



CaringKind: The Art of Alzheimer's Caregiving

Interview with Jed A. Levine



By Jean Galiana

ACCESS Health International

New York, September 2016



ACCESS
health international

Our vision is that all people, no matter where they live,
no matter what their age, have a right to access
high quality and affordable healthcare.

www.accessh.org

Copyright © 2016 ACCESS Health International

*ACCESS Health International, Inc.
1016 Fifth Avenue, Suite 11A/C
New York, New York 10028
United States*



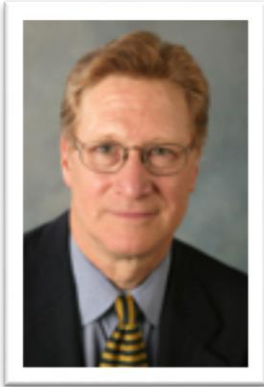
Elder and Long Term Care

An ACCESS Health International Program Area

Background

For over thirty years, CaringKind has provided free support, assistance, and education to those living with dementia and their caregivers who reside in the five boroughs of New York City. CaringKind also offers training for professionals who care for people living with dementia. In this interview, the Executive Vice President and Director of Programs and Services, Jed A. Levine, describes the support, education, and outreach programs of CaringKind. He also discusses their research of palliative care for those living with dementia.

About Jed A. Levine



Jed A. Levine is Executive Vice President and Director of Programs and Services at CaringKind, The Heart of Alzheimer's Caregiving, formerly known as the Alzheimer's Association, New York City Chapter. He is the principal investigator for the Palliative Care for Advanced Dementia: Training and Implementation project. He has been on staff since 1990.

Mr. Levine is the author of numerous articles on Alzheimer's disease and Alzheimer's care, the coauthor of a chapter in *Improving Hospital Care for Persons with Dementia*, and the coauthor of the chapter Alzheimer's Disease and Related Disorders in *Geriatric Mental Health Disaster and Emergency Preparedness*.

He holds a Master's degree in Applied Human Development with a specialization in Gerontology and Community Recreation Services from Columbia University's Teachers College. He has postgraduate training in group process from the Center for the Advancement of Group Studies, and is pursuing a certification in psychoanalytic training at the Center for Human Development.

He has taught at Columbia Mailman School of Public Health and Hunter College, School of the Health Professions. He was appointed by the Governor to the New York State Coordinating Council for Services Related to Alzheimer's and Other Dementias, serves on United States Senator Gillibrand's Working Group on Aging and was appointed by the Mayor to the Age-Friendly New York Commission at the New York Academy of Medicine.

Mr. Levine has presented nationally and internationally on dementia including the Japan US Conference on Dementia Strategy in Tokyo.

Interview

Jean Galiana (JG): What is the history of CaringKind?

Jed Levine (JL): Family caregivers founded the Alzheimer’s Society of NY & NJ (that would become Alzheimer’s Association, New York City Chapter, and then CaringKind in 2015) in the late seventies, at a time when there was no source of support, information, or education about Alzheimer’s disease. At that time, Alzheimer’s was still only a footnote in medical textbooks. It was not daily front page reading in the *New York Times*, the *Wall Street Journal*, or other newspapers, as it is today. Families came together to help each another. There were six other entities in the country that were doing the same kind of grassroots work. In the mid 1970s, this group of advocates met with Dr. Robert Butler, the father of gerontology. This was around the time the National Institute on Aging was being formed. Dr. Butler recognized that Alzheimer’s disease was going to become a major issue that needed both a local and a national response. He encouraged the formation of the national organization with local chapters. In 1985, we reincorporated under the Alzheimer’s Association as the New York City Chapter and, in December 2015, we returned to our roots as an independent 501C3 organization, rebranding in March 2016 as CaringKind.

New Yorkers have access to our extensive portfolio of programs, services, support, information, and education to help families who are dealing with a daunting challenge. I always say, “Unless you have done it, people do not really understand.” People do not understand how demanding and exhausting it is to care for someone living with dementia. Caregivers are not only caring for someone with memory loss, but someone who can no longer function on many other levels. The caregiver, who is likely an older individual, is also experiencing the loss of their family member, with whom they have spent most of their life. We help families and individuals cope with grieving for someone who is still living.

We recognize that the person receiving the diagnosis and their family are often in a lot of emotional pain. Sometimes



they are paralyzed with fear and the feeling of helplessness. Most people do not know where to begin. If they call us for information and direction, they also receive validation for what they are experiencing. Many report that they feel like they are losing their mind. We assure them that they are not crazy and that they do not have to face the challenge alone. We know a lot about providing good care for people with the disease and, equally important, about providing good care for the caregiver. We use technology to enhance and expand access, but Alzheimer's is such a profoundly human disease that we believe people are best served by delivering information and support in person. Our model is high touch, face to face, person to person, and voice to voice.

JG: How is CaringKind supported?

JL: Prior to the last state fiscal year, we were ninety seven percent philanthropically supported. Today, we receive more funding through the New York State Alzheimer's Community Assistance Program as a subcontractor to the Coalition of New York State Alzheimer's Association Chapters. We are also a subcontractor on a New York University Langone Medical Center grant. We have another grant from the state to work in Queens. We are now approximately eighty five percent philanthropically supported. That is still high. Our fundraising and constituent events teams are critical to ensuring that we have financial support. Our junior committee is an actively engaged group of young professionals, most of whom have had a parent or grandparent with the disease. They also raise funds to support our vision.

JG: Is your board actively involved?

JL: We have a great board. For most of them, this is a very personal mission, because the disease has affected someone in their family. Board support was critical to the success of our transition from the Alzheimer's Association to CaringKind. Three years ago, due to increased demand for our services, we doubled our space. It is uncommon for a relatively modest sized nonprofit to undertake such a big venture. We took the risk and doubled our footprint. We continued that expansion to add staff who are working in Staten Island and Queens and one person who is working in Brooklyn. That person will soon work in the Bronx also.

JG: If someone was recently diagnosed with dementia, how do they connect with CaringKind? Can they just walk in the door?

JL: They can certainly walk in the door but most people call. Many people find us online. They also connect through email. We also have an active, twenty four hour helpline (646-744-2900) for guidance, support, and advice. Additionally, we educate physicians and other healthcare providers about our programs and encourage them to refer caregivers to us. Doctors, as you would expect, do not have the training or the time to deal with caregiver issues. They also do not know the resources. Our Rapid Referral Program makes it easy for the doctor to tell a family member, “I would be happy to have someone at CaringKind give you a call.” After signing a release, we receive an email or fax from the doctor’s office and we call the family the next day. We reach out to them because when someone is caring for a person with Alzheimer’s, the idea of having one more thing to do, making one more call, often seems impossible.

JG: What clinicians participate in the rapid referral Program?

JL: Doctors, nurse practitioners, physician’s assistants, and medical office receptionists. One does not have to be a doctor to make the referral. Anyone can say, “I would love to have someone from CaringKind helpline give you a call to let you know about the services that are available in the community. They can help you navigate this situation.”

JG: What are the most common reasons that people call the helpline?

JL: People call for a wide variety of reasons. Often they are looking for some place to be diagnosed, or they need home care, or are interested in day care. Some call because of some new behavior or issue that the person with dementia is demonstrating. When our helpline specialists learn more about the situation and listen empathically, callers feel heard. They can then begin to address some of the issues at hand, and learn about the free support and education programs we offer at CaringKind. Some people call because they are concerned that they are experiencing memory difficulty. We connect the concerned caller to the medical and healthcare professional community to arrange an examination.

JG: Do caregivers call when they are overwhelmed and stressed?

JL: Many people call and don’t have specific questions. They simply need to talk. They are frustrated, exhausted, and feel helpless. We receive many calls from people who have reached the end of their rope. They tell us that they do not know what to do or where to turn. These calls can last thirty or forty minutes, or longer. We are able to provide relief by referring them to either a social worker or one of

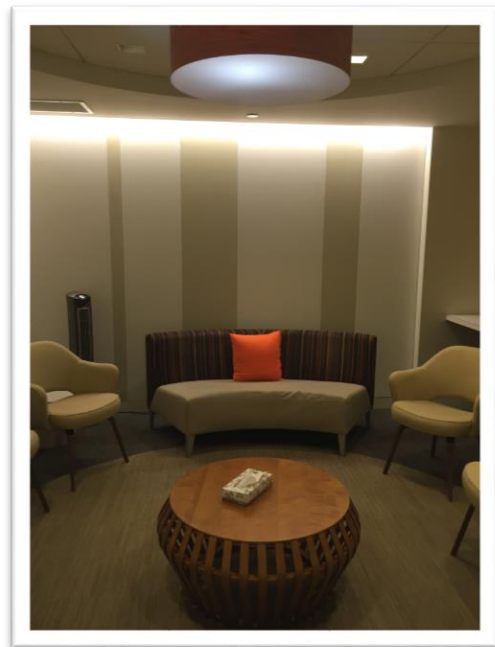
our programs. The callers are comforted to learn that there are supports available to them.

JG: How many helpline calls do you receive each month?

JL: We receive approximately seven hundred and fifty to nine hundred calls monthly. Most are during the day. The Medic Alert Foundation provides our after hour coverage. Although recently the overnight and weekend call volume is increasing. They send us reports the next day and we follow up with the caller.

JG: How many people does CaringKind serve in all of their programs combined?

JL: It is difficult to pin down that number, as there are individuals who are served in multiple programs. We have close to fifty thousand people on the mailing list for our newsletter. We have over ninety support groups with eight to ten participants per group. We conducted an informal survey and estimated that, including the trainees, the volunteers, and the support group members – approximately fifteen thousand people come through our doors each year. We serve a large number that is increasing as we expand into the boroughs with more on the ground outreach.



JG: Please describe the Early Stage Center.

JL: The Early Stage Center is close to my heart. In the early 1990s, we were mostly sponsoring support groups for family caregivers. We knew we had to offer more. Those with early stage Alzheimer's were not ready for adult day programs. They could not readily function in the programs for cognitively intact seniors. I was convinced by a colleague, Rhea Kahn, to co lead the first support group of people with early stage Alzheimer's. It was a deeply moving experience. There was a fullness of humanity in those sessions. We had many serious discussions about what it meant to have the disease, but there was also a lot of laughter, connection, and emotional support created in the room. Around that time, Rhea

and I hosted the first public seminar, featuring three or four of our early stage participants. It was one of the most dramatic evenings I remember. It was powerful to hear people telling their story for the first time publicly.

Eventually, because of the need for increased socialization, the participants expressed a desire to have lunch after the support group. At that time, we were located in another building, with a cafeteria upstairs. It was interesting because, in the cafeteria setting, we could see deficits that were not visible during our support group sessions. Soon we added museum and restaurant trips. They had difficulty making food choices. They could not manage the salad bar. It was a profound educational experience for us. That group grew to become the Early Stage Center. We now have eight programs per week and continue to grow.

JG: Please describe your support groups.

JL: We host approximately ninety support groups, most of which are for family caregivers. Fifteen to twenty of the support groups take place in our office. Most are held in community centers, hospitals, churches, synagogues, nursing homes, and community based organizations across the five boroughs. From 1990 to 2000, I co led the first support group for people with early stage dementia. Our clients asked for more so we created an entire program and an Early Stage Center.

JG: Please describe your groups and programs in the Early Stage Center?

JL: We have a program called Memory Works, which is a two hour cognitive stimulation program of trivia puzzle and word games. It is intense and people love it. We have three support groups for people with dementia. We provide meditation, yoga, and different arts programs including improv theatre. We have a film club. The club members watch a movie matinee weekly and participate in a group discussion afterwards. We held a photography program a couple of years ago. The group took photographs that were related to the theme that they had developed with the facilitator. We



had an exhibit and the participants discussed their work. Some of the participants had been avid photographers all of their lives and others had never been interested in photography before. Some were using very sophisticated cameras and others used their iPhones. The work was stunning. Geri Taylor, who was the subject of a twelve page *New York Times* article, "[Fraying at the Edges](#)," participated in the photography workshop.

JG: Please tell me about Geri Taylor.

JL: She is a member of our Early Stage Center who used to be a nurse and a healthcare administrator. When the author of the *New York Times* article first called, he said "I would love to write the story of someone living with early stage Alzheimer's disease. I pitched it to my editor. Do you think it is possible to find someone who would allow me to shadow them for a year?" I told him that I would check with our Early Stage staff for recommendations. Some people in the program have not even told anyone in their family, other than their spouse, that they have dementia. Finding an individual to be public about their diagnosis is not easy. Geri and her husband agreed, and the journalist, N.R. Kleinfeld, ended up spending two years with them. They had a great experience with the project and grew to really like each other.

We conducted a program called [To Whom I May Concern](#) in 2005. The program was a staged reading of notes and letters based on the words of people with dementia. [To Whom I May Concern](#) is a wonderful project that Maureen Matthews is still directing.

JG: Do you provide creative classes because they enable someone living with dementia to connect to parts of their brains that are still working well?

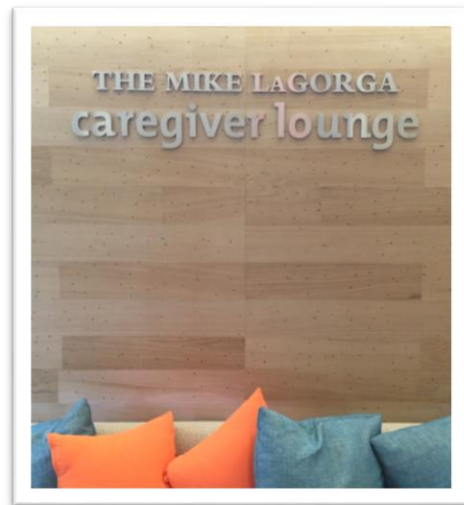
JL: I believe in the fullness of people with Alzheimer's because the emotional, social, creative, and spiritual parts of them remain available. We just need to find the right way to tap into and engage those areas of their brains. We also have a program where we connect our members with art museums, historical museums, and botanical gardens. We hope to arrange visits to the New York Aquarium in the future. We piloted a program with Lincoln Center last year that was great. Our members love these events. It is a normal, adult, socializing, and enriching experience.

JG: Please describe the training you offer at CaringKind.

JL: The professionals that we train are mostly direct care workers including homecare workers, certified nursing assistants, and people working in long term care. We also have a program for chaplains and clergy where we explore how to minister for people with dementia and their family members. The chaplains want to learn more about dementia to better serve the spiritual needs of people with the disease. We also provide some education in nursing and social work schools. That is an important component. We are going to need a better trained workforce as the number of people with dementia increases.

JG: Please describe the family caregiver workshop.

JL: The Family Caregiver Workshop teaches dementia care as a skill and provides a foundation of knowledge about Alzheimer's and dementia. We guide caregivers through some of the behavioral issues linked to dementia. We also help them understand what happens in the brain of the person with dementia. We offer communication techniques, activities, and methods of engaging. We stress how important it is for the caregivers to take care of themselves. The workshop serves to connect the caregivers to all of the other services here. We share special approaches to interaction with someone living with dementia and methods of dealing with dementia specific situations. We want to ensure that the caregiver understands how to best communicate with the individual living with dementia so that it does not escalate into a challenging behavior. This improves the quality of life for both. The training also helps the caregiver to more effectively assist with the activities of daily living.



JG: Do you reach out to diverse communities?

JL: We are making great strides in our efforts to reach minority communities. That was my priority when I became the program director in 2000. I wanted to make sure that any person in New York City who needed our information could access it within their language and the context of their culture. Just this morning, we held a press conference with the Chinese press about our Alzheimer's walks. We had five newspapers and one television station in attendance.

New York City is home to a large Chinese community. Alzheimer's is an issue in the Asian community, but people are not talking about it. We have made significant progress in raising the visibility of the disease and the fact that there are resources for help and support. We have a full time outreach manager in the Chinese community. She did such a good job that we needed to hire a full time social worker who could serve the new cases. Presently, we are hiring a full time trainer who speaks Cantonese and Mandarin so that we can deliver our family caregiver workshops and our dementia care training for professionals to Chinese speaking families and people. We did the same in the Latino community.

JG: Does the African American community have a higher incidence of dementia?

JL: African Americans develop dementia at double the rate of older whites.

JG: Was it difficult to penetrate the African American neighborhoods?

JL: It took us longer to establish trust within the African American community than any of the other communities that we serve. Our first African American outreach manager worked almost five years before people began to recognize that we would deliver on our promise of support and education. Finally, people from the African American community attended the legal and financial workshops, the understanding dementia workshops, and the family caregiver workshops. They eventually used our social work services also. People began to trust us because we were in the community. We started with Harlem and eventually became embedded there. Now we are in other boroughs as well. Our African American outreach manager attends the farmers' markets all over the city, to connect with more people.

JG: How many do you serve in the Wanderer's Safety program?

JL: There are approximately twenty eight thousand people in our Wanderer's Safety program. The program is a low technology program that supports wandering and emergency response for those living with dementia. It is a collaborative effort with the MedicAlert Foundation. When a person with dementia is missing, the MedicAlert NYC Wanderer's Safety program engages community support, including law enforcement trained in dementia behavior, to locate the individual.

JG: Do you advise caregivers on financial issues?

JL: We host meetings on legal and financial planning. The program is important because, in the United States, we do not have a comprehensive long term care insurance system. Most families simply cannot afford to pay for long term care over the duration of the disease. As the care need increases, we provide the basic information and guide families to consult with an elder attorney who can help them protect their assets. Asset protection is especially important if there is an older spouse who needs the assets for their support.

JG: Some people run their assets down to almost nothing to receive government support for long term care.

JL: Exactly. Unfortunately, that does happen because people do not know that there are ways to protect the assets for the spouse who is well. It depends upon the amount of assets the couple has. Even if a couple has a quarter of a million of dollars or half a million dollars, that is not going to last for the healthy spouse after paying for years of long term care. Someone needs to be able to step into the shoes of the person living with dementia to transact their personal and financial business. We advise the caregiver to have a durable power of attorney and the legal ability to make medical and healthcare decisions. If the caregiver needs legal guidance, we connect them to elder law attorneys.

We have a respite specialist who is with us through a subcontract with New York University Langone Medical Center Family Support Program. NYU Langone refers people to us for respite services. Through our special assistance fund grant, we help people who are on a path to long term care but need assistance immediately. For example, if someone is applying for Medicaid homecare, that process can take a few months or longer. If the person with dementia needs homecare immediately, our grant can offer respite to the caregiver by providing an aide for the interim. Our social workers can help the caregiver develop a long term care plan.

We host meetings about what to consider when placing your family member in a nursing home. We also host Understanding Dementia, which is a meeting for families who have just received a diagnosis or who are new to CaringKind. The meeting covers care needs, symptoms, stages, and types of diagnoses.

JG: Do people eventually progress out of the early stage program offerings?

JL: Yes. In the Early Stage Center, we are solely focused on those with early stage. At some point, we have to tell people that we are not the perfect fit for them

anymore. That is difficult. We then direct them to other programs. We have social workers on staff here who can provide support and continuity for them and for their families during the transition. This is also forecasted from the beginning so they know their time here will be a time limited experience.

JG: Do you host international visitors?

JL: We have had many visitors from around the world including Brazil, India, Australia, Scotland, Ireland, the UK, Canada, and Israel. Last year, we had visitors from Japan. We also had someone from the Swiss Alzheimer's Association who spent about a month in the Early Stage Center to learn about our programs. We also had two Korean medical students who spent two weeks here.

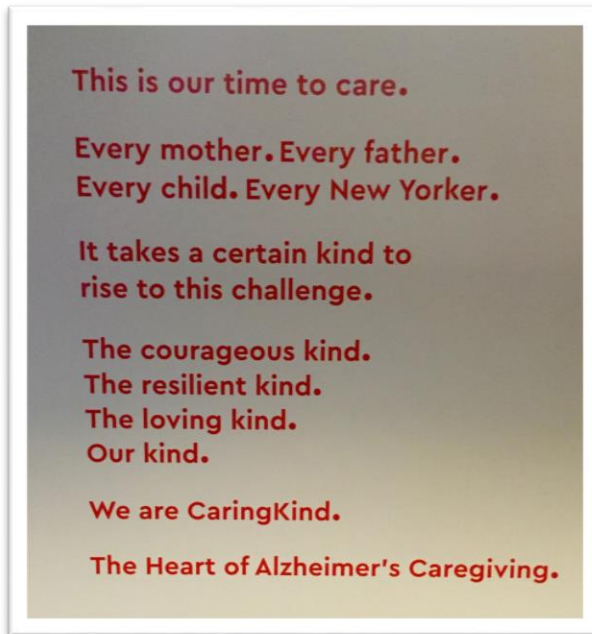
JG: Please describe the role of research at CaringKind.

JL: Research is an integral part of our mission. We collaborate with researchers in several ways. We have an alliance with the Cure Alzheimer's Fund, based in Boston. We also collaborate with research scientists in New York and around the country. We host research meetings. We examined the relationship of dementia to traumatic brain injury and repetitive head injury at our last annual meeting on research. We discussed not just chronic traumatic encephalopathy ([CTE](#)) but Alzheimer's, Parkinson's, and other dementias as well. The expert panel presented what we know about prevention and discussed the newest findings. I have always believed that we should help researchers recruit subjects. We do that through our website and social media. We also disseminate information about research. There is a lot of misinformation and oversimplified information about research studies and results that keep the public confused.

Last year, Dr. Richard Isaacson presented. He heads the [Alzheimer's Prevention Clinic at NewYork-Presbyterian Weill/Cornell Medical Center](#). He is researching every aspect of medical wellbeing including brain scans, height, weight, hip/waist ratio, body mass index, and blood work in a fine tuned, precise approach. His goal is to identify modifiable risk factors. According to his latest results, he estimates that he can identify modifiable risk factors in up to one third of the people he studies. Among many factors, those risk factors could include a tendency toward insulin resistance and particular sleep patterns. He is realistic that there will be a subset of people who, no matter what they do, cannot prevent or are unable to delay the onset or progression of dementia. His work and his hypotheses are compelling.

JG: Please describe the palliative care for dementia pilot programs that you conducted.

JL: I am very excited about the pilot programs. Nursing home and residential care for someone living with dementia is an area that I have felt discouraged about since I was working in nursing homes when I was seventeen years old. I knew that there were good people trying to do good work, but there was no system in place to provide and sustain high quality care for someone living with dementia. I am convinced that we have identified a model of care for someone living with dementia that can transform the experience of living in residential care.



We were faced with the question of what our role is in improving the care of people with dementia in nursing homes and other residential care settings. We hired a master of business and social work student from Columbia to write a white paper for us. She conducted interviews, performed an external review, an internal review, and research. We have always recognized that residential care is an important component of the long term care continuum.

Inspired by the findings, we hired a consultant, Ann Wyatt. She had extensive experience in long term care administration and in quality improvement and was very familiar with the needs of residents with dementia. We convened several meetings with nursing home leadership and held conferences for nursing home staff. We were building relationships and bridges. Ann heard about the [Comfort Matters](#) program at [Beatitudes](#) and she visited the campus in Phoenix, Arizona, to learn more about their dementia care model. Ann came back glowing and thought the model was phenomenal.

JG: How did you fund this pilot project at CaringKind?

JL: After a lot of work by our development staff, myself, Ann Wyatt, and Ed Cisek, our Director of Program Evaluation, we were fortunate to receive funding

from The Fan Fox and Leslie R. Samuels Foundation, United Hospital Fund, Mayday Fund, Altman Foundation, Lucius N. Littauer Foundation, The Milbank Foundation, and contributions from 1199SEIU Training and Employment Fund, The Caccappolo Family Foundation, and several individual board members, and our Junior Committee.

JG: Please describe how you are bringing Comfort Matters to New York City.

JL: Ann Wyatt had the idea to pilot Comfort Matters in New York City to see how it would work in a large urban setting. So we set out to test the Beatitudes model. We did not test it in terms of its effectiveness, because that had already been evidence based and we knew that the care model was effective. We wanted to examine how Comfort Matters would work in a large, densely populated, unionized, and highly diverse city. New York is a different landscape from Phoenix, Arizona. We conducted a pilot project that would include one unit in each of the three pilot site homes: Isabella Geriatric Center, The New Jewish Home in Manhattan, and Cobble Hill Health Center in Brooklyn. We developed a training and implementation plan. Training is great but it will not be effective unless you have a system to translate and operationalize that training. It is like the rubber band analogy: you can change the shape of a rubber band, but as soon as you take out the supports, it goes right back to where it was. We needed to create a system that supported the training. Sustainability was a major concern for us.

The key to the success was the commitment of the leadership. Each of the administrators embraced the culture change. We held weekly meetings on the units. The meetings were multidisciplinary, which is highly unusual. Today, several years after the initial phase of the grant, the pilot projects are still running because the organizations have recognized the value of the training and support. Each of the three homes is working toward accreditation of the Beatitudes model. Because of what we learned from the pilot projects, our board has adopted palliative care as a core principle for caring with people with dementia. One of our social workers is in the process of becoming a resident expert in it. Every aspect of what we do here at CaringKind has been influenced by the Comfort Matters model, which says very simply that people want to be comfortable. Comfort Matters acknowledges the fact that people with advanced dementia cannot tell you when they are in distress. Their behavior is their method of communicating that information. Nine times out of ten, if they are not cold, hungry, or tired, they are in pain. That is the basic premise on which the care

model is built. Caregivers use the behavior based pain assessment tool ([PAINAD](#)) as a way for all staff to identify when someone who is nonverbal or has limited language is in pain. We at CaringKind are proud that we are bringing this superb model of care to New York families. This will enable people to reinvasion the nursing homes of the past, to be residences where people want to work, where families want to visit, and where the residents – who are the most important people in that constellation – are well cared for.

JG: What points did you measure in the pilot programs?

JL: It has been an interesting model with an extensive evaluation component, but with a caveat. We examined resistance to care. We examined resident outcomes using the Minimum Data Set, which is a federally mandated assessment tool. We examined the use of medications. We measured staff knowledge and outcomes. We also examined service cost and utilization. The two year training, support, and implementation of Comfort Matters is cost neutral for providers and, we believe the care model creates areas for cost savings.

JG: What outcomes did you realize at the pilot sites?

JL: We have outcomes from the first year only. But the pilot sites are all continuing the training and implementation. The trends were definitely in the right direction. We have seen a decrease in the use of antipsychotics. The use of analgesics increased, which is good. That was relatively cost neutral. We found that we were moving in the right direction in terms of lowering resistance to care.

JG: What other plans do you have to spread the word about Comfort Matters?

JL: We are developing a clinical advisory board because there are some areas where additional and specialized expertise is needed. The board will include geriatricians, palliative care specialists, and nurses. The next step is to find a way to implement this in both not for profit and for profit nursing homes. We are determining how to inform and engage the public sector. We also are exploring methods to extend Comfort Matters into other settings including homecare and hospitals. I know that Beatitudes is planning to increase their capacity for accreditation because there is so much interest. We recently mailed over two thousand copies of "[Palliative Care for Persons with Dementia: Why Comfort Matters in Long-Term Care](#)," guidelines that were published in April.

Last year, Ann Wyatt presented at the Center to Advance Palliative Care. Their CEO, Diane E. Meier, has been a strong champion and advocate of Comfort Matters. Ann will also be presenting for the American Medical Directors Association, which she did last year as well. This is an association of doctors who are the medical directors of nursing homes. It is a great avenue to spread the knowledge.

JG: How do you differentiate hospice from palliative care?

JL: Hospice care is for people at the end of life. Palliative care is meant for anyone who is in discomfort, whether they have a treatable illness or not. Palliative care can exist along with aggressive treatment if that is appropriate. With a disease like Alzheimer's, palliative care should be part of the approach from the beginning. That is where there is still much confusion. It is crucial for us to view palliative care through the dementia lens. It is changing a little bit now, but palliative care used to be reserved for people with AIDS and people with cancer and other terminal illnesses. We are beginning to recognize the special care needs and understand the communication and cognitive challenges of people with dementia. We also must recognize that those living with dementia are still able to experience pleasure. They can experience comfort. They can experience the flavor of chocolate or other foods that they enjoy. Good palliative care for someone living with dementia is designed to create comfort, and connection.

JG: What is an example of a physician using a palliative care approach to someone living with dementia?

JL: It may be very simple things. For a person with dementia and diabetes, the doctor would decide whether it really is necessary to do a finger stick three times a day or not. Maybe once a day or once every other day is enough.

JG: Is that process more challenging with someone with dementia?

JL: Yes. It is painful. People living with dementia do not understand why someone is hurting them with a finger stick. They are not going to cooperate. Another example is for caregivers to be mindful of the way medications are delivered. If someone has difficulty swallowing, they are they going to spit out their pills. Reasoning with a person with dementia does not work. The person living with dementia only knows that they are choking. A better choice would be for the caregiver to find another way to administer the medication such as

grinding it into jelly, applesauce, or a smoothie. Caregivers need to be mindful of what they may be doing that is unnecessary and causes discomfort. Sometimes discomfort is necessary but we must always consider whether we are being aggressive with care or treatments. This is why we need more geriatricians. They understand the medical care of elderly in the context of improving function, quality of life, and the appropriate role of medications and the challenges of polypharmacy and medication management. When I took my father to a geriatrician many years ago, the doctor took him off approximately two thirds of his medications.

JG: What were the results of that decision?

JL: He was better, actually. And caring for him became much easier.

JG: Are you educating doctors about palliative care for those living with dementia?

JL: Our healthcare outreach manager is now working with Ann Wyatt, our palliative care manager, to bring this message to doctors.

JG: Thank you for this inspiring interview.

JL: Thank you for your interest in CaringKind.

END