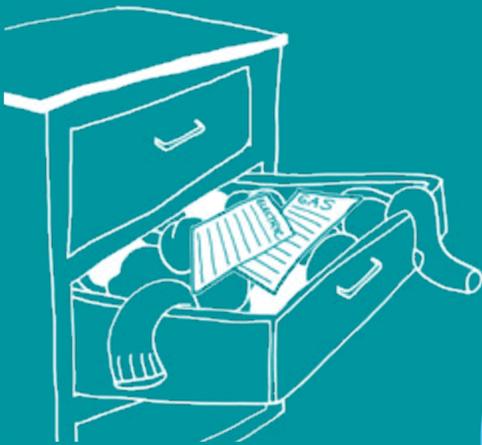


# caringkind

## The Heart of Alzheimer's Caregiving

FORMERLY KNOWN AS THE ALZHEIMER'S ASSOCIATION, NYC CHAPTER

Utility bills are piling up in the sock drawer.

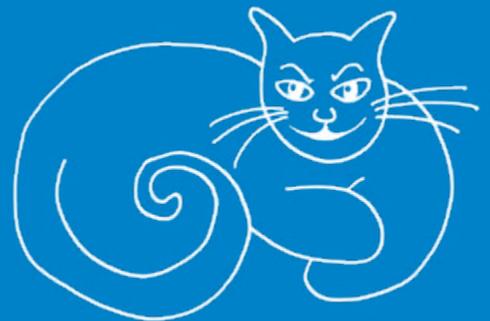


You found shoes in the freezer?

It's Never Too Early  
(Or Too Late)  
To Talk About  
Alzheimer's Support



Dad went to buy milk for the fifth time today.



The cat was fed ten times today!

### SUMMER 2016

- **SAVE THE DATE! Annual Meeting - 10/18/16**  
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Dear Friends,

You're on your way home from work when your wife calls and asks you to stop at the corner grocery store to pick up some milk. You oblige. The store owner, who's known you for years, looks puzzled. He confides that your wife has been in the store three times today—for milk.

Your father has Alzheimer's. He no longer recognizes you. He's increasingly paranoid. When he speaks, he makes no sense. He can't get around. You feel lost and alone.

No matter where you are on your caregiving journey, it is *never* too early – or too late – to talk to the professionals at CaringKind. Whether you have a suspicion that something might be wrong with a family member or friend or whether you've been struggling on your own for years caring for someone who has dementia, don't be afraid to ask for help. You don't have to travel this road alone.

A compassionate, trained CaringKind Helpline Specialist is always available to talk to you at 646-744-2900, 365 days a year, 24 hours a day, in more than 200 languages. That first call introduces you to a community of people who have walked in your shoes and understand what you're going through. Our free educational programs, support groups, social work services, and arts programs will envelop you in a world of care that will ease your burden and make each day a little brighter.

As many of you know, I wear two hats in the world of Alzheimer's caregiving. First, I was a caregiver for my parents, both of whom had dementia. And, even though I was in charge of this incredible organization that provides superb support to NYC's Alzheimer's community, when it came to making critical decisions about my mother's care, I was shocked to learn how much I didn't know.

I was blessed, however, to have CaringKind professionals help me navigate some very difficult decisions at the end of my mother's life. Looking back, I now know that I should have sought help much sooner than I did. But the important point is that I asked for help. And when I did, I was able to care for my mom with greater confidence and less stress. Each day was easier for me and for her.

The second hat is one I wear proudly: President and CEO of CaringKind. As we have moved through this time of significant change, your message came through loud and clear. You told us unanimously that you stand by our decision to focus on the best therapy available today: good caregiving.

So, almost a year into this very exciting transition, it's not too late for me to say THANK YOU. Whether you are an individual donor, corporate supporter, foundation or government official, your generosity is the driving force that allows us to create a world where the stigma of an Alzheimer's or dementia diagnosis no longer forces families to retreat within and where no one is afraid to ask for help.

Our disaffiliation from the national Alzheimer's Association has also allowed us to form an alliance with an extraordinary new research organization, Cure Alzheimer's Fund.



**LOU-ELLEN BARKAN**  
President & CEO  
lbarkan@caringkindnyc.org

Since its founding in 2004, Cure Alzheimer's Fund has contributed more than \$38 million to research, with 100% of every dollar raised going directly to fund some of the best scientific minds in the world. Even though our partnership is just launching, it's not too early for me to say thank you to CEO Tim Armour and his team for working with us to create this exciting new care and cure alliance.

I see clearly that great things are ahead for CaringKind. In the eight months since we returned to our roots as an independent, local organization, calls to our 24-hour Helpline, program participation, client interactions with social workers, and, most importantly, awareness of who we are and what we do are all dramatically up.

We know this also means the community's need is growing. So please remember, it's never too early or too late to ask for and get our help, to become a CaringKind supporter, or to become an advocate for good care. We are here for all New Yorkers. We are here for you.

Dear Readers,

**The explicit message of our recent and very successful subway ad campaign funded by a grant from the New York State Department of Health was, "It's never too early or too late to ask for Alzheimer's support." The implicit message is that the timing of when to reach out for help is highly personal, both for the person who is diagnosed and his or her family.**

Some go into action immediately, seeking help, looking for resources and information, and creating a plan. Others are not so quick to act for a variety of emotional and practical reasons. We are here to help find the right approach and resources for each individual and family.

Hearing the words "You have Alzheimer's" has a profound emotional impact on the person diagnosed, as well as family members. Denial is a normal, and healthy, coping response to the diagnosis, allowing time to process the information, work through the initial challenge to a sense of self, and protect against feeling real terror. But if denial persists, it inhibits the process of getting help and support.

The feelings of guilt, fear, and anger may reinforce or get in the way of the need to get help. Fortunately, CaringKind's staff is skilled in helping individuals process and understand the impact of a diagnosis and providing guidance for them to access critical resources. Although it is never too late to ask for help, there are several advantages to accessing CaringKind's programs and services earlier rather than later. Here's how you can get started:

- Call our 24-hour Helpline at 646-744-2900. Often we hear that callers wished they had called sooner. Our expert Helpline Specialists provide a supportive ear, access to local programs, and introductions to the wide range of services offered by CaringKind, including our extensive education and training programs.

- Enroll the person you are caring for in the MedicAlert® NYC Wanderer's Safety Program. Enrollment is available free of charge to those who cannot afford the fee, and provides identification in case the person with cognitive impairment goes missing. As we often say, we need to hope for the best and plan for the worst. If the bracelet is worn, everyone can breathe a little easier. Without it, an episode of wandering is even more terrifying for families and friends and challenging for the police officers who are trying to help.
- Begin long term care planning by speaking with a CaringKind Social Worker, and attend the educational meetings that explain the different care and respite options, as well as how to pay for them. This is best done when the individual still has capacity to participate in the discussions and make his or her wishes known. Although there are strategies to help with financing care at the time that it is needed, attending a Legal & Financial Seminar and meeting with an elder law attorney gives you both options and time to understand the complicated system of payment and access to long term care, as well as the opportunity to create a plan that is best for you and your family.
- Participating in the Harry and Jeanette Weinberg Early Stage Center provides persons with early stage Alzheimer's and other dementias the opportunity to socialize with others going through the same experience



**JED A. LEVINE**

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and to engage in stimulating and enriching (not to mention, fun!) programs. Because the program is limited to those with a diagnosis of mild cognitive impairment or early stage Alzheimer's, the earlier you apply, the better.

- Consider joining a support group even if you think it's too early – or too late. Many caregivers say they wish they had joined earlier. The sense of relief, of being understood, and of community is powerful and healing.
- Connect2culture® offers a wide range of art, music, dance and other cultural programs for persons with the disease and their family or paid caregivers. What a gift it is to experience the rich cultural variety of New York City in an environment that supports patrons with cognitive impairments, where no one has to be embarrassed or uncomfortable.

Remember all CaringKind programs are free of charge. You don't have to face Alzheimer's alone. It is never too early or too late. Call us at 646-744-2900 at any time to learn more about these programs or visit [caringkindnyc.org](http://caringkindnyc.org). You'll be glad you did.

## Interview with Dr. Richard Isaacson



**RICHARD S. ISAACSON, M.D.**

*Richard S. Isaacson, M.D., serves as Director of the Alzheimer's Prevention Clinic, Weill Cornell Memory Disorders Program, and Director of the Neurology Residency Training Program at Weill Cornell Medicine/ NewYork-Presbyterian Hospital.*

*Dr. Isaacson specializes in Alzheimer's disease (AD) risk reduction and treatment, mild cognitive impairment due to AD and pre-clinical AD. His research focuses on nutrition and the implementation of dietary and lifestyle interventions for AD management.*

**Jed Levine (JL):** Richard, thank you for taking the time to talk with us. Let's start by talking about how you became interested in Alzheimer's, dementia and cognitive health.

**Dr. Richard Isaacson (RI):** When I was in high school, my Uncle Bob was diagnosed with Alzheimer's. Back then it was called senility or senile dementia. We didn't know what it was, but he definitely changed. Initially, it was little things we blamed on age. Then, as he got worse, it wasn't just his memory, it was behavior and personality. That was the first time I saw Alzheimer's disease.

Throughout medical school, I was interested in the brain and planning to do neurology, which was the

most challenging subject for me. Also, my brother is a neurologist who specializes in Parkinson's, so maybe there's something in my DNA.

I've had four family members with Alzheimer's disease, so I've seen it from very early to late stage, when people go into institutional care. I got most involved with a cousin when she was diagnosed with memory issues. After I talked to her primary care doctor, I was certain I made the right choice to specialize in Alzheimer's disease.

**JL:** You definitely have a deep personal interest in this. Can you tell us about your work at Weill Cornell Medicine/ NewYork-Presbyterian Hospital?

**RI:** In 2005, I finished my training and in 2009, I saw an Alzheimer's patient whose son was a doctor. After the diagnosis, he asked, "So, Isaacson, I know you have several family members with this disease. What do you do to try to prevent it?" In 2009, I also saw my first patient referred for Alzheimer's risk reduction. Over the next several years, about 20 percent of my practice was focused on family members of patients with Alzheimer's to determine if they could do anything to reduce their risk.

In 2013, I was recruited by Weill Cornell Medicine to continue that work on a full-time basis. Now, 20 percent of my work is treatment that includes mild cognitive impairment due to Alzheimer's as well as Alzheimer's disease dementia. In 2013, we also opened up the Alzheimer's Prevention Clinic, which takes a deep dive into a person's risk. We try to identify their modifiable risks versus their non-modifiable risks, and then put together a personalized plan, based on genetics and multiple other factors. The term for this process

is "clinical precision medicine." The term "precision medicine" was coined at Cornell.

Clinical precision medicine is the best term because there is no one-size-fits-all approach when it comes to Alzheimer's treatment, Alzheimer's risk reduction, or the path towards Alzheimer's prevention.

**JL:** Were you concerned about the name being misleading or leading people to believe that there is actually more than you can deliver?

**RI:** I've been extraordinarily careful about using the word prevention. If you look on our flyers, we say, "A new approach to brain health," or we say, "A personalized approach to cognitive health." In our verbiage, we don't use the terms "Alzheimer's" and "prevention" in the same sentence frequently.

But, with our stake in the ground, we finally decided to be courageous and controversial and put the words "Alzheimer's" and "prevention" in the same sentence and we added the word "clinic."

The key here is that, in 2016, we can use these terms together similar to the way we do with other diseases. For example, when I say you can prevent a heart attack or you can prevent a stroke, I have to ask, can you really prevent a heart attack or stroke? Maybe, but you can't prevent all heart attacks and strokes.

Based on our hypothesis, supported by the data and our observations, a subset of patients who are at risk of Alzheimer's disease can prevent Alzheimer's, or at least delay it long enough for the development of a blockbuster drug. In other words, through lifestyle and other medical

changes, they can effectively prevent Alzheimer's disease.

The term "Alzheimer's prevention" is still controversial, but with Alzheimer's prevention trials going on now, people see me when they are over 65 to see if they qualify for an Alzheimer's prevention trial.

The A4 study has just changed the way the whole field will look at Alzheimer's disease and, hopefully, make the largest impact on Alzheimer's disease. That being said, we have five years or more until we see any data, and we don't have a blockbuster drug on the horizon yet.

In a clinical setting, we put people on an evidence-based, relatively low-risk, personalized, and clinically precise intervention plan to reduce risk. This is not something where someone says, "Okay, exercise and eat better." This is, "Well let's see, the evidence on nutrition is X, but your nutritional biomarkers are Y, Z, A, D, E, and K, so let's tell you to eat the following..." It's a customized plan that is so customized that, right now, we're one of only three Alzheimer's prevention type clinics in the United States.

**JL:** Where are the other two?

**RI:** The Alzheimer's Prevention Program at Cedars Sinai in Los Angeles and at the University of Alabama at Birmingham. Their title of the clinic is The UAB Alzheimer's Disease Risk Assessment and Intervention Clinic, which is, I would say, a more accurate term and a more careful term. Actually, it may be the best title. Dr. David Geldmacher was too cautious to put the words Alzheimer's and prevention together. I have always felt okay about it because if I have an Alzheimer's prevention clinical trial, that legitimizes it in some way.

When it comes down to it, we are applying the best evidence in terms of the randomized control trials. We are also applying our best epidemiological evidence to reduce someone's risk for Alzheimer's. Similar to heart disease or stroke, we are trying to reduce risk or delay onset. The problem is if someone thinks Alzheimer's is inevitable, the default is to do nothing proactively to protect themselves or reduce their risk. The number one reason patients in my clinic are not proactive is fear of the worst disease on Earth.

**JL:** There are things that are particularly terrifying about Alzheimer's.

**RI:** When people get the notion that there's nothing they can do and they keep eating a certain way, don't see their primary care doctor, don't take their blood pressure medicines or fight their diabetes, they haven't addressed easy modifiable risk factors that can protect brain function. We now have enough evidence to say that.

**JL:** That's an important distinction. Controlling things that you can control to maintain health and, as a byproduct, maintaining brain health is relevant. Even in the face of a difficult disease, the hope is that you're going to improve the quality of life and the outcome for the individual.

**RI:** Our team collectively spends up to seven hours for every patient to give that individualized "What can you do to reduce your risk?" Each patient has to fill out a 45-minute survey and take a 45-minute online course about the genetics, the risk factors, and the stages of Alzheimer's. I see each patient for an hour and a half. We do an hour and a half of cognitive testing, body measurements and cognitive games on the computer. These are followed by a team discussion conference that takes 20 to 30 minutes per patient.

The field is in its infancy, so we literally learn every day. What we're seeing now, and we have recently published some preliminary data on this, is that if people take control of their brain health and listen to the things that we tell them to do, there are certain areas of their cognition that will improve. As an example, processing speed will improve. Executive function will improve and this is not just "practice effect." This is six months later, validated data in multiple domains. We're improving cognitive function. You can read more at [www.ncbi.nlm.nih.gov/pubmed/27116241](http://www.ncbi.nlm.nih.gov/pubmed/27116241).

**JL:** Are you improving memory?

**RI:** We're not improving memory as robustly. Memory has been about the same. Improving memory is the hardest thing. But executive function, processing speed and overall cognitive function are absolutely improving in people that are the most compliant.

Biomarkers are also improving. Cholesterol and omega-3 fatty acid levels in the blood may improve. Homocysteine may come down and B vitamin levels may come up. Low vitamin D has been corrected. If we can hit this disease from a metabolic perspective before the amyloid gets there, then we can delay amyloid from depositing. That's what we are looking for.

Read more of the interview with Dr. Richard Isaacson in the Fall 2016 newsletter.

## 5<sup>th</sup> Annual Gathering for People with Early Stage Memory Disorders



**LONNIE NEMIROSS**  
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The 5<sup>th</sup> Annual Gathering for People with Early Stage Memory Disorders marked my first day on the job as an Early Stage Center Social Worker. It was an exciting and memorable start to my career with CaringKind, and a unique opportunity to begin getting to know staff and, most importantly, the Center's participants.

The Gathering, held on May 20, was attended by 50 people with a diagnosis of early stage dementia and their group leaders. Two early stage support groups traveled from Stamford, CT and Newburgh, NY to join our Early Stage Center participants for the event. As people arrived, smiling and greeting one another, it became evident to me just how special this day was for them. Throughout the event, participants met new people, conversed with and learned from one another, shared their experiences with memory loss, and simply enjoyed themselves.



From left: Manager of Early Stage Center Maria Mursch, Dr. Warachal E. Faison, Suzanne Tribe, Director of Early Stage Center Lauren Volkmer

The Gathering started with a light breakfast and warm welcome from Lou-Ellen Barkan. The morning session, entitled Here's Your Chance!, was led by Dr. Warachal E. Faison, geriatric psychiatrist and Medical Director of Women's and Men's Health at Pfizer. The session provided participants with the unique opportunity to talk candidly with a doctor about dementia for an extensive period of time. Dr. Faison answered numerous questions, covering an array of topics surrounding dementia, such as the latest on research, medications, disease progression, and nutrition. Dr. Faison also highlighted the importance of maintaining an active lifestyle, socially, physically and mentally, when in the early stage of dementia. Dr. Faison utilized an interactive approach in her discussion about changes in the brain, which made the conversation even more stimulating and less abstract.

After the morning session, participants enjoyed a delicious lunch, chatted, laughed, and got to know one another better. The afternoon session, entitled Connecting with Your Musical Self, was the highlight of the day. Board-certified music therapist Suzanne Tribe began by briefly discussing the history and purpose of music therapy, as well as settings where it is used. Suzanne then led a musical guided meditation and relaxation, which reminded everyone why it's important to focus on their breathing



Participants sing and play percussion during the afternoon session of The Gathering, called Connecting with Your Musical Self and led by Suzanne Tribe.

in times of stress. She then handed out small percussion instruments to anyone who wished to play them. As Suzanne led the group in such songs as "What a Wonderful World" and "This Little Light of Mine," participants played their instruments, sang along, and even danced! Afterwards, people shared the sense of happiness, tranquility, and enjoyment they felt as they participated in this workshop. One client noted the positive effect that music has on her mood. Another client was so inspired that he bought his own drum to play at home.

As Suzanne played her final song of the day, people sang and danced on their way out, bringing the 5<sup>th</sup> Annual Gathering to a close on the highest of notes. All in all, the Gathering was a success and so, too, was my first day as an Early Stage Center Social Worker. I am looking forward to not only attending the Gathering next year, but also being a part of the team to plan it.

## Expanding the State's Alzheimer's Community Assistance Program



**MATT KUDISH**

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The last year has been filled with significant changes at CaringKind. In addition to launching our new name and brand, we've simultaneously experienced unprecedented growth of our staff and our programs. With the support of the New York State Department of Health, CaringKind has been able to expand our much-needed programs and services throughout the city. CaringKind has received over \$1.1 million annually for the next two years through an expansion of the State's Alzheimer's Disease Community Assistance Program (AlzCAP). This project has enabled CaringKind to enhance several existing programs, as well as develop new programs to better support the unique needs of NYC's Alzheimer's communities.

CaringKind's 24-hour Helpline is how the vast majority of our clients first make contact with us. As news of the good work we do continues to spread, and call volume grows, it is increasingly important that we are able to continue to meet the needs of our callers. With this in mind, we have added two additional Helpline Specialists – both of whom are bilingual in English and Spanish. These new staff members enable us to not only respond to each call when it comes in, but to do so with unprecedented linguistic and culturally appropriate expertise. You can reach our Helpline 24/7/365 in 200 languages

by calling 646-744-2900 or emailing us at [helpline@caringkindnyc.org](mailto:helpline@caringkindnyc.org).

As more people connect with us, each with their own complicated dementia journey, we have seen an increase in referrals to our Social Work Services department. From individual and family counseling to the development and implementation of complex care plans and assistance navigating the ever-changing landscape that is long term care, our Social Workers are working with more clients than ever. As such, we took the opportunity to grow our Social Work team so we can both better meet the demands of our clients and conduct more meaningful outreach and education across diverse communities. We added two social workers in our Social Work Services department who are based at our midtown Manhattan headquarters, as well as two new Outreach Social Worker positions: a social worker dedicated to residents of Staten Island, and another to the Korean communities of NYC. To learn more about how our Social Work Services can assist you, call our 24-hour Helpline and ask to speak with a Social Worker, or visit us online at [caringkindnyc.org/socialwork](http://caringkindnyc.org/socialwork).

We have also expanded our Training department. Through the AlzCAP grant, we have hired a Chinese language trainer who will facilitate trainings throughout the NYC area in both English and Mandarin, including our nationally recognized Dementia Care Training for Professional Caregivers (DCTPC) and our 10-hour Family Caregiver Workshop. The DCTPC is a seven-day program designed exclusively to enhance the ability of paid caregivers of persons with dementia and is changing the way care is provided, and received,

for hundreds of persons affected by dementia each year. Training like this does not exist anywhere else in NYC.

Connect2culture® is CaringKind's cultural arts initiative for persons with dementia and their caregivers, and with this state funding, we have hired a full-time Manager of connect2culture, who will focus on working with cultural institutions throughout the city that have existing access programs, as well as providing expert guidance for new entities as they develop and launch successful programs. In addition to working with long-standing partners such as the Jewish Museum, the Brooklyn Museum and the Intrepid Air and Space Museum, we are thrilled to be partnering with new organizations including Lincoln Center for the Performing Arts, the Brooklyn Public Library, and the Brooklyn Botanic Garden. For more information about connect2culture, and to learn where programs are offered in your area, visit [caringkindnyc.org/connect2culture](http://caringkindnyc.org/connect2culture).

These funds have also allowed us to expand our Education department by hiring a manager to build on the many meetings we offer regularly. In the coming months we will bring several meetings to locations throughout the city and develop new programs for family caregivers and professionals alike, including more continuing education programs for social workers.

All of this growth and expansion is to ensure we are fully prepared to meet the needs of all New Yorkers affected by dementia. And with all of our programs and services available free of charge, it truly is never too early, or too late, to talk about Alzheimer's and dementia support.

# It's Never Too Early, But It Can Be Too Late



### ELIZABETH BRAVO SANTIAGO

Director of Wanderer's Safety Program

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It's never too early to enroll in the MedicAlert® NYC Wanderer's Safety Program, but it can be too late. During the winter I received a call from a Mrs. J inquiring about MedicAlert NYC for her husband. She wanted to know about the program and how it works.

MedicAlert NYC is an annual subscription service that provides caregivers and individuals with dementia the ability to create and manage their personal health record while maintaining security, privacy, and confidentiality. Every member is given a personalized stainless steel medical identification bracelet that provides first responders with critical information regarding medical conditions or any life-threatening allergies, as well as access to MedicAlert's 24/7 emergency hotline number.

Alzheimer's disease destroys brain cells which are responsible for memory, thinking, and behavior. Due to these changes, a person living with Alzheimer's or a related dementia can become disoriented in familiar surroundings and get lost at any time. We know that six out of ten people will wander and become lost.

Since a wandering incident can occur at any stage of the disease, as a precaution I told Mrs. J it's never too early to enroll Mr. J into the MedicAlert NYC and become prepared in the event that he wandered. I offered to enroll her husband over the phone.

However, Mrs. J declined and said that she would wait because he was not currently wandering and always came back from his regular walks. Several weeks went by and I received a call from a very upset Mrs. J. While at the doctor's office, she left her husband in the waiting room and asked him to stay there until she completed her routine checkup. When Mrs. J returned to the waiting room, Mr. J was not there. She looked in the men's room and adjacent waiting rooms, but he was nowhere to be found. While we were on the phone, Mrs. J told me she regretted putting off her husband's enrollment into the program, and that because he often misplaced his wallet, he currently did not have any identification on him. I reassured her that we would assist the police department in the search of her husband, and do everything we could to help find him. I am sure that some of you can relate to putting things off until tomorrow. But sometimes tomorrow can be too late.

A person diagnosed with Alzheimer's disease or a related dementia should always have some form of identification on them. Staying safe becomes increasingly important as the disease progresses and the person's abilities begin to change. The MedicAlert bracelet contains vital identification information, and is also difficult for a person to take off on their own. Here are some steps you can take to help you protect the person you care for:

- Please visit [caringkindnyc.org/wandersafety](http://caringkindnyc.org/wandersafety) or call our 24-hour Helpline at 646-744-2900 to enroll.
- Keep a record of the member's identification number and the 1-800-625-3780 24-hour hotline number.

- Take a photograph of the person you are enrolling. Keep this new photo on your phone or computer. During the enrollment process you will need to provide MedicAlert NYC with a current picture of the member. This picture will be provided to police if there is a wandering incident.
- Keep an article of the person's worn, unwashed clothing in a plastic bag to aid in finding him or her with the use of dogs in the event that the person wanders. However, in order for this to be most effective, change the article every 30 days.
- Let neighbors and friends in your community know the person you care for is diagnosed with Alzheimer's disease or a related dementia and has a tendency to wander, and if they see the person wandering to please contact you immediately.

There is a fee to enroll. But thanks to the generosity of City Council members, the Schnurmacher Foundation, the Helen J. Hoffritz Charitable Trust, the Warner Foundation and other donors, we can provide enrollment scholarships, so no New Yorker is turned away because of inability to pay. Please make the call or visit our website to find out more about this lifesaving program.

Mr. J. was found and safely returned home, and Mrs. J. enrolled him in MedicAlert NYC the very next day. She didn't want another wandering incident without the protection that the program provides.

## Support Group Leader Appreciation Breakfast



### ABIGAIL NATHANSON

Director of Support Groups  
anathanson@caringkindnyc.org

In my support group, a new member had been struggling with caregiving on her own for years. She shared at the end of her first meeting that hearing from the long-standing group members gave her a lot of hope to know that she can survive this and that there are people who will help her do so. Every year, the Support Group Program helps to facilitate over 2,300 caregiver support group sessions across the five boroughs, with hopeful moments like these happening every day. I am so grateful to the 80-plus volunteers and partners in our program who help to make it happen.

CaringKind is proud to support the thousands of hours of work that our volunteers and co-affiliated agencies provide, with training, supervision, referrals and ongoing guidance. One of the most fun ways we try to give back is with our annual Support Group Leaders Appreciation Breakfast. This year, we had a beautifully catered breakfast on June 3 at our Program Center, with speeches, gifts and a performance by a jazz trio that had our volunteers tapping their toes! This year's event was generously funded by the Junior Committee. We cannot thank them enough for their support.

If you're interested in learning more about joining a support group or becoming a support group leader, please give us a call on our 24-hour Helpline at 646-744-2900. We'd love to talk to you.



*Support group leaders enjoyed music by a jazz trio.*



*Above: Long-time support group leaders  
June Aaronson and Ginny Abrams.*



*Right: Self-care gifts included a meditation  
CD and mindfulness coloring book with  
colored pencils.*



*Left: Jed A. Levine enjoys a laugh with support group leader Dasha Kiper.*



*Right: Lou-Ellen Barkan shares her own experiences and thanks support group leaders  
for their invaluable work.*

## Driving and Dementia



**ANNE M. FOERG**  
Director of Social Work  
afoerg@caringkindnyc.org

Driving—it is the ultimate symbol of independence in American culture. As such, having to stop driving can be a devastating loss. Not only can it interfere with our ability to do the things we need to do, such as work, shop, worship, and socialize, it represents losing the freedom to choose what we do and when we do it. A person who is used to being in the driver's seat, both literally and figuratively, is now often at the mercy of others to meet his or her needs. Many who have had to stop driving describe a feeling of profound powerlessness.

Yet, the reality is that each person diagnosed with an irreversible form of dementia must stop driving at some point, as the progressive nature of the condition will render the brain unable to carry out the myriad tasks required to safely operate a vehicle. A common misconception is that people with dementia can continue to drive as long as they remember where they are traveling or if they have someone to navigate for them.

However, driving requires much more than memory. One must manage multiple tasks at the same time, including pressing the gas pedal, turning the steering wheel, and scanning the environment for potential hazards. One must possess the cognitive capacity to appropriately judge situations and react to them in a rapid manner, such as responding to a changing traffic

light, determining when to make a left turn, and allowing emergency vehicles to have the right of way. Multitasking, visuospatial awareness, and reaction times are all impaired for persons with dementia, and to complicate matters further, a person with dementia becomes less aware over time that these skills are becoming compromised.

All of these factors make it unsafe for a person with dementia to continue to drive. Therefore, it is best to start planning how and when this transition from driver to passenger should occur as early in the process as possible, in a manner that balances the independence and safety of the person with dementia as well as the safety of others.

Problems with driving can be an early warning sign of cognitive issues, so if an individual begins to experience difficulty with any of the aforementioned driving-related tasks, a medical evaluation should be scheduled immediately, especially if problems exist with memory and thinking in other areas of functioning. However, if the dementia diagnosis has been made, it is best for a trusted individual, such as a friend, family member, or doctor, to begin the conversation about developing a plan to taper driving with the eventual goal of stopping altogether.

Often, individuals with dementia recognize that some things have become more difficult, such as driving on busy highways or at night, and they will be willing to avoid those situations. They should be assisted in identifying other sources of support that alleviate the need to drive as much, such as grocery and medication delivery services, or a friend or family member who is willing to drive them to social events and important appointments. Equally

crucial is identifying other sources of transportation, such as buses, taxis, or senior center vans, that the person can utilize. This maximizes the ability to still travel without having to exclusively rely on another person.

When a person with dementia does not recognize his or her deficits, the conversation can be much more challenging. At this juncture, the intervention of a professional may be useful, as a person may be more accepting of what a doctor or social worker suggests than that of his or her spouse or adult child. Some doctors may “prescribe” the person stop driving or suggest the individual undergo a driving evaluation, a comprehensive assessment of the individual's visual, perceptual, cognitive and physical abilities, as well as a road test, if appropriate. Taking away a person's keys, disabling or selling

a vehicle, or alerting the Department of Motor Vehicles to an individual's diagnosis with the goal of having his or her license revoked are options that should only be utilized as a last resort, because it can preclude the person's involvement, exacerbating the

already present feelings of losing autonomy and control.

As with every other element of dealing with dementia, it is not easy to strike the perfect balance between supporting a person's independence and safety when it comes to driving. Each situation is unique and requires a thoughtful weighing of all the options and implications. As always, CaringKind is here to help. Please call our 24-hour Helpline at 646-744-2900 to speak with one of our professional staff about the issues you are facing related to dementia and driving.



I went to park my car in front of my apartment, which I'd done hundreds of times, but this time I drove over the curb, sidewalk, knocked down a small tree, and ran into a neighboring building. I shudder to think what might have happened if a child had been walking there! At the time, I did not know I had early-onset Alzheimer's. Only some years later, an MRI showed that I had several mini-strokes around that time. My advice: if you are diagnosed PLEASE DON'T DRIVE.  
-R., age 68

I first felt something was wrong when I noticed a subtle shaking of my hands while at the steering wheel and I was having problems parking. My doctor dismissed my concerns as normal. Then, one day I was driving at 65 mph and I suddenly didn't know what I was doing or where I was going. I was trembling uncontrollably. I managed to pull over safely, took lots of deep breaths, and eventually was able to focus. I have since stopped driving, and I hope that others with a diagnosis of Alzheimer's are inspired by this story to do the same.  
-F., age 65

I loved to drive and I was a good driver. Then came the diagnosis of MCI and a meeting with someone from CaringKind who suggested that I stop driving. Because I wanted my loved ones to be safe and feared a lawsuit as a result of a potential accident, I stopped driving at that point.  
-T., age 72

One day while looking at the trees, I heard a loud bang and realized that a red truck had been rear-ended — by ME! In my distraction, I had lost focus completely. In over 55 years of driving for work and travel, I had never had an accident. After this incident, I stopped driving — completely!  
-G., age 71

**We thank our participants in the Early Stage Center Program for sharing their moments when they decided to stop driving.**

# Palliative Care Guidelines Release



**ANN WYATT**  
Residential Care Policy &  
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On June 23, CaringKind hosted a breakfast to celebrate the publication of *Palliative Care for People with Dementia: Why Comfort Matters in Long-Term Care*, and the accomplishments of the three nursing homes that have been working to implement a palliative approach to care for people with dementia: Cobble Hill Health Center, Isabella Geriatric Center, and The New Jewish Home, Manhattan Campus. This model of care is based on the *Comfort Matters*® approach developed by the Beatitudes Campus in Phoenix, Arizona. Working with the homes were their hospice partners, Calvary Hospital Hospice, MJHS Hospice & Palliative Care, and Visiting Nurse Service of New York Hospice & Palliative Care.

Presentations were made by staff from each of the homes. Special guests included Donna M. Corrado, Commissioner, NYC Department for the Aging; Lilliam Barrios-Paoli, Chair, Board of Directors, NYC Health + Hospitals; Erin Fay and Elizabeth Berberian, NYS Department of Health; and several project funders, including Julio Urbina from the Fan Fox & Leslie R. Samuels Foundation, Alan Divack from the Lucius Littauer Foundation, and Hollis Holmes from the United Hospital Fund, as well as David Gould, formerly with the Fund. Jose Matta, Janice Dabney and others represented the 1199 SEIU Training & Employment Fund and The Greater New York Education Fund, also sources of



support for the project. Additional guests included representatives from MFY Legal Services, the Alliance of New York Family Councils, the Long-Term Care Community Coalition, the Coalition for the Institutionalized Aged and Disabled, PHInational,

the Carter Burden Center, and the Brookdale Center for Healthy Aging.

To read and download a free copy of the publication, visit [caringkindnyc.org/palliativecare](http://caringkindnyc.org/palliativecare).

“ My father just turned sixty and recently retired. He doesn't socialize as he did before, and I often can't get him to go out, even to sit on a park bench. He has missed two of our lunch dates in the past three months. Recently I brought him to a gathering of his old friends. They were discussing the latest crisis in the news and he just sat there without saying anything. Afterward, he told me that he didn't know what they had been talking about. What could be the cause of this? How should I handle these changes? ”



**STEPHANIE ARAGON**  
Director of Helpline  
helpline@caringkindnyc.org

Your loving concern for your father is evident. You point out a number of things that raise red flags. Is his change of behavior caused by giving up his life's work? What might be the reason for his lack of interest in friends and activities? Are we talking about a problem with his physical health, mental health or, perhaps, both? And what role does memory play in all of this?

A thorough medical evaluation might be the best next step in order to better understand what might be causing the

changes you're seeing in your father. Consulting with his primary doctor is a good place to start. If the doctor notices a significant change in your father he might suggest further testing. There are diagnostic centers in each of the five boroughs where Helpline Specialists can refer you. There your father will be seen by a variety of specialists over a few visits. It would be best if you or another family member accompanies him, since he will be asked to give a thorough family history. Physicians may request a CT scan or an MRI. The

diagnostic evaluation covers many aspects of health in order to rule out other illnesses and focus on what might be the cause or causes of your father's memory issues and personality changes. Medicare will pay for those over the age of 65; otherwise, other insurance will be accepted. With a full evaluation you will be better able to deal with your father's changes in the most appropriate way. For more information about these resources, please call our 24-hour Helpline at 646-744-2900.

“ My wife was diagnosed with Alzheimer's disease eight years ago and has declined every year since. At this point she is bedbound and cannot speak. Sometimes she seems to be in distress, and it's hard for me to connect with her. Is there anything I can do to try and bring her comfort? ”

We are so glad you reached out to us for support. There are many families caring for someone in the later stages of the disease. As your wife is unable to speak and bedbound, if she seems distressed you should check for bedsores on her lower back, her elbows, and the heels of her feet. Remember it is important to change her position every few hours and consider using a special mattress pad, such as the foam “egg crate” model. If she is unable to easily leave the house, know that we can refer you to doctors who make house calls.

Learn about palliative care, a type of medical care that focuses on relieving symptoms of a disease instead of trying to treat an illness. Palliative care's main emphasis is in the quality of life of the patient, in this case, your wife. When you feel she may be in distress, try putting on soothing music in her room and sitting with her; she will feel your presence. You know her best, her likes and dislikes. Touch is very powerful. Holding her hand or brushing her hair may be very comforting to her. You may also want to speak with her physician

about a referral to a palliative care specialist who can assist in alleviating any discomfort your wife may have.

You are certainly welcome to call our 24-hour Helpline at 646-744-2900 and schedule a meeting with a social worker to discuss future plans. *Encouraging Comfort Care: A Guide for Families of People with Dementia* is another great resource; you can find it on our website or we'd be happy to send you a copy. It is important that both you and your wife are comfortable at this important time in your lives.

**It's clear that even though our name has changed, the news media continues to rely on CaringKind, with our three decades of experience, as an important source of information about Alzheimer's disease, dementia and caregiving.**



CaringKind was featured in an extraordinary *New York Times* 12-page special supplement on Sunday, May 1. Called "Fraying at the Edges," the in-depth story by reporter N. R. Kleinfield followed CaringKind Harry and Jeanette Weinberg Early Stage Center client Geri Taylor and her husband Jim for 20 months, providing an unprecedented look into the day-to-day life of someone in the early stages of Alzheimer's. The CaringKind staff worked hard to supply the reporter with everything he needed to produce a deeply emotional article that featured interviews with Lou-Ellen Barkan, as well as Lauren Volkmer and Maria Mursch, the Director and Manager of the Early Stage Center, respectively. The article, which was also featured on *The New York Times*' social media platforms, called attention to the critical work we do at CaringKind, and how dementia impacts the entire family. CaringKind is very grateful to the Taylors for telling their story with such bravery, grace, and dignity.

CaringKind's stunning subway ad campaign was unveiled earlier this year and grabbed the attention of several media outlets, including NBC New York and *The Jewish Voice* newspaper. Through a series of five real-life scenarios, the ad campaign, called "That Moment When...", shines a light on situations and behaviors that many caregivers now recognize as the moments when they first realized something might be wrong with a family member or friend. The ads advise

New Yorkers that, "It's never too early (or too late) to talk about Alzheimer's support. Call our 24-hour Helpline. We're here anytime you need to talk."

We continued to spread the word about our free programs and services with a series of articles placed in local papers including the *New York Daily News*, *Queens Chronicle*, *Queens Tribune*, *Bay Ridge Courier*, *Brooklyn Graphic*, *Mill Marine Courier* and *Bay News*. Also, congratulations to Cheshire Schanker, Queens Outreach Social Worker, for starring in an important public service announcement about our services that aired on Queens Public Television.

CaringKind's annual TackleALZ NYC game was a great success! The game was featured on NY1, with Roger Clark interviewing our own Candace Douglas, Director of Constituent Events, as well as players from the BruCrew and Blondetourage teams.

Lou-Ellen continues to make news. She was honored with the Above & Beyond award by *City & State*, an important news source devoted to covering government, politics, and nonprofits in New York State. She was recognized as one of the 25 most remarkable women serving in nonprofit organizations. Leading up to the award ceremony, *City & State* published a Q&A with Lou-Ellen, who gave advice to caregivers saying, "You can't take care of someone else unless you take care of yourself." Jed Levine was front and center in media stories surrounding the

controversial comedic movie about Ronald Reagan and Alzheimer's disease. Jed was interviewed on PIX11 and CBS New York, talking about the right way to discuss the disease in cinema.

Jed was also quoted in a crucial story about caring for someone with Alzheimer's disease by *Healthline*, a healthcare blog whose mission is to improve health through information. Jed said, "The epidemic of Alzheimer's disease is on its way to being the greatest healthcare crisis in the nation's history."

And here is a piece of great news—Lou-Ellen has been invited by a series of local newspapers, including *Manhattan Express*, *Chelsea Now*, *Bronx Times*, *Caribbean Life*, *East Villager*, *The Villager*, *Times Ledger*, *New York Parenting*, *Brooklyn Paper* and *Downtown Express*, to write a monthly column called "Care Chronicle," which explores issues confronted by people living with dementia and those who care for them. The first of this series, which was published in June, introduced readers to Alzheimer's and dementia. Be on the lookout for her next installment!

## The Forgetting: 15 Years Later

By James Campbell

In the 2004 film *The Forgetting*, author David Shenk boldly declares that “We are at the end stage of the war against Alzheimer’s.” While progress has been robust, this is not the case today. What is certain is that until a cure is found, caregivers will continue to play a critical role in caring for persons with the disease. On May 2, CaringKind brought a panel of experts, Mr. Shenk included, to the Times Center in New York City for A Conversation with David Hyde Pierce & David Shenk: *The Forgetting* 15 Years Later, the 4th Annual Charles Evans Lecture on the Art and Science of Caregiving. The panel discussion provided keen insight into caregiving’s history and scale, from ancient times to the present, from personal experiences to national and global policy.

Following welcoming remarks from CaringKind’s Board Co-Chair Benjamin Jenkins, Lou-Ellen Barkan stressed the organization’s role as a place “that sees individuals and not a disease.” Jed A. Levine guided the panel of advocates and experts: David Hyde Pierce, David Shenk, and Rachael Bachleda.

David Hyde Pierce is a Tony and Emmy Award-winning actor. Along

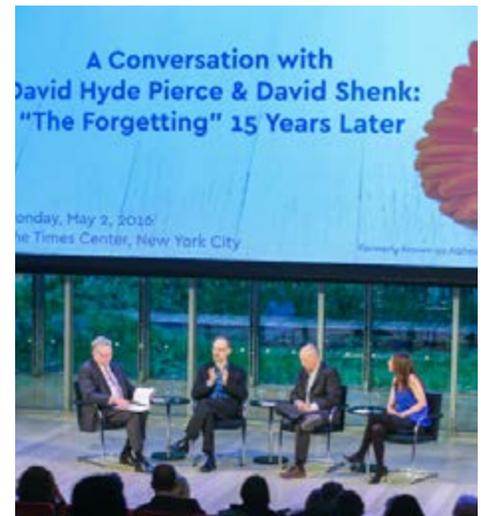
with his eminent acting career, Mr. Pierce is a staunch advocate for Alzheimer’s care and research and received the 2010 Tony Awards’ Isabelle Stevenson Award for his work.

David Shenk is the award-winning and bestselling author of *The Forgetting*. Mr. Shenk is a spokesperson on Alzheimer’s and has advised the President’s Council on Bioethics on dementia-related issues. He is a special advisor to the Cure Alzheimer’s Fund and he is the creator of the Living With Alzheimer’s film project.

Rachael Bachleda came to CaringKind ten years ago when her mother was diagnosed with Alzheimer’s. She is a member of CaringKind’s Junior Committee and is a five-time participant on the Athletes to End Alzheimer’s® New York City Marathon team.

Mr. Shenk began by reflecting on a conversation he overheard that led him to research the long history of Alzheimer’s and “tell the story of the disease as you would the biography of a person.” This story, said Mr. Pierce, “is like the disease itself,” in that “it is intensely personal and at the same time the battle against it is global.”

David Hyde Pierce’s work with the National Alzheimer’s Project helped to identify a major victory of this global battle: people are confident in voicing the idea that they are living with



Jed A. Levine moderates the discussion between actor and Alzheimer’s advocate David Hyde Pierce, author David Shenk, and caregiver Rachael Bachleda.

Alzheimer’s, not dying of it, essentially saying “don’t count me out yet.”

Ms. Bachleda intimately described the personal perspective, sharing the details of her father’s transformation into a caregiver, as well as her own. In particular she highlighted the importance of support groups in helping her cope with the “unique experiences” that caregivers face.

Alice Shure and Bonnie Pfeiffer-Evans, trustees of the Charles Evans Foundation, stated during their opening remarks that though the stigma around Alzheimer’s has faded, the “around the clock, demanding, and mostly thankless” role of the caregiver remains. The question is what kind of person does it take to fill this role? Ms. Barkan summed it up neatly: “It takes the courageous kind, it takes the listening kind, it takes the loving kind, it takes the caring kind.”

James Campbell is a freelance writer based in Brooklyn. He holds an MA in International Affairs from The New School and has written for various academic and human rights organizations, including the Anti-Trafficking Review.



From Left: Rachael Bachleda, Jed A. Levine, Lou-Ellen Barkan, David Shenk, Bonnie Pfeiffer-Evans, David Hyde Pierce, Alice Shure



## CAROL BERNE

Senior Vice President of Development  
cberne@caringkindnyc.org

As I write this report I am reminded that we are six months along as an independent New York City charity focused on care and support for individuals and families affected by Alzheimer's disease or a related dementia. Sometimes I think we have been a stand-alone charity for years and at other times it seems that we are just starting on our journey. What I do know and value is the singular dedication and commitment of our Board, our staff and the donor community who have advised us, advocated for us, and endorsed and supported our independence. The motivation behind all of this has been to ensure that there is a viable resource in New York City, staffed by professionals with extensive expertise in all facets of dementia care, to care for New Yorkers when they have no place else to turn.

Alzheimer's can be very lonely and isolating. And at some point, it is not medical care that is the answer. It is social services that will lead the way to ensuring a better quality of care for the person with the disease and a much better quality of life for the caregiver. But this care comes with a price. For us to keep our programs and services free of charge and to be able to continue to meet the needs of the ever-growing New York City Alzheimer's community,

every year we have to raise an increasing amount of money to meet our operating budget. For fiscal year 2017, which started July 1, that figure is over \$10 million.

We are not a college, university, or medical center that is able to augment philanthropy with tuition and hospital fees, patents and licenses on research advances, and numerous other financial revenue streams. We are 100% dependent on you.

You generously supported our Spring Mother's and Father's Day Campaign, which this year raised over \$128,365 and represented a remarkable 320% increase over the year before. You supported special programs, including our palliative care initiative which is transforming how care is provided to residents of nursing homes who have late-stage dementia. We now move forward to implementing this model of comfort care in other settings. And it is you who have left us in your estate plans to make sure that we can plan ahead, understanding that Alzheimer's is not going away anytime soon.

So in keeping with the theme of this newsletter, it is never too early or too late to donate: to honor someone important in your life, to support a program or service that has meaning to you, to name a room at CaringKind, to support our upcoming CaringKind Alzheimer's Walk, or to make a planned gift to help us in the future. We count on you. As always, please contact me directly at 646-744-2905 or cberne@caringkindnyc.org if you would like more information or would like to discuss a gift. Thank you.

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



CaringKind meets the Better Business Bureau Wise Giving Alliance Standards for Charity Accountability.

### Know Your Charity

The following organizations ARE NOT affiliated with CaringKind:

- Alzheimer's Association
- Alzheimer's Association, New York City Chapter
- Alzheimer's Disease Resource Center (ADRC)
- Alzheimer's Drug Discovery Foundation
- Alzheimer's Foundation of America (AFA)
- Bright Focus Foundation
- Long Island Alzheimer's Foundation (LIAF)
- Staten Island Alzheimer's Foundation (SIAF)

### 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](http://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.**

## Planning Today for Tomorrow

When CaringKind expanded to the third floor in March 2013 to build our Program Center for Education, and Training, and the Harry and Jeanette Weinberg Early Stage Center, we were able to do so because of the generosity of individuals who had planned ahead and left us in their estate plans. The bequests that we receive are from grateful clients who wish to give back in appreciation for the support and help they receive during the very difficult journey of caring for, or knowing, an individual with dementia.

Planned giving is a way to support CaringKind through your will, a retirement account, a trust, or other vehicles to make a charitable contribution after your death. Through estate planning, you can make a

meaningful impact helping others who are heartbreakingly affected by a diagnosis of Alzheimer's disease or a related dementia. For more than 30 years we have been a leader in dementia care, setting the gold standard for care.

Though we all hope for a cure or an effective treatment or therapy, we

know that in its absence, the best course of treatment is good care. Your contribution enables us to plan ahead so that we can develop innovative, creative, and leading-edge caregiving initiatives to ensure that caregivers today and tomorrow have a place to turn for the best in dementia care.

Gifts of any size are appreciated and every single gift is important to helping us. Please see the Ways to Give section on bequests on page 18 for further information or please contact Carol Berne at 646-744-2905 or [cberne@caringkindnyc.org](mailto:cberne@caringkindnyc.org).

**For more than 30 years, we have been a leader in dementia care, setting the gold standard.**

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- Staten Island Alzheimer's Foundation (SIAF)

# 2016 Forget-Me-Not Gala



Board member and Gala Chair Jon Henes, former NHL All-Star and Emmy Award winning broadcast analyst Ron Duguay and Gala MC Nigel Barker, photographer and TV personality



Eric Friedman, Board members Lori Oscher Friedman and Linda LaGorga



Young Leadership Honoree and Junior Committee President Laurel Crosby and Eric Burghoffer



Creative Leadership Honorees Sharon Washington, Jennifer Garvey-Blackwell and Susan Stroman, and David Hyde Pierce

*Honorees*



Members of the CaringKind Board of Directors



Lou-Ellen Barkan (center left) is joined by director Susan Stroman (third from left) and DOT cast members (from far left) Colin Hanlon, Sharon Washington, Marjorie Johnson, Stephen Moore, Libya Pugh, and Finnerty Steeves



Board Co-Chair John Latham and Kimberly Latham



Susan Stroman and David Hyde Pierce



Ron Duguay and Dr. Max Gomez



John Fiore and Board member Marianne Dziuba-Fiore



Steve Maggio, Board member Stephen E. Boxer, and Carol Berne



Board Co-Chair Stephen Casper and Jed A. Levine



Dr. Thomas Wisniewski, Dr. Warachal E. Faison, Dr. Mary Sano, Dr. Steven H. Ferris, Dr. Peter Davies, and Dr. Mary Mittelman



Board Co-Chairs Stephen Casper and John Latham, Board member and Gala Chair Jon Henes, and Board Co-Chair Benjamin Jenkins



Karen Ziman, Ken Ziman, and Lori Oscher Friedman



Board member David Weinberg and Samara Weinberg



Board member Jim Lavelle (back row, right) with family and friends



## Every Chair Tells a Story

### Reserve Your Personalized Place in the Park

Pay tribute to someone special in your life with a personalized Bryant Park “Memory Chair.” Today, there are nearly 400 Memory Chairs in Bryant Park (located adjacent to the New York Public Library on 42nd Street and 5th Avenue), and every chair tells a story. The Chairs have been dedicated to mothers and fathers, sisters and brothers, husbands and wives, and partners and friends – all of whom have been impacted by Alzheimer’s disease or a related dementia.

The Bryant Park Memory Chair program is an opportunity to claim a special place in the heart of one of New York City’s most celebrated parks, while honoring a loved one with dementia, thanking an extraordinary caregiver, or marking a special milestone in your life.

Your personalized plaque will be mounted on one of the chairs in Bryant Park, and inscribed with your personal message and the CaringKind logo. Not only will you contribute to the legacy of a loved one, but your donation will support the work of CaringKind, raise awareness about one of the most devastating diseases of our time, and support the ongoing efforts to maintain the beauty of Bryant Park.

For more information contact Crissy Vicendese at [cvicendese@caringkindnyc.org](mailto:cvicendese@caringkindnyc.org) or 646-744-2927.

[www.caringkindnyc.org/bryantpark](http://www.caringkindnyc.org/bryantpark)

# Save the Date!

## 29<sup>th</sup> Annual Research Meeting

caringkind

The Heart of Alzheimer's Caregiving

# Traumatic Brain Injury: Prevention, Treatment, and the Consequences

**Date:** Tuesday, October 18, 2016

**Place:** The Times Center  
242 West 41st Street  
New York City

**Time:** Check in: 5:30 p.m.  
Program: 6:00 p.m.  
Reception: 7:30 p.m.

For more information or to RSVP please visit  
[www.caringkindnyc.org/AnnualMeeting](http://www.caringkindnyc.org/AnnualMeeting)  
or call Crissy Vicendese at 646-744-2927

*This event is free of charge,  
and open to the public*

Moderated by

**Dr. Max Gomez**, CBS 2 Medical Reporter

### **Panelists:**

#### **Sam Gandy, MD, PhD**

Mount Sinai Endowed Chair of Alzheimer's Disease Research, Professor of Neurology and Psychiatry, Director of the Center for Cognitive Health and NFL Neurological Care.

#### **Robert A. Stern, MD**

Professor of Neurology, Neurosurgery, and Anatomy and Neurobiology at Boston University School of Medicine; Director of the Clinical Core of the BU Alzheimer's Disease Center; and Director of Clinical Research for the BU Chronic Traumatic Encephalopathy (CTE) Center.

*The Annual Meeting is generously supported by Bill and Jane Brachfeld*

## Finding Home Care



**MATT KUDISH**

Senior Vice President of Caregiver Services  
mkudish@caringkindnyc.org

After an Alzheimer's or dementia diagnosis, it's never too early to consider long term care options, including home care and hiring an aide. Together We Care™ is a website that was created by CaringKind as a way to bridge the gap between graduates of CaringKind's nationally recognized Dementia Care Training for Professional Caregivers program and family members seeking to hire aides trained in dementia care. If you are looking to hire an aide trained by New York City's leading

dementia care experts, Together We Care is the only resource you need. Visit TogetherWeCare.com to create your free account and begin your search today. After you have created your free account, you can:

**Post job listings.** Family members can create a job listing for the aides on the site to view and respond to. Take advantage of this opportunity to describe precisely what you're looking for and you need in a caregiver, and let our graduates contact you to learn more. Job listings are only viewable by graduates of our training program and are not able to be seen by the general public.

**Browse or search profiles.** Every profile on the website is a graduate of CaringKind's dementia care training program. Profiles include the aides':

- **Degrees & certifications**, including the institution from which they were awarded.
- **Availability options**, including the days of the week they are available for work, as well as whether they are looking for part-time, full-time, or live-in employment.
- **Transportation capabilities**, and if they have a valid driver's license.
- **Location**, and if they are able to work in the five boroughs, New Jersey, Westchester, Long Island, and Connecticut.

## Looking to hire private home care workers?



[www.TogetherWeCare.com](http://www.TogetherWeCare.com)  
can help in your search.

Create a free account, post an ad,  
and browse profiles.

Aides are professionally trained by  
CaringKind\* - The Heart of  
Alzheimer's Caregiving.

**Together We Care™**

Connecting trained home care workers  
with the families who need them

\*Formerly known as the Alzheimer's Association, New York City Chapter

## It's Never Too Early to Consider Nursing Home Options



**AMY TORRES**

Director of Training

atorres@caringkindnyc.org

If a person with dementia's needs can no longer be met safely at home, or if they require rehabilitative services after a hospitalization, it may be time to consider a move to a long term care facility. It is best if you begin looking for a long term care facility *before* the person with dementia actually needs it, as the process often takes longer than expected.

In order to be eligible for nursing home care, the person with dementia must require 24-hour skilled nursing or custodial care. A person requiring custodial care needs assistance with daily activities such as eating, dressing, bathing, ambulating, and medication management. Individuals applying from hospitals generally have higher admission priority because they typically have higher skilled nursing needs. Skilled care is provided by licensed professionals such as a registered nurse. Examples of skilled care include intravenous injections, physical therapy, and medication administration.

Nursing homes use an assessment tool called the **Patient Review Instrument (PRI)**, which is completed by a doctor or registered nurse to evaluate someone for admission. A family member should be present during the evaluation to report on one's functioning and the level of care required. It is common for someone to spend months on a waiting list if he or she is moving from his or her home into a nursing home.

There are many things to consider when deciding on a new home for the person with dementia. It is important to look beyond the physical characteristics of a facility and to place emphasis on the quality of care provided to residents. If possible, look for a home that you feel will be responsive to your requests, and will try to accommodate the person's daily routine.

When you are looking for a new home, you may notice facilities referring to a care perspective called "person-centered care" or "culture change." These terms refer to a movement which aims to make long term care facilities more home-like and to encourage resident choice and respect of resident routine. These facilities will likely be more open to individual input from residents, family members, and friends when responding to daily care needs.

Taking the following steps will help you decide which long term care facility is the right fit for the person with dementia:

- **Visit Several Homes.** When taking a tour, be sure you are shown a long term care floor. Facility staff may show visitors the sub-acute or rehabilitative floors, which may be better staffed and furnished. Ensure the facility is clean and odor free.
- **Choose a Place Convenient to You and Other Visitors.** Visit frequently. The more visitors the person with dementia has, the more likely it is that issues with care will be noticed and addressed.
- **Meet the Person with Dementia's Care Needs, Not Your Personal Preferences.** People with dementia have very different care needs. Some may have high skilled nursing needs

while others may require complete custodial care. For instance, if someone requires significant medical care, you may want to look for a facility that is affiliated with a hospital and is accustomed to caring for people with high medical needs. In this instance, it is more important to find a facility that can properly care for the person with dementia, rather than a facility that has many activities or a pleasant outside space.

- **Ensure Language and Cultural Needs Can Be Met.** If the person with dementia has specific language, religious or dietary needs, it is important to inquire whether the facility can accommodate those needs *prior to placement*.

The Department of Health does not currently have any regulations determining the definition of a "dementia unit." Although you may find that facilities advertise dementia units, without regulations this phrase is not necessarily helpful. It may be more important to find a facility providing quality care to other residents with similar needs to the person with dementia.

Caregivers often experience mixed emotions surrounding the decision to find a new home for the person for whom they have been caring. It is important to remember that moving someone to a long term care facility does not mean that you have failed in your caregiving efforts. Trust that you are making the best decisions for the person and for yourself. Although the transition to a long term care facility may be emotionally challenging, you can continue to have a rich relationship with that person.

# Carry an Umbrella

By Daniel G. Fish, Esq.

**It's important to overcome the resistance to planning in advance.**

Why is it that many people do not take the simple precaution of signing legal documents to protect themselves in the event they become unable to manage their affairs? There is a great deal of reluctance to think about illness and its possible consequences. Rational thinking gives way to anxiety, and anxiety gives way to inaction. This is the same as thinking "If I do not bring an umbrella, then it will not rain." The best approach is the Boy Scout motto: "Hope for the best and prepare for the worst." The good news is that the steps to take in this regard are straightforward, easy to implement, and very inexpensive.

Advance directives allow you to name a person to help if you cannot make financial and medical decisions on your own. They must be signed while you are alert and understand them. Some people think that advance directives are only for those who are facing an illness such as Alzheimer's disease. The truth is that all individuals over the age of 18 should plan for the possibility that they may be disabled (temporarily or permanently) and unable to manage their finances and their health.

*Daniel G. Fish is a partner with McLaughlin & Stern, LLP and a past president of the National Academy of Elder Law Attorneys.*

Learn more about these tools by attending CaringKind's Legal & Financial Seminar. To register, call our Helpline at 646-744-2900.

## Important Documents

### POWER OF ATTORNEY

A power of attorney (POA) allows you (the "principal") to designate one or more persons ("agent(s)" or "attorney(s)-in-fact") to manage your affairs. The authority of the agent(s) is sweeping; only the most trustworthy individual(s) should be selected. If you select multiple agents, you must decide whether to allow each agent to act independently or to require that all of the agents act together. It is also possible to name an agent to serve if one of the originally named agents is unable to serve (called a "successor agent") and to name an agent to act in the future (called the "springing power of attorney"). The principal does not lose the power to act or manage his or her finances by naming an agent(s), you are simply authorizing someone to act with you.

The power of attorney can be limited or general. A limited POA restricts the areas in which the agent(s) can act. The general POA allows the agent(s) to make all financial decisions that the principal could make him- or herself, if he or she was not incapacitated. A durable POA remains in effect even if you lose mental capacity.

Often, financial institutions will refuse to recognize the power of attorney. New York State statute requires financial institutions to accept a properly drawn POA; many financial institutions and government agencies have their own POA form and will not accept the general POA.

### LIVING WILL

A living will describes the kind of health care you would desire if you were seriously ill, particularly in situations where heroic measures would be considered. The living will does not appoint an agent, it simply informs your family and health care providers about the type of care that you want at the end of life.

### HEALTH CARE PROXY

A health care proxy allows you (the "principal") to appoint an agent to direct medical treatment if you become incapacitated. You can only designate one agent under the health care proxy to avoid confusion, but you can name an alternate agent. The health care proxy takes effect when a physician has determined that the principal cannot make decisions for her- or himself. The standard health care proxy allows the agent to make all medical decisions, with the exception of artificial nutrition and hydration. If you wish your agent to make decisions regarding these matters, you must specify this in the document. After you sign the health care proxy in front of two witnesses, you should submit a copy to each of your health care providers.

### GUARDIANSHIP

If no advance directives have been made and you can no longer manage your affairs, it may be necessary to seek a court-appointed guardian. However, as this is a costly and time-consuming option, it is recommended that all adult individuals complete advance directives.



## It's Never Too Early To connect2culture®



**NANCY LEE HENDLEY**  
Former Manager of connect2culture®

Suppose that you and a person with dementia could attend a concert at Lincoln Center for the Performing Arts, view art at The Met Cloisters, examine artifacts at the Intrepid Sea, Air & Space Museum, or pot a plant at the Brooklyn Botanic Garden? What might that experience look like?

After a diagnosis of dementia, it often becomes increasingly difficult for the person with dementia and for the caregiver to enjoy social outings. As the illness makes its way to the center of our lives, a lot of other living gets crowded out. For the person with dementia, trying to interpret environmental cues, finding just the right thought to contribute, determining the proper way to interact, and even following a conversation can be frustrating or discouraging. For the caregiver, concern over how the person with dementia will respond, wondering how the person will take to the activity, and concern about how others might react can make socializing a challenge. As a result we find ourselves with less and less desire to do things that used to bring us pleasure. Unfortunately, this kind of living keeps us from enjoying ourselves and tends to be a cause of distress and depression.

connect2culture® at CaringKind is a program supported by a generous grant from the New York State Department of Health to enhance the lives of persons with dementia and their caregivers. The goals of connect2culture are threefold:

to give support and education to existing cultural programs for people with dementia and their caregivers, to initiate and assist in creating additional cultural programs in various venues throughout the five boroughs, and to assist caregivers in finding appropriate activities for themselves and the person for whom they care.

In 2006 the Museum of Modern Art piloted Meet Me at MoMA, which brought persons with memory loss and their caregivers to the museum to view and discuss artworks in a safe, supportive group setting. Since then, a multitude of new and diverse offerings have launched and ongoing programs exist throughout the city. The Arts and Minds organization offers programs at The Studio Museum in Harlem, The New York Historical Society, and El Museo del Barrio (the first offering of its kind in Spanish in the city). Lincoln Center piloted two highly successful concerts this spring with six additional concerts on the schedule for next season. The Jewish Museum, The American Museum of Folk Art, The Metropolitan Museum of Art and The Met Cloisters provide outstanding, engaging programs. There are opportunities to sing with The Unforgettables, to participate in a Social Tea Dance with Rhythm Break Cares in Manhattan, and to Dance Like Nobody's Watching at the Brooklyn Library. The Brooklyn Museum offers an art viewing program. A pilot program at the Brooklyn Botanic Garden has brought gardening into the connect2culture scope.

Every program includes key components that help to ensure a successful outing. They are scheduled at an optimal time of the day, and many of them occur when the venue is closed to the public or set in a space with comfortable seating that

is exclusive for the event. Participants are personally greeted and small groups are formed. In addition to having expertise in a particular subject matter, educators are trained in dementia care and have a good understanding of the type of support that persons with dementia require. A limited number of works are presented and each session is developed specifically to engage persons with dementia with an approach that encourages conversation and input from every participant. Many programs offer tactile explorations and some offer an art making component. All of the programs are free of charge.

It is possible to envision these events; they are already in progress! I invite you to explore these valuable resources. We at connect2culture are dedicated to continuing to provide opportunities for you. Please feel free to call with your questions, concerns, and suggestions. For a complete list of connect2culture offerings please visit our website [caringkindnyc.org](http://caringkindnyc.org) or call the 24-hour Helpline at 646-744-2900.

*After ten years at CaringKind, as both a Dementia Care Trainer and the Manager of connect2culture, Nancy Lee Hendley has left CaringKind to pursue other opportunities. We thank her for her many years of dedicated service and wish her the best in her future endeavors.*

*We also welcome Meredith Wong as the new Manager of connect2culture. Meredith brings a wealth of experience with museum education and enthusiasm for developing access programs to the position and we are excited to have her on board. You can reach her at [mwong@caringkindnyc.org](mailto:mwong@caringkindnyc.org).*

# A Caregiver's Journey

By Jessica Gonzalez  
Junior Committee Social  
Media Chair

In hindsight, we noticed my mother's symptoms years ago. She began telling a story that was impractical and implausible. The story involved her coming with me to my high school friend's house traveling by bus, but my mom hated public transit with a passion. Over time other symptoms manifested: forgetting how to get somewhere, forgetting to cook dinner, forgetting the zip code we've had for over 30 years.

Finally in 2014, after asking the doctor to test her for years, we finally went with her to the appointment. She failed her cognitive test completely, and we now had a name for her condition: Alzheimer's. After a confirmation from a neurologist, we were sent home to live life without any recommendations, not even an information packet.

The first time I called CaringKind (then the NYC Chapter of the Alzheimer's Association), my mom had yelled at us and stormed out of the house. That day, through the Helpline, I signed up for my 10-hour Family Caregiver Workshop. I was the youngest person in my class, and only one of two participants in the group who were caring for a parent. It was a wonderful introduction to the nuts and bolts of a disease that would become a dominating force in my life.

After I tested the waters, my father completed the same workshop with CaringKind at a location in Brooklyn. Together, with our newfound knowledge, we enrolled in two studies that we found through CaringKind. Mine was an online

course on how caregiving affects a caregiver, and his was an in-person session with a researcher from the study, operated out of Columbia University, which was designed to help Latino families understand how the disease would affect their loved one and learn how to keep their loved one comfortable and engaged as the disease progresses.

In January 2015, I found the Junior Committee. What surprised and saddened me was seeing how many young people had already lost a parent

to Alzheimer's or dementia and how many were in the process of losing them. Having already used the services of CaringKind, I knew that whatever fundraising events we did or advocacy trips we took actually impacted lives. That spring I accompanied CaringKind staff, caregivers, and three other Junior Committee members to Washington, D.C. to advocate for more fundraising dollars to meet federally identified goals. It was an intense experience, seeing so many affected caregivers and contemplating the impact this disease had on everyone around me. The emotional toll of this disease is enormous, but the full economic and financial impact of this disease has not reached its peak.

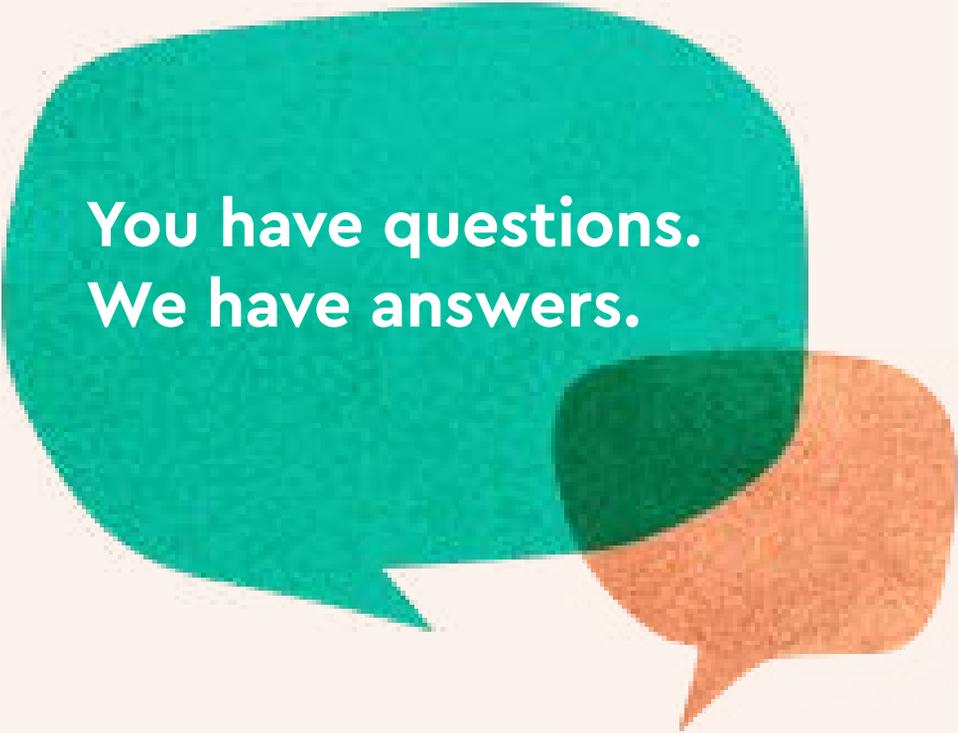
On May 1, 2016, I rode the TD Five Boro Bike Tour in support of CaringKind. The temperature reached a high of 50 degrees and rained the entire 40 miles. I finished those 40 miles frozen and soaked, but happy to have met my fundraising goals and know that for over 40 miles, I helped raise awareness of CaringKind and its mission.



Jessica crosses the finish line at the 2016 TD Five Boro Bike Tour as a member of team Athletes to End Alzheimer's.

Throughout this long goodbye, one person that should not be forgotten is my mother and her personality. She still has her spirit that makes her a unique individual, and while she cannot perform many activities independently, she still has her creativity. I started an Instagram account, @hildaalznails, just to keep up with her nail decorations, but it has evolved into so much more. Through Instagram we tell the story of her journey, both the good and the bad. We have also joined a larger online community that is raising awareness about Alzheimer's and dementia and breaking down the walls of silence that have surrounded this disease for so long. CaringKind is a strong advocate in this fight, helping to support those afflicted with these diseases and those who are caring for them.

If you're interested in learning more about the Junior Committee please visit our website at [caringkindnyc.org/juniorcommittee](http://caringkindnyc.org/juniorcommittee). If you or someone you know would like to join the committee please email [alznyjc@gmail.com](mailto:alznyjc@gmail.com).



**You have questions.  
We have answers.**

**Since the launch of our new brand in March we have received all sorts of questions and feedback—and we want to hear more!**

Your inquiries and opinions are very important to us here at CaringKind. With that being said, we are excited to introduce our new web-based Question & Feedback form. If you are interested in learning more about our new brand or have questions about any of our programs and services visit us at [caringkindnyc.org/feedback](https://caringkindnyc.org/feedback) and complete the online form.

Send us a note, show us some love, let us know about your recent experience, ask a question—just reach out. We'd love to hear from you! Who knows, your question might appear in the next newsletter!



**We'd love to  
hear from you!**

## April Showers Bring May...



**CANDACE DOUGLAS**  
Director of Constituent Events  
cdouglas@caringskindnyc.org

...Athletes to End Alzheimer's® all-stars! In May, between the TD Five Boro Bike Tour and TackleALZ NYC, our athletes raised over \$200,000 to support our programs and services while proudly raising awareness for CaringKind.

On the first day of May, clouds and rains loomed, but that would not stop the 30 members of our Bike Tour team who were ready to brave the soggy, but car-free roads of New York City. Starting in downtown Manhattan, they rode through all five boroughs, before eventually completing the tour on Staten Island by the ferry. And while the rains were unforgiving on tour day, our team's resolve remained intact because of their commitment to the cause and to those who live with or care for someone with Alzheimer's disease. As the first Bike Tour team representing the CaringKind Athletes to End Alzheimer's signature orange,



The 2016 Athletes to End Alzheimer's TD Five Boro Bike Tour team



The 2016 TackleALZ NYC players and coaches

they were proud to lend their bodies and voices to the caregiver mission.

Fast forward just two short weeks, and we would again be under the threat of thunderstorms while getting ready for another great night of flag football on Roosevelt Island. While this would be the sixth time this game was played, it would be the first under the newly rebranded event name TackleAlz NYC which further illustrates why these incredible women take the field, with the support of the amazing coaches who help them prepare. To embrace the inclusiveness that has long been one of the event's greatest strengths, the teams changed their names to the BruCrew and the Blondetourage.

As game day started, the fans were ready to buckle down for the night. Would the BruCrew, who had impressively raised over \$80K leading into the evening win back the trophy? Or would the reigning champs, the Blondetourage, who had for the second year in a row raised #100KbyGameday, be able to pull off the repeat? A physical but fair game played out for the crowd, and the game was too close to call all the way until the fourth quarter when the Blondetourage tied the score. But in that last quarter, a spark must have been lit because the BruCrew was able to light up its offense in

an impressive fashion to score multiple touchdowns, giving them the lead and final game victory score of 47-20. But the most important score of the night was the one shared by the nearly 100 participants from both teams: over \$190,000 raised to tackle Alzheimer's.

Throughout the season, the ladies and gentlemen of TackleALZ NYC have stood tall in the battle to destigmatize Alzheimer's and dementia and shine a light on the over 250,000 caregivers in New York City currently tackling this disease in their day-to-day lives. From rookie to seasoned vet to "retired" alumni both near and far, they stand together as a community united to raise awareness and funds for our cause. On behalf of the CaringKind Board, staff, and, most importantly, our clients, we thank all of our athletes for their dedication and support.



From left: 2016 TackleALZ NYC Hall of Fame inductees Ashley Ross, Jennifer New, Cassie Sklarz and Brie Corona-Galo. Each of these incredible athletes have raised over \$10,000 in their TackleALZ NYC careers.

# Join Us On Social Media!



# caringkind

## Alzheimer's

# Walk



This year we're launching our first Alzheimer's walk under our new name, **CaringKind**. We need you to walk with us to **give care**, **increase awareness** and **raise funds** to help everyone affected by an Alzheimer's or dementia diagnosis.

Join us! Register as a walker and you'll receive a free Walker Care Package with our signature orange shoelaces to help spread the word in the lead up to the event and wear proudly on the day of the walk.

**MANHATTAN  
SUNDAY,  
OCTOBER 16  
Riverside Park**

**BROOKLYN  
SUNDAY,  
SEPTEMBER 18  
Coney Island  
Boardwalk**

**QUEENS  
SUNDAY,  
SEPTEMBER 25  
Flushing Meadows  
Corona Park**

**STATEN ISLAND  
SUNDAY,  
OCTOBER 2  
South Beach**

**Sign up today for a 2016 CaringKind Alzheimer's Walk!**

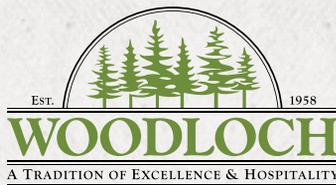
**[caringkindnyc.org/walk](http://caringkindnyc.org/walk) • (646) 744-2900**

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## Registration Form

24-hour Helpline 646-744-2900

[www.caringkindnyc.org/walk](http://www.caringkindnyc.org/walk)

Complete and mail to: ATTN: WALK

360 Lexington Avenue, 4<sup>th</sup> Fl. New York, NY 10017

Manhattan  Brooklyn  Queens  
 Staten Island

Participation Type:  Virtual Walker  Walker

Role:  Individual Walker  Join a Team  
 Create a Team

Team Name: \_\_\_\_\_

### Walker Information:

First Name: \_\_\_\_\_

Last Name: \_\_\_\_\_

Billing Address: \_\_\_\_\_  
\_\_\_\_\_

City: \_\_\_\_\_

State: \_\_\_\_\_

Zip: \_\_\_\_\_

Phone Number: \_\_\_\_\_

Email: \_\_\_\_\_

### Assumption of Risk, Release and Permission:

This event involves walking – an activity which may include risks such as, but not limited to, falls, interaction with other participants, effects of weather, traffic and conditions of the road. In consideration of being allowed to participate in this event, I hereby expressly assume all risks, including bodily and personal injury, death, property loss or other damages of any kind arising in any way out of my attendance or participation in this walk and related activities. It is my responsibility to dress appropriately. Although route maps, rest stops, refreshments, and other assistance may be made available during this event, I am solely responsible for my own health and safety. I represent that I am physically fit and able to attend or participate in this event. I hereby for myself, my heirs, executors and administrators, release, discharge and agree not to sue CaringKind (f/k/a the Alzheimer's Association, New York City Chapter), its offices, their respective officers, directors, volunteers, employees, sponsors and agents, from any and all liability, claims, demands and causes of action whatsoever, arising out of my participation in or attendance at this event and related activities whether resulting from the negligence of any of the above or from any other cause. I agree that my assumption of risk and release hereunder shall be as broad and inclusive as is permitted under applicable law. If any portion of this agreement is held invalid, the remainder shall continue in full force and effect. I grant full permission in perpetuity to the organizers of this event to use, re-use, publish and re-publish my name and image as a participant in the event in photographs, video or other recordings.



I have read, understand and agree to the terms of this agreement. If Participant is a minor, the parent or guardian must agree to the below:

I am the legal guardian of Participant, and I hereby consent to his/her participation. I have read the foregoing agreement, and I hereby agree on behalf of myself and Participant to its terms.

Signature: \_\_\_\_\_

**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:**

AHS Caring Communities  
Atria Senior Living, Kew Gardens  
Heights & Hills  
Riverstone Senior Life Services  
The Elly & Brochie Kleinman OHEL  
Regional Family Center  
Selfhelp Alzheimer's Resource Program

## 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 17	1:00 - 3:00 p.m.	Brooklyn
August 17	5:30 - 7:30 p.m.	Manhattan
August 24	5:30 - 7:30 p.m.	Manhattan
September 1	6:00 - 8:00 p.m.	Queens
September 9	12:00 - 2:00 p.m.	Manhattan
September 13	5:30 - 7:30 p.m.	Manhattan
September 21	5:30 - 7:30 p.m.	Manhattan
September 21	6:00 - 8:00 p.m.	Brooklyn
October 5	3:00 - 5:00 p.m.	Queens
October 11	5:30 - 7:30 p.m.	Manhattan
October 14	12:00 - 2:00 p.m.	Manhattan
October 19	1:00 - 3:00 p.m.	Brooklyn
October 19	5:30 - 7:30 p.m.	Manhattan
November 3	3:30 - 5:30 p.m.	Queens
November 8	5:30 - 7:30 p.m.	Manhattan

### Upcoming Dates Just for Professionals:

September 14	3:00 - 5:00 p.m.	Manhattan
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### Upcoming Dates in Spanish:

August 17	5:30 - 7:30 p.m.	Manhattan
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### Upcoming Dates in Chinese:

August 27	10:30 a.m. - 12:30 p.m. (Mandarin)	Manhattan
October 29	10:30 a.m. - 12:30 p.m. (Cantonese)	Manhattan

## 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 Dates:

Manhattan	
September 20	5:30 - 7:00 p.m.

## 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:

September 1	5:30 - 7:00 p.m.	Manhattan
October 6	5:30 - 7:00 p.m.	Manhattan
November 3	5:30 - 7:00 p.m.	Manhattan

## 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:

Tuesdays	September 6, 12, 20, 27	5:30 - 8:00 p.m.	Manhattan
Wednesdays	September 7, 14, 21, 28	12:00 - 2:30 p.m.	Manhattan
Mondays	October 3, 17, 24, 31	5:30 - 8:00 p.m.	Manhattan
Thursdays	October 6, 13, 20, 27	12:00 - 2:30 p.m.	Manhattan

### Upcoming Series Dates in Spanish:

Thursdays	October 6, 13, 20, 27	5:30 - 8:00 p.m.	Manhattan
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## Legal & Financial Seminar

An attorney specializing in elder law discusses important topics 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 15	5:30 - 7:00 p.m.
August 25	5:30 - 7:00 p.m.

September 19	5:30 - 7:00 p.m.
September 22	5:30 - 7:00 p.m.

October 3	12:00 - 1:30 p.m.
October 17	5:30 - 7:00 p.m.
October 27	5:30 - 7:00 p.m.
November 7	12:00 - 1:30 p.m.

### Upcoming Dates in Cantonese:

Manhattan

September 29	2:30 - 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.):

### September 12

*Listen Up! Why Hearing Health is Important for Families Living with Dementia*

- Learn how to address the causes and signs of hearing loss
- Discover communication strategies and technological support available
- Find out ways to manage the emotional impacts related to hearing challenges

**Speakers:** Jeffrey Wax, LCSWR, Director of the Emotional Health and Wellness Center at the Center for Hearing and Communication (CHC); Carolyn Ginsburg Stern, Manager of the Center for Hearing and Aging at the CHC

### October 17

*Lewy Body Dementia: One of the Most Common Dementias You've Never Heard Of*

- How is LBD different from Alzheimer's disease and Parkinson's disease?
- Why is it often misdiagnosed?
- What kind of support is available for caregivers in NYC

**Speakers:** Norma Loeb, Founder & Executive Director at the Lewy Body Dementia Resource Center of New York; Yael Zweig, Adult & Geriatric Nurse Practitioner at the NYU Langone Medical Center

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