

## New York City Chapter

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Giving up? Incurable? **Palliative Care** Hopeless?

The truth about palliative care

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# New York City Chapter

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Dear Friends,

I know from both personal experience and professional observation that few things in life are more heartbreaking, painful and difficult than watching a loved one in the late stages of Alzheimer's. The feeling of helplessness for a family caregiver can be overwhelming.

Similarly, healthcare professionals working in residential settings tell us that providing care for advanced dementia patients is one of their greatest challenges. And, as the population of dementia patients grows, their challenges will grow. But, the goal will remain the same: to establish humane and cost-effective procedures that keep a patient comfortable. This sounds simple and easy, but it is difficult if not impossible when a patient is unable to tell you where it hurts, why she won't eat or why he's screaming uncontrollably.

As you'll read in this special issue of our newsletter, the Chapter has taken a leadership role in piloting a pioneering model of palliative care in three New York City residential care facilities. Our goal: to improve care for people with late-stage dementia.

Our pilot program, the Palliative Care for Advanced Dementia Project, is a true collaboration of families, nursing homes, hospice care providers and healthcare professionals. The project is based on an innovative and very successful model of care developed at the Beatitudes Campus with their partner, Hospice of the Valley, in Phoenix, Arizona, with the participation of both the Desert Southwest and Greater Illinois Chapters.

Now in its second year, the project is showing promising results, allowing patients with advanced dementia to live more comfortably and bringing peace of mind to family members, all while improving the quality of work

life for staff members, and at the same or less cost.

You can read more about the terrific potential of the project in this issue (see page 8), but I think there is also another story here. The Palliative Care Project was only possible because our community partners pulled together. From Beatitudes who created the model, to our dedicated and innovative staff whose vision brought the program to New York, and to our courageous residential care partners at Cobble Hill Health Center, Isabella Geriatric Center and Jewish Home Lifecare, 106th Street Campus, and their hospice providers, VNSNY, Metropolitan Jewish Geriatric Services and Calvary, we are all accomplishing more together than we could ever have done alone.

Inside each institution, the willingness of the administrators, nurses, doctors, CNAs, social workers, recreation and dietary workers, housekeepers, and families to try something new has been inspiring. The payoff for all of us is greater success today and the hope that we can help many more people effectively in the future.

So, what are we learning? First of all, the solutions will be innovative, but much less complex than we imagined. Greater flexibility in residential schedules for meals, rest and programs may actually be less expensive and more effective in providing comfortable care for late-stage dementia patients than the rigid routines we have today. If our current



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findings hold, The Palliative Care Project has the potential to radically change the way we deliver residential care, not only in New York City, but nationwide.

**Honor someone special for our Mother's Day & Father's Day Campaign on page 17.**

Our bold project would not have been possible without the generous support of our funders, including NYC Chapter Board and Junior Committee members. We deeply thank the United Hospital Fund, The Fan Fox and Leslie R. Samuels Foundation, Inc., The Milbank Foundation for Rehabilitation, the Mayday Fund, The PARC Foundation and a number of family foundations for their support. In addition, the Altman Foundation has awarded us a capacity building grant that will enable us to develop a strategic plan and define our role in palliative care in the months ahead.

Thank you to all of these friends of the Chapter and to the many more who are helping us achieve our goals. We are proud to be New Yorkers and working alongside the many outstanding organizations in our community. Our accomplishments will be shared by many, today and in the years ahead.

Dear Readers,

**W**hat do we mean when we talk about palliative care? Very simply, it is a means to provide comfort to those in physical, emotional, or spiritual pain. It's what we all want for ourselves and for those we care for deeply. The goal is to relieve pain and the stress of illness.

Here is what it is not:

- It is not only for those at the end of life. Palliative care can and should be provided to those with curable illnesses, chronic illnesses, or terminal illnesses, no matter how long they may be ill.
- It is not hospice care. Hospice care incorporates palliative approaches to make the patient more comfortable. Hospice care is only for those with end-stage terminal illnesses who are likely to die within six months.
- It is not just for persons with cancer or HIV/AIDS.
- It is not "giving up" on the patient; it is a way of providing the best possible care to improve the quality of life for the individual.
- It is not a passive withdrawal or removal of care but rather the active provision of comfort to support the patient.

Over the past year and a half the New York City Chapter has been privileged to have initiated a proven model of palliative care to residents with advanced dementia in pilot units at Cobble Hill Health Center, Isabella Geriatric Center and Jewish Home Lifecare, 106th Street Campus, with the support of their hospice providers, VNSNY, MJHS, and Calvary.

The model, based on practices developed, proven and refined at the Beatitudes Campus in Phoenix, Arizona, is based on the idea that

persons with advanced dementia who no longer communicate verbally, can still communicate through behavior.

When someone in the advanced stages turns their head when being fed, or pushes away the spoon, that is a message. If they scream in pain when a diaper is changed, or when being dressed, that is a message. When they are nodding asleep in their wheelchair after sitting for three hours without being re-positioned, in a dayroom with the TV on, that is a message too.

We are so proud of the work that our three partner homes have accomplished, and of our Chapter team and our Beatitudes partners and colleagues. With their help, we have already accomplished so much.

We are grateful to our colleagues at the Desert Southwest and Greater Illinois Chapters for their role in developing the model.

One focus of the project is to educate families about the palliative approach, helping them understand that even as people are at the end of life with late-stage dementia, there is so much we can do to make them comfortable. Residents can enjoy the everyday pleasures of chocolate, hand massage, familiar music, a nap, or pictures of puppies or babies.

Our project also addresses the important issue of identifying and appropriately treating pain in those who can't tell you that a shoulder hurts or a knee is stiff and uncomfortable. The person with advanced dementia often



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communicates discomfort by pushing away a nurse's aide, or kicking, screaming or spitting.

The resident is labeled "difficult" and given anti-psychotic medication, which is often inappropriate and takes away the resident's only means of communicating discomfort. It does not address the underlying cause of the behavior, and the person is still in pain.

Moving to palliative care may feel like a defeat, but in reality it is a victory over our helplessness. Once we let go of the expectation that the person with dementia will get better and recognize that there is a whole arsenal that we can use to comfort, soothe, and connect with the person, we move from an aggressive treatment model to a supportive model that provides comfort for the person with dementia and for the caregiver.

I recognize the psychological hurdles and anger that family members must overcome to admit that they are powerless in preventing the inevitable decline in an Alzheimer's patient.

We have heard wonderful stories about the effectiveness of this approach. One woman who was cranky and miserable in the dayroom, calling out "Help Me! Help me!!" was soothed by simply being taken to her room to lie down for an hour. Another patient refused to be changed, dressed, or bathed. She yelled, bit, spat, and kicked the aides when they tried to get near her. One of the nurses investigated, and discovered that she had an old

back injury; every movement was excruciating. Prior to placement she had been on a regimen of pain medications that were no longer prescribed when she was transferred to the nursing home. The nurse advocated for a low dose of pain meds through a patch, and ALL of the patient's aggressive behaviors ceased. Once comfortable, she enjoyed the attention of the staff and her family. Everyone benefitted from the new approach to her care.

There are so many people to thank for making this project possible, including our funders. We are confident that the future of care for persons with dementia must, and will, include a palliative approach.

As we learn more from this pilot project, we will share our findings. It is our intention to incorporate palliative care in all that we do, and to inform the palliative care world about the special needs of persons with dementia.

If you need to know more about palliative care, or anything related to dementia care, or you just need to talk, call us. We are here to help 24-hours a day at 800-272-3900 or [alz.org/nyc](http://alz.org/nyc).

## Encouraging Comfort Care Guides



A Guide for Families of People with Dementia Living in Care Facilities

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Following on the heels of our successful press conference with then Manhattan Borough President Scott Stringer and the release of a joint report titled, *Crisis for Caregivers: Alzheimer's Disease in New York City* – which garnered major print and broadcast news coverage – the Chapter continues to drive the public dialogue about Alzheimer's disease.

This quarter, we hit the primetime national stage with Lou-Ellen Barkan's appearance on *The Willis Report* broadcast on FOX Business News. Investigative journalist Gerri Willis sat down with Lou-Ellen to discuss the global Alzheimer's epidemic and predictions that the number of people with dementia will reach 135 million by the year 2050.

Lou-Ellen explained that the numbers were not surprising. She said, "In developing countries, we have historically had very little access to healthcare data. Today, with better access, we are seeing more accurate numbers in the incidence and diagnosis of Alzheimer's. It's also significant that, historically, life expectancy in developing countries was short. Today, people are living longer. And, since age is the greatest predictor of Alzheimer's, it's expected that the number of Alzheimer's cases are increasing."

Barkan added that a major challenge on the horizon is to assure that The National Alzheimer's Project Act (NAPA), signed into law three years ago by President Obama, gets and maintains the financial resources necessary to change the trajectory of the disease.

In March, the Alzheimer's Association released its 2014 Alzheimer's Disease Facts and Figures report. WABC-TV reported on the findings and interviewed the Chapter's Lou-Ellen Barkan and Candace Douglas. Lou-Ellen talked about the need for advocacy for both funding and research, while Candace discussed what it has been like caring for her grandmother who has Alzheimer's. Lou-Ellen was also interviewed that same day about the report on 1010WINS.

In a touching story about music therapy called "Music for the Soul" in *Long-Term Living* magazine, Jed Levine explained that the growing use of new technologies helps make music therapy much more accessible to the Alzheimer's community. He said, "This is a wonderful time because we are much more sophisticated in understanding what a person with dementia is experiencing, and we have many more tools to reach that person."

On the local news front, community papers in Brooklyn and Queens reported on an extraordinary and generous \$348,000 grant from the Stavros Niarchos Foundation that will allow the Chapter to expand its current satellite office in Brooklyn and open a new office in Queens. *New York Nonprofit Press*, *The Home Reporter*, *The Brooklyn Daily Eagle*, *Queens Tribune* and *Queens Chronicle* reported that residents of those boroughs will now benefit

from the Chapter's extensive expertise in dementia care close to home.

News of Hillary Stuchin's appointment as Director of Public Policy at the Chapter was covered in important political and philanthropic publications including *The Chronicle of Philanthropy*, *City & State* and *New York Nonprofit Press*. Hillary earned a Master of Urban Planning degree from NYU's Robert F. Wagner School of Public Service.

With a full calendar of upcoming events and other important issues on the agenda, be sure to keep your eye out for more *Chapter in the News!*

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## What Difference Can Palliative Care Make for the Person with Advanced Dementia?



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The purpose of providing palliative care is to prevent or alleviate suffering, whether someone has a curable illness, a chronic illness, or an illness that is reaching the terminal stages. The intent is to work with the patient to maximize pain and symptom control, including ensuring that the patient is informed and knowledgeable about the risks and benefits of specific treatments or diagnostic procedures (will this test, this treatment, this hospitalization hurt more than it helps?).

Since Alzheimer's is a progressive, terminal illness, it is especially important to understand how pain and distress may be prevented or lessened. This understanding can be very challenging because of the memory and cognitive changes that increase over time. Earlier in the illness, people are usually able to tell us when they are in pain or distress, but this becomes less and less likely as the disease progresses.

Later in the disease process, it is more likely to be someone's actions, rather than their words, which communicate to us that they are in distress. Unfortunately, all too often these behavioral expressions are not understood as distress; rather, they are often assumed to be the inevitable consequences of dementia, as part of the disease itself. Sadly, this assumption has frequently led to the overuse of anti-anxiety and anti-psychotic medications, which means that the actual underlying cause of the

distress is never addressed, and the person with dementia is left to suffer.

A hallmark of excellent dementia care, then, is the determination, knowledge and skill of getting to the heart of the matter: Why is this person upset? What can we do about it? Some solutions come more quickly than others, but it is almost always possible to get to the root of the problem, and thus to a way of alleviating the person's distress. For palliative care to be effective for people with dementia, special attention to understanding their needs is essential.

While the principles of good palliative care for people with dementia are relevant at any point in the spectrum of the disease, they are especially helpful for the later stages, when the natural bodily functions are slowing down, and the potential for suffering increases. The average time from diagnosis to death is eight to ten years, although it can last up to 20 years, and the average person with Alzheimer's spends 40% of this time in the advanced stage of the illness.

Because so many people with dementia end their lives in nursing homes, for the past few years the Chapter has been investigating effective models for the care of people with advanced dementia in the nursing home setting. This search led us to the Beatitudes Campus in Phoenix, Arizona, where considerable research and development has gone into implementing what Beatitudes now call the Comfort First™ approach. Beatitudes worked closely with their partner, Hospice of the Valley, in developing this model.

Beginning in July 2012, the Chapter began a 30-month project with three New York City nursing homes (Cobble Hill Health Center,

**Because so many people with dementia end their lives in nursing homes, for the past few years the Chapter has been investigating effective models for the care of people with advanced dementia in the nursing home setting.**

Isabella Geriatric Center and Jewish Home Lifecare, 106th Street Campus) and the three hospices with which they work (Calvary, MJHS and VNS), to introduce the Beatitudes Campus model to New York City. The intent of the project is for each of these homes to implement, both on their dementia units as well as wherever else in their facilities people with dementia reside, the care practices promoted by Beatitudes. Education and implementation of these newly learned practices are now underway in all three of these homes.

The staff at Beatitudes Campus began their work in the late 1990's, because they believed the care they were providing to residents on their dementia unit was not acceptable. Residents were frequently in distress, calling out, moaning, and sometimes rejecting care when offered assistance with activities of daily living. There was a lot of



staff turnover on the unit because it was not a place where people liked to work, and many families were reluctant to visit. Starting with the premise that behavior is communication, over time, resident by resident, the staff determined that much of the discomfort they observed could be traced to the unmet needs of people living there: (1) the person was hungry, (2) the person was too cold or too hot, (3) the person needed to use the bathroom, (4) the person was in pain, (5) the person was overwhelmed and overstimulated by the environment, (6) the person was tired, (7) the person was lonely, (8) the person was bored.

In a first example of how Beatitudes began to address these needs, they mounted a campaign to better identify and treat pain, which is much more common among people with dementia than is currently understood. Many times when someone is in pain, it is expressed through calling out, moaning, or agitation, sometimes even striking out at caregivers. If non-pharmacological solutions are not effective, then analgesics are explored. These drugs very often prove effective, treating the very real pain and thus altering the distressed behavior, far more so than anti-psychotics, which are not at all effective with pain.

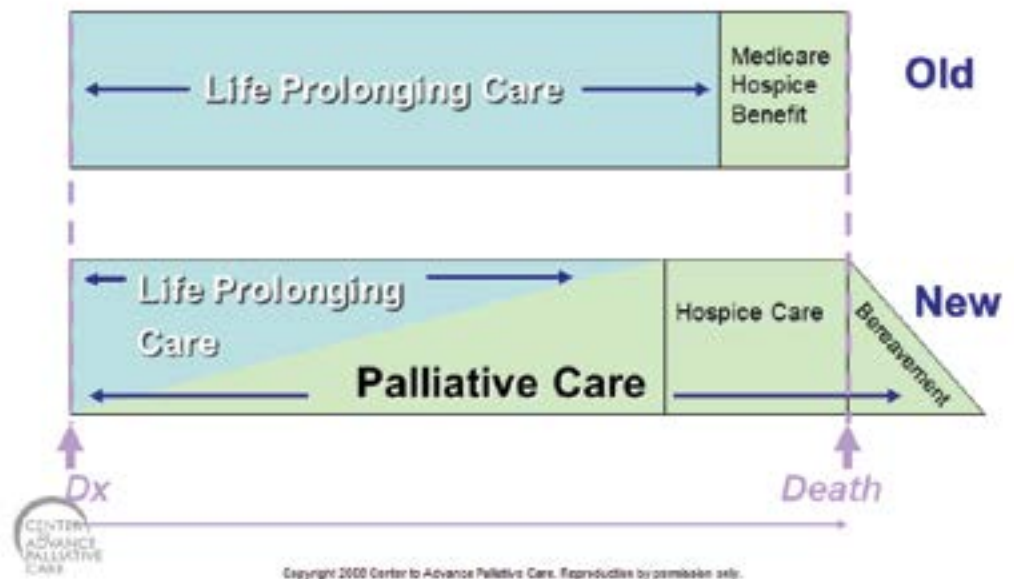
In a second example, they realized that restricting food options can increase the risk of weight loss. Both the American Diabetes Society and the Academy of Nutrition and Dietetics (formerly the American Dietetic Association) recommend liberalized diets in residential care settings. To address this, Beatitudes eliminated special diets, and now makes snack foods available around the clock. These snacks are offered individually to residents every hour or so, rather than the standard three times a day nourishment times, which is most

common. They are often finger foods, offered in small portions, geared to what staff can see that residents truly enjoy: cookies, peanut butter and jelly sandwiches, fruit slices, chocolate, lollipops, ice cream. Knowing what people with dementia like to eat is even more important than knowing what they don't like to eat.

Individualized approaches to meaningful engagement, sleep patterns that result in real rest, a calm environment, and anticipation of needs (is someone too hot, too

In addition to the daily care practices described previously, there are significant decisions that need to be made by people with dementia (while they are still able) or by their family and friends. These have to do with aggressive medical treatment, traditionally used with the goal of curing, which are more often than not inappropriate for someone with advanced dementia. In 2005, the Alzheimer's Association commissioned Dr. Ladislav Volicer to review the available research regarding common medical treatments performed on people

### Conceptual Shift for Palliative Care



cold, do they need assistance with toileting?) are also keys to comfort. Significantly, at Beatitudes where staff once preferred not to work on the dementia unit, now staff working on other units request to be on the waiting list to work for this neighborhood, although vacancies are rare. They now educate others all over the country and around the world in their Comfort First™ approach.

with advanced dementia. As his review attests, there are very real limits to many of these, including: (1) artificial nutrition through gastric tube feeding does not prolong life nor does it prevent pneumonia, malnutrition or pressure ulcers, nor does tube feeding reduce risk of infections or improve one's comfort; (2) antibiotic therapy does not prolong life and is not necessary for symptom control; when antibiotics

are used, they may cause significant harmful effects, and the diagnostic procedures associated with the use of antibiotics add to the resident's confusion and discomfort; (3) cardiopulmonary resuscitation (CPR) is far less likely to be successful in a person with dementia than in one who is cognitively intact. Those who initially survive

CPR are taken to an intensive care unit of a hospital where most die within 24 hours; (4) infection is the most common cause of hospitalization, but hospitalization is not necessary for optimal treatment, as immediate survival and mortality rates are similar whether treatment is provided in a long-term care facility or a hospital.

Palliative care does not mean giving up; it means taking active steps to discover what comforts someone and even gives them pleasure, and taking active steps to prevent unnecessary pain and suffering. These are, of course, highly individual decisions that need to be made on the basis of the person's past values and best interests.

## Speakers Bureau

Presentations on Alzheimer's Disease & Resources for Community Organizations, Corporations, Senior Centers, Clubs, Congregations, Schools and Others.

- What is Alzheimer's disease?
- 10 warning signs
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- Where to go for help



[www.alznyc.org/speakers](http://www.alznyc.org/speakers)

# EmblemHealth Connects Patients and Caregivers to Vital Resources with Rapid Referral

By Greg Johnson, Director, Community Outreach  
 Creator, Care for the Family Caregiver  
 EmblemHealth

The Alzheimer's Association Rapid Referral program has become an integral tool for EmblemHealth to target, identify and deliver the right resources to patients and their families who need them quickly.

It is just one example of how EmblemHealth partners with local organizations to provide the best resources to its members. Along with Rapid Referral, EmblemHealth is expanding its collaboration with the Alzheimer's Association to bring more services and tools to members and their families.

When the diagnosis is Alzheimer's disease or dementia, a family and patient may not know where to turn for help. EmblemHealth's Point of Care staff, a multidisciplinary team that manages care for vulnerable patients, often sees families in this situation.

EmblemHealth's Point of Care staff have found that the Rapid Referral program is exactly what it says it is. By contacting the Alzheimer's Association, they can get needed resources to patients and families often in as little as two days.

Speed is important to EmblemHealth's Point of Care staff. Finding resources quickly for members with dementia or Alzheimer's disease means that members receive the care they need.

Often after hospitalization, both patients and families may be confused about what to do next. Maybe they do not understand medicines prescribed for them and how often to take them, or need to be reconnected to a primary care physician or specialist to continue

medical treatment or for a follow up. EmblemHealth also provides assistance to families and friends of patients through its Care for the Family Caregiver service.

Rapid Referral is only part of how EmblemHealth is collaborating with the Alzheimer's Association to bring more services to members.

- On emblemhealth.com, EmblemHealth is launching an Alzheimer's and dementia education page to educate members and their caregivers, providing links to content and resources on the Alzheimer's Association's website.
- Members of the Association also have been invited to provide educational seminars on Alzheimer's disease and dementia at EmblemHealth Neighborhood Care locations in Harlem, Cambria Heights, Queens and Chinatown.
- EmblemHealth and the Alzheimer's Association are also working together to educate providers about the resources available to families through webinars, speaking engagements and by providing links to Rapid Referral in EmblemHealth's online Provider Toolkit.

The Point of Care staff talks to families on an ongoing basis and knows that the resources of the Alzheimer's Association are both used and valuable. Through this partnership of information, EmblemHealth has been able to

better serve its members so they can manage one of the most complicated illnesses.

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No Co-pay, Shared Is Needed

FAX or E-MAIL TO: Alzheimer's Association New York City Chapter Helpline

FAX NUMBER: 212.497.4178

EMAIL ADDRESS: [RapidReferral@alz.org](mailto:RapidReferral@alz.org)

DATE: \_\_\_\_\_

I, \_\_\_\_\_  
Please PRINT first and last name in exact legibility.

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

Phone (Area) \_\_\_\_\_ (cell) \_\_\_\_\_

I am a person diagnosed with dementia.  
 I am a caregiver for a person with dementia.

give my permission to the referring provider named below to give my name and telephone number to the Alzheimer's Association, New York City Chapter, so that a Helpline consultant can contact me about the best support and educational services that are available.

Health Care Provider: \_\_\_\_\_

Title: \_\_\_\_\_

Please refer to: \_\_\_\_\_

E-Mail: \_\_\_\_\_

I understand that my name and phone number will not be given to any other agency other than for the purpose stated above.

I understand that I can revoke my permission at any time by contacting the above named referring provider.

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

ALZHEIMER'S ASSOCIATION NEW YORK CITY CHAPTER  
 301 Livingston Avenue, 4th Floor, New York, NY 10017  
 24-hour Helpline 800.272.3900

## Palliative Care From Theory to Practice



**Jed A. Levine**  
Executive Vice President  
Director of Programs & Services  
[JLevine@alzny.org](mailto:JLevine@alzny.org)

**S**haron Corso's husband, Anthony, was diagnosed with Alzheimer's disease in 2005. As the disease progressed, Sharon struggled with taking care of her husband at home. During the difficult period when Anthony wandered, he ended up in ERs, private psychiatric facilities and homes without Alzheimer's units. Some facilities rejected him. But with the help of the Chapter's residential care specialist, Sharon was able to place him in a facility with a floor specifically for people with dementia, Isabella Geriatric Center. Isabella is one of the partners in the Chapter's Palliative Care Project.

**Jed Levine (JL):** Thank you, Sharon, for taking the time to speak with us about your experience with palliative care for your husband, Anthony, at Isabella Geriatric Center. What makes this care different from other homes he was in?

**Sharon Corso (SC):** They have a specific floor for wanderers, where he is not mixed in with the general population. At other facilities, if he was mixed in [with the general population] the staff would yell, pull him out of the [other residents'] rooms, which would cause him to react, and become combative. Afterwards, the staff would label him as violent, send him to the emergency room in a hospital where the doctors would shoot him full of Haldol, and he'd be a vegetable when he came back. After the fourth time, they refused to take him back.

**JL:** What happened then?

**SC:** Another home accepted him. Within four hours, they labeled him as violent. When the transporter

came, she recognized what was going on. She said, "He's not violent. He's only an Alzheimer's patient." She spoke to him gently, and said, "Let's take a ride." Then he was cooperative.

**JL:** She knew how to talk to him.

**SC:** Yes, and then he ended up in a psychiatric unit at a hospital. I was so grateful they held him for three months. There was a nurse there who knew exactly how to handle Anthony. He knew, if he doesn't want to eat, leave him alone. If he doesn't want to get dressed, walk away and come back later. The other patients knew how to take care of him. From there, it was a hard struggle finding a permanent placement for him, but with the help of the Chapter and some others, I got him into Isabella.

**JL:** What was that transition like?

**SC:** Even then I was so nervous, but they told me not to worry, we don't throw anyone out. We understand him; he's not the first patient we've had like that, and he won't be the last. It will be fine. Go home, get some sleep, and don't worry if the phone rings.

**JL:** How reassuring!

**SC:** Very. Did I believe it? No! Not until I became accustomed to it. I was so fragile and afraid at the time. Like most people, I didn't get the meaning of palliative care. Most people think it is for people with six months to live. The real meaning of palliative care is relieving and preventing suffering. If anyone doesn't think an Alzheimer's patient doesn't suffer...they do, in the brain. I was blessed to find Isabella. Even though it's an hour and half travel



each way for me, I don't care. He has blossomed with the caring people he has now. Families from the other floors are jealous of the 8th floor.

**JL:** What is Anthony like now?

**SC:** I don't know what Anthony would be like without this palliative care program. He dances, he smiles. I'm not saying he doesn't have his bad moments, but the staff knows what to do. Most of the time he's happy in his mind and he's flourishing.

**JL:** What was this whole experience like before you moved Anthony to Isabella?

**SC:** Hell. In one word: HELL! The process of going to the other home – it drained me. I didn't have a moment's peace. I wouldn't socialize; I couldn't even talk on the phone. I was so tired; exhausted. If you think I am thin now – I was even thinner then, even though I ate. I developed an ulcer. I got sick.

**JL:** There's an important message in your experience. The palliative care approach is helpful to the resident, but it's equally helpful to the family members. If the person with dementia is not in distress, the

family members are not distressed.

**SC:** I go out now. Of course I miss Anthony, but I am happy that he is happy.

**JL:** Explain more about that.

**SC:** I used to not be able to go out when he was living with me. And before we got him into Isabella, I worried about him and still did not take care of myself. Now that I know how well they treat him with this palliative care program, I worry less. They let him have his own routine. For example, when I visit the staff tells me that Anthony is the poster boy for letting patients sleep late. It is a great example of how to treat a person with dementia and tailor to his needs. They told me that if he was sleeping and they got him up, he was not a happy camper

**JL:** Of course! I'd be cranky too.

Do you know that the nurses on Anthony's floor actually have fun with the patients? They throw a birthday party once a month and those nurses were dancing up a storm. They have a good time with them; they laugh with them. Who could ask for anything more? He has a better life there than he had at home with me.

Anthony has a roommate and he takes care of him. Anthony takes him for a walk down the hall. My heart just bursts with joy when that happens. It brings tears to my eyes.

**JL:** So how does this help you? How do you keep your strength up?

**SC:** My strength comes from the smile I get when I see Anthony. I was able to start being social again. I do a lot of things. I meet my friends, go to the theater, and I enjoy being on my own.

**JL:** I think a lot of people don't understand how difficult it is to be an Alzheimer's caregiver, and to create a life outside the caregiving relationship.

**SC:** Everyone should take the caregivers course (The Family Caregiver Workshop offered by the Chapter). It made a huge difference. I learned how to speak to him and how not to speak to him. I was mad as hell...why did I have to change?

**JL:** You had every right to be angry.

**SC:** But you know what? It made a better person out of me. I am a much better person, much more tolerant of Anthony.

**JL:** Eight years is a long time.

**SC:** It was not all that difficult. The last three were the hardest. And Anthony is in a good place, and so am I.

**JL:** Thank you, Sharon, for speaking with us and sharing your experience.

**The real meaning of palliative care is relieving and preventing suffering.**

**SC:** So now, they let him sleep in if he doesn't want to get up. They let him sleep until 3 pm. Some of the other families complain about their relatives sleeping in or not following a routine. One woman complained that when she arrived her mother hadn't had her teeth brushed. I said, "So what? Who knew if when the staff went to her she became agitated? Maybe they'll try later." I don't sweat that stuff. I know that when Anthony gets up at three in the afternoon, the first thing is to get him something to eat, make sure he's changed. I don't know if his teeth are brushed yet. It's OK with me. It's exactly what you should do with him. Do what makes him happy.



**MORE CARE  
FOR THOSE  
WHO CARE  
EVERY DAY**

Thank you for being a family caregiver.

At EmblemHealth, we are committed to helping you get the information, assistance and support you need and deserve. That's why we've been supporting family caregivers for over a decade.

Visit and "like" our Facebook page today. Share your stories, your thoughts and your experiences with a larger community of caregivers — people just like you.

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careforthefamilycaregiver



**EmblemHealth**  
WHAT CARE FEELS LIKE.

## You Did a Little BIG Thing to #ENDALZ!



**Hillary Stuchin**  
Director of Public Policy  
[HStuchin@alzny.org](mailto:HStuchin@alzny.org)

Thank you, Advocates and Ambassadors!

In January 2014, we made an important step forward in the fight against Alzheimer's disease when Congress approved \$122 million in additional funding for research, care, and support services; the largest ever increase in federal funding for Alzheimer's disease.

This funding exceeds President Obama's initial budget request of \$100 million. We could not have achieved this major victory without the efforts and support of all of our dedicated Alzheimer's Association Advocates and Ambassadors, whose voices were crucial in gaining funding for one of our nation's costliest diseases.

The new Alzheimer's federal funding is a part of the \$1 billion increase in funding for the National Institutes of Health (NIH). This funding will allow the NIH to continue research studies and clinical trials already underway, and begin new ones, many crucial to the discovery and advancement of effective Alzheimer's disease therapies and treatments.

The NYC Chapter's city and state advocacy efforts also continue. Our *Crisis for Caregivers: Alzheimer's Disease in New York City* report was released in December 2013. In the report, the social and economic impact of Alzheimer's disease and caregiving are highlighted and recommendations are made to encourage new policies and increased support in New York City.

At the state level, we regularly encourage Governor Cuomo, our Assembly members, and Senators to increase New York State funding



*The New York State Alzheimer's Association Coalition Advocates and Chapter Staff raising awareness for Alzheimer's disease in Albany, March 5, 2014*



*New York State Rally to End Alzheimer's, Albany, March 5, 2014*

for Alzheimer's disease from a paltry \$559,000 per year to \$5 million per year.

With the unrelenting support of our Ambassadors and Advocates, we can continue to make a difference on Capitol Hill, in Albany, and at City Hall.

To learn more about Alzheimer's advocacy and what you can do to help, contact Hillary Stuchin at [hstuchin@alzny.org](mailto:hstuchin@alzny.org) or 646-744-2965.



## Taking on Alzheimer's for our Future

By Marielle Mindlin Bernstein  
Junior Committee President

**T**he Junior Committee (JC) is ready to take on Alzheimer's for our future.

Alzheimer's has affected us all in one way or another, and now it's our time to take on this disease head-on so that we can have a brighter future. We know it is our responsibility to raise awareness, raise funds, and put our "young" faces to this disease, so that our generation will not have to suffer as caregivers and as patients.

The JC started off 2014 by welcoming our new executive board. Marielle Mindlin Bernstein (President), Julie Scherr (Vice President), Maxine Squires (Secretary), and Gabrielle Maguire (Treasurer) are thrilled to

be taking on their new roles and have already been working extremely hard to set up the JC for a fantastic year.

The JC is planning a wide variety of programs and events for 2014. In addition to our Outreach programs (where we engage directly with Alzheimer's patients), and our science updates (where our advisor updates the group on the latest advancements), we are looking forward to engaging in both awareness and fundraising events.

We sent three JC members to the Albany Advocacy Day in March, and four members to the Advocacy Forum in Washington, D.C., to lobby and fight for our cause. Our Corporate Relations committee is looking to expand and take advantage of the connections JC members have with corporations. In addition to our very

successful Masked 'Til Midnight Gala, we're currently planning smaller fundraisers so that there is something for everyone.

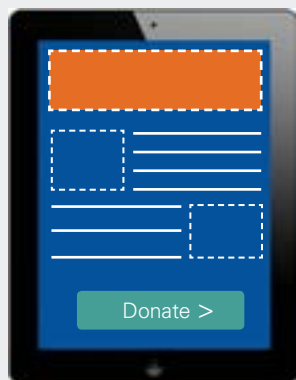
In general we want to increase our presence, so that people know who we are and what we are here to do. We plan to do this by writing articles, making videos, using social media, and igniting our generation to take action.

We are always looking for new members at the JC, so please come and join us. All are welcome!

You can always find out the latest information about us and our events on our website at [www.alznyc.org](http://www.alznyc.org) or on Facebook at [www.facebook.com/juniorcommittee](http://www.facebook.com/juniorcommittee).

## Get Involved! Become a Chapter Champion

Your support of our mission means so much to us, and to the millions of people living with Alzheimer's. Make a difference in the fight against Alzheimer's.



### Celebrate a Special Occasion With Us!

Let us design a project to celebrate your special occasion.

Birthdays, anniversaries, Bar and Bat Mitzvahs, graduations, weddings. All are opportunities to give something back. You can raise awareness, support the cause and make a special event more meaningful for you and your guests. We can help by designing a personalized website for your event. You can make a difference in the fight against Alzheimer's.

### We Provide:

- **A Website** - your choice of a blog or webpage complete with a donation scroll to keep track of your progress
- **Marketing and Branding** - we will help you market your project, events, and any other ideas you might have to raise awareness and funds
- **Support** - we will do our best to help you hit the ground running from beginning to end

For more information and examples of our Chapter Champions, visit  
[www.alznyc.org/champions](http://www.alznyc.org/champions)



**Carol Berne**

Senior Vice President of Development,  
Director of Leadership Giving

[CBerne@alzny.org](mailto:CBerne@alzny.org)

Over the course of more than 35 years, the NYC Chapter has been defined as a leader in dementia care by championing bold ideas and taking intelligent risks. In keeping the needs of caregivers and persons with dementia at the center of our work, we have been able to design programs and services to help manage the challenges associated with Alzheimer's disease and enhance quality of life. With significant support from grant makers and individuals who are willing to invest in the potential of our ideas, we have been able to make our mark as an innovator in dementia care.

Our Palliative Care Project, which is featured largely throughout this newsletter, is undoubtedly one of the more ambitious projects that the Chapter has ever embarked upon. This 30-month pilot program, which launched July 1, 2012, involves partnerships with three residential care facilities and their three hospice partners; and includes extensive evaluations and meticulous planning to spread improved palliative care practices facility-wide. It is not just the scope of the project that makes this project ambitious, but the very subject of palliative care.

To carry out this project required significant private support and a tremendous vote of confidence from some of New York City's most respected foundations. The Altman Foundation, The Fan Fox and Leslie R. Samuel Foundation, Inc.,

The Mayday Fund, The Milbank Foundation for Rehabilitation, The PARC Foundation and the United Hospital Fund, as well as individual donors and the NYC Chapter, encouraged us to take on this project with their financial support. In just a little over a year, \$650,000 was raised—in addition to our fundraising efforts for core programs and services.

While working to complete the pilot phase, we are already planning next steps. With a capacity building grant from the Altman Foundation we are defining our role in palliative care and determining the best methods to fulfill this role. This will include integrating palliative care into our work at the Chapter while continuing to make this approach to care more accessible throughout NYC and beyond.

Hand in hand with our philanthropic partners, we are changing the way care is provided to persons with dementia. As you read this issue of the newsletter, and all we have accomplished, I hope that you share in our pride.

And please see page 17 for how the Chapter has helped a caregiver. We hope that you will support our Mother's Day and Father's Day Campaign.

As always, please contact me at 646-744-2905 or [cberne@alzny.org](mailto:cberne@alzny.org) if you would like further information.

## Know Your Charity

The following organizations ARE NOT affiliated with the Alzheimer's Association:

American Health Assistance Foundation  
Alzheimer's Foundation of America (AFA)  
Long Island Alzheimer's Foundation (LIAF)  
Staten Island Alzheimer's Foundation (SIAF)  
Alzheimer's Disease Resource Center (ADRC)

## Ways to Give

### Giving by Check

Please make checks payable to the Alzheimer's Association, New York City Chapter. For your convenience, a self-addressed postage paid envelope has been provided in this newsletter.

### Online/Credit Card

Visit [www.alz.org/nyc](http://www.alz.org/nyc) 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. Full fair-market value deduction is allowed provided the security has been held more than one year (long-term capital gain property); otherwise, the deduction is limited to the donor's adjusted tax basis.

### Bequests

By remembering the Alzheimer's Association, New York City Chapter 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 the Alzheimer's Association, New York City Chapter, 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 NYC Chapter program or research program.)*

### Life Insurance and Retirement Plans

The Alzheimer's Association, New York City Chapter can be named a beneficiary of your retirement plan or insurance policy.

### Tribute Gifts

Tribute gifts provide a special opportunity to honor the memory of a family member, friend or colleague, or to recognize an individual or a life occasion.

### Corporate Giving

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

Please note that gifts and bequests made by NYC donors are shared between the NYC Chapter and the National Alzheimer's Association unless the donor specifically requests that the gift be restricted for research or for a New York City Chapter program.

Please contact Carol Berne, Senior Vice President of Development, Director of Leadership Giving, at 646-744-2905 or [cberne@alzny.org](mailto:cberne@alzny.org) if you would like additional information.



The Alzheimer's Association, New York City Chapter meets the Better Business Bureau Wise Giving Alliance Standards for Charity Accountability.

The NYC Chapter 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.



May 2014

## Dear Friends of the NYC Chapter,

"Donna, I'm here with your mother. She was wandering around the hallway, not knowing where to go."

My heart froze. I was so afraid. This call from a kind neighbor turned out to be a defining moment in my family's life. I could no longer deny the extent of my mother's dementia. It was clear that she could not live alone. We moved mom in with us the next week.

Initially I was paralyzed with fear, not knowing where to turn for help. Through my company, I was put in touch with the New York City Chapter. It was there where I began to learn all I could to help my mother and access the support I needed as a caregiver.

I attended educational programs, including Understanding Dementia, Legal and Financial, and Medicaid Home Care seminars, as well as the Family Caregiver Workshop. These programs provided practical advice on how to care for my mother, all offered free of charge. I also joined a support group where I met other daughters who were dealing with the same issues as I was. We learned from each other, exchanging information gained during educational sessions and through our personal experiences as caregivers.

Throughout the next three increasingly difficult yet extremely rewarding years, my husband and I cared for my mother in our home. As her care needs grew more demanding, I began to think about nursing homes and attended the Chapter's seminar Placing Your Relative in a Nursing Home. Around that time my mother fell and broke her hip and upon the advice of professionals, we decided to place her in a nursing home. It remains the hardest decision I have ever had to make. Fortunately, the support I received from the Chapter's dementia care experts and my support group "sisters" reinforced that I made the right choice.

One day I would like to assist other caregivers who are just beginning their journey. When I am no longer a caregiver I plan to become a support group leader to give back for the help that I received. This spring, as we celebrate Mother's Day and Father's Day, I hope you will consider honoring someone important to you and make a gift to the NYC Chapter. Your gift helps caregivers access the services to guide them through their journey. Thank you.

Sincerely,



DonnaMarie Arrigo

P.S. You can also make a secure donation online at [www.alznyc.org/mothersfatherscampaign](http://www.alznyc.org/mothersfatherscampaign).

P.P.S. Please consider dedicating a chair in Bryant Park as a way to honor someone special in your life or the lives of others by visiting [www.alznyc.org/bryantpark](http://www.alznyc.org/bryantpark), or call Crissy Vicendese at 646-744-2927 for more information.



## Dedication of The Dorene Scolnic Training Center



*Dorene (center) with brother Jeff Halis and his wife Nancy celebrate this special occasion*



*Friends and family gather to celebrate the dedication of The Dorene Scolnic Training Center*



*President & CEO, Lou-Ellen Barkan, unveils The Dorene Scolnic Training Center*



*Dorene and her daughter Sarah*



*Lauren Volkmer, Dementia Care Trainer (left), and Dorene Scolnic following their remarks*



*Dorene with her son Danny and her newest grandchild, Leah, who is named for Dorene's mother*

On Thursday evening, January 9, 2014, we celebrated the dedication of The Dorene Scolnic Training Center, in recognition of family caregiver Dorene Scolnic. This special honor was made possible by a generous gift from her brother and his family to recognize Dorene for her many years of caring for their mother who had Alzheimer's disease.

At the dedication, surrounded by her family and close friends Dorene so eloquently expressed, "This was not something I did alone... I had my wonderful immediate family, my extended family, friends and the amazing caretakers of mom. Everyone in this room this evening was a part of the circle, being there for me and

my family, listening, helping, and just supporting."

The celebration also served as a reminder of the devotion and love of caregiving. As Dorene further remarked, "I want so say very proudly that I am the daughter of an Alzheimer's patient, and I was honored to care for my mother in my home."

The Dorene Scolnic Training Center will be the heart of the Chapter's training and education programs; and will host a variety of programs including the Family Caregiver Workshops, which equip family caregivers with the tools and knowledge they need to care for their loved ones with dementia.



*Dorene Scolnic (front, 4th from left) and family gather for a photo at the dedication of The Dorene Scolnic Training Center*

## Innovations in Alzheimer's Research

On Thursday, January 16, 2014, 40 friends of the New York City Chapter gathered at the home of Board Co-Chair Jeffrey Jones and Ken Berger to kick off our 2014 Innovations in Alzheimer's Research series.

Drs. Mony J. de Leon and Ricardo Osorio, of the Center for Brain Health, NYU Langone Medical Center, spoke about the importance of sleep for brain health, and the relationship between Alzheimer's disease and sleep in the elderly population. Innovations in Research is designed to bring the latest findings in Alzheimer's research to friends and supporters of the NYC Chapter.



*From left, Jed Levine, Chapter Executive VP, Director of Programs & Services; Co-host Jeffrey Jones; Dr. Ricardo Osorio; Dr. Mony de Leon; and Co-host Ken Berger*



## Reserve Your Personalized Place in the Park

At this special time of year, as we welcome Spring and celebrate Mother's and Father's Days, recognize someone important in your life or the lives of others by dedicating a Bryant Park Chair in their honor. The poetic plaques that adorn the chairs enhance the beauty of the park, and are a lovely tribute for those most important to you.

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

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

## Protecting Your Family From Financial Fraud



**Matt Kudish**  
Senior VP of Caregiver Services  
[MKudish@alzny.org](mailto:MKudish@alzny.org)

In this day and age, no one is truly immune from being taken advantage of by a scam or a hoax. Individuals with dementia—not to mention their caregivers who are often overwhelmed and stressed—can be particularly vulnerable to a variety of forms of fraud, in many cases culminating in financial abuse.

Perpetrators come in all shapes and sizes. Some are deliberate, taking days, weeks, months or even years to develop a sense of rapport with their victims. Neighbors or other “concerned citizens” may appear as if they are trying to help by assisting with household chores or errands. Over time, they may insidiously maneuver their way into the lives of vulnerable, trusting individuals or families, slowly taking on more and more responsibility, from personal tasks such as paying bills and in some cases, managing finances. Once they’ve gained access to account information, credit card numbers, or other personal data, it can be quite easy for them to manipulate accounts and access money from an unsuspecting victim.

Others move more quickly, giving false claims about products they sell or the efficacy or value of services they provide. Some of these types of scams involve perpetrators contacting victims by phone and offering a service. Unsuspecting individuals might feel they’re getting a great bargain and provide personal data. Other scams of this nature involve someone claiming to be a representative from a company with which the vulnerable individual has done business, and will ask for social security numbers and dates of birth, allowing the perpetrators just what they need to gain access to other accounts. Still other scams originate via email.

Foreign scams that involve unsuspecting individuals receiving an email from a stranger informing them they have won a large cash prize. The “winners” are told that, in order to collect, they must send a smaller amount of money to cover the wire transfer of funds. People across the world have transferred their money only to learn that there was never any prize. Another common email scam involves a perpetrator hacking into an email account, allowing the perpetrator to send an email message as if from a friend. The email usually states that the friend is stuck in a foreign country or dangerous situation and requests that you wire money to help the friend get home. Many people have wired the money as instructed only to find later that the friend had never been in the difficult situation. By the time it is realized these are scams, the money is long gone and untraceable.

More recently we have heard about fraud occurring by perpetrators who have been approved by government agencies to provide assistance in applying for specific benefits or entitlements. A recent article in *The New York Times*, “Winning Veterans’ Trust, and Profiting From It” (December 23, 2013) included several stories of people who paid for assistance from persons accredited by the Department of Veterans Affairs (VA) to gain access to a VA benefit, only to find they were never eligible and, as a result, ended up in debt to private residential facilities. The article shed light on the loose oversight the federal government has on this particular program, as well as the importance for each of us to become educated consumers.

Below are just a few things we can do to protect ourselves from these types of situations.

- A good first rule of thumb is that if something sounds too good to be true, it probably is. If you are suspicious, pay attention to that feeling. Too often we dismiss

instincts that we should listen to.

- If you receive a suspicious call, be sure to obtain the caller’s full name, company and a telephone number where he or she can be reached. Do not feel as if you must make a decision in the moment. Tell the caller you want time to think about the offer and that you’ll get back in touch. Do the necessary research to ensure the call is legitimate before following up.
- Protect your vulnerable family member from potential abuse by limiting or removing access to valuable items including bank account information, credit cards and other personal data. Limit the amount of cash on hand and secure jewelry and other valuables in safe locations.
- Remember that dementia impairs one’s ability to make good decisions. If you’re concerned about a person with dementia being approached in his or her home, explore options for companions or home care services so he or she is not alone.

In this day and age it can be hard to know who to trust. In some instances, we are able to look back and recognize that perhaps there were red flags along the way. But in other cases, we are trusting and relying upon precisely the people we’re supposed to and there’s nothing we could have seen coming. The NYC Chapter is here to help. Let our professional staff with years of experience in these areas help you navigate these waters. If you’re unsure if a situation is legitimate or not, call our 24-hour Helpline at 800-272-3900 and let us try to help you figure it out. And if you feel you have been the victim of a scam or other financial fraud, call 311 to connect with the most appropriate city agency.

When we pay closer attention to our instincts and become more aware of potential red flags, we can protect ourselves and our family members from these and other types of financial crimes.

Dear Helpline,

It's been seven years since my mother was diagnosed with dementia and in the past two months she has been in and out of the hospital three times. I hate seeing my mother hooked up to tubes when she is in the hospital. When she is at home, she seems distressed and does not eat. It makes me uncomfortable to think that she may be in pain. How can I make her more comfortable?

- George



**Stephanie Aragon**  
Manager, Helpline  
[Helpline@alz.org](mailto:Helpline@alz.org)

Dear George,

**T**his must be a very difficult time for you and your family. Seeing someone so close to you who is unable to participate in activities of daily living such as eating and being unable to directly indicate what is causing personal discomfort causes stress to everyone around your mother. It is at this point that decisions must be made as to how to proceed with her care. Recently, palliative care has become a widely discussed topic among medical staff as well as families; in fact many hospitals have doctors and even units dedicated to palliative care.

Palliative care - or comfort care - primarily focuses on relieving pain. Unfortunately, many people mistakenly believe that palliative care is only provided during the last months of a person's life when in actuality it can start years earlier. Palliative care is appropriate for a person of any age, at any stage of a serious illness, and it can be provided along with curative treatment. Palliative care focuses on relief from the symptoms, pain and stress of an illness regardless of the diagnosis. The goal of palliative care is to improve the quality of life for the

person with the illness and involved family and friends.

Palliative care focuses on the physical, emotional and spiritual concerns that arise with a chronic illness. A palliative care approach should put an end to your mom being routinely readmitted to the hospital because it encourages a continuity of care across healthcare settings. Palliative care actively involves you in your mother's care. In order to prevent suffering at any stage of life, it is a good idea to include palliative care instructions in advance directives. Ideally, everyone would be able to state his or her wishes before the pressure of an emergency. If your mother has not expressed her wishes or no longer can, it's the healthcare proxy's role to talk with your mother's primary care physician as well as other relatives to create a care plan for your mother.

When thinking of palliative care, think of a person-centered approach in which you consider what matters most to your mother and how you can make her comfortable. Think of the pros and cons of continuing with treatment while keeping in mind that your mother's comfort is the guiding factor in the decision. Some questions to ask are: Is it necessary to continue to administer all medications? Should my mother be admitted to the hospital for acute medical conditions such as a urinary tract infection (UTI)?

One key thing to remember when trying to comfort your mother is behavior is communication.

If your mother cannot communicate verbally, she may communicate through her behavior. If your mother refuses to eat or spits out the food you give her, offer a different food. Some people with dementia prefer soft and sweet foods such as pudding, ice cream, soft cookies or you may want to consider giving your mother Carnation Instant Breakfast instead of Ensure.

Palliative care will allow you to provide the best quality of life for your mother at any stage of the disease. The NYC Chapter website, [www.alz.org/nyc](http://www.alz.org/nyc), has a section dedicated to palliative care. In this section, you will find a downloadable booklet entitled "Encouraging Comfort Care: A Guide for Families of People with Dementia Living in Care Facilities". The booklet was developed by the Alzheimer's Association, Greater Illinois Chapter and offers useful information to encourage and provide comfort to people with dementia.

Keep in mind that you can also schedule an appointment to meet with one of our Care Consultants to discuss in detail how to make your mother comfortable during her illness. To connect with us, call us around the clock at 800-272-3900.

## Japan-U.S. International Dialogue on Dementia



**Jed A. Levine**  
Executive VP, Director of Programs  
& Services  
[JLevine@alzny.org](mailto:JLevine@alzny.org)

Last December I was honored to represent the NYC Chapter at The Japan-U.S. Conference on Dementia Strategy organized by the Tokyo Metropolitan Institute of Medical Science and funded by the Japan Health and Welfare Bureau for the Elderly, Ministry of Health, Labour and Welfare. I was joined by Ruth Katz, Acting Deputy Assistant Secretary for Disability, Aging, and Long-Term Care Policy, U.S. Health and Human Services Department. Ms. Katz presented the U.S. National Plan to Address Alzheimer's Disease. My tasks were to describe the Chapter's programs and services, explain how they interface with the National Plan, and how they meet the needs of families coping with Alzheimer's in the largest city in the U.S.

I am happy to report that there was considerable interest in our resources for caregivers and the broad scope and variety of our programs, all centered on providing education, information, care and support for persons with the disease, their families and professional caregivers. There was also interest in our cultural and arts programs, the role of advocacy, and the Palliative Care for Advanced Dementia Project, a concept that is relatively new to Japan. There was great interest in the recently issued *Caregivers in Crisis: Alzheimer's Disease in New York City* report that the Chapter produced with former Borough President Scott Stringer's office, and our plans for developing a city-wide plan to address the issues and impact of Alzheimer's.

Speakers from Japan addressed the Japanese "Orange" Plan, the five year national dementia plan



(Top) Chapter Executive VP, Director of Programs & Services, Jed Levine and Ruth Katz listening to comments by Yume Shindo, Tokyo Dementia Care Research and Training Center (Middle) Jed Levine presenting the NYC Chapter's programs and services (Bottom) Jed Levine presenting the Chapter's Care ADvocate publication

published in 2012 and launched in 2013, dementia strategies in the Tokyo metropolitan area and resources for those living at home in Setagaya City, one of the 27 municipalities that make up Tokyo. The conference concluded with a lively panel discussion on the challenges of meeting the needs of persons with dementia in a large metropolitan area.

In the course of the conference, I learned a great deal about the Japanese and their challenges. The country has the highest life expectancy in the world: age 79 for men, 86 for women as compared to 75 for men and 80 for women in the U.S., according to the 2006 World Health Report. With over 20% of the population now age 65 or older, Japan is already where the U.S. will be in 10 years and is facing challenges that are just ahead for the U.S. Some examples: increased long-term care needs, the increased aging caregiver population and an increased number of working women who are no longer able to provide full-time care to their aging relatives.

Of course, there are also major differences between the U.S. and Japan. Our systems of paying for care are radically different. So much of our time needs to be spent helping families navigate the complex and convoluted system of paying for long-term care while cobbling together a cohesive and effective plan to provide and cover the costs of the best possible care for a relative with dementia.

In contrast, Japan has a public, universal long-term care system that is run by the government and administered by each municipality. Everyone over the age of 40 contributes a set percentage of their income, and everyone is covered, no matter their ability to pay, or the availability of caregiving by family members. Many services are home and community based, and the bias is toward keeping individuals at home, in their community, although institutional care is available as needed.



December 19<sup>th</sup>, 2013 Tokyo Metropolitan Institute of Medical Science

In our meeting, there was much discussion of the small group home model that is popular in Japan, and the importance of integrated, coordinated, community care. The goal of the Japanese long-term care system is to help families care for their affected relatives by assisting with some of the caregiving tasks. As the U.S. embarks on our first universal, national healthcare system, (which does not address long term care), it is incumbent on us to remember the long-term care needs of those with dementia, especially as those costs are projected to rise and ultimately may bankrupt the existing Medicare and Medicaid systems. We have much to learn from the Japanese model, which has over 10 years of history and has gone through multiple revisions.

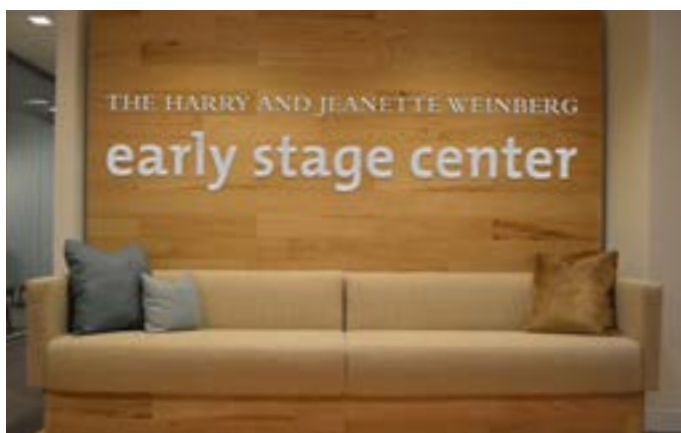
This fascinating trip reinforced how much we have to learn from other countries as we develop programs that are cost-effective and provide humane, person-centered care for the entire family. It also drove home that while we must continue to devote resources to find ways to prevent and cure dementia, it is equally critical that we address the needs of individuals and families who deal with these challenges every day.



*Living in the Land of Limbo* is the first anthology of short stories and poems about family caregivers. These men and women find themselves in “limbo” as they struggle to take

care of a family member or friend in the uncertain world of chronic illness, including Alzheimer’s disease and other dementias. Many of the authors are well-known poets and writers, for example, Alice Munro, Lorrie Moore, Julie Otsuka, and Robert Pinsky. Others have not been published in mainstream media. Carol Levine, the editor, directs the Families and Health Care Project at the United Hospital Fund, and was the caregiver for her late husband. The book is available from Vanderbilt University Press ([www.VanderbiltUniversityPress.com](http://www.VanderbiltUniversityPress.com)), Amazon, Barnes & Noble online, and at bookstores.

## Continuing to Meet the Needs



**Matt Kudish**  
Senior VP of Caregiver Services  
[MKudish@alzny.org](mailto:MKudish@alzny.org)

As we prepare to celebrate our first anniversary in our expanded space, the third floor at our midtown office, it seems an appropriate time to look back on the past year and examine all we have done in these last 12 months.

Programmatically, we have seen significant growth in the programs now housed on our new floor.

The three months immediately following our move, (April 1–June 30, 2013) represented a period of significant growth for nearly all of our programs impacted by the expansion, as compared to the previous quarter (Jan 1–March 30, 2013). Highlights include:

- Our 24-hour Helpline had 1,360 interactions, including calls and e-mails, an 80% increase from the previous quarter;
- Our 24-hour Helpline responded to 545 new callers, a 35% increase from the previous quarter;
- Our Care Consultants had 628 interactions, a 114% increase from the previous quarter;

- Our Education Meetings attracted 332 caregivers, a 14% increase from the previous quarter.

The Harry and Jeanette Weinberg Early Stage Center opened in April 2013, a month later than the rest of the third floor to ensure the comfort-level of our early stage clients. We now have an expanded comprehensive program dedicated solely to this particular client base and the Center is now open three days a week for client programs. Covering the same timeframe as above, Early Stage Center highlights include:

- We had 388 interactions with clients, a 19% increase over the previous quarter, and 65 office consultations, an increase of 59% over the same period;
- We conducted 57 group meetings with 322 attendees (a 68% increase in the group meetings and a 52% increase in number of attendees from the previous quarter).

We held six trainings/conferences for early stage clients and their care partners, as compared to two trainings/conferences in the previous quarter, representing an increase of 200% in trainings, and a 28% increase in the number of attendees, over the previous quarter.

### Longer Term Impact of Expansion

As we had expected, the growth trends continued into the first two quarters of FY14 (July 1–December 30, 2013), as the Chapter's expansion efforts became more widely known within the community. The following statistics draw attention to the long-term impact that the expansion has had on our programs over the course of the 2013 calendar year.

- Our 24-hour Helpline experienced 70% growth in total interactions, including calls and e-mails, as well as a 483% increase in the number of in-person counseling sessions;
- We held 74 Caregiver Education meetings, a 7.25% increase from the previous six months;
- We held 244 support group meetings throughout the city, a 2.5% increase from the previous six months;
- Our education meetings attracted 799 caregivers, a 28% increase from the previous six months;
- Our Care Consultants had 1,302 interactions (phone, e-mail, in-person), a 41% increase from the previous six months;
- The Chapter conducted 15 Family Caregiver Workshops,



a 7% increase from the previous six months, reaching 145 family caregivers;

- Our Early Stage Center held 102 group meetings, a 12% increase from the previous six months.

In addition to the impressive growth of our programs, the Chapter took this opportunity to reorganize the programs in the new space into a new program area, Caregiver Services. This change has allowed us to streamline our service delivery, making things more efficient both for our clients as well as our staff.

This new structure has provided an even greater opportunity for collaboration between programs, which provides staff with new

opportunities to work together and support one another in this often challenging field. The following are just a few examples of the way our new, more holistic approach has changed the way we work with clients.

Our 24-hour Helpline staff is working more closely with callers who are concerned about themselves or those diagnosed, or caring for someone in the early stage. This support has freed up our Early Stage staff to focus more on those clients who participate in the offerings of our Harry & Jeanette Weinberg Early Stage Center. Care Consultants are working with Early Stage staff, too, in order to assist families in managing the transition from early stage to middle, and beyond. This

more collaborative approach to our work enables us to assist clients more completely and walk with them throughout their journey.

Each day we continue to explore ways in which we can enhance the work we are doing, and together we strive to provide meaningful support and lighten the load of the dementia communities of New York City. To learn more about the exciting work we're doing, please call our 24-hour Helpline at 800-272-3900.

## Brooklyn Nets Partnership

### #ENDALZ Night with the Brooklyn Nets



**Sharon Lee**  
Manager, Marketing & Communications  
[SLee@alzny.org](mailto:SLee@alzny.org)

On Friday, January 24th, the Brooklyn Nets, basketball fanatics and members of the Alzheimer's community united at Barclays Center as the Nets took on the Dallas Mavericks. The Nets designated this home game as #ENDALZ Night to create greater awareness of Alzheimer's disease.

The game ball was presented by Lou-Ellen Barkan, Chapter President and CEO, Board members Stephen Casper

and Marianne Dziuba-Fiore, and Chapter supporter Mel Barkan. Nets point guard Shaun Livingston recorded a public service announcement for #ENDALZ Night that played at halftime. In it, he says, "Like basketball, fighting Alzheimer's is a team effort. The New York City Chapter of the Alzheimer's Association is here to help."

The Chapter had two information tables in the arena during the game. Fans and supporters of the Chapter stopped by to take home information and materials about Alzheimer's and how to help.

Fans who purchased their tickets through the Chapter supported Alzheimer's research and free services that are available to all New Yorkers who have Alzheimer's and to those who are taking care of someone with dementia.

Also, the top of 388 Bridge - the tallest building in Brooklyn - was lit in purple to mark #ENDALZ Night.

The Chapter is proud to work with the Brooklyn Nets to increase public awareness about Alzheimer's disease. Thank you to those who attended #ENDALZ Night wearing purple!



# DementiaAides.org



**Matt Kudish**  
Senior VP of Caregiver Services  
[MKudish@alznyc.org](mailto:MKudish@alznyc.org)

In October 2013, the Chapter launched an exciting new resource for family caregivers and home care workers. Two years in the making, DementiaAides.org is a web-based program that enables graduates of the Chapter's nationally recognized Dementia Care Training for Professionals who are interested in finding employment as home care workers to create and post online profiles. Family members looking to hire private home care workers are able to browse or search active profiles and contact the people whom they are interested in meeting.

We are delighted to report that in just a few short months, DementiaAides.org has over 100 graduates registered, with 40 active profiles as of this writing.

In order to learn more about our graduates and their use of the site, we recently conducted a brief survey. Graduates report that the site is easy to use, and two-thirds of respondents report having been contacted by a family who saw their profile on the website, in some instances leading to an employment agreement.

In a relatively short period of time, we are already seeing fabulous outcomes from DementiaAides.org and are thrilled with the impact this resource is making in the lives of persons with dementia, and family and professional caregivers alike. Upcoming enhancements of the site include the

ability for family members to create profiles and log in. This will enable family members to bookmark profiles they're interested in reviewing later and keep a list of aides with whom they are interested in connecting. This will also allow the Chapter to better capture the number of family members using the site, as well as to survey family members, in addition to aides, to learn more about their experience with the site and ways we can improve it moving forward. We will continue to update the site to ensure it remains as useful a resource as possible for the dementia communities of New York City.

For more information, visit [DementiaAides.org](http://DementiaAides.org) or reach us through our 24-hour Helpline at 800-272-3900 or via e-mail at [helpline@alznyc.org](mailto:helpline@alznyc.org).

## February & March 2014 50-hour Dementia Care Training for Professionals Graduates



*Juana Aristy, Carol Ayala, Stella Baker, Martha Burbano, Maria Columna, Yris Diaz, Irma Guisa, Josefa Matos, Deisy Medina, Maria Angelica Morel, Elena O'Brien, Eva Oyaga, Gladys Quintanilla, James Taborda, Waldina Terreros, Maria Ubillus, Miriam Vicente, Dalila Villacis, Adalgiza Romero.*



*Sharlene Collingwood, Shelly Collingwood, Jennifer Corry, Christine Dowling-Berns, Jayne Fox, Carmen Graham, Carol Harryson, Sheryl Irish, Ayawavi Menan, Betty Mitchell, Maria Mursch, Ladimila Sena, Loretta Shepherd, Mariana Tejada, Juana Vasquez, Palametia Williams*

## The Polar Vortex Couldn't Stop Team Athletes to End Alzheimer's



**Candace Douglas**  
Manager of Constituent Events  
CDouglas@alnyc.org

**D**uring the cold months of winter in New York City, when Mother Nature was at its worst and words like “snow accumulation” and “polar vortex” were being used on a daily basis, a group of 58 athletes were braving the elements in preparation to represent team Athletes to End Alzheimer's for the NYC Half Marathon.

Throughout three months of training that regularly boasted single digit temperatures, and puddles of black ice to avoid, our athletes ran together and grew stronger as a team. They knew that no matter how difficult the struggle would be to get to the finish line in downtown Manhattan, it would always pale in comparison to those faced by people with Alzheimer's disease and their caregivers. Together they have raised over \$100,000 in support of the programs and services offered by the Alzheimer's Association, NYC Chapter as well as critical funding for research to find a cure.

While the challenges to prepare for any athletic event may vary strongly, the motivation behind WHY our athletes participate remains ever-

present and non-wavering. They all believe that they can be an active part in the journey to the end of Alzheimer's disease. In 2014 alone, almost 300 athletes will proudly don purple and swim, bike, run and play football, while becoming physical advocates for the over five million Americans across the country suffering with this disease, who often cannot advocate for themselves.

In addition, the NYC Chapter is proud to have expanded our program to now allow any athlete participating in *any* event across the country to join our ranks as an Athlete to End Alzheimer's and raise awareness and funds for our cause. If you're participating in an event this year, and are looking to give back in the process, please contact [athletes@alnyc.org](mailto:athletes@alnyc.org) or call 646-744-2966 to find out how you can turn your event into a race for our cause.

As the spring settles in and the temperature shifts, our team will focus on being active in New York City in different ways. The first weekend of May brings our fifth annual entry into the TD Five Boro Bike Tour, where once again our cyclists will proudly sport their Athletes to End Alzheimer's jerseys as part of the largest cycling event in the nation. A few short weeks later, on Saturday, May 17, the

ladies of Blondes vs. Brunettes® will once again take over Octagon Field on Roosevelt Island with the mission to tackle Alzheimer's (but not each other) in our fourth annual powderpuff flag football fundraiser. Tickets are still available for this exciting family-friendly event and can be purchased at [www.bvbnyc.org](http://www.bvbnyc.org).

As always, we thank all of our athletes who are taking up the fight against Alzheimer's disease here in New York City and around the globe. With continued dedication to the cause, together as a team, we will all rejoice when one day, knowing that we were a part of the journey, we live in a world without Alzheimer's.

**For more information about the Athletes to End Alzheimer's program, please visit:**

**[alnyc.org/athletes](http://alnyc.org/athletes)**



## MedicAlert® + Alzheimer's Association Safe Return®



**Elizabeth Bravo Santiago**  
Manager, MedicAlert + Safe Return  
[ESantiago@alznyc.org](mailto:ESantiago@alznyc.org)

Thanks to our ongoing partnership with the New York City Police Department, our MedicAlert® + Alzheimer's Association Safe Return® (MASR) staff members Anastasiya Lee and Juliana Villegas were nominated by Sergeant Ernesto Castro Jr. from the Community Affairs Research and Development Department to participate in the Citizens' Police Academy program.

The Citizens' Police Academy is a 14-week training program offered every year by the New York City Police Department. Since the program was first implemented in 1993, as part of NYPD's effort to develop a working relationship with the community, over 3,200 community representatives from every borough have attended this program.

During the 14 weeks, Anastasiya and Juliana were trained in the legal, social and procedural aspects of policing. They can now better assess the roles and responsibilities in fostering productive police-community partnerships. They also continue to ensure the safety of persons diagnosed with Alzheimer's and other related dementias with commitment, compassion and dedication.

Our MASR staff members go into the community and educate the public about the MASR program, as well as the other free programs and services offered at the New York City Chapter. Our staff members are very committed and proud to reach out to the community during missing and found person incidents.



As soon as a missing person report is generated by the police department and called into the MedicAlert and Safe Return Emergency Line, our staff begins to assist by contacting family members, confirming identifying information, getting permission to go forward with our protocols, including faxing missing person bulletins, and initiating media attention. They also update the detective on the case with any new information.

We are always available to assist caregivers, providing support during the period that a person with dementia is missing, and afterwards to provide guidance and care planning to ensure the safety of the person with Alzheimer's disease or a related dementia. For the first half of this fiscal year, we have responded to 159 incidents of missing or found individuals.

If you know of someone who has Alzheimer's disease or a related

dementia and would like information about how to enroll them into our MedicAlert® + Alzheimer's Association Safe Return® program please visit [www.alz.org/nyc](http://www.alz.org/nyc) or call our 24-hour Helpline at 800-272-3900.

Please join us in congratulating Anastasiya and Juliana for completing the Citizens' Policy Academy Training!

### Concerned About Wandering?

Call our 24-hour Helpline at 1-800-272-3900 or visit us online at [www.alz.org/nyc](http://www.alz.org/nyc).

Nine years after an initial diagnosis of Alzheimer's, Mrs. Smith is 89 years old, has 24-hour care and is primarily bedbound and unable to feed herself. She cannot respond coherently to questions, although she occasionally says well known phrases, like "how are you?" She has struggled with recurrent urinary tract infections, and has recently been admitted for aspiration pneumonia. Because she apparently "mis-swallowed" and some food got into her lungs causing the pneumonia, the medical resident asked about placing a tube to feed Mrs. Smith directly through her stomach.

**A**lzheimer's disease (AD) and other dementias are progressive, life shortening, and lead to death, often after prolonged periods of medical complications, leaving families with difficult decisions in the latest stages of the disease. Palliative care or comfort care, a specialized medical approach for people with life-limiting illnesses, focuses on relieving distressing symptoms (e.g., depression, agitation) and pain, providing ways to address these dilemmas for patients with dementia and their families.

Palliative care is delivered by doctors, nurses, social workers and other specialists who work together with a patient's medical team to provide an extra layer of support and guidance. It is appropriate at any stage in a serious illness. Palliative care can ease the burden of AD for patients and families by focusing medical attention to ensure to deliver the best quality of life. The team can facilitate the advanced planning and discussion of issues that can provide peace of mind, decrease the burden on loved ones, and comfort the patient in the late stages of the disease.

When started early the patient can more readily participate in these discussions and help make decisions about feeding options, antibiotics, hospitalization, and the best place for care to be delivered. Knowing that their family members are going to be supported may be comforting for persons receiving palliative care.

Palliative care teams can help plan ways to establish and maintain daily

routines attuned to patients' personal preferences, which comforts patients and families. These routines may include physical exercise, offering favorite foods, and music and reminiscence therapy.

Other efforts may insure a positive environment that promotes quality of life by creating calm and quiet spaces, and using proper lighting to decrease shadows and facilitate good sleep habits. Palliative care teams may help treat some of the symptoms of AD, such as depression, anxiety, agitation, and difficulty sleeping.

The palliative care team can also help the family understand what might trigger distressing behaviors in a patient with AD. For example, patients with dementia are often undertreated for pain because they are unable to verbalize the need for medications, and caretakers need to be attentive to signs like grimacing, groaning, and other physical manifestations of pain.

Palliative care teams are highly trained in helping patients and families deal with the complex healthcare system. This is important because many patients with AD have other medical problems such as heart disease, lung disease or conditions that are debilitating and painful, and palliative care can ease the symptoms and pain these might cause. In places with no such teams, physicians and families can work together to employ the principles of symptom management and comfort care. In the case of Mrs. Smith, the palliative care team explained to her family and doctors

that the management of infections and pneumonia can often be done at home, avoiding risks of hospitalization, and explained that research suggests that the placement of a feeding tube may lead to other complications without increasing life expectancy or quality of life in end stage dementia. Choices that maximize comfort over prolonged life may be considered.

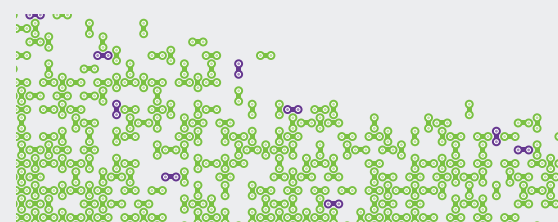
Palliative care teams are found in hospitals, hospices and out-patient clinics. For more information, go to [www.getpalliativecare.org](http://www.getpalliativecare.org).

Furthermore, the Alzheimer's Association, New York City Chapter has a number of helpful publications for caregivers such as "End of Life Decisions" and "Encouraging Comfort Care: A Guide for Families of People with Dementia Living in Care Facilities" which can help guide families and their primary physicians, and which are both available on our website, [www.alz.org/nyc](http://www.alz.org/nyc).

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[www.alz.org/trialmatch](http://www.alz.org/trialmatch)



# Spring 2014 Calendar

## MAY

### 1 Thursday

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

Time: 12:30 – 2:00 p.m.

Borough: Queens

*Note: This meeting is for family caregivers only.*

Medicaid Home Care Seminar: A Practical Guide to the System

Time: 5:30 – 7:00 p.m.

Borough: Manhattan

*Note: Prior attendance at a Legal & Financial Seminar is required.*

### 4 Sunday

TD Bike Tour

Time: 7:00 a.m. – 3:00 p.m.

Borough: Manhattan

### 5 Monday

Legal & Financial Seminar

Time: 12:00 – 1:30 p.m.

Borough: Manhattan

### 9 Friday

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

Time: 12:00 – 1:30 p.m.

Borough: Manhattan

*Note: This meeting is for family caregivers only.*

### 12 Monday

Educational Meeting

Time: 6:00 – 8:00 p.m.

Borough: Manhattan

Topic: Days Well Spent: Activities with Meaning

Speaker: Nancy Lee Hendley, Dementia Care Trainer, Alzheimer's Association, NYC Chapter

RSVP Online at [www.alz.org/nyc](http://www.alz.org/nyc)

### 13 Tuesday

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

Time: 5:30 – 7:00 p.m.

Borough: Manhattan

*Note: This meeting is for family caregivers only.*

### 17 Saturday

Blondes vs. Brunettes Powderpuff Football Game

Time: 6:30 – 9:00 p.m.

Borough: Manhattan

### 19 Monday

Legal & Financial Seminar

Time: 5:30 – 7:00 p.m.

Borough: Manhattan

### 20 Tuesday

Placing Your Relative in a Nursing Home

Time: 5:30 – 7:00 p.m.

Borough: Manhattan

### 21 Wednesday

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

Time: 5:30 – 7:00 p.m.

Borough: Manhattan

*Note: This meeting is for family caregivers only.*

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

Time: 6:00 – 7:30 p.m.

Borough: Brooklyn

*Note: This meeting is for family caregivers only.*

### 22 Thursday

Legal & Financial Seminar

Time: 5:30 – 7:00 p.m.

Borough: Manhattan

## JUNE

### 2 Monday

Legal & Financial Seminar

Time: 12:00 – 1:30 p.m.

Borough: Manhattan

2014 "Forget-Me-Not" Gala

Time: 6:30 – 11:00 p.m.

Borough: Manhattan

### 4 Wednesday

Understanding Dementia: What You Need to Know and Where to Go - **Just for Latinos!**

Time: 5:30 – 7:00 p.m.

Borough: Manhattan

*Note: This meeting is for family caregivers only.*

### 5 Thursday

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

Time: 12:30 – 2:00 p.m.

Borough: Queens

*Note: This meeting is for family caregivers only.*

Medicaid Home Care Seminar: A Practical Guide to the System

Time: 5:30 – 7:00 p.m.

Borough: Manhattan

*Note: Prior attendance at a Legal & Financial Seminar is required.*

### 9 Monday

Educational Meeting

Time: 6:00 – 8:00 p.m.

Borough: Manhattan

Topic: Using Personalized Music to Improve Quality of Life

Speaker: Dan Cohen, Founding Executive Director of Music & Memory, MSW

RSVP Online at [www.alz.org/nyc](http://www.alz.org/nyc)

### 10 Tuesday

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

Time: 5:30 – 7:00 p.m.

Borough: Manhattan

*Note: This meeting is for family caregivers only.*

### 11 Wednesday

Understanding Dementia: What You Need to Know and Where to Go - **For Health-Care and Social Service Professionals**

Time: 3:00 – 5:00 p.m.

Borough: Manhattan

*Note: This meeting is **not** for family caregivers*

### 13 Friday

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

Time: 12:00 – 1:30 p.m.

Borough: Manhattan

*Note: This meeting is for family caregivers only.*

#### Registration is **REQUIRED**.

All meetings are free of charge.

RSVP online for Monday Educational Meetings at [www.alz.org/nyc](http://www.alz.org/nyc)

Please call our  
24-hour Helpline at  
**800-272-3900**  
to register for meetings.

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:

CAPE at the Samuel Field YM-YWHA  
Riverstone Senior Life Services  
Heights & Hills  
Presbyterian Senior Services

## JUNE

**16 Monday**

Legal &amp; Financial Seminar

Time: 5:30 – 7:00 p.m.

Borough: Manhattan

**17 Tuesday**

Placing Your Relative in a Nursing Home

Time: 5:30 – 7:00 p.m.

Borough: Manhattan

**18 Wednesday**

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

Time: 5:30 – 7:00 p.m.

Borough: Manhattan

*Note: This meeting is for family caregivers only.*

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

Time: 1:00 - 2:30 p.m.

Borough: Brooklyn

*Note: This meeting is for family caregivers only.***26 Thursday**

Legal &amp; Financial Seminar

Time: 5:30 – 7:00 p.m.

Borough: Manhattan



## connect <sup>2</sup> culture®

Looking for a way to spend time with someone with dementia? **Check out Connect2Culture!**

Connect2Culture is the Chapter's cultural arts program which, in partnership with major NYC cultural institutions, provides meaningful activities for caregivers and persons with dementia. Visit a museum and explore art, participate in our We Sing! sing-along program, or dance with our ballroom partner Rhythm Break Cares at a social tea dance.

For more information about Connect2Culture, visit [www.alznyc.org/c2c](http://www.alznyc.org/c2c)



## Walking Wanda Attends Opening Day at Yankees Stadium

The Alzheimer's Association, NYC Chapter is proud to introduce "Walking Wanda", our new Walk to End Alzheimer's mascot! Look out for her as she travels across the city, and the world, bringing our mission to end Alzheimer's to a neighborhood near you. Follow her travels by using #WalkingWanda on Twitter, Instagram and Facebook.

## JULY

**3 Thursday**

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

Time: 12:30 – 2:00 p.m.

Borough: Queens

*Note: This meeting is for family caregivers only.***7 Monday**

Legal &amp; Financial Seminar

Time: 12:00 – 1:30 p.m.

Borough: Manhattan

**8 Tuesday**

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

Time: 5:30 – 7:00 p.m.

Borough: Manhattan

*Note: This meeting is for family caregivers only.***10 Thursday**

Medicaid Home Care Seminar: A Practical Guide to the System

Time: 5:30 – 7:00 p.m.

Borough: Manhattan

*Note: Prior attendance at a Legal & Financial Seminar is required.***11 Friday**

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

Time: 12:00 – 1:30 p.m.

Borough: Manhattan

*Note: This meeting is for family caregivers only.***14 Monday**

Educational Meeting

Time: 6:00 – 8:00 p.m.

Borough: Manhattan

Topic: Research Update

Speaker: Karen L. Bell, MD, Professor of Neurology at CUMC Taub Institute for Research of Alzheimer's Disease

RSVP Online at [www.alz.org/nyc](http://www.alz.org/nyc)**15 Tuesday**

Placing Your Relative in a Nursing Home

Time: 5:30 – 7:00 p.m.

Borough: Manhattan

**16 Wednesday**

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

Time: 5:30 – 7:00 p.m.

Borough: Manhattan

*Note: This meeting is for family caregivers only.*

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

Time: 6:00 – 7:30 p.m.

Borough: Brooklyn

*Note: This meeting is for family caregivers only.***21 Monday**

Legal &amp; Financial Seminar

Time: 5:30 – 7:00 p.m.

Borough: Manhattan

**23 Wednesday**Understanding Dementia: What You Need to Know and Where to Go - **IN SPANISH**

Time: 5:30 – 7:00 p.m.

Borough: Upper Manhattan

*Note: This meeting is for family caregivers only.***24 Thursday**

Legal &amp; Financial Seminar

Time: 5:30 – 7:00 p.m.

Borough: Manhattan

**28 Monday**Legal & Financial Seminar - **Just for Latinos!**

Time: 5:30 – 7:00 p.m.

Borough: Manhattan

**30 Wednesday**

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

Time: 5:30 – 7:00 p.m.

Borough: Upper Manhattan

*Note: This meeting is for family caregivers only.*

### Family Caregiver Workshop

The Family Caregiver Workshop is a 10-hour education program devoted to the needs of the family caregiver. The workshop covers a number of topics including:

- Understanding cognitive, behavioral, and functional changes due to dementia
- Developing skills and strategies to enhance communication
- Problem-solving of common dementia-related behaviors
- Caring for the caregiver/practicing self-care

Attendance is required at all meetings during a workshop series.

**Call our 24-hr Helpline at 800-272-3900 for workshop schedule.**

**New York City Chapter**

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

CHANGE SERVICE REQUESTED  
[www.alz.org/nyc](http://www.alz.org/nyc)  
646 744 2900  
800 272 3900 — 24-hour Helpline

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# EVERYONE HAS A REASON TO END ALZHEIMER'S.

## WALK WITH US THIS OCTOBER!

**Sunday, October 19, 2014**

**Riverside Park, Manhattan | 9:00am**

*Also, join us for our Walks in Brooklyn & Queens!*



24-hour Helpline  
800-272-3900

[alznyc.org/walk](http://alznyc.org/walk)  
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