

caringkind

The Heart of Alzheimer's Caregiving

**Caring for Today
with the
Technology of Tomorrow**



SUMMER 2017

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Dear Friends,

My mother, born before the Great Depression, was an early and avid fan of technology. As far back as I can remember, we were always the first family on the block to have new-fangled gadgets and gizmos like a television set and a telephone answering machine. Ours was the size of a small refrigerator. We had a mobile phone long before flip phones or iPhones were even fathomed and our car air conditioner was a huge success, even though it was so big, it was nearly impossible for passengers to fit in the front seat.

Mom intuitively understood technology's value and its application for making life easier and more comfortable. This was particularly true as my parents aged, as my father's dementia progressed and as mom became a full-time caregiver. I still remember her discovery of something she called a "pop-up chair." With the push of a button the seat lifted and mom no longer had to call the local police to help get dad out of his chair and into bed. "A phenomenal piece of equipment," she said.

Mom's fervor for all-things-tech rubbed off on me personally and professionally. Once I realized that technology could make my mother's caregiving responsibilities easier, I started to look for products that would help her. One of the first was an electronic rolodex that allowed her to enter contact information for friends, neighbors and all the members of her extensive health care network. She finally got rid of that little black address book with the missing pages held together by a rubber band.

At CaringKind, we are carrying on mom's legacy and embracing technology with enthusiasm. Our staff routinely uses a variety of electronic and mobile devices to make their work even more effective. And earlier this year, we hosted an inaugural Technology Fair to showcase the possibilities of "Caring for Today with the Technology of Tomorrow." More than a dozen vendors put their innovative ideas

on display, showcasing a broad array of products to assist people with Alzheimer's and dementia and their caregivers. Inspired by the Tech Fair's success, we will replicate it – bigger and better – at our annual CaringKind Alzheimer's Walk on October 15th in Riverside Park. Vendors will be on hand with exciting new products that are specifically designed for our community.

I'm particularly proud of CaringKind's contribution to the second generation of an app called Balance: for Alzheimer's Caregiving. Now available in the app Store, it was created by the Hebrew Home at Riverdale, to assist family caregivers. The Balance app facilitates tracking and sharing daily activities among those caring for a person with dementia. This includes meals, medication, medical appointments and family visits, ensuring that every involved and responsible person has the most up-to-date information.

CaringKind has added critical resources to the Balance app including access to our 24-hour Helpline, our MedicAlert® NYC Wanderer's Safety Program and Together We Care™, a program that matches trained and certified home health aides with families looking for a dementia trained aide.

CaringKind has also partnered with Pratt students and professors to create a host of new and very creative products for people



LOU-ELLEN BARKAN
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with dementia and their caregivers. Among my favorites is a hat with built in headphones that automatically play music when the hat is worn.

Every one of these innovative ideas was generated from a personal observation by a social worker or caregiver identifying a real need. And we know that caregivers have extraordinary needs, so we want to hear from you. Let us know what would make your job as a caregiver easier. We are working with some very talented people who just might be able to turn your idea into a product to help you and others facing the same challenges.

Finally, an important reminder; as great as technology is, even mom knew that it wasn't the only game in town. It's no substitute for a knowledgeable, caring, trained professional who listens. Remember, you can pick up the phone and find one at any time. Just call CaringKind at 646-744-2900. We are always here for you – to listen and to learn.

Dear Readers,

We live in a world revolutionized by technology, a world unimaginable just a few short years ago. We have devices that connect us to friends and family around the globe, can access information in a second, and can measure heart rate, respiration, eye movement, blood sugar and other functions and instantaneously transmit these findings to a healthcare provider. The possibilities are endless.

For individuals facing the challenges of living with or caring for someone with Alzheimer's or a related dementia, technology holds the promise of easing the burden, strengthening connections, adding to the toolbox of activities that can engage the person who is affected, and provide comfort or stimulate memories.

In this issue you will read about some innovative products that were designed specifically for the Alzheimer's family. We were excited to feature many of them in our inaugural Tech Fair in the spring. However, I encourage you to be creative about using the technology that exists and has become part of our daily lives. For example:

- Use calendar reminders to prompt busy caregivers to call in a prescription renewal.
- Send a group text to friends and family who have offered to help, if you need a break on Friday night.
- Find pictures of your relative's home country, town, or favorite sport, or performer to stimulate conversation.
- Find YouTube clips of favorite TV shows or movies.
- Use the Amtrak app to make that reservation to Philadelphia when you need to travel.
- Take photos of a pet or grandchildren to show to your relative.
- Find word games and trivia sites.
- Listen together to radio podcasts, if he or she always enjoyed *Fresh Air*, or *Wait, Wait...Don't Tell Me!*

- Scan important documents and list of medications, doctors' names and contact information and upload to a secure location. In case of an emergency or natural disaster you'll be glad you have access to this information.

- Purchase the Balance: for Alzheimer's Caregivers app. We are proud partners of The Hebrew Home at Riverdale on this project.

- Use online services to order a meal or deliver groceries.

- Download a meditation app to guide you and remind you to meditate daily.

- Enroll in the MedicAlert® NYC Wanderer's Safety Program online: www.caringkindnyc.org/wandersafety.

- Use Fitbit or a similar tracker to make sure you're getting your 10,000 steps daily, and to track your sleep.

- Use Antidote to find clinical trials for Alzheimer's and related dementias: www.caringkindnyc.org/clinicaltrials.

As I said, the possibilities are endless. Please share ways that you use technology to make your lives as caregivers or individuals with the disease easier. Please send your ideas to us at DBruzese@caringkindnyc.org and we will publish the top 15 in next quarter's newsletter.

Now, a caveat: the internet is a great source of information, but caution is necessary. Not everything on the web is vetted and there are schemes to defraud unwary caregivers and persons with dementia with unfounded promises of cure or treatment. As much as



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technology can improve and enhance the experience of living with Alzheimer's disease or caregiving, it's important to maintain perspective. Alzheimer's is a uniquely human disease and requires uniquely human support. Technology is a complement to the human interaction that is critical to maintaining our mental health and well-being.

Speaking to a Helpline Specialist on the CaringKind Helpline, attending a support group or having a meeting with one of our social workers is a dynamic, interactive experience. Not only is information exchanged, but there is an opportunity to share feelings, be understood deeply and to connect in a profoundly human way. We are a social species, talking with one another is healing and normalizing.

Many people affected by Alzheimer's report feeling isolated and alone. Sharing online in a chat room or message board might be helpful, but for many it can't hold a candle to the deep connections that are formed in the in-person support groups or speaking with a caring, compassionate staff member. So, use technology creatively and wisely and, as always, if you need our help, please call our 24-hour Helpline at 646-744-2900 or email us at helpline@caringkindnyc.org. We are here for you.

CaringKind kicked-off this spring with live television coverage of our TackleALZ NYC game on NY1 News and NY1 Noticias. Anchor Roger Clark interviewed players from the BruCrew and Blondetourage teams, as well as Candace Douglas, Director of Constituent Events. Coverage ran throughout the day. *The Roosevelt Island Daily* was also present, reporting on the game including several photos of the action.



This year's Forget-Me-Not Gala was a record-breaking success thanks to Gala Chair Fred Hassan; Corporate Leadership Honoree, Allergan, and their Chairman and CEO Brent Saunders; emcee, CBS 2 Medical Reporter Dr. Max Gomez; and our 550 guests, who helped raise \$1.8 million! *New York Social Diary*, *New York Nonprofit Media*, *Black Tie International Magazine* and *Hamptons.com* all featured coverage of the festivities.

Lou-Ellen Barkan continues to be a thought leader with a recent op-ed in the *New York Daily News*. Focused on the underfunding of the Department of the Aging and the impact on caregiving, she wrote, "It's unconscionable that at a time when the needs of some of our most vulnerable citizens are growing that support for senior centers, case managers, respite programs and home care – all vital resources for caregivers – is not keeping up with the demand and has been entirely overlooked by the current administration."

Lou-Ellen also advocates through her monthly column, "Care Chronicle," which appears in about a dozen local newspapers across the boroughs, and offers ways to improve the day-to-day lives of caregivers. Recent topics have included Technology for Caregivers, as well as Summer Safety. The technology column featured the Balance: for Alzheimer's Caregivers App, designed by the National Alzheimer's Center, a division of Hebrew Home at Riverdale in partnership with

CaringKind, which includes interactive caregiver communications, calendars, pill reminders, news updates, a medical record tracker, physician notification tool, and much more.

CaringKind also continues to be recognized for bringing Comfort Matters®, an innovative dementia care education program, to four New York City nursing homes. CaringKind's Jed Levine who played an integral role in the Comfort Matters initiative, was quoted in PADONA, the journal associated with The American Society for Long Term Care Nurses, on how Comfort Matters revolutionizes palliative care for dementia patients.

Jed was also interviewed as an expert on the topic of wandering for a radio news piece on WNYC. "It Was the Scariest Night of My Life: When Seniors Go Missing in New York" was featured on the popular NPR show *All Things Considered* and examined how the NYPD and community organizations are addressing the growing population of seniors at risk for wandering.

CaringKind continues to touch caregivers in New York City's many diverse communities through caregiving training programs and workshops, as well as our English, Spanish, and Chinese language Understanding Dementia seminars. Featured on more than 100 local events websites and calendars, these programs are extremely well attended. And, thanks

to Weijing Shi, our incredible Chinese Outreach Manager, CaringKind was featured in a Chinese-language television program on Sinovision TV. The program was aired around Mother's Day, and focused the day-to-day life of a mother/daughter caregiver relationship.

CaringKind rounded out the spring season with several terrific events and conferences that were featured across local events websites and calendars. The Charles Evans Lecture, "Here But Not Here – Learning to Live With Ambiguous Loss" and the conference for audiology professionals, "Hearing Loss, Dementia and Healthy Aging: Audiologist as Gatekeeper?" were both presented to sold-out houses. The inaugural Technology Fair piqued the interest of hundreds of clients and community partners wanting to know about the latest innovations for caregivers.

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“ I took over caregiving responsibilities for my father eight months ago. I visit your website a few times a month to learn more about Alzheimer's disease and how to care for my dad. I recently switched jobs and now will frequently travel between Chicago and New York. How can I continue to manage my father's care when I am out of town? ”

— Howard



STEPHANIE ARAGON

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Dear Howard,

Long distance caregiving can sometimes be challenging but there are several ways to make it a bit easier. It is helpful to try to keep in direct contact with your dad by phone as often as possible. Having a relative or friend check in with you and your dad can be very reassuring. Be sure to have a list of his medications and important phone numbers placed either on the refrigerator or near a phone; EMTs often look there in an emergency. Registering your father in our MedicAlert® NYC Wanderer's Safety Program and having him wear an identification bracelet or necklace is also important to ensure that he is reunited with you should he go missing and it provides a personal health record.

There are various mobile applications that can help make your caregiving journey easier. Most offer a profile of the person with dementia which includes basic information like his or her date of birth, gender, and the contact information for his or her physicians. The app can also be used to track medication, listing all medications with their purpose as well as dosages, prescribing physician, pharmacy, and RX number. Some sync with your calendar and send reminders when it's time for the person with dementia to take his or her medicine. There is even a journal section for recording notes for the next doctor's visit.

Multiple user access is available so that you can share this information with other relatives or a trusted neighbor, if appropriate.

Yes, technology can make life a lot easier but don't forget about the human touch. People are the answer, and you don't have to look far to find the right people. CaringKind is the heart of Alzheimer's caregiving and we are available 24 hours a day to listen to your concerns and provide support throughout your caregiving journey.

Helpline Specialists are always ready to lend an ear and can steer you in the right direction regarding which seminars and workshops to attend along with which programs you would benefit most from. Additionally, they can discuss different strategies to help with your dad's care, products for the kitchen such as knob covers for the stove, or handling restless behavior.

Once you start going to seminars or support group sessions you will be meeting people dealing with situations similar to your own and hearing how they deal with them. This is not to deny the importance of friends who listen and do not judge, and who may offer you a break by staying with your relative for a couple of hours or inviting you to get out of the house and join them for a cup of coffee.

It is important to make sure that your father feels comfortable and is occupied during the day. Depending on his level of cognition, the following options are available: CaringKind's Harry & Jeannette Weinberg Early Stage Center, which offers programs for those in the very early stages, adult day programs in both social and medical models in all five boroughs, and home care agencies paid privately or through Medicaid.

Helpline Specialists can also make an introduction to our social work department so you can meet with one of our social workers for an in-depth consultation regarding the current situation that you face with the person with dementia, or situations with other family members. We are here to provide advice and link you to programs for you, the caregiver, as well as the person being cared for. Please feel free to call us any time at 646-744-2900.

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

Low-Tech Identification Bracelet Saves Lives



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It's a fact that six out of ten people with dementia will wander at some point during the disease. A person with Alzheimer's or dementia may not remember his or her name or address and can easily become disoriented in familiar places. Although it may seem that a person is just wandering around aimlessly they are often trying to go somewhere for a specific reason or purpose.

It is very important that we allow persons who have a diagnosis of Alzheimer's to remain as independent as possible, while ensuring their safety. Over the last several years there has been an increase in the number of products that use technology to monitor the whereabouts of individuals with dementia or other conditions like autism or developmental disabilities.

One of the most popular products is a locator app. This is a piece of software that operates through a browser or offline on your computer, phone, tablet or any other electronic device. Once you download the app, you can keep track of the person. These tracking devices sound like a great solution, and are appealing, but often are not as practical in real life situations. They usually require charging, sometimes daily or overnight. In addition to the purchase fee there is usually a monthly fee based on usage or the specific plan offered. The cost is out of reach for many families. Sometimes these tracking devices are not specific about where the person actually

is, whether they are walking, driving or taking public transportation. Because of the unreliability of GPS (Global Positioning Systems), alarmingly, it may appear as though the individual is walking on, or is in the water only because they are near a river. In high rise buildings it might not be possible to determine what floor the individual is on. And it is important that the person with Alzheimer's remembers to take the device with them in order for the caregiver to keep track of them. As the disease progresses and a person's cognitive ability declines they might not remember to take a phone or other tracking device. Some tracking devices are put in shoes, however it is not uncommon for a person to wander barefoot because they didn't remember to put their shoes on.

Caregivers, ask yourself, what do you have to rely on if this were to happen? What is your backup identification product?

CaringKind offers the MedicAlert® NYC Wanderer's Safety Program identification product. The Wanderer's Safety Program provides a low-tech identification bracelet which is easy to apply for, and is very effective when a person's wrist is measured correctly and the product is worn on the dominant wrist. Our product has a unique and secure latch design making it extremely difficult to remove.

The Wanderer's Safety Program enrolls over 125 new members monthly. Because a missing person incident is so often emotional and stressful for the family, the Wanderer's Safety Program team will reach out to the caregiver providing support, understanding and a compassionate ear until the missing person is found. We average three to five missing person incidents, including Silver Alerts, on

a weekly basis and continue to have a 98% success rate. The Wanderer's Safety Program is proud to be a part of the New York City Police Department's Patrol Guide. Emergency responders are trained to report all "Special Missing Category Incidents" to the MedicAlert 24/7 Emergency Hotline. We operate as a live 24-hour emergency response service for any person with dementia who experiences a medical emergency, or who may wander and become lost.

At the time of enrollment, we ask caregivers to provide the member's physical characteristics, list of medications, conditions and any known allergies. We also request a current photo. This information is kept confidential in our MedicAlert NYC Wanderer's Safety Program National Database and is only given to the police or emergency room staff.

Another feature we offer is an optional caregiver membership and medical identification product (bracelet or necklace). Caregiver membership includes the same benefits as for the enrollee. Caregivers wear a MedicAlert NYC identification product to alert others that she or he provides care for a MedicAlert member who is memory impaired.

Our MedicAlert NYC Wanderer's Safety product saves lives and is a great complement to higher tech tracking and locator devices.

For more information, call 646-744-2900 or visit caringkindnyc.org/wandersafety.



The Power of One-On-One Human Interaction



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Tom was a proactive caregiver to his wife, Lynette, who had been diagnosed in the early stage of Alzheimer's disease in late 2015. Several months after retiring from her job as a bookkeeper, Lynette noticed that she was having trouble managing the couple's checkbook as she always had. She also had difficulty keeping track of the plans that she made with family and friends, as spending more time with those closest to her was something she had looked forward to after retirement. These uncharacteristic changes prompted Tom to suggest that Lynette see a neurologist, which resulted in the diagnosis.

The diagnosis came as a great shock to both Tom and Lynette. As any worried husband would, Tom immediately sought solutions to help Lynette cope with these changes. Always one to seek out the newest technological gadget, he purchased a smartphone and loaded it with applications to help her keep track of contacts, appointments, and important information like her medication regimen. He helped her to set alarms that reminded her when to do important tasks, and linked all of it to his phone giving him access to the same information. This way Tom could provide support when necessary. He also purchased an electronic medication dispenser which pre-poured Lynette's medication each week so that she could easily access the proper pill when the reminder alarm sounded. This addition, in conjunction with the reminder on her phone was a bit of coordination of which Tom was particularly proud! While it was challenging for Lynette to learn these new systems, she eventually caught on to a point that they became useful, thus

allowing the couple to focus on enjoying their time together.

Yet over time, Tom found that the systems he had set up began to lose their utility. Lynette began forgetting what the reminders meant and how to turn them off. Tom recognized that he needed to become more involved with Lynette's day-to-day tasks, including administering her daily medication and escorting her everywhere. He not only needed to ensure Lynette's safety, but also to remind her when and how to complete many of the tasks that she used to do on her own. He soon became exhausted. Tom found some respite in his continued ability to sleep in late, a habit he had always enjoyed, as Lynette would get up in the morning, prepare herself a simple breakfast, and watch the morning news.

One morning, however, that all changed. Tom awoke at his usual time, but instead of finding Lynette in front of the television, he found an empty couch. He quickly called out Lynette's name, but received no answer. Panicked, Tom did a quick search of the apartment to no avail. He immediately ran out to search for Lynette. Thankfully, he found her chatting with a neighbor in the lobby, albeit in her pajamas, but this incident prompted Tom to reach out to CaringKind for assistance about what to do next.

Tom met with a CaringKind social worker to discuss the situation and immediately expressed interest in finding technology that could assist him and Lynette in this next phase of her condition. After learning about Tom's interest in technology, and his creative use of it as a caregiver, the social worker did discuss options to ensure Lynette's safety. The social worker introduced Tom to products such as an automatic stove shut-off system which could be installed to prevent a fire if Lynette were to forget to turn off the burner after making her morning tea, as well as GPS systems, such as a watch or shoe insert, should Lynette wander or get lost. Yet the social worker also discussed the benefit

of low-tech solutions to these situations, including door chimes to alert Tom if Lynette opened the door or a specialized door lock to prevent her from opening it in the first place.

Tom liked these solutions, but the social worker also noted his exhaustion and reflected on the fact that while these products could be part of a good overall plan of care, they would not provide Tom with the time and the space he needed for himself. They discussed how Lynette's needs would continue to grow, and Tom expressed fear that he would not have the stamina it would require, as he was already finding it hard without the rest he had been used to. Our social worker confirmed that this would be the case if Tom did not consider engaging additional support. Lynette needed a person present with her at most times, but that person could not always be Tom. The social worker then suggested that it was time to think about introducing a companion. Tom admitted to avoiding the thought of this next step because it would mean acknowledging Lynette's decline, but he had not considered the impact of the decline on him. As beneficial as technology can be, our social worker noted that when it comes to caring for a person with dementia, nothing can take the place of one-on-one human interaction.

With our social worker's guidance, Tom found a day program for Lynette to attend, which allowed him a few hours of respite each day, during which he could nap, go out with a friend, or go to his doctor's appointments. This break was enough to help Tom get up earlier in the morning so that he could spend time with Lynette, but it also made him more comfortable with the idea of hiring a companion. Tom found other ways in which technology was helpful to him as a caregiver, including the use of a smartphone application that allowed him and the companion to share information about Lynette. But in caring for a person with dementia, Tom recognized that there is no substitute for the human touch.

Connecting Professional Caregivers to the Families Who Need Them



AMY TORRES

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Most individuals that receive a diagnosis of Alzheimer's disease or dementia, at some point, will require the assistance of a professional caregiver at home. Friends and family members supporting someone with cognitive impairment may feel overwhelmed at the thought of having to hire and introduce someone new into the home. Not only is hiring a professional caregiver a sign that the person's deficits may be increasing but the introduction of a new individual in the home may be simply too overwhelming for the person struggling with the disease. The process of finding someone suitable for the person with dementia's needs is understandably daunting and, for many, fraught with worry.

CaringKind understands that people with dementia require a skilled caregiver, one

who understands the range of diseases that can cause cognitive impairment; a caregiver that is willing to be flexible and can exercise patience, that has a high level of tolerance for the variety of behaviors that may crop up, and is willing to validate the person with dementia's feelings even when they don't understand them.

Our Dementia Care Training Program for Professional Caregivers (DCTPC) has been training home health aides, certified nursing assistants, personal companions and other direct caregivers for over 25 years in best practices for dementia care.

A frequent misconception when hiring a professional caregiver is assuming the individual has had training in dementia care. Most seasoned caregivers learn about dementia and how to manage behaviors through trial and error. Professionals that want to expand their knowledge must seek out training courses on their own. When accessing home care through an insurance program, friends and family members often do not get to choose the caregiver sent by the agency. This makes it even more difficult to find

a knowledgeable caregiver who suits the person with dementia and the household.

In an effort to connect graduates of our professional training program and friends or family members looking to incorporate a private pay, professional caregiver into the home, CaringKind created a website called Together We Care™. This networking website is an opportunity for DCTPC graduates who are looking to put their learned caregiving skills into practice and connect with friends and family members looking for those skills.

Friends and family members seeking to hire a DCTPC graduate can register with the site and create a job posting that highlights the skills, hobbies and scheduling in which they are interested. Professional caregivers create a profile and then have an opportunity to not only highlight their work experience but also speak to who they are as a caregiver and with whom they prefer to work. When browsing profiles, friends and family members can also filter by availability and scheduling, language, transportation capabilities and additional degrees and certifications.

Home care is a very personal service and Together We Care is a resource that seeks to connect people on a meaningful level; one that acknowledges caregiving for a person with dementia is so much more than the clinical tasks taught in schools. It involves the connection of the right caregiver for the person with dementia.

For more information, please call our 24-hour Helpline at 646-744-2900.



The Beautiful Stuff, Too



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“When I go on vacation, my brain just shuts off, I don’t think about my mom or the dementia at all,” a member of my support group recently said. She was trying to convince another group member to take a vacation, as he hadn’t been away in several years and the stress was taking its toll on his wellbeing. She was concerned about how he was coping. Other group members chimed in with similar experiences.

He said thank you, but didn’t make eye contact and continued to look dejected. Another member noticed his expression and knew him from over the years to be the kind of person unlikely to be able to “shut off” his brain and recognized that he probably couldn’t relate to that well-meaning suggestion.

She turned to him and gently said, “When I go on vacation, I don’t shut my brain off. I am still thinking about my mom and everything I must do. But at least I can think about beautiful stuff, too.”

Bingo. She saw his face, understood that he couldn’t turn off his brain, but found a way to help him see a benefit of going on vacation anyway. He turned to her, a more relaxed expression on his face when he smiled and said, “Thank you, that’s a good point, I hadn’t thought of it that way,” and promised to consider it.

That moment, which happens hundreds of times a month, in groups all over the city, demonstrates the power of an ongoing, in-person support group. Caregivers’ lives are filled with demands and stress, and often,

people who want to care and help but don’t know how to put it into the right words. Even caregivers who are going through it too have different experiences, like in the scenario above.

Some of the group members felt comforted knowing that it was okay to stop thinking about the person they were caring for sometimes. Others felt comforted knowing that it was also okay to not be able to do that. It may seem obvious, but moments like those are profoundly important for many caregivers who struggle with guilt and finding a balance of self-care.

That’s the power of a group – one person’s experience didn’t fully resonate, but because the members know each other so well, another member could pick up on non-verbal cues and find another way to connect. The members of my support group have built the kind of connection and relationship that comes from years of showing up for each other, supporting each other, sharing with each other and seeing each other.

As humans, we have a deep-seated need to connect with other people. Societies are built around the idea that people with things in common can relate to each other and build intertwined lives. Our dementia caregiver support groups serve a similar function. Caregivers get what other caregivers go through. Even when they come from different parts of the world, work different kinds of jobs, have different family or financial situations, they have a lot in common. They know the stress, exhaustion and fear that comes with being a caregiver for someone with dementia, and in the groups, help each other through the process, many times over a period of years.

If you look at the support group, on the outside, they might not look like people who would normally connect on such a deep emotional level. Some parents are being cared for by 24-hour private aides,

others by family or Medicaid homecare. Some people are retired; some are still working. Some have families who have been in the United States for centuries, others, just a few years or decades. Their parents speak four different languages. There’s a doctor, a city worker and a playwright. Some have siblings, partners and friends, others get their support mainly from the group.

But twice a month, every month, year after year, they all come together and share their experiences. Most have cried at some point and they’ve all laughed. They validate each other’s efforts to be a good son or daughter, a good caregiver, a good person. They hear each other through the difficult stuff – the anger and the guilt, the times they don’t know how they’ll manage, the fears about their own future. They nudge each other when they’re stuck in a perspective that doesn’t seem to work, and most importantly, celebrate each other’s accomplishments – whether that means finally writing another play, even though their mother will never get to see it, or setting a boundary with an overbearing sibling.

Sometimes the accomplishment is as simple and profound as taking the time to consider that adding the beautiful stuff might make taking a vacation worthwhile, even if they think about their mom the whole time. And that’s always worth celebrating.

Call our
24-hour Helpline
(646) 744-2900 to
learn more about
whether a support
group is right
for you.

Caring Through Music: A New Short Film

by **CaringKind and Bang & Olufsen**

Caring Through Music documents the transformative power of music, and documents how relatives and caregivers use music to spark memories for people with Alzheimer's.

Caring Through Music, a short film by CaringKind, New York City's leading expert on Alzheimer's and dementia caregiving, with the support of B&O PLAY, a unit of audio company Bang & Olufsen, premiered to the public at large.

Inspired by research showing that music is stored in a part of the brain not affected by the same degree of memory loss associated with Alzheimer's or dementia, *Caring Through Music* explores how music is being used as a tool to reconnect with memories of the past in the lives of those affected by these cognitive diseases.

"The film is an honest, touching, and deeply intimate portrait of how music can open the door to memories long forgotten, and how caregivers and family members can use music to create real emotional connections with a person battling dementia," says Lou-Ellen Barkan, President and CEO of CaringKind, and continues:

"We believe the film, along with audio equipment donated by B&O PLAY for

our programs in New York City, will allow us to further our mission of providing support to anyone whose life is touched by Alzheimer's or dementia."

A film about the musical being

Video Director Jeppe Kolstrup, whose own grandfather had Alzheimer's, and his team filmed people with dementia and Alzheimer's and their caregivers listening to music from their past at CaringKind's New York City headquarters.

"My vision was to allow the viewer a window into the experiences, good and bad, that the relatives of a person with Alzheimer's go through," said Jeppe Kolstrup. "I want to bring the viewer through some of the same emotions that the families go through – and really underline the effects of music on the person with Alzheimer's and everyone involved in their care."

Music as a transformative force

Beyond supporting the short film, B&O PLAY has donated headphones and speakers to CaringKind to enhance the on-site programs for family members and professional caregivers. The equipment will also support CaringKind's innovative early stage center and provide much-needed respite from the burden of care for family caregivers visiting CaringKind.

"At Bang & Olufsen, we strongly believe in the power of music as a transformational

force. *Caring Through Music* is a beautiful and moving film; emotionally powerful with deep meaning for individuals and families affected by a dementia diagnosis, and we hope that the film can help create awareness about dementia and the positive impact of music," said Jens Jermiin, Director at B&O PLAY.

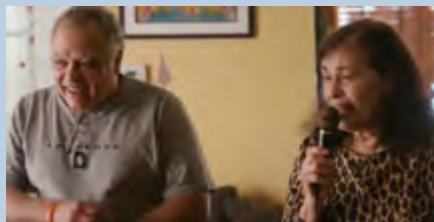
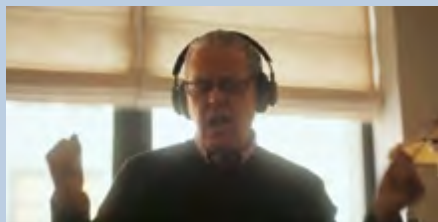
See the short film

Caring Through Music was brought to life as a collaboration between CaringKind, B&O PLAY and Copenhagen-based creative agency SeLigeMig. The short film is available on:

CaringKind's website:

<http://www.caringkindnyc.org/caringthroughmusic>

B&O PLAY is a leading lifestyle audio brand, part of the world-renowned Bang & Olufsen, firmly grounded in 90 years of acoustics, design excellence, and craftsmanship. For more information, visit www.beoplay.com.



Scenes from "Caring Through Music"

Education in Person vs. Online



MARILUCY LOPES

Director of Education & Outreach

mlopes@caringkindnyc.org

The telephone number of your favorite take-out restaurant. Your doctor's office address. Tomorrow's weather. All this information can be found on the internet. Obtaining this information is quick, convenient, and (often quite literally) in the palm of your hands if you own a smartphone. Information about dementia and Alzheimer's disease can be accessed through the internet too – through websites, journals, articles, web links, and more. For many reasons, the internet is an educational tool with immense value. Not only can you learn about the basics of dementia, read about warning signs and common symptoms, but in your quest for information, you can also find questions asked and comments posted by millions of individuals throughout the world, who are searching for information about dementia or Alzheimer's, just like you. So, you might wonder why attending an educational seminar at CaringKind would be helpful, when information about dementia can be found online?

Not all information found online is accurate information, and when it comes to dementia and Alzheimer's, a disease that impacts the brain, it's important to be sure you're getting the information from experts in the field, such as staff at CaringKind. While it can be helpful to use the internet to search for an answer to a question such as, "What is the difference between Alzheimer's and dementia?" There are many questions that need specialized attention in order

to be answered properly. By attending an educational seminar at CaringKind, a person gets to learn why one of the most important elements of Alzheimer's and dementia care, is about personalized knowledge on how the disease will impact the individual with Alzheimer's or dementia, and how it will impact the caregiver's life too. With online forums, what works for one person's situation and life, won't necessarily be the best option for your needs.

CaringKind provides answers to questions about dementia and Alzheimer's, but more importantly, helps you learn what you can do, when education can only go so far. To understand dementia, is to understand that there will be limits to answers for every question. This is because with no current prevention or cure for Alzheimer's and related dementias, it is natural that some questions will remain unanswered. CaringKind has specifically developed our educational seminars to address the unknown areas of Alzheimer's and related dementias. For example, our Understanding Dementia Seminar will provide you with the most accurate information about the disease process, different stages, and current medications in a clear, concise, and organized way. Many caregivers will come to the seminar with a sense of what the disease is based on information they read online, only to discover some of the information they read was not accurate, or did not apply to their personal situation.

CaringKind provides answers for caregivers or individuals who want to learn more about dementia, and does so in a person-centered way. CaringKind understands that in addition to dementia, all aspects of a person, such

as their personality, history, likes and dislikes, are important to understanding how to support a person. CaringKind education provides accurate information, and takes into account your personal experience, which in many ways will protect you from coming across rumors or false information that can be scattered throughout the web.

Through our 24-hour Helpline, callers are given the opportunity to register for any of our free educational seminars and can attend them as often as needed.

In addition to the Understanding Dementia seminar mentioned previously, family members and friends can also learn about other issues impacted by Alzheimer's disease and other types of dementia, such as the financial, social, emotional, and physical changes which can occur in our other seminars. Other seminars include the Legal and Financial Seminar, Medicaid Home Care Seminar, Placing your Relative in a Nursing Home Seminar, and lastly, a Monthly Educational Seminar which hosts various topics, based on subjects caregivers want to learn more about.

Information about these seminars are available on our website, at www.caringkindnyc.org/education, but remember, to reap the benefits of in-person education by signing up for these seminars via our 24-hour Helpline at 646-744-2900.

Hearing Loss, Dementia and Healthy Aging: Audiologist as Gatekeeper?

by Carolyn Ginsburg Stern

*Manager, Center for Hearing
and Aging, Center for Hearing
and Communication*

Two out of three people over the age of 75 have hearing loss and one in ten over the age of 65 has Alzheimer's or a related dementia. Research shows that untreated hearing loss in the elderly is associated with increased cognitive decline. Professionals working with this age group are often faced with questions on how best to manage the specific needs of their patients who are experiencing both hearing loss and dementia. To address this, the Center for Hearing and Communication (CHC) and CaringKind partnered in presenting a unique conference on May 11: "Hearing Loss, Dementia and Healthy Aging: Audiologist as Gatekeeper?"

There was an audience of 100 audiologists and related professionals, all eager to deepen their understanding of how Alzheimer's disease and related dementias impact current and future older adult clients with hearing loss. CaringKind's CEO, Lou-Ellen Barkan, emphasized the importance of this conference stating, "We know in the absence of an effective pharmaceutical therapy for the disease, the best therapy is good care which includes consideration of our clients' physical well-being, which as we know more and more includes hearing loss." CHC's Executive Director, Laurie Hanin, added, "It is vitally important that health care providers understand the need to address hearing loss as we get older. Untreated hearing loss in the elderly is linked to a greater risk of falls, social isolation and dementia. Audiologists

need to know more about the ever increasing dementia epidemic they may already experience with clients in their practices."

Experts in their respective fields provided a wealth of new knowledge and practical information throughout the day-long conference. Presenters included Dr. Joshua Chodosh, geriatrician and professor at NYU School of Medicine; Anne Foerg, Director of Social Work Services at CaringKind; Dr. Kathy Pichora-Fuller, a researcher trained audiologist and professor in the Department of Psychology at the University of Toronto; Dr. Barbara Weinstein, a leading researcher and expert on audiology and aging at the Graduate Center, CUNY; Amy Torres, Director of Training at CaringKind and Dr. Ellen Lafargue, audiologist and Co-Director of the Shelley and Steven Einhorn Audiology and Communication Centers at CHC. Jed Levine, Executive VP at CaringKind served as moderator. Special thanks to Brooklyn College for sponsoring continuing education credits from ASHA and corporate sponsors, Oticon, Signia, Caption Call and CapTel.

Key takeaways from the conference include:

- Hearing loss can create communication strain for the person with dementia, the elderly spouse or caregiver, or both.
- Studies show that improving the quality of sound through amplification such as hearing aids could put less strain on the brain and free up energy needed to improve functioning.
- Enhancing communication through amplification can improve mood and



increase social interactions, thereby reducing loneliness and isolation.

- Addressing hearing loss can help one stay connected, engaged and aware of the surroundings, key for someone with a diagnosis of dementia.
- Tools are available to enable audiologists to bring up observations regarding their client's cognitive functioning.

The conference provided an unprecedented opportunity to acknowledge that audiologists can serve as gatekeepers for dementia. As Dr. Weinstein said, "One of the many reasons why audiologists could serve as a gatekeeper is that they have long term relationships with their patients, and can note when there is a change in their communication behaviors." And, as Jed Levine emphasized, "if we could help connect individuals with dementia to diagnostic resources, and care and support programs early in the process, they could be a part of the conversation." As gatekeepers, that's an important role we can play.

Carolyn Ginsburg Stern is passionate about helping older adults and those with dementia get the hearing health needed to lead productive and connected lives. For any questions or comments, please contact Carolyn at 917-305-7812 or cgstern@chchearing.org.

A Purpose

by Grace McElroy

Head of Partnerships & Distribution, Antidote

It's April 25, 2017, and I have the opportunity to participate in CaringKind's First Annual Technology Fair. The fair took place at CaringKind's office in Manhattan. Caregivers attended the event to explore new technologies that showcase the benefits and the promise of patient engagement technology.

My display is simple – a table featuring some literature and a laptop set to demonstrate Antidote Match™, the first truly patient-centric clinical trial search tool. Match, which is available free of charge, powers clinical trial search on caringkindnyc.org and a rapidly expanding network of patient communities, health portals, and advocacy group sites.

At Antidote, I help build the network by connecting with mission-driven organizations, like CaringKind, where I work primarily with leadership and staff. On this occasion, this three-day event affords me the chance to get to know the caregivers – those people who both benefit from, and inspire, the work of all the amazing professionals at CaringKind. I am excited and honored for the opportunity.

Al*, a tall man with a friendly smile and a firm handshake, is the first caregiver to approach my table. Al is in his late 70s trying to do anything for his wife who was diagnosed with dementia years ago.

"What do you have here?" Al asks with enthusiasm and anticipation. I tell

him that for the first time, using our technology, caregivers can answer a few questions, and within a minute, match to appropriate clinical studies for which their loved one may be eligible.

"Oh," Al says with noticeable disappointment. "I gave up on searching for clinical trials years ago." He then shares his personal experience of getting lost, frustrated, and dejected using ClinicalTrials.gov. I tell him that the government site was created solely for researchers and not for patients and caregivers. And then, I show him Antidote Match.

I watch Al as he uses Match. In a minute, after answering just a few questions, Al receives a list of trials. He shakes his head and smiles, "That's truly amazing," and adds, "I wish I had your tool years ago." I want to tell Al that it isn't too late for his wife to join a trial and leave a legacy that may help her or others in the future. But I don't. Despite his strength and optimism, I can only imagine how much his physical and emotional capacities are already stretched.

As the event closes, I am overcome by interactions with people like Al and the reception of our product. I share my experience with our team located in New York, London, Indianapolis, Philadelphia, San Francisco and Sarasota. I tell them about all the caregivers I met and their positive, and in most cases, thankful, response to Match. It's virtual high-fives all around by the team when they hear that their hard work is making a difference and serving a purpose.

About Antidote

Antidote is a digital health company on a mission. Our aim is to accelerate

the breakthroughs of new treatments by bridging the gap between medical research and the people who need them. In a world where 80% of clinical trials are delayed or closed due to lack of awareness, Antidote uses cutting-edge technology to match the right patients with the right trials, helping medical researchers make faster progress, and offering new treatment options to patients in need. Antidote was launched as TrialReach in 2010, and is based in the US and UK. This is a global effort to advance health care for everyone. To find out how you can help shape medical history, visit <http://www.antidote.me>.

**Name has been changed*

Grace McElroy is passionate about helping patients and caregivers get access to promising new treatments through clinical trials. As Head of Partnerships and Distribution, Grace and the Partnerships team, has brought Antidote's free, best in-class clinical trials search tool to CaringKind and over 140 partner organizations, to help patients connect to medical research.

Find a Research Trial.

**Know your options
in 60 seconds.**

**Access the latest
treatments.**

**Receive
world-class care.**

Powered by
antidote //

for more info:
caringkindnyc.org/clinicaltrials/



CAROL BERNE

Senior Vice President of Development
cberne@caringkindnyc.org

We are now in our second year as CaringKind, and we are busier than ever. The numbers of clients in all program areas and Helpline callers continue to grow, showing us that the CaringKind name is reaching those who need us most. The importance of our work was recently reinforced in a major study conducted by The Centers for Disease Control (CDC), which found that over the past fifteen years (1999 – 2014) the death rate in the U.S. from Alzheimer's disease increased by 55%. The report further stated that as the number of older Americans with Alzheimer's disease rises, more family members are assuming the emotionally and physically challenging role of caregivers than ever before, and that "supportive interventions can lessen the burden for caregivers and improve the quality of care for people with Alzheimer's disease."

CaringKind has been at the forefront of improving standards of care and quality of care for over 30 years. Though there is no cure for Alzheimer's there is a way to transform a life and to have hope for the future – and that is through good care. In so many ways, CaringKind has been a leader in the field. Our palliative care initiative, for example, which started as a pilot in 2012, is transforming the way care is provided in nursing homes for persons with late stage dementia. We continue to set the standards in this area and continue to receive nationwide recognition for bringing dementia-capable palliative care to a large, urbanized and unionized environment, and now to other settings.

We also launched a Technology Fair this year, at CaringKind, to bring the latest technological advances (from hearing assistive devices to mobile apps) to help caregivers as well as their relative with dementia better manage their daily lives. The overwhelming response from our clients indicated the tremendous interest in technology's role in caregiving. Our "innovators" were not only established companies but also young entrepreneurs who were personally affected by dementia and saw technology as the future to caregiving.

We are dependent on financial support to keep our doors open and our programs free of charge. One of the most important ways you can help us is by supporting one of our four CaringKind Alzheimer's Walks this fall. This year we will bring the Technology Exposition to the Riverside Park Walk on October 15th so that our Walkers can experience the technological advances helping caregivers today and in the future. Whether making a donation, forming a Walk team, or getting your company involved, your participation is crucial to us. Please call 646-744-2900 to register or please email us at: walk@caringkindnyc.org.

As always if you wish to make a gift to support a specific program or service, or to recognize one of our staff members who has been helpful to you, please give me a call at 646-744-2905 or email me at cberne@caringkindnyc.org. Thank you. See you at the Walk.

Ways to Give

Giving by Check

Please make checks payable to CaringKind. For your convenience, a self-addressed postage paid envelope has been provided in this newsletter.

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, 4th 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@caringkindnyc.org if you would
like additional information.

Research Update A Good Night's Rest: Sleep, Aging, and the Brain.

On May 10, longtime friend and supporter Tami Schneider hosted an evening with Dr. Ricardo S. Osorio, Research Assistant Professor of Psychiatry at the NYU Center for Brain Health, for special friends and supporters. Dr. Osorio led an informative and lively discussion on the relationship of sleep, aging, and the brain.



From left: Lou-Ellen Barkan, Dr. Ricardo Osorio, Tami Schneider, Jed A. Levine

Art Show Check Presentation

Arlene Panicello-Cosgrove (left) and her husband Deacon Bob Cosgrove visited CaringKind on April 27 to present a \$3,000 donation to CaringKind President & CEO Lou-Ellen Barkan and Senior Vice President of Development Carol Berne. Panicello-Cosgrove hosted a one-woman art show featuring 50 of her original paintings on April 2, with the proceeds to support CaringKind programs.



The 5th Annual Dinner and Seminar for Asian Physicians and Practitioners



Photo: Visiting Nurse Service of New York.

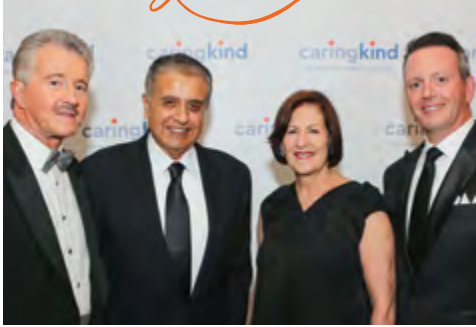
Christopher Olivia, MD - Chief Executive Officer VNS NY; Teresa M. Lin, MBA, Director, Cultural Market Development Initiatives; Jed Levine, Executive Director of Programs & Services at CaringKind.



Photo: Visiting Nurse Service of New York.

Jed A. Levine, Weijing Shi, Manager of Chinese Outreach at CaringKind, Dr. Jonathan Chang.

Forget-Me-Not Gala 2017



From left: Dr. Max Gomez, CBS 2 Medical Reporter; Fred Hassan, Partner & Managing Director, Warburg Pincus LLC; Lou-Ellen Barkan, President & CEO of CaringKind; Brent Saunders, Chairman, President and CEO of Allergan



Judy McLendon and Heath B. McLendon, CaringKind Board member Emeritus and Honoree



CaringKind Board members from left to right: Jonathan S. Henes, John R. Latham, Board Co-Chair, and Jeffrey N. Jones



CaringKind Board members from left to right: Susan V. Kayser, Esq., Board Member Emeritus; Sharon K. Kilmer, Vice Chair & Treasurer; Nathan Halegua, and Linda LaGorga



Board member Peter Hill, Therese McGovern and Patti Hill



Actors Victor Garber and Ron Rifkin



Allergan employees gather for a group photo. Front Row – left to right: Dan Zavodnick, Senior Counsel; Fran DeSena, VP, US Brand & R&D Communications | International Communications & PR; Kim Nitzky, Product Manager; Stuart Ragins, VP, Sales Planning & Analytics; Loredana Cromarty, AVP, Government Affairs; Kristin Paladini, Manager, Production Services; Alicia Brandt, Director, Product Management Back Row – left to right: Majid Kerolous, Director, Medical Affairs; Julie Snyder, Executive Director, Product Management; Brent Saunders, Chairman, President and Chief Executive Officer; Jacqueline D'Onofrio, Associate Director, Product Management; Erin Capra, Director, Product Management; Will Kane, SVP, Marketing – US General Medicine



Peter Schweitzer and Anne McBride Schreiber, CaringKind Board member



From left: CaringKind Board members Jim Lavelle and Marianne Dziuba-Fiore and John Fiore



Michelle Walker and Steve Boxer, CaringKind Board member



Gwyn Grenrock, Executive Director of the Allergan Foundation; Carol Berne, Senior Vice President of Development at CaringKind; Nancy Bayerlein, Senior Manager of Strategic Alliance Advocacy at Allergan



CaringKind Board members gather for a group photo. Back row from left to right: Wayne S. Miller, Jeffrey N. Jones, Heath B. McLendon, David L. Weinberg, John R. Latham, Sharon K. Kilmer, David Hirsh, Jonathan S. Henes. Front row from left to right: Nathan Halegua, Pauline Yeung-Ha, Marilyn L. Cohen, Linda LaGorga, Anne McBride Schreiber, Steven E. Boxer, Marianne Dziuba-Fiore, Susan V. Kayser, Esq.



The live auction was conducted by Jonathan S. Henes, Partner at Kirkland & Ellis LLP and CaringKind Board member.



Dr. Mary Sano and Dr. Warachal E. Faison



Deirdre Quinn, Lou-Ellen Barkan, President & CEO of CaringKind and Kevin Bauer



Brent Saunders, Chairman, President and CEO of Allergan accepted the Corporate Leadership Award on behalf of Allergan from Fred Hassan, Partner & Managing Director, Warburg Pincus LLC.



CaringKind honored its longest-serving Board member William M. Brachfeld.



From left: William Graham, Elaine Thomas, CaringKind Board member, Diery Prudent, Mariza Scotch



Dr. Warachal E. Faison, Pfizer Inc., Dr. Myon de Leon, Dr. Jessica Zwerling, Dr. Lawrence Honig, Dr. Peter Davies, and Dr. Silvia Fossati



Eric Friedman, Lou-Ellen Barkan, President & CEO of CaringKind, and Lori Oscher Friedman, CaringKind Board member

Here But Not Here — Learning to Live With Ambiguous Loss

by James Campbell

How do we mourn the loss of someone who has not yet died? What pitfalls and opportunities for growth are there in caring for someone who is there but not there? CaringKind addressed these difficult questions head on in a wide-ranging discussion at the 5th annual Charles Evans Lecture on the Art and Science of Caregiving, held on April 24, 2017 at the Times Center in New York City.

Following a short introduction from Bonnie Pfeifer Evans and Alice Shure of the Charles Evans Foundation, CaringKind President and CEO, Lou-Ellen Barkan, painted an evocative picture of caring for her father as he succumbed to Alzheimer's. Like a ghost, he "turned slowly... from a fully-colored human, to a grey, translucent outline, and finally to a wisp of smoke before disappearing entirely," only to sometimes reappear as if he had not become ill. This ambiguity, and the pain that can flow from it is a natural, if often unspoken, part of caregiving.

Understanding how caregivers can balance their own lives while providing quality care sat at the core of the evening's discussion. In his introductory comments, moderator

and CaringKind Executive Vice President, Jed Levine, laid out the ramifications – physical, psychological, and spiritual – of caregiving, as exemplified in what he called "the dichotomy of absence but presence at the same time."

The panelists presented a wealth of knowledge drawn from years of academic and clinical expertise and first-hand caregiving experience. Dr. Pauline Boss is Professor Emeritus at the University of Minnesota and the principal theorist in the study of ambiguous loss. Her work addresses the families of those missing physically due to disasters such as the 9/11 attacks and psychologically when the body is present but the mind is not. Karin Marder entered the world of caregiving in 2003 when her husband Jason was diagnosed with Alzheimer's. They soon became involved in CaringKind, attending workshops and developing a community of fellow caregivers.

Psychologically ambiguous loss is a special sort of loss, one without the rituals and closure we are accustomed to when confronting death. Dr. Boss explained that this ambiguity comes at a cost for caregivers, who die at a rate 66% higher than others in the same age group.

"Caregiving," she said, "is dangerous to your health."

Ms. Marder concurred with the concept of ambiguous loss, and the stressors that come with it. "You're constantly grieving, constantly mourning the loss of what was, you're mourning the loss of what is and certainly mourning what is... down the road." This mourning brings with it a deep loneliness, which Ms. Marder addresses by surrounding herself with positive friends and the people in her CaringKind support group. She also continues to find solace in her relationship with Jason, finding moments, where despite everything, they "can just sit and laugh together."

As the evening drew to a close, one question remained unanswered: "Where is hope in the Alzheimer's experience for caregivers?" "The hope is," said Dr. Boss, "that if you get through, your resilience will make you shine... and that's the kind of people the world needs."

James Campbell is a freelance writer based in New York City. He holds an MA in International Affairs from The New School and has written for various academic, non-profit and human rights organizations.



Photo: Barry Hyman

From left: Lou-Ellen Barkan, Dr. Pauline Boss, Susan V. Kayser, Jed A. Levine, Alice Shure, Bonnie Pfeifer Evans, Karin Marder



Photo: Barry Hyman

Jed A. Levine moderates the discussion between author and family therapist Dr. Pauline Boss and family caregiver Karin Marder.

CaringKind on the Cutting Edge



EDWARD CISEK

Vice President of Program Evaluation
ecisek@caringkindnyc.org

In April, we were thrilled to host CaringKind's first annual technology fair! The three-day event, titled "Caring for Today with the Technology of Tomorrow" introduced our community partners and hundreds of family and professional caregivers to products – many of which are brand new – that can help people with dementia and their caregivers. The purpose of the event was to help bring awareness to this growing field.

CaringKind's President and CEO, Lou Ellen Barkan, kicked off the opening night by describing how technology for this population is ripe for innovation. As more products enter the market, and developers are more in tune with the needs of people with dementia and their families, caregivers are getting more

comfortable using them. Jed Levine, CaringKind's Executive Vice President, Director of Programs and Services, added that these products complement our "high touch" programs and have the potential to enhance the social connections that counteract the isolating effects of dementia and ease the burden of caregiving.

Allison Becker, from Aging2.0 NY, the keynote speaker for the event, concluded the opening night presentations by revealing Aging2.0's "grand challenges" for innovators in the aging space. These innovation priorities include: care coordination, daily living, engagement and purpose, family caregiving, medication management, and cognitive impairment.

Aging2.0's priorities were well represented at the fair. Products included mechanical pets to provide comfort, devices for the hearing impaired, and iPad apps designed to facilitate communication between family caregivers. Fair attendees commented on how much these products

are sorely needed, and appreciated having an event dedicated solely to this theme. CaringKind would like to thank the following for participating in the fair:

- The Alzheimer's Store
- Alz You Need
- Antidote
- Balance: for Alzheimer's Caregiving
- Center for Hearing and Communication
- GreyMatters
- Hasbro's Joy for All Companion Pets
- LabFinder
- MedicAlert NYC Wanderer's Safety Program
- Memory Lane
- Music and Memory
- Philips Lighting
- Pratt Institute
- SafeWander
- Technology for Caregiving

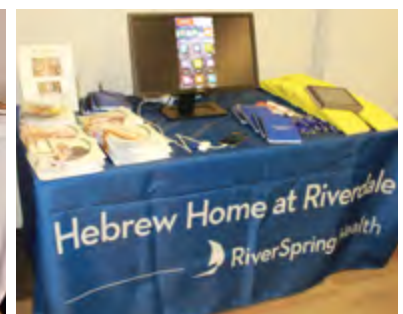
Join us at our annual CaringKind Walk in Manhattan on October 15 as we, for the first time, include a Technology Exposition area!



Lou-Ellen Barkan, Allison Becker, Jed A. Levine, and Ed Cisek on opening night.



Center for Hearing and Communication



Hebrew Home at Riverdale

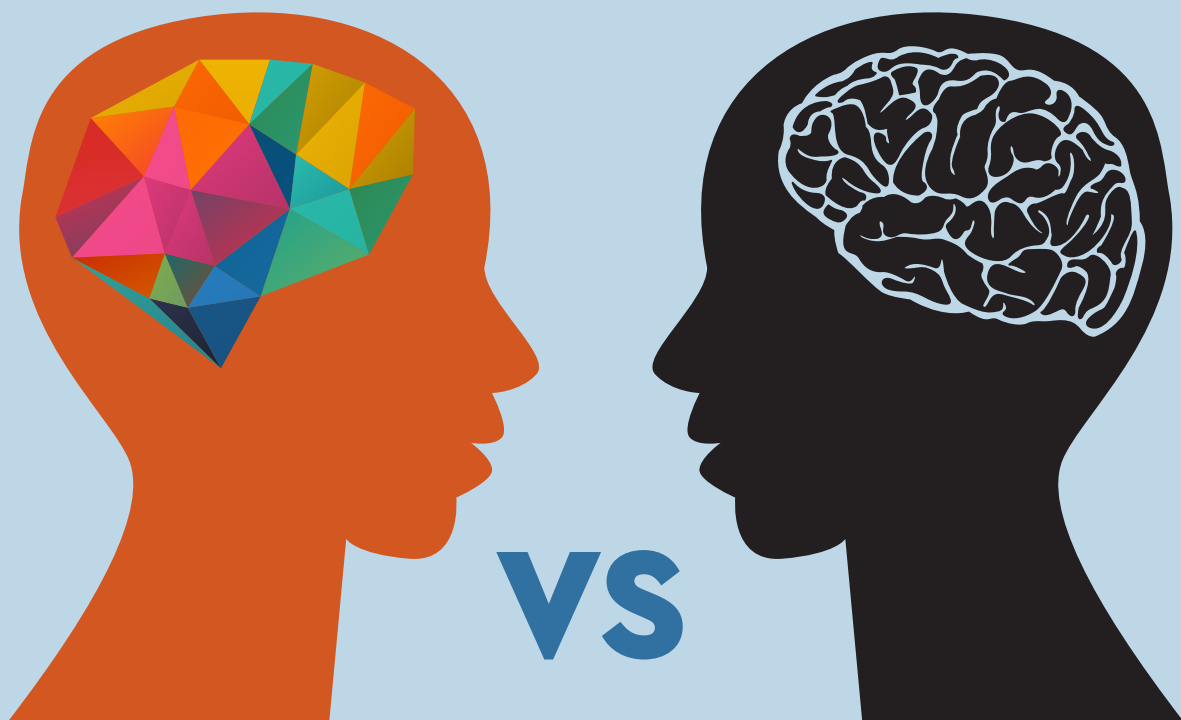


Products available from The Alzheimer's Store



Save the Date

CaringKind's Annual Meeting



Competing Paradigms in Alzheimer's Research: Are We Closer to a Cure?

Monday, October 23, 2017

Check In – 5:30 pm

Program – 6:00 pm

The Times Center

242 W 41st Street

New York, NY

RSVP: caringkindnyc.org/annualmeeting

New Balance App Designed for Alzheimer's Caregivers

by **David V. Pomeranz**
Chief Operating Officer of
RiverSpring Health

We are living in a time when mobile phones and tablets are information hubs for everyday life. Need help? There's an app for that. When it comes to caring for someone with Alzheimer's, the latest in technology is a welcome friend to manage a stressful and often chaotic time. And when there are multiple caregivers in a family, often living many miles apart, it is even more important to communicate any time, anywhere in real time.

A newly redesigned app by the National Alzheimer Center (NAC) and CaringKind is an ideal tool to help caregivers manage the complexity of caring for a loved one with the disease. Whether tracking changes in behavior or managing multiple doctors' appointments, the Balance app easily organizes information and serves as a resource.

Balance app icons include:

24-hour Helpline: Caring and compassionate staff from Caringkind are just one click away 24/7 to answer any questions, provide support and reassurance.

Learning: Learn everything you need to know about living with Alzheimer's – from getting diagnosed, to learning about the stages of the disease, to understanding how to effectively care for someone with Alzheimer's.

Caregiving: Caregivers have the toughest job on the planet! This section provides helpful tips and information about daily caregiving – from bathing and hygiene to dressing and handling agitation.

Pill Box: Manage daily medications by inputting medication names, dosing schedule, and refill dates and getting

notifications on when to provide medicine to your loved one.

Schedule: Effectively manage your loved one's schedule – share calendars with other caregivers' calendars.

Doctor Diary: Track changes in mood, activity, memory and other behaviors and share directly with your doctor in real time. No more waiting for your next doctor's visit to share essential updates.

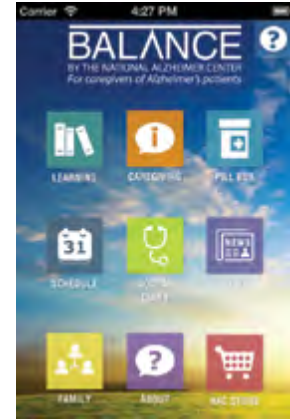
News: Practically everyday there is a new development about Alzheimer's. Always stay on top of these breakthroughs, latest news and information about Alzheimer's to keep up with research, treatments and other developments.

Family: Connect with other family members for sharing calendars and working together to provide complete care for your loved one.

About: Learn about NAC and Caringkind. NAC Store: Find the latest books, medical devices, vitamins and other essential Alzheimer's products and services to purchase.

MedicAlert® NYC Wanderer's Safety Program: MedicAlert® Foundation provides protection through a national emergency response service for individuals living with Alzheimer's disease and related dementia who wander or have a medical emergency. With 60% of persons with dementia at risk for wandering and becoming lost, the MedicAlert® NYC Wanderer's Safety Program activates a community support network when a person with dementia is reported lost or is found in the community. The network, including law enforcement agencies, work to help reunite the person who wandered with the caregiver or a family member. Enrolling in the program has never been easier.

Together We Care™: TogetherWeCare.com was created to bridge the gap between aides who have completed the



CaringKind Dementia Care Training for Professional Caregivers and families seeking to hire trained aides to provide care. Aides who have completed CaringKind's training are afforded the opportunity to create a profile and families are able to view, search profiles and post a job ad.

The Balance app is available for 99 cents on the App Store.

Caring for a loved one with Alzheimer's is all about balance. We created this app because an Alzheimer's patient typically has multiple medications, multiple caregivers, and multiple doctors all juggling many responsibilities at once. This app will help you manage better.

The National Alzheimer Center, a division of the Hebrew Home at Riverdale, was formed in 1986 to better understand, treat and advance care options for Alzheimer's and dementia. The Hebrew Home at Riverdale is part of RiverSpring Health, a non-profit senior care organization that cares for over 12,000 older adults throughout the New York metropolitan area through managed health care, assisted living, housing, rehabilitation, community programs, home health care and its internationally recognized nursing home. Follow NAC and the Hebrew Home at Riverdale on Facebook at www.facebook.com/hebrewhome or on Twitter @RiverSpringHlth.

Coping with Hibernators and Armchair Quarterbacks

by **Daniel Kuhn, LCSW**,
Vice-President of Education,
All Trust Home Care,
Author of *Alzheimer's Early Stages:
First Steps for Family, Friends and
Caregivers*.

Caring for someone with Alzheimer's disease or a related dementia requires practical help and moral support from other people on a regular basis. You are fortunate if you have family members and friends who can fill this need. It may also be necessary to hire someone to help with a variety of household and personal care tasks. Such helpers may be instrumental in preserving your well-being over the course of dementia. To describe them as "lifesavers" may not be an exaggeration. On the other hand, there may also be people whose absence or presence may be problematic. They can frustrate you and undermine your confidence in making care decisions. I refer to such individuals as "hibernators" and "armchair quarterbacks."

Hibernators are those relatives or friends who might be expected to be of service but excuse themselves from helping you. Like bears in winter, they cannot handle the bad weather and retreat into the privacy and security of their own lives. Trying to engage them seldom succeeds despite your repeated efforts. Much time and energy can be wasted persuading them to get involved in caring for someone with dementia. It is tempting to become bitter and resentful in response to their neglect. However, your negative reactions can become self-destructive

and all-consuming. It is better to focus instead on finding real sources of help. Reaching out to others and appreciating the efforts of those who are involved rather than being upset about those who are not involved is a step in the right direction.

Armchair quarterbacks are those football fans who sit at home watching a game on television and second-guess the players or coaches after a play has occurred. It is obviously much easier to question such decisions from a distance instead of playing in the actual game.

Armchair quarterbacks may think that they know how to play the game but they lack experience or credibility. So it is with relatives and friends who think that they know all about caring for someone with dementia and offer you unsolicited advice or criticism. They may have read books on the subject, attended seminars, and talked to experts. They may offer you countless ideas about drug treatments, health care providers or services. They second-guess your decisions. Their seemingly good intentions are overshadowed by their unwillingness to help out in practical ways. What they have to say falls on deaf ears because they are not actually "in the game."

Again, there is great potential for personal animosity in these relationships.

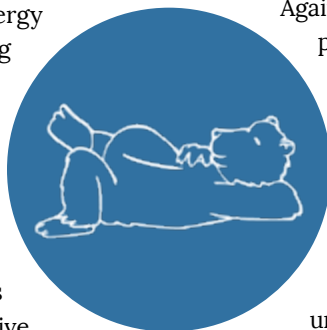
Armchair quarterbacks may care enough to change their ways and become active helpers. Setting limits on their unwanted advice may be a first

step toward gaining their cooperation. They may need encouragement and directions on how to get directly involved in providing hands-on help. Giving them opportunities to spend significant time with someone living with dementia may be enlightening to them. For example, invite them to spend a weekend in your shoes, alone with the person who needs care. If armchair quarterbacks are unwilling to get involved on a practical level, it is best to avoid them as much as possible. However, if you are forgiving and patient with them, they should be encouraged to take part in sharing the responsibilities of day-to-day care.

You need to surround yourself with other people who can enable you to maintain a positive attitude in the midst of a difficult situation. People who truly listen to you and care for your needs as well as

the needs of the person in your care are vital. Encounters with hibernators and armchair quarterbacks can be emotionally draining. Eliminating or minimizing their influence while preserving your relationships with helpful people is essential to your well-being. Caring for someone with dementia over the long haul requires other caring relationships.

To learn more about caring for someone with dementia and caring for yourself, see this free guide: www.nia.nih.gov/alzheimers/publication/caring-person-alzheimers-disease/about-guide.



The Art of Design for Alzheimer's

by Alex Shwader

Associate Professor at Pratt Institute

Having a parent is a universal human experience. Without parents, it is safe to say, none of us would exist. Our relationship with those who are responsible for our existence is unique, sometimes fraught, sometimes joyous, but always profound. With them, our first relationship, we practice being human. If we are fortunate, they are our guides into personhood and help shape us into loving beings.

Many reading this newsletter have experienced a drastic change in this relationship when a parent is diagnosed with Alzheimer's disease or another form of dementia. For the same reason, other readers have experienced a change in relation with a spouse that transforms it into one that is parent-like. The question "What can I do to help?" can leave even those whose parents helped them become doctors experience feelings of helplessness. My mother raised me to become an artist, an architect, and a teacher; not a skillset with obvious benefit for those living with a diagnosis. However, she also raised me to think outside the box and it was this attitude that led me to pick up the phone and reach out to Matt Kudish at CaringKind when I was in the beginning stages of forming an answer to this question through a college level course I was teaching.

I teach in the Industrial Design department at Pratt Institute in Brooklyn. This school advances innovation though the permission they give their faculty to tailor courses to their passions

and strengths while encouraging collaboration with premiere institutions such as The Cooper Hewitt as we did after the first semester. During the time that I cared for my own mother, I couldn't find products for daily life that were directed toward her changing mind. In my first conversation with Matt we talked about this gap in the daily lives of those diagnosed and those caring for them and agreed that by working together we could merge advanced design thinking of Pratt and The Cooper Hewitt with CaringKind's first hand research through experience to fill it. Two years later, we have developed more than 25 products that won an Editor's Design Award when they were exhibited at the International Contemporary Furniture Fair in May of 2017.

Each semester students would begin researching Alzheimer's disease through secondary and tertiary sources such as journals and internet research. With this they began a month-long process of developing twenty ideas for products. In the second week, we went to CaringKind where students began experiencing the way that primary research can break design assumptions and expand thinking by speaking directly with the people for whom they are designing. Every semester this experience resulted in a remarkable jump in imagination and quality of products.

Returning three weeks later, sketches showing hundreds of ideas for products were vetted by Matt Kudish and his staff. One or two per student were then chosen to move forward into prototyping. Students then returned to Pratt to focus on how to make these products real by selecting materials and manufacturing processes. After a month and several

iterations of the idea we returned to CaringKind again to present our work to family and professional caregivers. Their feedback was eye-opening for students, giving input based on years of real life experience. With this wealth of new information students worked for the next month to refine products to a working prototype to present to a panel consisting of members from CaringKind and The Cooper Hewitt for a final discussion of the work.

By the end of the course students developed products for people whose familiar environments had become strange. Each work is meant to retail for less than \$100 using primarily analog technologies. In doing so, these remarkable young people have managed to multiply moments of joy, preserve dignity, and ease caregiving for those managing the disease.

Alex Schweder has been a Visiting Associate Professor at Pratt Institute since 2012 where he has taught in several departments including Industrial Design. Here, under the guidance of Chair Constantin Boym, Schweder collaborated with CaringKind and The Cooper Hewitt Museum to teach a course called "Design for the Mind". In this studio, students developed working prototypes of products they invented for people with Alzheimer's Disease and their caregivers. Schweder is an alumnus of Pratt and went on to pursue his Masters and Doctoral work at Princeton and the University of Cambridge respectively.

48 Hours in May



CANDACE DOUGLAS
Director of Constituent Events
cdouglas@caringskindnyc.org

Over the first weekend in May, more than 100 athletes donned the CaringKind colors to raise an impressive \$200,000 in support of New Yorkers affected by Alzheimer's and dementia.

May is always a big month for CaringKind's Athletes to End Alzheimer's™ (ATEA) team with our annual TackleALZ NYC game and the TD Five Boro Bike Tour. This year, fate aligned to have both events fall on the first weekend of the month, with ATEA fans being able to take in a nail-bitingly close flag football game, followed less than 12 hours later by our fantastic athletes dominating the car free streets of all five boroughs of New York City on their bikes.

First up on Saturday, the pumped-up players of the BruCrew were vying for a repeat victory over the determined Blondetourage. In the months leading up to the game, both teams had held multiple practices, ran countless routes and rallied together for several fundraisers, all



Players Rachel Dender, Leizl Montecillo & Virginia Lei are inducted into the 2017 TackleALZ NYC Hall of Fame for raising over \$10,000 in their careers by Honorary Coaches and former NFL players, Jude Waddy, Bobby Sewall & Noah Burroughs and CaringKind staff Jed Levine and Candace Douglas.

leading up to Gameday. For all that work, the audience was rightfully treated to the best game in the seven-year history of the event. Every single play counted, with the lights coming up on the field in the third quarter to match the mounting intensity.

After a hotly contested but fair game, the Blondetourage pulled off their second win in the series over the BruCrew with a final score of 38-30. And while that milestone was celebrated, all the players, past and present of TackleALZ NYC should hold their heads high because this seventh game in the series marked a cumulative fundraising total of over \$1,000,000 for this event!

The excitement of Saturday night's TackleALZ NYC game must have chased the rain away, because Sunday morning dawned sunny and perfect for the dozen cyclists riding in the TD Five Boro Bike Tour for CaringKind. Team members represented five states, one to echo each borough they would touch throughout the day. As the team gathered Sunday morning in Manhattan, everyone paused

to reflect on why they joined CaringKind's team. Many had experienced the loss of a loved one to Alzheimer's or dementia. Some were thinking about the people they are actively caring for at home. Before the starting horn was blown, every team member secured their helmets, knowing that the 40 miles they committed to riding would put us one step closer to a community committed to helping anyone affected by an Alzheimer's or dementia diagnosis.

At the close of an exhausting, but exhilarating weekend, a round of thanks were due to the community of Athletes to End Alzheimer's who got May off to an excellent start, raising awareness and funds while testing themselves physically on fields and roads across our great city. Your efforts are always seen, heard and felt by all those on this Alzheimer's journey.

Interested in joining CaringKind's Athletes to End Alzheimer's™ team for the TCS NYC Marathon or another event? Visit www.caringskindnyc.org/athletes or contact athletes@caringskindnyc.org.



The 2017 TackleALZ NYC Players and Coaches



TD Five Boro Bike Tour Team

Fundraising Recap

By Lauren Longobardi
Junior Committee President

The Junior Committee has been working hard – and playing hard – at a variety of new fundraising events throughout the first half of 2017. In February, we hosted our first paint night at the Paint Place on the Upper West Side. The sold-out room was comprised of Junior Committee members, and old and new friends! Each brought along their favorite bottle of wine and came ready to paint. The picture chosen was the New York City skyline at dusk. While following direction from the instructor, we sipped wine,

listening to music, and created some real masterpieces. Over 50% of the proceeds of each ticket was donated to the Junior Committee!

In May, we hosted our first restaurant night at Sauce on the Lower East Side. Over 70 committee members and friends joined together on a warm summer night and dined on family style Italian food. Reservation times were scattered throughout the evening, so regardless what time people ended up getting there,

you always saw a friendly face. Over 15% of the proceeds of the evening were donated to the Junior Committee!

Collectively, paint night and restaurant night raised over \$1,100! We look forward hosting more successful events like these in the second half of the year, like our Gala on October 27th.



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:

August 8	5:30 - 7:30 p.m.	Manhattan
August 11	12:00 - 2:00 p.m.	Manhattan
August 16	1:00 - 3:00 p.m.	Brooklyn
August 16	5:30 - 7:30 p.m.	Manhattan

September 8	12:00 - 2:00 p.m.	Manhattan
September 12	5:30 - 7:30 p.m.	Manhattan
September 14	6:00 - 8:00 p.m.	Brooklyn
September 19	6:00 - 8:00 p.m.	Brooklyn
September 20	5:30 - 7:30 p.m.	Manhattan

October 10	5:30 - 7:30 p.m.	Manhattan
October 13	12:00 - 2:00 p.m.	Manhattan
October 17	1:00 - 3:00 p.m.	Brooklyn
October 18	5:30 - 7:30 p.m.	Manhattan
October 22	2:00 - 4:00 p.m.	Queens

Upcoming Date in Spanish:

September 15	12:00 - 2:00 p.m.	Manhattan/Harlem
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Upcoming Dates in Chinese:

August 19	10:30 a.m. - 12:30 p.m. (Mandarin)	Queens
October 21	5:30 - 7:30 p.m. (Cantonese)	Manhattan

Seminars for Professionals

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

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

September 13	3:00 - 5:00 p.m.	Manhattan
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Enhancing Communication with Persons with Dementia

October 11	3:00 - 5:00 p.m.	Manhattan
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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:

August 16	3:00 - 4:30 p.m.	Bronx
September 7	5:30 - 7:00 p.m.	Manhattan
October 5	5:30 - 7:00 p.m.	Manhattan

Upcoming Dates in Spanish and new locations coming soon.

Placing Your Relative in a Nursing Home

Sessions educate caregivers about the steps involved in nursing placement, paying for care, easing the transition, and being a successful advocate for the resident.

Upcoming Date in English:

Manhattan	
September 19	5:30 - 7:00 p.m.

Legal & Financial Seminar

An attorney specializing in elder law discusses important topics Alzheimer's and dementia caregivers should understand before meeting with a personal attorney. Topics include power of attorney, guardianship, Medicaid eligibility, long-term care insurance, healthcare proxy, and more.

It is recommended that you attend an Understanding Dementia: What You Need to Know and Where to Go Seminar prior to attending.

Upcoming Dates in English:

Manhattan	
August 7	12:00 - 1:30 p.m.
August 21	5:30 - 7:00 p.m.
August 24	5:30 - 7:00 p.m.

September 11	12:00 - 1:30 p.m.
September 18	5:30 - 7:00 p.m.
September 28	5:30 - 7:00 p.m.

October 2	12:00 - 1:30 p.m.
October 16	5:30 - 7:00 p.m.
October 26	5:30 - 7:00 p.m.

Queens	
August 8	3:00 - 4:30 p.m.

Upcoming Date in Chinese (Mandarin):
Manhattan

September 21	2:00 - 4:00 p.m.
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Monthly Education Meetings

Meeting topics change monthly based on questions received from caregivers.
Upcoming Series Dates (all meetings from 6:00 – 8:00 p.m.):

August 14

Communication and Dementia

- Discover strategies for effective communication.
- Learn how communication changes in all stages.
- Explore verbal and visual cues that can be used to improve connection.

Speaker: Amy Torres, *Director of Training, CaringKind*

September 11

Genetic Counseling for Dementia: Should I be tested?

- Learn about genetic forms of dementia and the genes that cause them.
- Analyze family histories for genetic risk.
- Understand the process of genetic counseling and the benefits, risks, and limitations of genetic testing.

Speaker: Jill S. Goldman, *MS, MPhil, CGC, Genetic Counselor, Taub Institute, Columbia University Medical Center*

October 16

Navigating the Health Care System: How Next Step in Care Can Help

- Understand what to expect as a caregiver at the doctor's office, in the emergency room, hospital, and other health settings.
- Learn ways to advocate for your family member and yourself during care transitions.
- Identify which resources can act as tools to support your caregiver role.

Speaker: Kristina Ramos-Callan, *Program Manager, United Hospital Fund*

**Please call our
24-hour Helpline
at 646-744-2900
to register.**

**Registration is required.
Space is limited.**

All meetings are free of charge
and subject to change.

You may notice that
specific locations of upcoming
meetings are not listed. You will
receive location information during
your registration call.

*We wish to thank the
following community partners
for providing meeting space:*

Atria Senior Living, Kew Gardens
Carter Burden/Leonard Covello
Senior Program
Heights & Hills
Selfhelp Alzheimer's Resource Program
Queens Library
Avis – South Shore JCC
The Brielle at Seaview
Hand in Hand Together Homecare

Family Caregiver Workshops

During this 10-hour workshop series, caregivers learn to view the world from the perspective of the person with dementia. They also learn how to communicate more effectively with the person for whom they are caring and receive new insights on how to manage the challenging behaviors often associated with Alzheimer's disease, as well as the importance of self-care. Attendance is required at all workshops in a series.

Upcoming Series Dates in English:

Mondays	August 7, 14, 21, 28	Afternoons	Manhattan
Mondays	Sept 11, 18, 25, Oct 2	Evenings	Manhattan

Upcoming Series Dates in Spanish:

Tuesdays	Sept 12, 19, 26, Oct 3	Evenings	Bronx
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Upcoming Series Dates in Chinese:

Thursdays	August 3, 10, 17, 24	Evenings	Manhattan
Thursdays	October 26, Nov 2, 9, 16	Afternoons	Location TBD

**For more
information,
please call our
24-hour Helpline
at 646-744-2900
or go online at
caringkindnyc.org**

Programs and Services

24-hour Helpline
646-744-2900

Social Work Services

The Harry and Jeanette
Weinberg Early Stage Center

Support Groups

MedicAlert® NYC Wanderer's
Safety Program

Palliative and Residential
Care Program

connect2culture®

Together We Care™

Education and Training

Understanding Dementia for
Caregivers & Professionals

Dementia Care Training for
Professional Caregivers

Monthly Education Meeting

Legal & Financial Seminar

Medicaid Home Care
Seminar

Placing Your Relative in a
Nursing Home

Family Caregiver Workshop

More information at
www.caringkindnyc.org

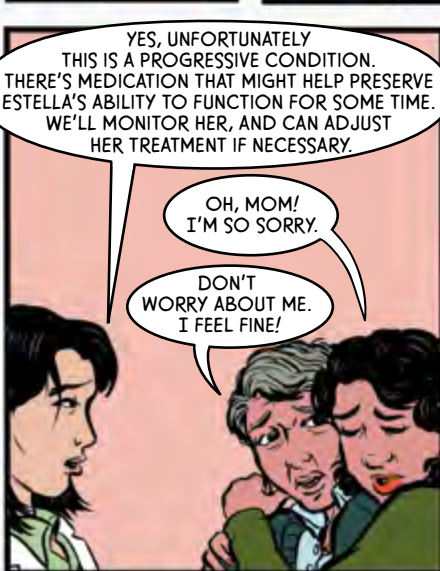
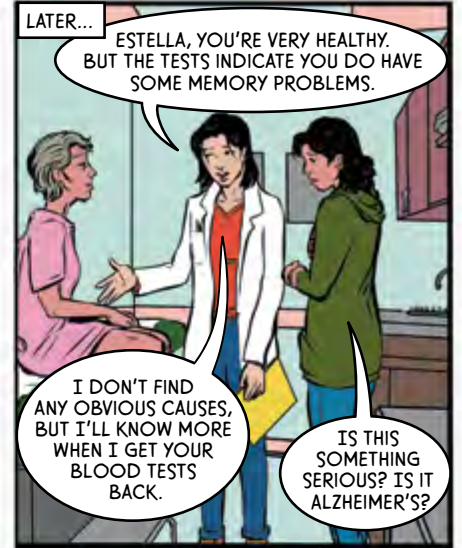
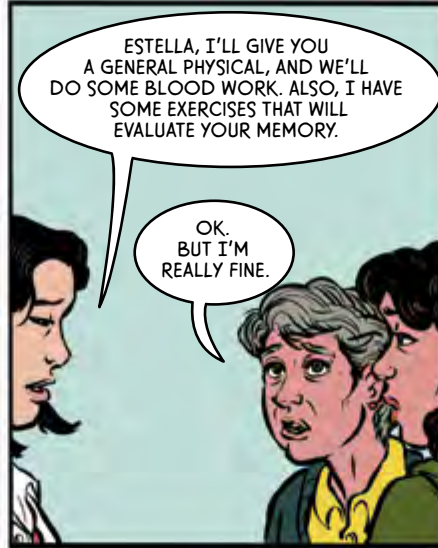
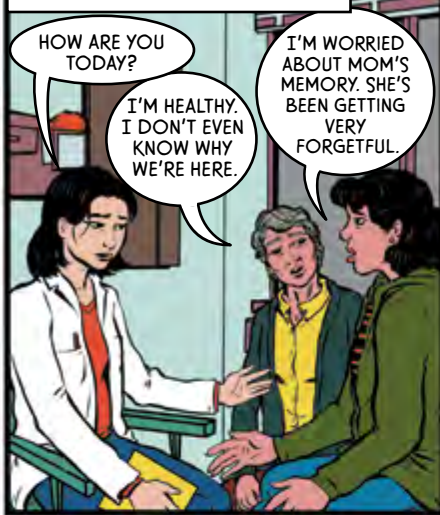
caringkindchronicles

Writer: Jennifer Camper Artist: Ivan Velez

Episode 3 Previous episodes: caringkindnyc.org/comic



TINA TAKES ESTELLA TO THE DOCTOR.



The Rapid Referral Program provides a free and easy way for medical professionals to directly link patients with memory loss to a CaringKind Helpline Specialist. For information, contact Healthcare Outreach: (646) 744-2969 or NMariano@caringkindnyc.org.



The Heart of Alzheimer's Caregiving

360 Lexington Avenue, 4th Floor
New York, NY 10017

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caringkindnyc.org

646-744-2900 — 24-hour Helpline

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caringkind *Walk* Alzheimer's

Walk Because You Care

NEW!
Tech Expo
Caring for Today
with the
Technology
of Tomorrow

**Walk For
Your Husband**
who loved
Riverside Park.



**Walk For
Your Mom**
who introduced
you to
Broadway.



SIGN UP TODAY!

caringkindnyc.org/walk

24-hour Helpline 646-744-2900 walk@caringkindnyc.org

MANHATTAN
October 15 9
am
Riverside
Park

QUEENS
September 17
9 am
Flushing Meadows
Corona Park



BROOKLYN
September 24
9 am
Coney Island
Boardwalk

**STATEN
ISLAND**
October 1
9 am
South Beach