Dementia Action Alliance: Redefining Living with Dementia

Interview with Karen Love, Jackie Pinkowitz, and Lon Pinkowitz

By Jean Galiana

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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.

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Background

The Dementia Action Alliance is a volunteer coalition engaged in changing the understanding of and attitudes toward dementia. The coalition serves as a trusted source for conversations, education, and advocacy. The mission of the Dementia Action Alliance is to help create a world where people living with dementia can live full, productive, respected, and engaged lives, and their families and care partners are fully supported. The coalition strives to make inclusion in community life the standard for those living with dementia.

The activities of the coalition include convening and connecting people living with dementia to amplify their voices, which will better inform policies, practices, and research that affect them. The coalition is committed to dispelling the beliefs that contribute to the stigma and discrimination of those living with dementia by promoting the “lived experience,” stories of real people with dementia as they engage in life in numerous meaningful ways. The alliance also educates the public about the varieties and stages of dementia. The alliance advocates for policies, practices, and research that optimize the wellbeing of those living with dementia, and provides resource materials about living fully with dementia.

The Dementia Action Alliance is led by a board of directors and an advisory council of true experts—individuals living with dementia. The coalition members believe that highlighting the insights and experiences of those living with dementia is crucial to removing the barriers that prevent them from living fully inclusive, productive lives without discrimination or stigma. The Dementia Action Alliance partners with an active team of thought leaders, organizations, and communities.

The coalition has established workgroups that focus on arts and dementia, communications, optimizing wellbeing, and technology and dementia.

The Dementia Action Alliance is dedicated to creating person centered support for those living with dementia. The coalition developed person centered dementia values and principles that they believe will nurture the emotional, social, physical, and spiritual wellbeing of a person living with dementia. Their video, “Person Centered Matters,” captures these values and principles. Other publications of the Dementia Action Alliance include: “Living with Dementia: Changing the Status Quo,” “Dementia Priorities Identified from a National Survey,” “Dementia Care: The Quality Chasm,” and “Words Matter: See ME Not My Dementia.”

The Dementia Action Alliance resource center hosts links to blogs, books, Facebook pages, reports, papers and other publications, videos and films, and websites that educate a variety of audiences about dementia from a variety of perspectives.

In this interview, Karen Love, Jackie Pinkowitz, and Lon Pinkowitz describe the history of the Dementia Action Alliance. They detail their continued efforts to
connect those living with dementia to community members and policymakers to help end the stigma of dementia by portraying people with cognitive challenges living purposeful and inclusive lives.

**About Karen Love**

Karen Love is a gerontologist and an expert in aging supports and services with a specialty in dementia care. Professionally, she began as a speech therapist and transitioned into long term care administration, serving in numerous positions, including administer and director of dementia services. For the past sixteen years, Ms. Love has been a consultant and researcher on cultural change in long term care settings as well as on practices that enhance the wellbeing of individuals living with dementia and those who care about and for them.

In 1996, she founded a nonprofit advocacy and education organization named [CCAL - Advancing Person-Centered Living](#). CCAL is a founding co leader of the Dementia Action Alliance. The Alliance, directed by a leadership board of individuals living with dementia and mild cognitive impairment, is a national collaborative coalition dedicated to helping people live fully with dementia, supporting those who care about them, and stopping stigmatizing practices that erode wellbeing. Ms. Love currently serves as the executive director of the Dementia Action Alliance.

She has cofounded three national aging advocacy organizations, testified twice before the US Senate Special Subcommittee on Aging, published extensively, and spoken on national television as an advocate for the elderly.

**About Jackie Pinkowitz, M.Ed.**

As board chair of the Dementia Action Alliance and managing partner of [Future Age](#), Ms. Pinkowitz focuses on enhancing person centered or person directed services as well as living in the aging and disability sectors across home, community, and residential settings. She serves as the consumer advisor to [QualityHealth.com](#). There Ms. Pinkowitz assists in creating national consumer centered initiatives for corporations and consults with technology application companies to advance quality of care and quality of life. She has written numerous articles in professional, consumer, and peer reviewed publications and is a frequent speaker at national conferences and summits. Ms. Pinkowitz was a co leader of the Retirement Research Foundation Project, “Coalesce and Connect—Building a National Network of Dementia Care Voices.” Ms. Pinkowitz and her co authors
received the 2015 Edna Stilwell Writing Award from the *Journal of Gerontological Nursing* based on the project. Ms. Pinkowitz served on the project management team for the National Institute of Health funded Center for Excellence in Assisted Living–University of North Carolina (CEAL–UNC) Community Based Participatory Research Project for Person Centered Care in Assisted Living in 2013. She served as vice chair of the national Center for Excellence in Assisted Living in Washington, DC, for three years and as a member of the Association of Healthcare Research Quality (AHRQ)/Center for Excellence in Assisted Living Disclosure Collaborative and the Center for Excellence in Assisted Living–University of North Carolina Community Based Participatory Research Collaborative on Medication Management. She earned her masters degree in education from Rutgers University and holds advanced certification in special needs populations.

**About Lon Pinkowitz**

Lon Pinkowitz serves on the Dementia Action Alliance board of directors. He focuses on advancing healthcare management and long term care services through emerging technologies and person centered approaches. As a consultant, Mr. Pinkowitz applies his expertise in sales and marketing, marketing communications, and organizational systems to assist startup companies. He worked for Tsumura International as vice president of New Business Development/International Sales and Marketing. Lon has a masters degree in personnel and counseling from New York University.
Interview

Jean Galiana (JG): What inspired you to create the Dementia Action Alliance?

Karen Love (KL): I worked in a nursing home as a nursing aid when I was in high school. That experience underpinned what has become my life passion. I fell in love with the residents. I was especially drawn to older people with dementia. I would ask myself why we were not helping them up to dress in the morning. I also wondered why we were not involving them in activities or making efforts to connect with them. I was a bright eyed eighteen year old and was deeply concerned about older people being left out. The nursing home management wanted bathing to be done in the morning. I began sneaking people in for an evening shower because they did not want to bathe in the morning. I felt the residents with dementia were treated in a dehumanizing manner.

When I was in graduate school at George Washington University, I worked for the healthcare services graduate program’s long term care program. We searched for models of best practice in dementia care. In the late eighties and early nineties, there were not many available. The British geriatric psychologist Tom Kitwood was leading the cause and is considered the father of person centered dementia care internationally. He innately knew how to connect with people living with cognitive impairments. He published important findings that influenced dementia care thereafter.

I then began to manage assisted living facilities. At that time, trying to run a person centered assisted living residence was like living in the Wild West. I felt the need to organize a group of like minded industry professionals to explore how the industry could make important changes as a group. I launched a national consumer advocacy organization named the Consumer Consortium for Assisted Living.

Jackie Pinkowitz’s mother was living with dementia in an assisted living home in Michigan. Three years later, Jackie’s father in law was diagnosed with Alzheimer’s. My father also had been diagnosed with Alzheimer’s. Our personal experiences made us dedicated to change dementia care and fight the stigma of dementia.

Jackie Pinkowitz (JP): The Dementia Action Alliance is mission driven. That is why we use the tagline, powered by people with purpose. I like to say, powered by people with purpose and passion.

KL: We created the consortium at the beginning of the increase in the elder population in the United States. Nursing homes were not prepared to care for the increasing number of people with dementia. Nursing homes were not properly regulated. I remember stories of abuse and neglect in long term care facilities.
Eventually we witnessed significant advances like the Omnibus Reconciliation Act (OBRA) in 1987. Shortly after the act passed, regulations were established that limited the number of residents in each room to three or fewer. I know that does not sound impressive, but before the act passed, some nursing homes had six people living in one room. Only minor attention was given to special diets. There was little dementia specific training. Pharmacists would review medications only every three months.

We collaborated with then senator John Breaux. He saw the wisdom in our mission. With our urging, he and his staff succeeded in bringing the top industry players together. The consortium was composed of providers, advocates, and physicians. The consortium began an eighteen month period of growth and development. We were one of the few groups that were actively advocating for person centered long term care. It was a big challenge because there were many old fashioned thinkers in the industry. Eventually we became disruptive in productive ways. Over the years, we shifted our focus and our activities to person centered dementia living.

**JG:** What led you to survey what caregivers and those living with dementia want to be national dementia funding priorities?

**KL:** The National Alzheimer’s Project Act (NAPA) was passed in 2011. It was the first time the United States brought people together to address Alzheimer’s disease, but not dementia. The act was focused mostly on a cure for Alzheimer’s. We thought they should include all dementias and should fund supports for those living with dementia and their caregivers. That is when we drafted our white paper entitled *Dementia Priorities Identified from a National Survey*. The survey found that people with dementia and their caregivers wish that more national spending was devoted to supporting them in their daily lives.

**JP:** The National Alzheimer’s Project Act was the catalyst to our forming the Dementia Action Alliance. There was no national discussion about the millions of individuals who were trying to help family members with dementia. We founded the Dementia Action Alliance to help the families and those living with dementia receive support and services. Our focus is care more than cure.

**KL:** We were disheartened that the government built a federal advisory council of researchers and clinicians that did not include anyone living with dementia.

**JG:** How do you include those living with dementia in the Dementia Action Alliance?

**JP:** Karen and I were committed to the concept, *nothing about us without us*, from the very beginning of the Dementia Action Alliance. The expression comes from the disability world. I used to teach special needs children, and later my mother developed Alzheimer’s so I had that philosophy and mindset. We knew that the voices of those living with dementia were not being heard anywhere that mattered. We created an advisory council entirely of people living with dementia.
**JP:** Karen and I realized the importance and value of having those living with dementia involved in all public and private organizations in the field of dementia. We built a national collaborative that enables people living with dementia to connect virtually and talk to one another around the world to share their insights and issues.

**JG:** Tell me about your workgroups.

**KL:** The people whom we coalesce participate in a variety of workgroups that reflect their specific areas of leadership. There is at least one person living with dementia in every workgroup. Their perspective is crucial. They offer insights and solve issues from their unique vantage point. What could be better? I do not know why every organization dealing with any aspect of dementia does not include those living with dementia. They are an invaluable resource.

We also connect those living with dementia to policymakers on the federal, state, and community level. Last year, Sandy Halperin, the well known advocate who is living with dementia, met with Kathy Greenlee, who is the assistant secretary of the Administration for Aging.

People living with dementia also need to be included in society. As their condition progresses, a person living with dementia loses the ability to self initiate. That is often the reason why those living with dementia are not doing anything. They are inactive not because they do not want to be active, but because they need to be kick started through engagement. Inclusion and involvement is better for their health. It is better for their overall wellbeing. Many basic needs of people living with dementia, such as engagement, go unmet.

**JG:** Other countries began the aging expansion before the United States. Are they ahead of us in regard to dementia support and care?

**KL:** David Cameron convened the first G8 Summit on Dementia. The government of the United Kingdom appropriated a fair amount of funds toward dementia care. The government did not direct the funding. They made the awards to good people on the ground level to direct it.

**JG:** Were the outcomes tracked?

**KL:** Yes. The Joseph Rowntree Foundation conducted the evaluation. The Dementia Friendly United Kingdom is a robust initiative. Dementia Friendly began because they lead the world in the growth of the older population. Japan is also producing innovative robotic products for the elderly.

**JG:** Are you referring to PARO the seal?

**KL:** If you have ever seen someone with PARO the seal, they love it. Japan is also developing more sophisticated robotics besides PARO.
**JG:** Please describe your thoughts about transitioning to a bio psycho social spiritual culture.

**KL:** Atul Gawande speaks beautifully about the bio psycho social spiritual culture. He believes that we have been wrong about how we imagine healthcare. We think healthcare is about safety and physical health. Our focus should be wellbeing. Wellbeing cannot be realized through physical health alone. Wellbeing includes biology, psychology, and spirituality—the bio psycho social spiritual paradigm. Spirituality does not have to be religion. It can be watching a beautiful sunset. Spirituality is whatever touches your heart. All of these dimensions make up our wellbeing, especially for someone with dementia. I have done a lot of research over the years on engagement. Much of the brain remains unused. When we connect with someone or do something that is fun, part of the brain has the power to release neurotransmitter chemicals that make us happy. There are ways of connecting through those windows to reach people with dementia.

**JP:** These methods of connection need to be researched in depth and practiced by everyone involved, from the patient’s family to the hospital that treats them. Education and awareness can inspire inclusion for those living with dementia in all settings, including the clinic and the neighborhood.

**KL:** The United States, and much of the world, is focused largely on the biological component of wellbeing. We use an acute healthcare model to treat a long term condition. We are trying to respectfully disrupt the beliefs, attitudes, and practices about dementia in our country.

**JP:** We work to make the invisible visible.

**JG:** What do you view as invisible, regarding dementia?

**JP:** The spending practices that prioritize finding a cure, but neglect the needs of the caregiver and those living with dementia; the stigma that exists around dementia; and the need for dementia friendly communities and businesses.

**JG:** What activities are you involved with that address those issues?

**KL:** [Caring Conversations](#) is one.

**JG:** Please describe Caring Conversations.

**JP:** We host friendly, informal gatherings of approximately thirty people. They include people living with dementia, family caregivers, residents of the community such as police officers and shop owners, and clinicians. We meet for an hour and a half. It is a facilitated conversation. Caring Conversations is a friendly platform for the participants to share their thoughts about issues regarding dementia. Caregivers may share their challenges and methods that can help others. Providers and others hear and see people with dementia differently after these conversations. Many people have the misperception that all dementia is end stage. Those living with dementia interact with the members in the group,
which helps the others to see the person before the disease. People from the gathering may leave the conversation thinking, “There is the artist,” rather than, “There is the woman suffering from dementia.”

**Lon Pinkowitz (LP):** We have also hosted pharmaceutical company executives who are developing a product for dementia. They interacted with and learned directly from their end user. Before the conversation, they were far from understanding how a person can live well with dementia. That was an important conversation.

**JG:** Something as simple as facilitating a conversation could potentially affect the development of particular drugs or influence the motivation behind the development?

**JP:** Yes. We hope that it also stimulates community champions who will be inspired to host Caring Conversations on a regular basis. The conversations can be about a variety of subjects. The conversation can be focused on how to make the community more dementia friendly. This needs to happen not only through the built environment, but through creating person to person, human connections. Anyone is welcome to contact us if they would like to host a Caring Conversation in their community. We will support and guide their efforts.

**KL:** Here is one of our conversations in Washington, DC. The daughter of a woman living with dementia is speaking.

“Dementia presents differently for each individual. I think the scary thing, for people who have loved ones and friends with dementia, is the unknown. You do not know how it is going to affect each person. I think the unknown is very scary. If you have a friend who is going through breast cancer, you know what to expect because there is a mastectomy, there is radiation, there is chemotherapy. Maybe their hair will fall out. Dementia, it is different case by case. I spoke with people whose grandparents had dementia and whose parents had dementia. One woman told us, ‘We loved it when my grandfather got dementia because he was a really mean guy before, but with dementia he was the sweetest person ever.’ We spoke with someone else who had a completely different experience. Another issue is that people do not know what to say to a person who has dementia.”

We select our conversation group carefully. We hosted a Caring Conversation in Washington because there are many people working on the federal level, who make policies and national decisions, who do not understand what it is like to live with dementia. We invited them to have a conversation with five people living with dementia. The person who sat next to the daughter who just spoke is a pharmaceutical executive. Another participant is a senior executive vice president from AARP National. We had two chief executive officers and long term care service providers. Forty two people participated in that Caring Conversation. Their chairs were arranged in a large horseshoe shape so everyone could see one another.
LP: No one wanted to leave.

KL: Yes, we got kicked out of the space we had rented.

LP: We could have been in there for two days. No one wanted to stop talking.

KL: It was a two hour conversation. It showed us that there is a need and a desire for this type of interaction. We hope to have Caring Conversations all over the country. The conversation is important, but what the participants choose to do with the new knowledge is more important. The conversations plant the seeds within the community. We facilitate connections and collaborations. We establish a small community think tank, of sorts, that focuses on dementia. The conversation participants take the lead thereafter.

JP: They take the message to the street. They know that they can always reach out to us. It is surprising how many calls Karen and I receive from people everywhere. We are always available to listen with an open heart. Sometimes the conversation participants need our expertise and support. Sometimes they just wish to maintain a relationship with like minded people.

KL: We can validate their concerns about dementia or their struggles with dementia because we have been there ourselves, and our advisory council is made up of those living with dementia.

JP: Another component of the Caring Conversation is that we want to encourage people to create a Caring Wishes notebook. Often it is difficult for someone with dementia to communicate wishes regarding their care plan and their lifestyle choices. We would like to help them document their wishes regarding their quality of life when considering future care and living options. Sandy Halperin helped us create the template. As I mentioned earlier, he is living with dementia and has been a longtime advocate for those with dementia.

JG: How does the Caring Wishes notebook process work?

KL: We offer a guide to starting the care plan discussion and provide the template during the Caring Conversations.

JG: Please tell me about the North American Dementia Education Conference.

KL: We are aligned with organizations doing important work in dementia and with those living with dementia. Because of that, we decided to create opportunities for idea sharing and collaboration. We will host the first conference in 2017 in Atlanta, Georgia.

JG: Have you chosen the areas of focus for the conference?

JP: There will be a technology track because we have a technology workgroup.

KL: Other areas of focus will include arts and dementia, optimizing wellbeing, and meaningful engagement.
We entitled the conference “North American” because we have connections in Canada who we wish to include. The Canadian province of Ontario has many person centered dementia care initiatives. Some of the other provinces do not. The Canadian government funds are directed toward those living with dementia and not solely toward finding a cure. Our government directs only a smattering of funding through the US Administration on Aging and the Health Resources and Services Administration directed toward supporting those living with dementia and their formal and informal caregivers. The large majority of funding is allocated to research to find a cure.

**JP:** If we ask what matters most to the people living with dementia and their families and friends, the answers are simple and basic. They want relationships and connections with their families, friends, and clinical care team.

**LP:** We want healthcare clinicians to understand that people living with dementia are people first and patients second. If we keep referring to them as a patient, we are going to think about them as a patient. Clinicians need to consider the whole person and their life, rather than only focusing on what is wrong physically and how to fix it.

**KL:** We are a smaller organization and need to dedicate our efforts where we can make an impact. We spent two years with the National Quality Forum on various work committees advocating for dementia care. We made a little bit of progress. For example, they were using the term “Alzheimer’s” exclusively, and they agreed to change it to “dementia including Alzheimer’s.”

**LP:** It took a long time before they would make that change.

**KL:** We realized we were not helping a lot of people by putting our efforts in that direction. Now we are working on the community level. We think the change will come from grassroots community organizations instead of us banging on doors in Washington.

**JP:** We have not walked away from advocacy completely. We are still actively involved in multiple forums around dementia.

**KL:** We have three seats on the Dementia Friendly America initiative.

**JG:** Please describe the Dementia Kindness Challenge.

**JP:** It is a social media challenge.

**KL:** Brian LeBlanc, who is living with dementia and one of our board members, runs the social media for the Dementia Action Alliance. People living with dementia, their friends, or family can make a video and upload it. The video will be short and will be about their family or themselves. They will share personal experiences and then say something like, “I want you to know that Alzheimer’s does not define me. I am still myself with additional challenges. I am taking the Dementia Kindness Challenge by uploading this video to YouTube, donating ten
dollars for the challenge to promote awareness, and challenging someone I know to take the challenge to spread kindness.” The Dementia Kindness Challenge is affirmation for people living with dementia that dementia does not define them. They are still themselves. That is powerful. It is educational. It is awareness.

JP: The Dementia Kindness Challenge contests the stigma of dementia by pulling the issue out of the shadows and shining a light on the faces of the people directly and indirectly affected by the disease. It reminds us that few are immune. We will all either have dementia or have family or friends living with dementia. We are all in this together, so let us remove the stigma.

JG: What are the challenges for the Dementia Action Alliance?

JP: If we had more partners for funding, we would like to launch a national public awareness campaign.

JG: Is the lack of funding what is preventing you from launching the campaign?

KL: Without a doubt.

LP: That is ninety five percent of what is holding us back.

JP: We want to change the national attitude about dementia.

KL: We want to put a face on dementia and engage those living with dementia to be the spokespeople. We would love to give more national attention to the Brian LeBlancs and Sandy Halperins who are living throughout the country.

JP: Let them speak for themselves.

KL: Yes, after all, they are the experts.

JP: We want to increase our funding to establish a larger presence. We would like to have presence in every major convention, including some state conventions. With host partners, we could potentially facilitate Caring Conversations in communities across the US. We want to be a support, an educator, and a facilitator. We also want to inspire advocacy on the community, the state, and the federal level.

KL: People want to be involved. They just need to know how. That is where we come into the picture.

JG: Who funds the Dementia Action Alliance?

JP: We are funded mostly by grants from foundations. We established the virtual infrastructure, the foundational papers, and resources that make us credible and impactful, and as a result, fundable. The Retirement Research Foundation spurred us on by telling us, “There is no one trying to connect and bring together people living with dementia so that their voices and their choices can be heard.” That was when we changed the name and the focus of the organization, about five
years ago. We realized we could make the most impact through our focus on dementia because of this fast growing demographic.

**KL:** No organizations were hosting national leadership discussions. In 2012, the Consumer Consortium for Assisted Living convened the first Thought Leader Summit on dementia. Our organization, the Eden Alternative, the Pioneer Network, Planetree, and the American Medical Directors Association made up the steering group. We had sixty people at our first Thought Leaders Summit. We began to develop the operational framework for person centered dementia care. At the time, the concept was groundbreaking.

Now, the Dementia Action Alliance is a collaboration of volunteers who embrace our vision and mission. Anyone who has an interest in making our nation a better place to live with dementia and in supporting those who are caring for someone living with dementia is welcome to be a Dementia Action Alliance partner.

**JG:** Tell me about the Compassionate Touch initiative.

**KL:** The Administration on Aging (AOA) sponsored one of the projects that I led called Compassionate Touch and Reiki. We taught Companionate Touch to two hundred and fifty aides of a nonprofit homecare agency. Some aides were transgender because there is a population of transgender people in the district who want to have aides like themselves. Classes were given to twenty aides at a time. We had thirteen classes. Compassionate Touch is simple. It is not the hand massage that you receive when you are having your nails done. Compassionate Touch is about being with the person and the gentleness of holding someone’s hand. It can accompany companionable silence or a little bit of discussion. We teach the touch points for the hands and the arms to create a relaxed, happy feeling. After the training, seventy five aides volunteered to take their learning a step further by registering for the level one Reiki practitioner training. The level one training is an hour. This nonprofit organization brought their aides in three times a year for additional training. This is unusual because the organization must pay the aides when they are not working. We taught not only the massage techniques. We taught engagement and connection.

I will never forget one aide in particular. Her name is Patricia Simms. She was the one in the class who appeared to be disinterested. To engage her, I gave her a leadership role. By the end of that training session, she shared her experience of Compassionate Touch and engagement with a woman for whom she was caring. Patricia said, ‘Let me tell you about this one client I have. She had been in the hospital for over a week and could not walk when she got home, so she was in a wheelchair. I knew she would be frail and weak. The training taught me to think about what I could use to build her strengths and work toward her abilities, not her limitations. I had taken her outside in her wheelchair, and we were pushing down the sidewalk. No one was paying any attention to us, and all of a sudden I said, ‘Ok Mrs. B, my turn.’ Ms. B looked up at me and asked what I meant. I told her that it was my turn for a ride. I had given her a ride, now she should give me a
ride. Because Mrs. B knew she had the wheelchair to hold on to while walking, she agreed and I helped her navigate around the chair. Then I sat in the wheelchair. Mrs. B had lived in the neighborhood for a long time. All the people who had previously passed and paid no attention heard the two of us laughing. People asked for a ride for themselves and told us it looked fun. They were engaging with Mrs. B. It was an entirely different interaction. This was not only fun, it got Mrs. B to exercise and become stronger faster.” Patricia added, “I visited Mrs. B daily because she had just been released from the hospital. Every morning when I arrived, after our wheelchair switcheroo, Mrs. B was sitting by the front door. She could not wait to go out. She was motivated. She had gotten herself out of bed.”

**JP:** She had something to look forward to.

**KL:** Yes. It was unscientific and anecdotal, but Patricia told us, “I have taken care of many people who have come out of the hospital, and it takes a long time to get them up and walking again. Mrs. B was up and walking within ten days.”

Another aide, who participated in the training, described how she used compassionate touch with an ornery older woman who had arthritis in her knees. This woman hated to get out of bed. The aide remembered that warmth was the heart of the Compassionate Touch training. She would tell the older woman, “Oh Mrs. L, let us get those knees massaged. It will take some of the pain away.” The aide did some gentle massage. Then the client would swing her legs around and get up. The aide told us, “I would spend an hour trying to get her out of bed before. This was motivating in a whole new way.” There is some placebo effect. Warmth, touch, and connection trigger different parts of the brain, so it is not necessarily just placebo.

Mrs. L felt like she was cared for. This simple process is free and does not take long. No specialists were involved, and Mrs. L was ready to get out of bed. We know these trainings have an impact. We are seeking funding and partners to train as many health providers and volunteers as possible. The plan and strategy of the Dementia Action Alliance is to grow a bigger base so we can bring our various initiatives to more people. We also want to share the stories that remind us that it is about human connection and that dementia has a human face. What we teach is person centeredness. That is what all care is about. Stop just doing, and be present in a real way. We have heard many success stories from those trainings.

**JG:** Did you only do the Compassionate Touch training once as an experiment or do you conduct trainings regularly?

**KL:** The United States Administration on Aging funded only that one pilot program. We think that they should fund the next translation. We made an impact. Our challenge is how to bring this training to many more people.

**JG:** Thank you for this interesting discussion and your dedication to dementia.
JP: Thank you for your interest in our work.

LP: Thank you.

KL: Thank you for spreading the mission of the Dementia Action Alliance.

END