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The Heart of Alzheimer's Caregiving

TOOLS YOU CAN USE

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NYC Wanderer's
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Support
Groups

Understanding
Dementia
Seminars

Family Caregiver
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Legal & Financial
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Beginnings
at CaringKind

connect2culture®

...and more!

Volume Four 2019

• Please see our Year-End Letter on page 10.

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Dear Reader,

These days, like many of you, I'm a family caregiver. In addition to my job as CaringKind's CEO and President, I am CEO, CFO and COO, Executive Assistant, nurse, pharmacy tech, and chief cook and bottle washer at home. And I'm in charge of laundry! It's exhausting, but it's helped me know when to ask for help.

Caring for a relative or friend with dementia requires many strengths and skills. Some are transferable from other parts of our life, but others are new and challenging. Caregivers have a lot to learn, and like any other job, they need an orientation and basic education, followed by in-depth training and practice.

Good coaches help, too. And because Alzheimer's, Lewy Body Dementia and Frontal Temporal Dementia progress over time, caregivers need to keep up their studies. What worked yesterday might not work today.

To complicate matters, the job comes with a huge emotional and psychological price. The person you care for is changing in ways that seem unimaginable. It's painful, sad, frustrating and hard to manage. To help, CaringKind has been building and sharing our Caregiver toolkit filled with specialized programs, services and resources for over 40 years.

Our mission is to provide the support and guidance caregivers need when they need it. Our goal is to fill your toolbox and keep it up to date with supplies that fit your unique problems and concerns today and as the disease progresses. I think of CaringKind as the Home Depot for caregivers.

The best place to start is by calling our 24-hour Helpline: 646-744-2900. These are some of the ways we can help:

- If you need help figuring out the long-term care system, come to a Legal &

Financial Seminar, attend a Medicaid Home Care Meeting, and speak to one of our social workers.

- Are you concerned about wandering, or has your relative has gotten lost? Enroll in our MedicAlert Wanderer's Safety Program®.
- Are you looking for a place to feel less alone, to work through the complex and frustrating feelings about caregiving? Do you need a place where you are understood? Join a support group.
- Are you looking for a way to engage in the cultural life of New York City? Attend one of our connect2culture® programs, either at a museum, historical society, botanical garden, library, or performing arts center.
- Do you want to learn more about how to engage your relative, to communicate better, and to truly understand the experience of having dementia? Are you seeking information about providing care? Attend a Family Caregiver Workshop.

We know that caregivers have a diverse set of needs and challenges, so we offer different educational programs each month. In the upcoming months we will be talking about Diabetes and Dementia, Dealing with Family Conflict, Behavioral Symptoms of Dementia, Lewy Body Dementia, Frontal Temporal Degeneration, and more. To register for these programs, please call our 24-hour Helpline at 646-744-2900.



JED A. LEVINE
President & CEO
jlevine@caringkindnyc.org

Alzheimer's and other dementing illnesses require a well-stocked toolbox, but just as important, as you can't build a house alone, you can't manage caregiving alone.

CaringKind is here for you. Just call 646-744-2900 or visit our website at www.caringkindnyc.org.

We are pleased to announce that we are now offering "Beginnings at CaringKind", a socialization program for people in the early stages of dementia. Beginnings will meet two days a week. There is a fee for attending.

If you are interested in learning more, please call the Helpline at 646-744-2900.

Making the Call



STEPHANIE ARAGON
Director of Helpline
helpline@caringkindnyc.org

Your life is a busy one. There is never enough time with the demands of the job, the commute, and running the house. With preparing meals, shopping and laundry. You have responsibilities for your kids or grandkids. It's hard to make time to visit your mother, to bring her groceries, medication and take her to her medical appointments. Your sister moved out of state last year. You seldom speak with her and when you do, it always leads to an argument.

The trouble is, nothing seems to go smoothly with mom. She says the same things every time you call. You can't get accurate information. Then, when you visit, the apartment looks neglected and the food you left for her is uneaten and spoiling. The last straw was when she told you, weeks after April 15th, that she had not paid her income taxes. Recently she accused the cleaning lady of stealing her



wristwatch. The woman was indignant, saying, "I never even opened a drawer." When you say that the laundry is piling up, mom says that she doesn't have quarters for the washing machines. You give her a roll of quarters, but no laundry gets done. She speaks disparagingly of old friends. Is she is going crazy? Is it depression?

On Sunday afternoon you have lunch with your old friend, Sue. You haven't seen Sue since her mother, who had Alzheimer's, died. Just as you're putting your coats on to leave, Sue asks, "How's your mother?" When you spill out the latest, Sue says, "That sounds like Alzheimer's. Call CaringKind."

"But I don't know if it's Alzheimer's disease," you say. Sue tells you that CaringKind understands the implications of Alzheimer's and related dementias. She gives you the phone number.

The next day, you sit at the phone wondering what to say, what to ask. How can they understand? They don't know anything about mom. What she's been through in life, or her many strengths. Then you pick up the phone. Someone answers and asks, "How can I help you?" You answer, "I don't know where to begin."

"Take your time," she says. So, you tell your story and describe the ways that mom's behavior has been troubling. You learn about CaringKind's free seminar, *Understanding Dementia*, where you can learn more and ask questions. You learn about diagnostic centers that provide in-depth evaluations of mom's health, memory problems, and other matters. You are offered a free packet of information on meetings, support groups, and on dealing with the activities of daily life: dressing, bathing, taking medications. And with a

computer, you can access the CaringKind website with many additional resources.

The CaringKind Helpline Specialist is calm and her accepting manner is reassuring. At the end of the call, you provide your contact information. She adds you to the CaringKind mailing list and says you can call anytime.

**The 24-hour
Helpline is available
around the clock,
365 days a year.
646-744-2900**

After you hang up, your jittery feeling is gone. You feel calmer and more relaxed. Sue was right. CaringKind understands. They will hold your hand through your challenging caregiving journey. You are no longer alone. And one call made all the difference.



Self-Care in Support Groups

By Dasha Kiper
*Consulting Clinical Supervisor,
Support Groups*

When Ben Schultz, a man in his late 70s, joined a support group, he expected that his wife would be the focus of the group's attention. But he soon learned otherwise. The members spoke about their own difficulties, about what caring for someone with dementia was doing to them. And for the first time in four years of looking after someone, Ben admitted that he, as much as his wife, had changed. His even-keeled nature was cracking; he had become increasingly irritable, even occasionally snapping at his wife. He slept less, ate more, and the weight he put on led to back pain and sleep apnea. His concentration suffered and he began making mistakes at work. But what distressed him most was his own intermittent apathy. He found himself at times not caring about anything, which is decidedly not what a caregiver ought to feel.

He tentatively admitted all this to the group, concerned that its members would judge him. But, of course, he was met only with sympathy and understanding. Everyone knew what Ben was feeling because everyone in one form or another had been there. Then someone asked him what was he was doing for self-care. The question threw him. The concept of self-care was foreign to him. What did it have to do with his life? He had responsibilities, his wife relied on him, and his children depended on him to keep the family together. Just the thought of self-care made him feel selfish and guilty.

Although the group did not push him, it wanted him to know the benefits of self-

care. All the members testified how self-care kept them from either unraveling or becoming completely detached—how, in fact, it made them better caregivers. They asked him to consider what brought him pleasure or made him feel replenished. At first, Ben had no idea. His adult life had been spent taking care of others. In fact, his self-worth and identity were inextricably tied to his caring for other people. It was what he expected of himself.

Nonetheless, after joining the group, Ben began to think about what he used to enjoy before Alzheimer's had struck his wife. One night, he pulled out some old comedy albums he had loved while growing up, vinyl records with riffs by Bob Newhart, George Carlin, Carl Reiner and Mel Brooks. At the next meeting, he told the group that he had actually been startled to hear himself laugh out loud. It reminded him, he said, of his old self when he still had some life in him. A few meetings later, he hit the group with a shocker: He was going to join an improv class. The members spontaneously burst into applause, and Ben was so touched by their happiness that it dissipated any guilt he felt for finally choosing himself over his wife.

So Ben joined the improv group and suddenly a whole new community opened up to him. Here were people who enjoyed comedy, whose purpose was to find humor even in the darkest places, and the laughter they evoked in him, as well as laughter he less often evoked in them, recharged him. The sense of hopelessness and isolation he had been carrying around began to lift, and so did his depression. He began to make doctors appointments for himself. He focused better at work and when he came home, he was less



impatient with his wife. Only by practicing what the group had "preached" did he come to appreciate how linked his own care was to the care he was able to provide for his wife.

Self-care, he realized, was something deeper and more challenging than simply allowing pleasure into one's life. It entailed reacquainting oneself with what gives life purpose. So Ben experienced for himself what the research on caregiving bears out: Being a caregiver is a liability to one's physical and mental health because along with the stress of caregiving comes a higher risk of developing a dementia disorder.

Today Ben serves as an example for new caregivers, teaching them what his group taught him: Self-care is not a luxury; it is a way of protecting oneself in order to protect others. It is both a gift and a shield.



CaringKind Alzheimer's Walks 2019

THANK YOU to our Walkers for making our CaringKind Alzheimer's Walks such a huge success! With the help of more than 50 volunteers, our Brooklyn Walkers raised \$60,000 in support of Alzheimer's and dementia caregiving. And with the help of more than 100 volunteers, our Manhattan Walkers raised over \$400,000. Here are

just a few of the moments captured at our Walks! To see all of our Walk photos, go to caringkindnyc.org/walk. We encourage you to share these photos on your social media accounts! When you do, please tag us @caringkindnyc. Your fundraising pages online are still active through November 30, so keep sharing! Thank you again!



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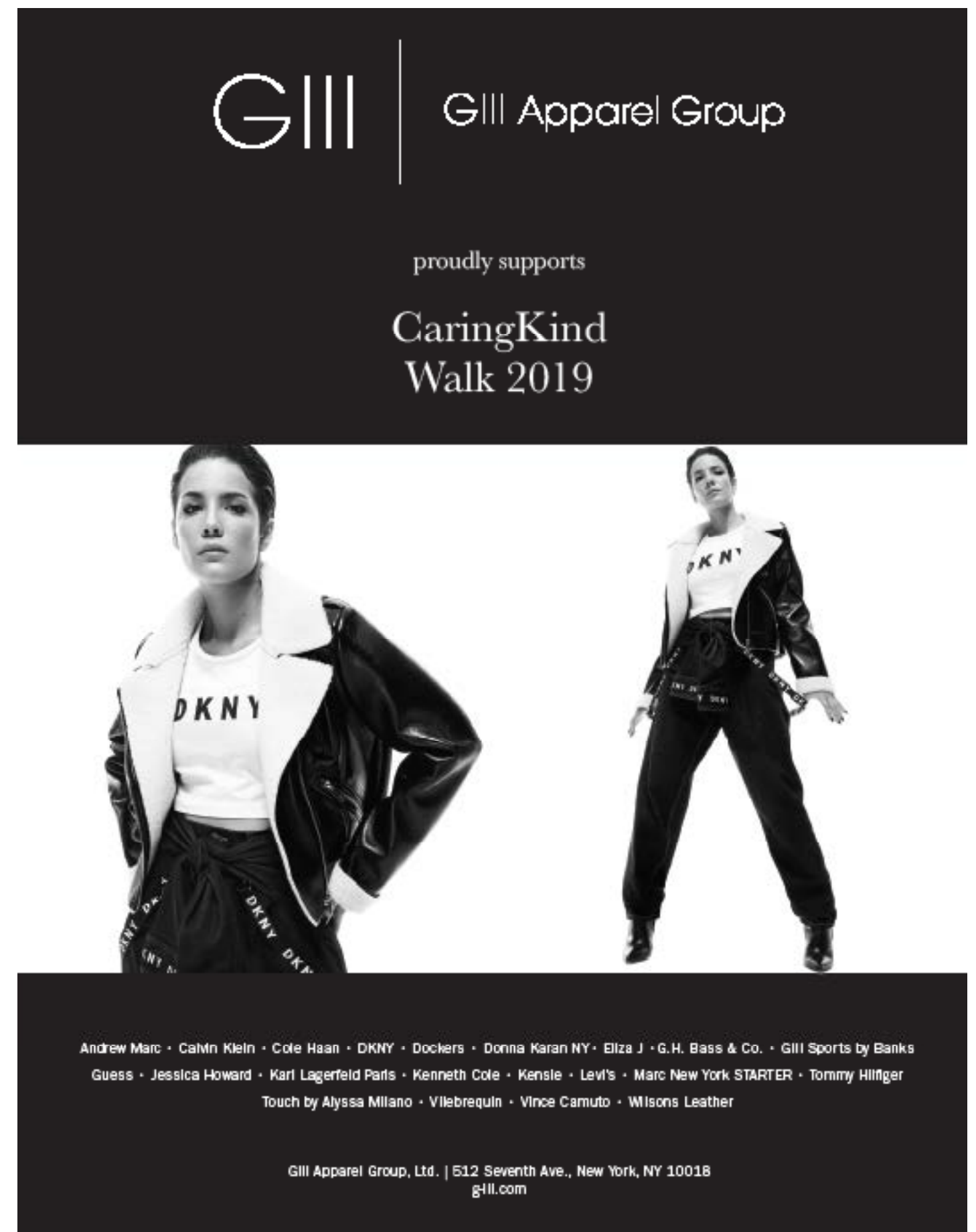
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Family Caregiver Workshop: A Tool of Support



NANCY HENDLEY
Dementia Care Trainer

It has been well established that Alzheimer’s disease and other dementias affect not only the person with the diagnosis but also the friends and family of that person. Spouses, children, adult children, and friends struggle to comprehend the changes brought on by the disease process. The challenges that we face as care partners are numerous and confusing. Exactly what is dementia? How will the disease progress? What kind of help is available for the person with dementia? Is there help for me? What will the future hold? These questions alone can be frightening and overwhelming.

Fortunately, CaringKind has been assisting family members to answer these questions for over thirty-five years. The Family Caregiver Workshop offers family and care partners practical tips and tools to navigate the challenging world of dementia care. The ten-hour workshop consists of four two-and-a-half-hour modules that meet one day or one evening per week for four consecutive weeks. Currently, the workshop is offered in English, Spanish and Chinese. Each module has a specific themes Understanding Dementia, Enhancing Communication, All Behavior Has Meaning, Care for the Caregiver, and Designing Strength-Based Activities. The class size is limited so that each participant has the opportunity to reflect upon the material as it pertains to their situation.

Understanding Dementia The first module in the Family Caregiver Workshop is an in-depth look that distinguishes Alzheimer’s

disease and other dementias: the signs and symptoms, diagnostic process, current treatments, and stages of the disease. This information encourages care partners to appreciate the scope of the illness so that they can plan for the future. One family member commented, “Before this meeting, I wasn’t sure what was going on with my mom. I just kept taking on tasks that she no longer seemed able to do. Now I realize that a lot of what was happening was related to her dementia.”

Enhancing Communication This module focuses on the changes in communication for the person with dementia as the illness progresses. Over time, the person with dementia experiences increasing difficulty expressing themselves and understanding others. People may struggle to have their needs and desires known. Brain changes make word-finding difficult. The attention span decreases. It can be challenging to hold a thought long enough to have a lucid conversation. Care partners need to be aware of the difficulty that the person is experiencing. As the person is unable to change, the care partner needs to be willing to adapt.

In the workshop, participants develop their own set of communication keys – shortcut prompts to enhance interactions with people with dementia. Some examples include: slow down, get to eye level, use five-word sentences, know when to back off, or try again. One participant shared, “Wow! Slowing down – it never occurred to me that mom was having trouble taking in information. I was talking fast. I didn’t know she needed me to slow down, to use fewer words. It has made a world of difference.”

All Behavior Has Meaning As caregivers, we need to look for the root causes of challenging behaviors. In the workshop, participants explore possible triggers in the environment, in the person, and

in the care partner. We brainstorm environmental challenges: too light, dark, noisy, no obvious cues or signage, unfamiliar places. We investigate behaviors that might be related to the person: pain, fatigue, UTI, arthritis, hearing problems. Behaviors that stem from care partners could be: caregiver stress, not understanding the illness, utilizing the wrong approach, rushing the person, expecting too much or too little from the person with dementia. One daughter shared, “I always thought my dad was just grouchy all the time. He was complaining and we did not know why. It took a while but after taking the workshop I figured out that he was uncomfortable in the chair. We changed the chair and he has been more content.”

Care for the Caregiver and Designing Strength-Based Activities Caring for people with a diagnosis can be a full-time job. Even when we have help, daily concerns can overwhelm us. Self-care cannot be overemphasized. Most care partners have additional obligations. In the workshop, we discuss ways of finding time for ourselves and look to discover new or additional sources of support. Care partners are encouraged to join a support group as a way to balance the caregiving load. The connect2culture program at CaringKind is introduced as a way of connecting care partners to cultural activities throughout the city. An adult son who recently completed the workshop said, “The workshop was life-giving, informative and incredible. . . a true game-changer for me! Thank you for being so excellent at what you do!”

Every year, CaringKind provides practical tools to our client families. If you or someone you know can benefit from our Family Caregiver Workshop, please register by calling 1-646-744-2900. We know it will make a difference!

Tools for Saving Lives



SERENE NIE
Social Work Supervisor
SNie@caringkindnyc.org

Driving is a particularly challenging area to manage following a dementia diagnosis. Access to a car represents independence. Taking it away may feel disrespectful and punitive. But independence must be balanced against the safety of both the individual and the community. A physician can provide guidance on the individual’s ability to drive, but as the disease progresses and the individual can no longer drive, caregivers need tools to manage this difficult discussion openly and productively.

“At the Crossroads,” a booklet developed by the Hartford Center for Mature Market Excellence, focuses on the importance of planning early, assessing driving abilities, easing the transition from driver to passenger and having a positive and productive conversation with the person with dementia that includes family members. This booklet is a useful tool that allows family members to rehearse “the talk.” Several worksheets are provided to plan and explore various issues: what are the warning signs for drivers with dementia? What are alternative transportation options to get around? What are the care recipient’s usual driving activities and frequency? There are resources for planning the conversation and identifying family and/or friends who can be helpful.

“At the Crossroads” is a very helpful tool and it can be downloaded online

at https://s0.hfdstatic.com/sites/the_hartford/files/cmme-crossroads.pdf You can also call the CaringKind Helpline at 646-744-2900 and we will send you an English or Spanish version of the booklet.

Another practical guide is *Dementia and Driving: a Decision Aid*, developed by group of faculty members at Australia’s University of Wollongong. While some local policy and regulations might not be directly applicable, the guide provides an easy and simple checklist to use for someone with mild cognitive impairment or in the early stage of Alzheimer’s.

- Step 1:** Clarify your decision.
- Step 2:** Identify resources to make your decision.
- Step 3:** Consider your options.
- Step 4:** Take the next steps.

This guide is designed to give care recipients a voice in the decision and makes them part of the plan.

Another option is to submit a driver review to The New York State Department of Motor Vehicles. This can be done anonymously and is most effective when accompanied by a physician’s medical review statement. Once the DMV receives the request via mail, an appointment is set

up to evaluate the person’s driving ability and judgement.

CaringKind’s Social Work staff can talk with you individually or as a family to develop your action plan. We can meet in person or on the phone. We provide these services in English, Spanish and Chinese with licensed social workers. If needed, CaringKind has a translation service that accesses over 200 languages.

Don’t wait to have this important discussion. If you are worried about a person with dementia who is driving, please call 646-744-2900 to speak to one of our professional staff about the issues you are facing related to dementia and driving. This conversation could save a life.

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Dear Friends,

CaringKind plays a leading role in providing much-needed support and care for individuals and families affected by Alzheimer's disease and related dementias. To support their needs, we advocate for the advancement of research, we partner with the medical and scientific community and we participate in clinical trials. Our public awareness campaigns and advocacy efforts ensure that elected officials at the local, state and national levels understand the challenges faced by families affected by a dementia diagnosis.

In spite of the combined efforts of CaringKind and our partners, we know that effective therapies are a long way off. And, while we wait, millions of families are struggling to handle the responsibility of caring for their loved ones. Dementia isn't just breaking hearts... it is also breaking pocketbooks. **We can no longer put off funding programs and services for Alzheimer's and dementia care.**

We are proud to report that with the support of friends like you, CaringKind used your contributions in 2019 to provide an exceptional number of programs and services to our clients. Here are some highlights:

- We responded to **8,000 calls on our 24-hour Helpline**, the gateway to our services.
- Our licensed social workers provided more than **850 counseling sessions**.
- We educated **more than 1,000 caregivers** through our learning seminars, covering topics from Legal and Financial Planning to Resources for Long-Term Care. We trained over **500 family and professional caregivers**, empowering them with skills and resources to provide the best possible care while easing their own burdens.
- We **added more than 1,000 people** with dementia to the more than 30,000 already registered in our CaringKind MedicAlert® NYC Wanderer's Safety Program.
- We hosted **80 ongoing support groups**, each facilitated by a trained and supervised professional.
- We trained docents and staff at **18 of NYC's most prominent cultural institutions**, bringing their outstanding resources within reach of our clients and their families.
- We held major conferences focused on care and research, attended by **over 500 participants**.
- We **expanded our national reach**, fielding requests for information and training throughout the country. This includes requests for our innovative Palliative Care program, which has become the gold standard for late-stage dementia care.

CaringKind relies on donations from New Yorkers like you to fund our operations and to keep our programs free of charge. Without you, there would be no CaringKind.

Every dollar you donate is 100% tax deductible and directly supports our community.

As the year comes to a close, we hope you consider a generous donation to CaringKind so that we can continue to offer our life-changing programs in the year ahead. On behalf of the families we serve, I wish you a healthy, peaceful and productive 2020 and thank you for supporting our work today and into the future.

Sincerely,

Lou-ellen Barkan, Founding Director



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 646-744-2900.
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).



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.



Life Insurance and Retirement Plans

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



Corporate Giving

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



Monthly Giving

By giving to CaringKind each month, you'll join a community committed to providing the gold standard of dementia care for all New Yorkers.



Tribute Gifts and Campaigns

Honor a loved one, or someone special in your life, or give back for the help that you received by a caring professional at CaringKind.

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

CaringKind is a tax-exempt organization under Section 501(C)(3) of the Internal Revenue Code (Tax ID number 13-3277408) and your gifts are tax deductible to the full extent of the law.

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

Know Your Charity
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

Becoming an Informed Caregiver



LOU-ELLEN BARKAN
Founding Director
lbarkan@caringkindnyc.org

Early in my career, I had a mentor who gave me some priceless advice. I was working through my first major project when Paul stopped by to see how I was doing. I updated him and shared my accomplishments, but I didn't disclose the difficulties I was having.

Paul was a senior executive with years of experience. He saw right through me. "Do you want to tell me what's not going well?"

"Everything is fine," I said.

Paul laughed. "Come on," he said. "How can you solve problems if you don't ask for help?"

Reluctantly, I shared my concerns. I was having trouble locating resources and understanding technical information. Executives were not returning my calls or setting up meetings. Paul heard my concerns and showed me where to find the information. He called product experts to explain complex material. Finally, he set up meetings with a dozen senior executives. To this day, I'm convinced that my success was the direct result of Paul's intervention.

As he left my office, Paul gave me some advice. "Always remember," he said. "Asking for help is a sign of strength, not a sign of weakness. Help is out there, but you need to ask for it."

When I became my mother's caregiver, I took Paul's advice. I asked for help from medical professionals. I talked with experts in long-term care and social services. I hired specialists to help me identify and submit the appropriate forms for government programs, including Veterans services. Over time, even the most complex issues sorted themselves out. Mom had better care and I felt more confident that I was doing my best. I got the help I needed, but I had to ask for it.

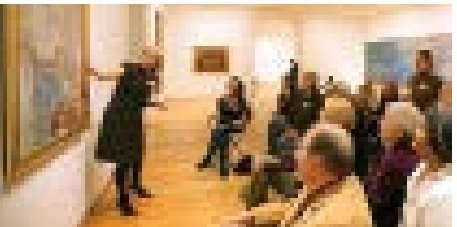
In my opinion, Paul had it right; asking for help is the only way to get it. For dementia caregivers, CaringKind's Helpline is the absolutely best way to start. If you are caring for someone or know someone who needs our help, put aside any fears about asking for advice and make that call. Make it today and you will change your life and the life of someone you care about.

Cultural Resources in NYC



MEREDITH WONG
Manager of connect2culture®
mwong@caringkindnyc.org

Planning a visit to a museum can be a challenge. How to get there? What are transportation options? Where to go once you've arrived? When trying to answer these and similar questions, caregivers may decide not to visit a cultural institution or participate in a program simply because it's logistically difficult. To offset this, museums try to make their institutions as accessible as possible. They work hard to make both the physical facility and their programs easy to navigate and enjoy.



Prior to visiting an art or history museum, taking a walk around a botanical garden, or attending a music performance, caregivers want to know who to ask about accessibility and the resources the institution has to help during a visit. The first stop for answers may be Access Program Coordinators/Managers, who help the caregivers prepare for a visit by providing details on entry and security processes, the availability of assistive listening devices or hearing loops for someone with hearing loss and, where and when to arrive for scheduled programs.

Museum educators may also enhance a visit with sensory materials; larger

reproductions of artwork which can be touched, or textile and fragrance samples to make the experience more concrete for someone with dementia. They may have pre-visit materials to prepare, including floor maps of the galleries, and suggestions for less busy times to visit. These simple tips can create a more enjoyable visit.

Cultural institutions learn from visitors how to be more welcoming and supportive. They post clearer signage to orient visitors to the space. They integrate accessible technology into the visitor experience and they create programs that make the most of participants' abilities. Guided programs for people with dementia and caregivers provide an opportunity for both to explore and discover together. The museum's goal is to help the visitor make connections and use every asset of the institution to access and participate in programs. And, just as exploring art can be rewarding, interactive visits to concerts, dance workshops, and botanical gardens can also be enriching experiences.

Our city offers wonderful opportunities. Audience members at *Lincoln Center Moments* or *Orpheus Reflections* might be inspired to move or clap during the music performance. Participants in *AileyDance* workshops are welcome to move and dance, inspired by different types of music and dance styles. The *Memory Tours* at the Brooklyn Botanic Gardens integrate leisurely and sensory-rich walking tours through areas of their gardens so that participants can experience seasonal growth.

The city's art museums have long offered programs that combine gallery explorations with art making. From the Metropolitan Museum of Art to the Brooklyn Museum and the Jewish Museum,



resources and institutions working to engage individuals and families impacted by a dementia diagnosis.

We hope you will take the opportunity to enjoy these experiences, many of which have been informed by CaringKind's connect2culture® partnerships. And, if you have any questions, call CaringKind's 24-hour Helpline at 646-744-2900. We are happy to answer questions and provide information. Happy Visiting!



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Seniors in Touch

Seniors in Touch is a social adult day program that provides social, recreational, and therapeutic activities to older adults living with cognitive or physical impairments. Our program enhances the overall quality of life, well-being, and daily functioning of our participants, while providing peace of mind for their caregivers.

For more information, please call Program Supervisor Jamillah Williams at 347-377-5471

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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 trial to address this hypothesis.

This study includes:

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



CONTACT US

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Getting the Bracelet



ELIZABETH BRAVO SANTIAGO
Director of Wanderer's Safety Program
esantiago@caringkindnyc.org

As Alzheimer's disease and related dementias advance, one issue that comes to the forefront is wandering. Two out of three people with dementia are likely to wander at some point during the course of the illness. Nevertheless, caregivers often say, "I don't have to worry because she has never tried it. She has never wandered." Or, "I do not think anything is wrong. He always finds his way back home. But please don't tell my daughter."

Why does someone wander? The Mayo Clinic identifies several possible causes. A person with dementia may feel stress or fear resulting from an overstimulating or confusing environment, may be searching for someone or an object, may be bored and looking for something to do, may be trying to fulfill a basic need – like looking for a bathroom or food – or may be following a familiar routine, like commuting to a former office.

As the risk of wandering increases, caregivers struggle between maintaining a person's safety and preserving a sense of independence. Fortunately, there are things we can do to strike that delicate balance. You can install simple devices that alert you when a door or window is opened. You can camouflage doors by hanging curtains or pictures in front of them. Most importantly, you can ensure that the person with dementia has identification in case they wander and get lost.

CaringKind's MedicAlert® NYC Wanderer's Safety Program provides this resource. The person with dementia receives a simple, low-tech bracelet inscribed with a statement that the person is memory impaired, the person's first name, a numerical code linked to a health record, and a 24-hour Emergency Hotline phone number: 800-625-3780.

Getting the bracelet is easy. First, the caregiver sends us a wrist measurement of the person's dominant hand. Why? Placing the identification bracelet on the person's dominant wrist makes it difficult for them to open the latch and remove the bracelet. Adding a half inch to the wrist measurement makes for a comfortable, yet secure, fit.

Next, the caregiver provides personal and medical information that is placed into a confidential database along with their picture. This information is available exclusively to emergency responders when someone is missing.

CaringKind is proud that our long-standing partnership with the New York

City Police Department has supported our successful record of finding those who wander. And, in addition, CaringKind sends Missing Persons bulletins, with the information on file, to emergency rooms, hospitals, and other local agencies throughout the five boroughs.

CaringKind provides ongoing support for the caregiver during the crucial time that someone is missing, and, once the person is found, our social workers work with the caregiver to plan for future care.

Please note that although MedicAlert® charges a membership fee, CaringKind offers scholarships for families facing a hardship.

To register, please visit:
<https://caringkindnyc.org/wandersafety/>
or call our

24-hour Helpline at: 646-744-2900
You may very well save a life and you will certainly increase your own peace of mind.

United Federation of Teachers

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Fill your Toolbox with Education



EDWARD CISEK
Chief Program Officer and
Vice President of Program Evaluation
ecisek@caringkindnyc.org

As caregivers, we are often faced with challenging situations that are charged with emotion. Our instinct is to react quickly. It's important, however, to take a step back, take a deep breath, remember that there is an underlying disease at work here, and dip into our mental "toolbox."

At CaringKind, our education offerings are designed to stock that toolbox with a variety of tools that you can use in caregiving situations. For example, at our *Understanding Dementia* seminar, you'll learn how to adjust your expectations as dementia progresses. At our *Legal and Financial* seminar, you'll learn what questions to ask an elder law attorney as you plan care for the future. And at our *Medicaid Home Care* seminar, you'll learn

the steps it takes to find professional caregiving help.

In the coming months, you can expand your toolbox with our educational seminars. Join us on November 11 for our *Behavior has Meaning* seminar. Our Director of Training, Amy Torres, will explain how learning to interpret behavior as a form of communication can make it easier to communicate with a person with dementia. On December 9, Heidi Hartmann-Rothe, Clinical Care Coordinator at NYU's Division of Geriatric Medicine and Palliative Care, will discuss the interplay between dementia and diabetes as she presents *Sugar and Spice: A Recipe for Care for People with Diabetes and Dementia and their Care Partners*.

In 2020 we're planning seminars on Family Conflict, Lewy Body Dementia, Frontal Temporal Dementia and much more.

Be sure to check our Education Calendar included in this and every issue of our newsletter. Just a reminder, though,

registration is required for these meetings so please call our Helpline.

In addition to our seminars, we have many tip sheets available. Some of our most popular tools are "Communication Tips for Alzheimer's Caregivers," "Identifying Distress: Possible Causes of Personality and Behavioral Changes," and "Caring for Yourself."

There are also many electronic resources for caregivers. Stay tuned for more information about our Fourth Annual Technology and Caregiving Fair. In the meantime, browse some products and companies that participated in this year's fair at caringkindnyc.org/techfairvendors. Need more tools for your toolbox, or help figuring out which tool to use? Easy, just call our Helpline at 646-744-2900 and we'd be glad to assist.

Holiday Tips

Holidays can be meaningful enriching times for both the person with dementia and his or her family. Here are some tips for these special times:

- Celebrate the holidays that are important to you.
- Involve the person with dementia in simple holiday preparations.
- Set your own limits, and be clear about them with others.
- Prepare quiet distractions to use, such as a family photo album, if the person with dementia becomes upset or overstimulated.

Please call our Helpline at 646-299-7400 for our complete Holiday Hints handout.

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Monthly Education Meetings

Meeting topics change monthly.
All meetings are from 6:00 – 8:00 p.m.

Monday, November 11
Behavior Has Meaning

- Recognize how dementia impacts behavior.
- Understand root causes of behavioral changes.
- Formulate strategies to adapt and adjust responses to behaviors.

Speaker:
Amy Torres, Director of Training, CaringKind

Monday, December 9
Sugar and Spice: A Recipe for Care for People with Diabetes and Dementia and their Care Partners

- How does diabetes affect the body and mind?
- How can you support a person with dementia and diabetes?
- How can you overcome some challenges of providing care for a person with dementia and diabetes, and take care of yourself?

Speaker:
Heidi C. Hartmann-Rothe, RN, MS, CDE, NBC-HWC
Clinical Care Coordinator, Division of Geriatric Medicine and Palliative Care, NYU School of Medicine, NYU Langone Health

Family Caregiver Workshops

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 workshops in a series.

Upcoming Dates in English
Two Workshops, Mornings in Manhattan
Nov. 4, 11, 18, 25
Nov. 27, Dec. 4, 11, 18

Upcoming Dates in Spanish:
Evenings in Manhattan, Nov. 4, 11, 18, 25

Upcoming Dates in Chinese:
Afternoons in Queens, Oct. 18, 25, Nov. 1, 8

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.

Upcoming Dates in English:

Nov. 8	12:00 - 2:00 pm	Manhattan
Nov. 19	2:00 - 4:00 pm	Brooklyn
Nov. 20	5:30 - 7:30 pm	Manhattan
Dec. 13	12:00 - 2:00 pm	Manhattan
Dec. 17	2:00 - 4:00 pm	Brooklyn
Dec. 18	5:30 - 7:30 pm	Manhattan

Upcoming Date in Chinese (Mandarin)

Nov. 3	1:30 - 3:30 pm	Queens
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Upcoming Date in Spanish

Dec. 6	11:00am - 1:00pm	Manhattan
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Legal & Financial Seminar

An attorney specializing in elder law discusses important topics caregivers should understand before meeting with an attorney, including: power of attorney, guardianship, Medicaid eligibility, long-term care insurance, healthcare proxy, and more.

Prior attendance of an Understanding Dementia seminar is recommended.

Dates in English:

Manhattan
Nov. 412:00 - 1:30 pm
Nov. 185:30 - 7:00 pm
Dec. 212:00 - 1:30 pm
Dec. 165:30 - 7:00 pm

Dates in Chinese (Cantonese):

Manhattan
Dec. 20 1:30 - 3:30 pm

We thank our community partners for providing meeting space:

- Hand in Hand Together
- Homecare
- Heights & Hills
- Queens Library
- Visiting Nurse Service of New York – Chinatown
- NNORC

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.

Upcoming Dates in English:

Manhattan
Thursdays, 5:30 - 7:00 pm
November 7
December 5

To register, please call our
24-hour Helpline at 646-744-2900
or visit
www.caringkindnyc.org

Registration is required.
Space is limited.

All meetings are free of charge and subject to change.

Location information provided upon registration.

caringkind chronicles

Writer: Jennifer Camper Artist: Ivan Velez

Story 2 Episode 4 Previous Stories: caringkindnyc.org/comic



CaringKind provides free programs and services for people with Alzheimer's and dementia and for their caregivers.
24-hour Helpline: 646-744-2900 ~ www.caringkindnyc.org

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The Heart of Alzheimer's Caregiving



Programs and Services

24-hour Helpline: 646-744-2900

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Beginnings at CaringKind



Education and Training

Understanding Dementia for Caregivers & Professionals

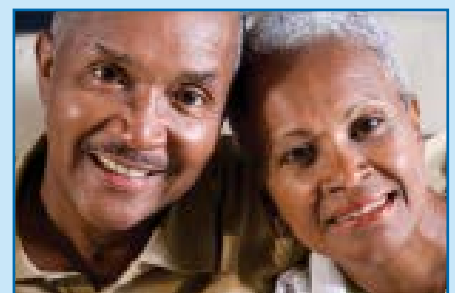
Dementia Care Training for Professional Caregivers

Monthly Education Meeting

Legal & Financial Seminar

Medicaid Home Care Seminar

Family Caregiver Workshop



**New York City's
leading expert
on Alzheimer's and
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