver. This makes support groups more essential than ever. A support group is a place where caregivers can find an emotional outlet. It is often the only time when caregivers can focus on their own well-being. Members encourage each other not to forget their own needs and remind themselves to establish boundaries and practice self-care.

I had a real concern for my mom following the pandemic. Having to work from home has produced a whole new dynamic in caring for my mom. And initially I questioned how and if I could do both, particularly with a demanding employer. Thank heaven for my group: it restores my faith in myself.

I feel blessed to have a support group during these uncertain, challenging times. Each individual in our group, along with our leader, creates an open space to express different layers of emotions. I don't usually express my anger or vulnerabilities easily, but I do in group, and during these stressful times support groups are more important than ever.

As a caregiver assisting a loved one with a deteriorating illness that affects everyone, it is easy to forget one's self. Support groups remind us of the importance of taking care of ourselves in order to take care of others. During COVID-19, we have to make sure not to lose ourselves entirely in the caregiving role.

There are many support groups to choose from:

Spousal Groups
Adult Children Groups
Siblings Groups
African American Groups
Spanish Speaking Groups
Chinese Speaking Groups
Young Adult Groups

For more information on how to join a support group, please call our Helpline: 646-744-2900.

The challenge of COVID-19 is that caregivers' preexisting worries have been magnified. Many caregivers not living with the care receiver already felt enormous guilt and a lack of control. Such feelings only intensified as nursing homes became COVID-19 hot spots and visitation was prohibited. And, of course, health care aides became much harder to find. Meanwhile, caregivers living with the care receiver met with greater burdens and consequently greater pressure, frustration, and exhaustion.

Since COVID-19 I have lost the aides I so much depended on. Now I must take care of my mom completely alone, with no help, while holding down a full-time job. I feel grateful I still have my group, which has become a life-preserver when I feel so overwhelmed and alone.

Despite the apparent change in support groups as they transition from in-person to virtual, our mission has remained the same: to provide a space where caregivers feel connected with people who truly understand them and whose compassion is based on similar experience. Now more than ever, caregivers need and deserve this kind of support.

CaringKind and Coronavirus: Supporting Our Community During the COVID-19 Pandemic

As we continue to encounter this unprecedented time of COVID-19 together, we at CaringKind want you to know that you are not alone. CaringKind is on the front line of the COVID-19 crisis and has taken steps to protect our staff and volunteers while we serve our clients, among the city's most vulnerable adults. Our New York City community is faced with fear and isolation as the restrictions due to the pandemic persist. Caregivers and those with Alzheimer's or related dementias are struggling even more as they try to find ways to cope with the challenges of confinement and changes in routine.

In response to this directive, the CaringKind office closed Tuesday, March 17, and we have suspended all in-person trainings, meetings, and programs; however, we have migrated programs and services to virtual platforms to provide seamless support to meet your needs and to bring relief as you continue this challenging and necessary work of providing care.

Helpline serves as our gateway for people in need of our services. Professionally staffed by caring, knowledgeable dementia experts, we are equipped to answer questions, make referrals, enroll participants into meetings, provide guidance, and perhaps most importantly listen to your concerns. We know that caring for someone with Alzheimer's or dementia can be overwhelming at times, especially now.



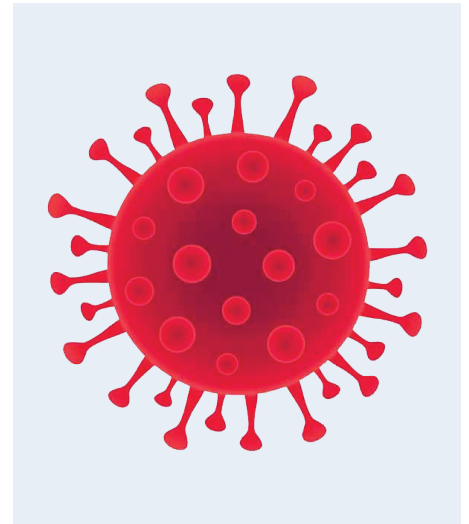
Social Workers are available to assist caregivers with navigating the more complex caregiving challenges that arise. Social workers can assist caregivers as the disease progresses, offering assistance with future planning, home care options, Medicaid planning, and nursing home placement. They are also available for short term counseling.

CaringKind's MedicAlert® NYC Wanderer's Safety Program is acutely aware of the possible dangers if a person wanders away from home. In this time of COVID-19, ensuring the safety and well-being of the person with dementia is of paramount importance. This program is lifesaving and helps safely return those who wander back to their loved ones.



Family Caregiver Support Groups are available through teleconferencing and video platforms. These groups continue to provide support for dementia caregivers. Many caregivers have said that being in a support group has been a "lifeline" to them as they continue to provide care for the person with dementia. This is an essential support system that is especially needed during the pandemic.

Connect2culture® partners with prestigious cultural institutions throughout New York City, and presented a virtual mini-series through live webinars



that provided engaging and informative programs for caregivers and people with dementia during COVID-19. These webinars have been recorded and can be accessed on our CaringKind website — please go to the connect2culture resources section: caringkindnyc.org/c2c-resources

Beginnings for persons with early- and middle-stage dementia is on hiatus. Some activities have been transformed into virtual events and can be found on the CaringKind website under COVID-19 Resources, Tips & Activities for Families and Caregivers. This socialization program offers a holistic approach to social, intellectual, and physical engagement and is being considered for a virtual platform.

Education continues to offer seminars through live webinars and previously recorded videos on a regular basis. Understanding Dementia, Legal and Financial, Medicaid Home Care and Monthly Education meetings offer a sound foundation of what caregivers need to navigate this illness. Special seminars are also offered. Please consult the website under Education and Training meetings for additional information.

Community Outreach specialists provide information, support, and one-on-one consultations services, currently in a virtual setting. CaringKind serves the needs of specific communities, including: Spanish Outreach, Chinese Outreach, African American Outreach, and Orthodox Jewish Community Outreach.

Training is currently moving toward a virtual platform online that will be made available to professional caregivers. Family caregiver workshops are being offered virtually. Call our helpline for more information: 646-744-2900.

Our **Website** has a dedicated section COVID-19 Resources, Tips & Activities for

Families and Caregivers replete with advice and engaging and interactive activities for both the person with dementia and their caregiver. It also includes a wealth of resources specific to COVID-19. This section is regularly updated with the most recent services, videos and programs including Creative At Home Activities – short videos that offer simple activities to do at home with materials on hand that can be richly satisfying for the person with dementia.

Education Meeting: Fun Activities for People with Dementia offers resources for persons at all stages of the illness. You can access a recording of this meeting on our website.

For more information,
visit our website at
www.caringkindnyc.org
or call our Helpline at
646-744-2900.

Please know that we are
here for you and
will continue to help you
navigate the challenges of
these uncertain times.



2020 Virtual Forget-Me-Not Gala



CAROL BERNE

Senior Vice President of Development
cberne@cknyc.org

Our 2020 Gala will be held virtually on Monday, October 26 at 6:30 PM. We have put together an engaging, educational, and entertaining program for our guests. Ivan Cheung, Global President at Eisai Neurology and Chairman at Eisai USA, will be recognized with our Corporate Leadership Award. Jed A. Levine will receive our Lifetime Leadership award for his many years of dedicated service to helping families affected by dementia. Our good friend, Bill Ritter, anchor, WABC TV Eyewitness News, will serve as emcee, and our Dinner Chair is Rachel L. Posner.

We are delighted to celebrate our innovative connect2culture program, which is bringing the joy and richness of the arts to hundreds of isolated caregivers and the person in their care, helping to make their lives better during these especially challenging times. The evening's centerpiece will be a roundtable discussion moderated by Dr. Max Gomez, CBS-2 medical reporter, about the positive impact of the arts on individuals with dementia, and a special performance by a musician with NY Pops, one of our connect2culture partners.

Please invite your friends, family, and colleagues, and join us on October 26, to support the essential work of CaringKind.

For more Gala information, please visit www.cknyc.org/gala. Thank you!

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 or 2927. We accept MasterCard, Visa, and American Express.

Appreciated Securities

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

Bequests

By remembering CaringKind in your will, you can have a significant impact on improving the quality of care for those affected by Alzheimer's disease. Your bequest may have estate tax planning benefits as well. The following is sample bequest language for discussion with your attorney:
I, _____ (first and last name, city, state, zip), give, devise and bequeath to CaringKind (or Alzheimer's Disease and Related Disorders, New York City, Inc.) with offices located at 360 Lexington Avenue, 3rd Floor, New York, New York 10017, (insert written amount of gift, percentage of the estate, or residuary of estate, or description of property) to be used for (insert "its unrestricted use" or name of CaringKind program).

Life Insurance and Retirement Plans

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

Donor Advised Funds

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

Corporate Giving

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

The following organizations ARE NOT affiliated with CaringKind:

Alzheimer's Association
Alzheimer's Association, NYC Chapter
Alzheimer's Disease Resource Center (ADRC)
Alzheimer's Drug Discovery Foundation
Bright Focus Foundation

caringkind
The Heart of Alzheimer's Caregiving

VIRTUAL

2020 Forget-Me-Not Gala

October 26, 2020 ~ 6:30pm

Master of Ceremonies
Bill Ritter, Anchor, WABC TV, Eyewitness News

Corporate Leadership Honoree
Ivan Cheung, Global President, Eisai Neurology; Chairman, Eisai USA

Lifetime Leadership Honoree
Jed A. Levine

Gala Chair
Rachel L. Posner

Celebrating CaringKind's innovative connect2culture® program.

For more information, please contact Carol Berne at cberne@cknyc.org or 646-744-2905 or visit www.caringkindnyc.org/gala

Are You a Champion of Caregiving? Welcome to the Club!



CHRISTIAN DOUCETTE
Director of Community Engagement
cdoucette@cknyc.org

We've dedicated the cover of this newsletter to a new program at CaringKind that we're calling "Caregiver Champions." Our cover features the first 100 Champions who are included in the Class of 2021.

Caregiver Champions are individuals who support the work of CaringKind by way of caregiving, advocacy, and of course, fundraising. Launched as part of our annual Walk, Caregiver Champions are known in our community for the work they do on behalf of Alzheimer's and dementia caregiving. We wanted to bring all of our Champions together in a spirit of camaraderie to forge new connections and demonstrate just how strong the foundation is for New York City families affected by Alzheimer's and dementia.

Leading the Class of 2021 are four volunteers who embody the spirit of Caregiver Champions:

Liz Hamburg is the founder of Candoo Tech, providing in-person and remote tech support and training for older adults to keep them safe, independent, and connected.

Dick Helstein is a CaringKind board member and currently president of Creative Focus, a marketing and advertising consulting firm.

Carol Lenz's mother and mother-in-law were affected by Alzheimer's disease and

dementia. She has organized an annual fundraiser in Connecticut, directing funds to family support and research.

Patricia Gibbs was an active caregiver for her husband, who passed away at age 59 from Alzheimer's disease. She has been an advocate and fundraiser since 2007 for a variety of Alzheimer's causes.

All of our Caregiver Champions will be **featured on our honor wall** in elegant black-and-white portraits, both online and in our training center. Champions will be **honored at an annual breakfast or luncheon** (when gathering is permitted), as well as **receive special communications and first-looks** at upcoming programs. And, each year, the **first Caregiver Champions will be featured** on the cover of our newsletter – just like this one!

In addition to their advocacy, Champions also pledge to give or raise a minimum of \$500 on behalf of CaringKind. The Class of 2021 may fulfill that pledge anytime

between July 1, 2020 – June 30, 2021. CaringKind will help our Champions raise those funds by creating a fundraising page on our platform.

To meet our Caregiver Champions, visit caringkindnyc.org/champions. You can become a Champion from there. (You don't have to upload a photo if you prefer not to. If you choose to, we'll edit your photo so that it's aesthetically consistent with the other photos as shown here.)

If you know someone who should be included in our Caregiver Champions program, please nominate them by emailing their name and contact information to Chris Doucette at cdoucette@cknyc.org.

We would be honored if you join this illustrious group. We can guarantee that you'll be in good company.



Reflections on connect2culture Webinars



MEREDITH WONG

Manager of connect2culture®
mwong@cknyc.org

Connect2culture's partners have been hard at work transitioning many of their programs to the internet. While all have closed their physical spaces, their ongoing efforts to maintain and build participation in their programs online have resulted in creative ways to engage caregivers and the people in their care while keeping everyone safe. As our partners moved to virtual spaces, connect2culture's response was to connect families with these new creative opportunities for self-care.

On April 6, connect2culture piloted a webinar primarily for caregivers, Creative Explorations at Home, that introduced some of these online programs. While visual and performing arts organizations and botanic gardens have not and will not be able to have in-person programs for a while, they have quickly realized the potential to grow their reach beyond New York's borders.



Alvin Ailey Photo: Charles Chessler



Orpheus Photo: Tristan Cook

On every Monday over three months, these webinars included:

- Virtual walks through Brooklyn Botanic Garden's Cherry Esplanade
- A peek into a NYC subway ride at the American Folk Art Museum
- Performance by oboist Katelyn Simon
- Interactive dance/movement activity by teaching artist Magda Kaczmarks

Other participating partners were the Metropolitan Museum of Art, the Intrepid Sea, Air and Space Museum, the Museum of Modern Art, Lincoln Center, Arts & Minds, and a special performance by musicians from Orpheus Chamber Orchestra, who celebrated Memorial Day with us.

While we might all agree that virtual programs are not ideal, they are a way for teaching artists and families to safely share space, experience laughter, and participate in discussion. Currently, spending time in public is still risky, so these virtual interactions are often one of the few ways families under an enormous amount of stress can take care of themselves. These programs offer participants the opportunity to socialize, exchange stories or observations, and take part in activities. For the same reasons that caregivers and the people in their care attend in-person programs, virtual programs aim to help

alleviate feelings of anxiety and loneliness. One caregiver shared, "I participated in the Alvin Ailey program at Lincoln Center Moments with my demented mother and I can speak firsthand to the value, even on Zoom, of this effort. What made it so moving for her was someone knowing her name and asking her to participate. Watching her, I could see it was transformative for my mother to engage with the beautiful facilitators."

As connect2culture and our partners look ahead to the approaching months, we all realize that not only are we supporting families who have had to stay at home because of COVID-19 with virtual programs, but these same activities can be valuable resources for those homebound due to other health issues. Caregivers continue to support these efforts with their participation and kind words, for which we are all grateful.



Museum of Modern Art



NY Botanical Garden

CaringKind Cares During COVID-19



JED A. LEVINE
President Emeritus,
Director of External Relations
jlevine@cknyc.org

By now, you know I've transitioned from President and CEO to a new role, President Emeritus and Director of External Relations. I am thrilled to be working again with my friend and colleague Eleonora Tornatore. I was impressed with Eleonora when I first met her as an intern over 20 years ago and then as a staff member working on a grant to change the culture of dementia care in nursing homes. I have watched and admired her work developing excellent dementia programming in assisted living in Connecticut and then her growth to a savvy senior executive at the Connecticut Chapter of the Alzheimer's Association. Her passion, commitment, and belief in the mission has never wavered, and we are fortunate to have her as our new CEO.

When I planned this transition over a year ago, I could not have imagined how much our world would change. The new coronavirus has forced us to pivot to a totally virtual platform for all our programs. Our amazing staff is working from home after we closed the office on March 17th. Our clients, persons with dementia and their families, and professional caregivers are at greatest risk for serious illness and death if they become infected. Calls to our Helpline and Social Work staff are up. Calls are longer, more complicated, and the stress of dementia caregiving, (never easy) has been compounded by the lockdown and the lack of usual services and supports.

A recent study was done by US Against Alzheimer's and the AList (which we were proud to participate in — many of our clients were surveyed and responded). It confirms what we're hearing in the

support groups, on the Helpline, and in our education and training programs. Here are the summary results from the fifth UsAgainstAlzheimer's A-LIST® survey:

This new survey, taken July 16-21, shows the continued effects of the COVID-19 pandemic on the Alzheimer's community, including signs of faster declines in memory and behavior among people living with Alzheimer's or another dementia. Two-thirds (67%) of the 167 caregivers in the survey said they observed a decline in their loved ones' memory or behaviors since the coronavirus-related restrictions, closures, and isolation have been in place. In addition, 40% of the 40 patient respondents said their cognition had declined somewhat and another 2% reported significant declines since restrictions began.

These survey results confirm why our free programs of care and support are so important and are needed now more than ever. Our staff is truly on the frontlines of this pandemic, providing vitally important contact, connection, information, and hope. One of the major issues for dementia caregivers is social isolation; friends and family often stay away. They are uncomfortable with the person who has cognitive challenges. It is too painful to see a beloved uncle or grandfather, who was the patriarch of the family, have trouble with simple tasks, get confused, agitated, or fearful. The isolation is made that much worse by COVID-19 and the legitimate fear of getting infected. Our services provide community, connection, and the welcome relief of being understood. For families who are caregiving 24/7, there is no relief from the task. There is help through CaringKind.

Our staff has put together helpful activities and suggestions about what to do, tips on stress reduction, and where to get more information or help. Take a look at our COVID-19 resource page on our website: caringkindnyc.org/covid19-resources

Let me remind you that now, as never before, is the time to practice self-care.

The practices and approaches we've promoted for decades have never been so important or needed.

1. Find time for yourself, if only a moment, to take a break.
2. Breathe – if you feel tension rising, take a moment for a few deep breaths and then go back to the task at hand.
3. Move! Exercise, even walking in the apartment or hallway, can be healthful and relaxing. Even better, do it safely outdoors. Wear your mask and stay socially distanced.
4. Get help! Dementia caregiving can never be done alone, especially now during COVID-19. Call the CaringKind Helpline 646-744-2900, join a support group, attend an educational webinar.
5. Now is not the time for self-denial. If a piece of chocolate or a glass of wine at the end of the day helps you relax or is pleasurable, don't hold back.
6. Connect with others – use FaceTime, Zoom and other platforms to connect with family, friends, faith communities, and CaringKind!
7. Remind yourself you're doing the best you can.
8. Self-Care is not SELFISH! It is needed so you can continue to care for your person with memory loss.

We are here to help, but we, too must ask for your help. As much as the community relies on us, we rely on the community. Please join us as we launch our virtual Walk on October 11th with a great program, emcee Bill Ritter of WABC-TV will be back, as will David Hyde Pierce, (with Broadway friends to entertain our virtual walkers!) and more.

CaringKind is 95% privately supported. If you can, please support us, create a walk team, support a walker (you can always support me!), and help us keep our services free of charge for all who need us.

Helping Caregivers Address Challenging Behaviors During COVID-19



NANCY HENDLEY
Dementia Care Trainer

During COVID-19, challenging behavior issues may be more pronounced in part because both the caregiver and care recipient are quarantined. Changes in routine, the closure of adult day programs, and disruptions in the delivery of care, have adversely impacted life for all involved. Fear of disease transmission has complicated our normal ways of relating to each other. Using excerpts from the Family Caregiver Workshop, we will explore possible ways to navigate these difficulties by seeking the root causes of challenging behaviors.

Finding equilibrium in this exceptionally difficult time requires a “team” approach. This is where CaringKind can be of extraordinary help. Reaching out to our Helpline, attending our Education meetings, and enrolling in a Family Caregiver Workshop can help diminish isolation — the feeling that we have to manage all of this on our own and afford caregivers the support that is needed.



A core principle in our workshops is that all **behavior is communication**. As caregivers, we must keep in mind that as people with dementia are losing the ability to express themselves, they may “act out” or behave in ways to alert us that something is amiss. We know that simply asking the person to stop rarely works, and sometimes causes more distress. Taking the time to **discover the source** of the person’s behavior will provide a better opportunity to address their unmet needs and ameliorate future problems or difficulties.

One of the exercises offered in the Family Caregiver Workshop assists caregivers to identify possible triggers for challenging behaviors.

Environment

Is the environment too noisy? Unexpected or unexplained noises can cause a person to be fearful. Is there too much or too little stimulation? Too much going on in an environment can be confusing and overwhelming. Too little stimulation can leave the person unsure of what they are supposed to do. Is there clutter causing confusion? It can be difficult for the person to do what you ask if their space is not clear. Is there enough light? Shadows can be frightening for the person. Is there a clear routine or schedule? Disruption to routines can be disorienting to the person and cause anxiety.

Changes brought on by disease progression, physical health, or emotional state

Is the person’s behavior due to disease progression? Knowing the stages can help to prepare us for changes. Are they becoming increasingly frustrated by the inability to express themselves? Can we find simpler ways to communicate? Are these changes in the brain causing

confusion for the person in tasks that they were able to complete previously? Is the person in pain? The person may not be able to report their pain. How can we determine if they are indeed in pain? Are they constipated? Is there a UTI? Is the person simply uncomfortable? Do they need a hug or to have their hand held?

Behaviors caused by us, the care-partners

At times, we are causing the person’s behaviors. Are we relaxed? The person’s mood is often a direct reflection of how we, the caregivers, are feeling. Are we asking questions constantly or making unreasonable demands? People with dementia often complain of being “bossed around” — instead, can we determine their preferences? Allow them to be in charge? Are we approaching the person slowly? Are we using too much language? Are we ignoring the person or not offering enough activity? Do they need affection? Are we asking the person to do tasks that are too challenging/too simple?

These are the broad categories — the number of triggers is, of course, greater than I have listed here. Once we have an idea of what might be a cause, we can work to eliminate the distress. Providing *comfort* is a good place for us to begin. If we see behavior as discomfort or as an unmet need, our response can be based in providing comfort, or meeting the need, rather than stopping the behavior. This gives us a better chance of succeeding.

You are not alone. Please reach out to CaringKind by calling our Helpline at 646-744-2900. We are here for you.

Walk Your Way – 2020 CaringKind Alzheimer's Walk



CHRISTIAN DOUCETTE

Director of Community Engagement
cdoucette@cknyc.org

With so many challenges facing the world right now, it was pretty easy to select the theme for this year's Walk –

**Caregiving & Community:
Now More Than Ever.**



Raise \$100
and get
the 2020
T-Shirt
design!

Now more than ever, we depend on each other to help survive the challenges we face. For example, the best thing we can do to defeat the COVID-19 virus is for everyone to wear masks in public.

That's what we can do about COVID-19. But what do we do about Alzheimer's and dementia caregiving?

We walk.

CaringKind's Alzheimer's Walk is our largest community fundraising event of the year. The Walk is the fuel that powers CaringKind and enables us to provide life-saving programs from our Helpline to our Support Groups — all free of charge to any family who needs us.

So, we ask you to join us on October 11. We may not be able to assemble like we usually do, but we can still wear our orange CaringKind Walk T-shirts and walk in our neighborhoods at the same time. Let's show our neighbors that we walk in support of Alzheimer's and dementia caregiving. And maybe we'll meet a neighbor walking for

our cause as well! If so, let's introduce ourselves and take a selfie together! We can show the world what's possible when communities come together.



Walk Safely and Celebrate Together Online!

Sign up online:
walk@caringkindnyc.org



Watch our helpful Tutorials!

SUNDAY OCT. 11

Ceremony: Online

**Walk:
In Your Neighborhood**

**Post-Walk Program:
Online**

Sunday, October 11

- | | |
|----------------|---|
| 9:30 - 9:45 am | Yoga class livestream by Avita Bansee. |
| 10:00 am | Opening Ceremony, Awards, and Ribbon Cutting — all via livestream. |
| 10:30 am | Wear your orange Walk shirt and walk in your community! |
| 1:00 - 1:40 pm | Virtual Tables – a variety of topics all through live video channels like zoom. <ul style="list-style-type: none"> • A variety of channels discussing CaringKind programs. • Learn about the latest technology from our tech fair participants. • Our sponsors will demonstrate their products and services. |
| 1:30 - 2:00 pm | Livestream panel: COVID-19 & Caregiving, moderated by Ann Wyatt. |
| 2:30 pm | Livestream concert: David Hyde Pierce and his Broadway friends! |

Tentative schedule; subject to change



Inspir. | CARNEGIE HILL

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*Inspir Carnegie Hill is pending approval from the State of New York, Department of Health, for the following licenses: Adult Home, Enriched Housing and Assisted Living Residence, with Enhanced and Special Needs Assisted Living Residence certifications.

Free Live Webinars

Until we can safely offer in-person Education seminars, we are excited to offer the following live webinars online.



Monthly Education Meetings

Meeting topics change monthly and are in English.
Online Live Webinars – Register at:

caringkindnyc.org/rsvp-monthlyeducation

Wednesday, September 2 2:00–3:30 pm
Navigating the Medicaid Home Care System

Monday, September 14 6:00–8 pm
Placing Your Relative in a Nursing Home

Monday, October 19 6:00–8 pm
Coping with the Anger and Guilt While Caregiving

Family Caregiver Workshop

During this 10-hour workshop series, caregivers learn to view the world from the perspective of the person with dementia. Topics covered include: communication, managing behavior, and self-care. Attendance is required at all 4 sessions in a series.

Online Interactive Workshops

Upcoming Series in English:

Tuesday Mornings, September 1, 8, 15, 22
Tuesday Afternoons, October 6, 13, 20, 27

Upcoming Series in Spanish:

Saturday Mornings, September 5, 12, 19, 26
Friday Afternoons, September 28; Oct. 5, 12, 19

Upcoming Series in Chinese (Mandarin):

Tuesday Afternoons, October 20, 27; Nov 3, 10

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

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

Online Live Webinars

Upcoming Dates in English:

Sept 11	2:00 - 2:00 pm
Sept 14	5:30 - 7:30 pm
Oct 9	12:00 - 2:00 pm
Oct 19	5:30 - 7:30 pm
Nov 13	12:00 - 2:00 pm
Nov 16	5:30 - 7:30 pm

Upcoming Date in Spanish:

Sept 29	5:30 - 7:30 pm
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Legal & Financial Seminar

An elder law attorney discusses important topics caregivers should understand before meeting with their own attorney. Topics include: power of attorney, guardianship, Medicaid eligibility, long-term care insurance, healthcare proxy, and more.

Prior attendance at an Understanding Dementia seminar is recommended.

Online Live Webinars

Upcoming Dates in English:

Sept 14	12:00 - 1:30 pm
Sept 21	5:30 - 7:00 pm
Oct 5	12:00–1:30 pm
Oct 13*	6:00–8:00 pm
Nov 2	12:00–1:30 pm
Nov 16	5:30 - 7:00 pm

**in partnership with Heights and Hills*

Medicaid Home Care Seminar: A Practical Guide to the System

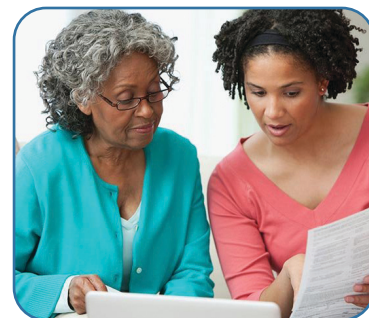
Caregivers are guided through the application process for Medicaid home care service.

Prior attendance at a Legal & Financial Seminar is required.

Online Live Webinars

Upcoming Dates in English:

5:30 - 7:00 pm
Sept 3, Oct. 1, Nov. 5



To register, please call the
CaringKind Helpline at 646-744-2900.

Registration is required. Space is limited.
All meetings are free of charge and subject to change.
Online links provided upon registration.



caringkind Alzheimer's Walk

Walk Safely & Celebrate Together Online!

SUNDAY, OCTOBER 11, 2020

Ceremony: Online

Walk: In Your Neighborhood

Post-Walk Program: Online

CaringKind is NYC's central resource for dementia care, providing free programs and services for over forty years for individuals and families affected by Alzheimer's or other dementias.

Walk Because You Care

SIGN UP TODAY!

caringkindnyc.org/walk

**CaringKind Helpline:
646-744-2900**

walk@caringkindnyc.org

*CaringKind was formerly known as the
Alzheimer's Association, New York City Chapter.*

