

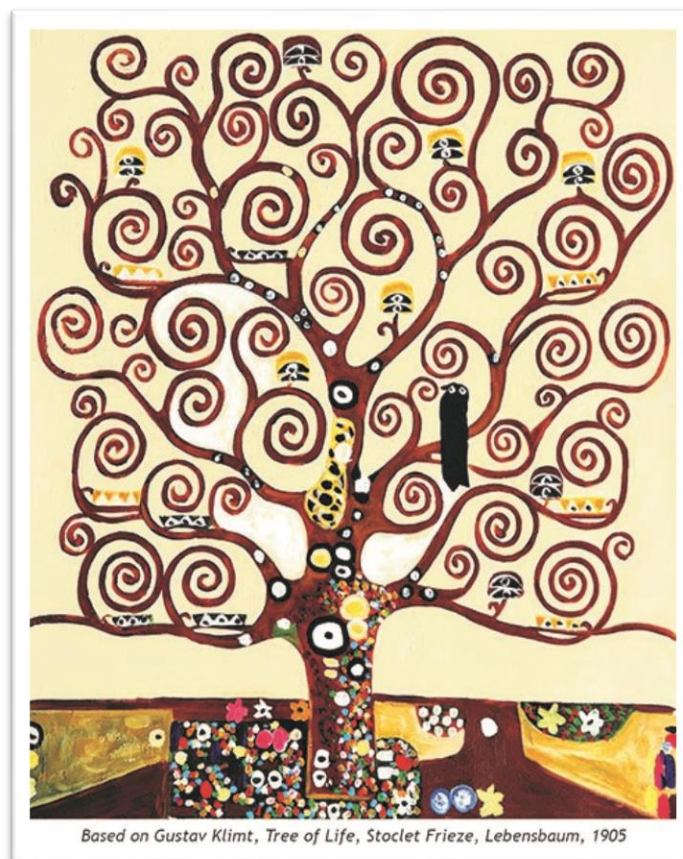


MedicAlert® NYC Wanderer's Safety Program and

CaringKind:

The Heart of Alzheimer's Caregiving

Interview with Elizabeth Santiago



By Jean Galiana

ACCESS Health International

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Elder and Long Term Care

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Background

The MedicAlert® NYC [Wanderer's Safety](#) Program is designed to locate missing people who are living with dementia and to support their caregivers. New York City based CaringKind has over twenty five thousand five hundred enrolled individuals in the program. In this interview, Elizabeth Santiago describes the Wanderer's Safety Program at CaringKind and shares case studies of caregivers and those living with dementia whom the program has served.

About Elizabeth Santiago



Elizabeth Bravo Santiago is the MedicAlert® NYC Wanderer's Safety Program Director at CaringKind: The Heart of Alzheimer's Caregiving, formerly known as the Alzheimer's Association, New York City Chapter. She is responsible for the overall operation, marketing, and management of the MedicAlert® NYC Wanderer's Safety Program. Her goal is to ensure that the program is available to all New Yorkers who need it.

Mrs. Santiago received her undergraduate degree in Therapeutic Recreation from Lehman College, City University of New York. She has over twenty five years of experience working with people diagnosed with Alzheimer's disease and other dementias.

As part of her role, Mrs. Santiago works closely in partnership with the New York City Police Department, providing training and education to police officers, detectives, public safety officers, and others working in law enforcement. She also educates family caregivers and paid professionals about the MedicAlert® NYC Wanderer's Safety Program and other ways to ensure the safety of persons with dementia.

Mrs. Santiago received the 2006 National Safe Return Recognition Award for increasing Safe Return registration by one hundred and seventeen percent.

Interview

Jean Galiana (JG): How did you become involved in the Wanderer's Safety Program?

Elizabeth Santiago (ES): I have a bachelor of science degree in therapeutic recreation and experience working with patients living with dementia in the nursing home setting. I worked in a nursing home for fourteen years and decided I wanted a change. I had the privilege to volunteer for the Alzheimer's Latino Coalition. They were having a conference at that time. After meeting Jed Levine at the conference, I came to work here at CaringKind.

JG: Did your experience in memory care give you insights into wandering?

ES: Yes. While I was at the nursing home we had episodes of wandering. One morning I was walking to work, and there was a resident sitting in the local McDonald's. I walked in and he said to me, "They are not giving me my breakfast." I told the manager I would pay for whatever the resident had ordered. I called the nursing home and told them I would be late because I was with a resident who was having breakfast at McDonald's.

At a later date, on our way to the movies, my husband and I saw Mr. G under the Bruckner Boulevard trestle smoking a cigarette. He was easy to recognize because he wore an eye patch. We brought him back to the nursing home. So yes, I did have firsthand experiences with wandering. I learned that people wander for a variety of reasons. Maybe they want pancakes and sausage instead of the Kosher food served at the nursing home. Mr. G just wanted to smoke, which was not allowed in the nursing home.

JG: How did the wandering program at CaringKind begin?

ES: In 1990, Jed Levine started the program in collaboration with metro area chapters. They were aware that wandering was becoming a big issue. We had caregivers in our programs who were concerned about their family members wandering. One woman contacted us looking for her father. Staff provided support and worked with the family to create and physically post a missing person bulletin. We contacted the police department. Sadly, he was found deceased near the little red light house underneath the George Washington Bridge. That experience galvanized Jed's resolve to build a wanderer's safety program.

JG: How did they build the program?

ES: When Jed was hired, the first project he worked on was creating the structure for the program. We created protocols for responding to lost and found persons with dementia and the materials for the program with identifiers, clothing labels, bracelets, and wallet cards. We also created a marketing plan. We hired night operators who were “housebound” and responded to incidents during evenings, weekends, and holidays.

The Helmsley Foundation generously provided seed money for the first five years. The program was initially called the Helmsley Alzheimer’s Alert Program. After a press conference at the Empire State Building with the Helmsley’s, we were contacted by Senator Mark Hatfield, who was interested in making the program available nationwide, not just in New York. Senator Hatfield related to the issue of wandering because his father had dementia. Jed and the executive director went to Washington, DC, to meet with Senator Hatfield’s office to discuss expanding the program. Someone who has been touched by dementia is more likely to help the mission. Soon almost everyone will know someone who has a connection to the disease. We received funding from the Juvenile Justice Department as a result of that meeting. We have continued to grow since then. We have a detective assigned to the CaringKind wandering program.

JG: Does the detective search for the wanderers?

ES: Yes. He works in the Missing Persons Unit.

JG: Has he been trained in the behaviors of someone living with dementia and wandering?

ES: He understands the disease. He and I connect often. Normally he would receive a missing person’s case seven to ten days after the case is reported. With a wanderer with dementia he takes the case immediately.

JG: How would it work if I had a father with dementia and I realized he had wandered off?

ES: You would dial 911 if your father wandered off. The police department would take your report. The case would then be sent to the detective unit. The detective would come to your home, take another assessment, and ask for a picture of your father. The detective would then canvass the area. The rest of the police department precincts would be alerted to keep a lookout for the special missing

person. They would also report the missing person to the MedicAlert® Wanderer's Safety Program. At that time, MedicAlert® would contact CaringKind, and I would receive a missing person incident report.

The wanderer does not have to be enrolled in programs at CaringKind for me to assist in the search. I call up the reporter of the incident, who is usually the caregiver. I review the report to make sure we have all the details and facts correct. Then I send out a missing person bulletin and put the alert on social media. It gives me the opportunity to speak to the caregiver. I also tell the caregiver that I am there for support. I briefly describe the programs and services we offer. I am not a police officer and I am not a detective, which can make it easier for caregivers to speak to me.

JG: Do the caregivers worry that you will judge them because the person with dementia wandered?

ES: I make it clear that I am not there to judge or blame them. I let them know I understand that wandering happens and I find a way to support them. When the police visit, the caregiver reports the basic story. I am less intimidating and I learn more of the personal details, such as whether there is another romantic interest involved or if alcohol or drugs are an issue. One caregiver, the wife of a man with dementia, told me, "Ever since we have been married, he has liked to go to hotels with other women. He would return after two or three days. He has always been like that."

JG: Was he repeating a life pattern even while living with dementia?

ES: Yes. If he regularly frequented certain hotels, he will continue to go back to those hotels. I told the caregiver that this was important information and I needed to share it. I reassured her that the personal details would be considered confidential. I shared the details, and the police officer and the detective on the case visited several hotels. They found the wanderer. I play the role of advocate and provide support for the caregiver.

JG: How do you encourage people to trust you and feel safe enough to ask for help?

ES: Culture is a big issue. New York City is home to many Latinos, African Americans, Asians, Russians, and other people from all over the world. I think they are comforted by the fact that I am Latina. I have to build trust with them. I

have a cellphone that caregivers can call at any time. Caregivers often think that nothing is being done to find the lost person when they do not receive regular updates from the police department. I maintain regular contact with the caregiver to reassure them that the police are still looking. Then I focus on the caregiver and ask if she is eating and drinking, and taking her medications. I ask the caregiver if I can call one of her friends or family members so she is not alone during the stressful situation. I treat caregivers as though they were my family members.

JG: How long are people usually missing?

ES: The length of time that a person is missing ranges on average from forty eight to seventy two hours. It is difficult to identify a wanderer who does not remember his name. We have had many individuals who reverted to their maiden names or even used the maiden names of their parents. We send a list of all possible names to the police precincts and local hospitals.

JG: Is that why you want people to wear an identification bracelet?

ES: If a police officer finds someone who is wearing a bracelet and is confused, the police department will call and ask whether I have that person in our system. If I do not have them registered through CaringKind, I refer the police department to MedicAlert® because they have a large national database. A person could be registered in the MedicAlert® system because they developed an allergy ten years ago and purchased a MedicAlert® ID bracelet. We might receive a report that a person from New Jersey or Kentucky is missing and that person will be found in New York.

JG: Please describe how you use the MedicAlert® bracelets?

ES: If a caregiver residing in one of the five boroughs reports someone missing, I receive the incident report from the police department. If the caregiver is not already enrolled in the Wanderer's Safety Program, I contact them to encourage them to enroll. I offer to send an application or to complete the application myself over the phone. We have applications in many languages. MedicAlert® charges a one time fee of sixty two dollars. Some people can afford to pay that fee, but many cannot. We provide a scholarship for those who cannot afford to pay the fee. The caregiver must be caring for someone living in one of the five boroughs who has been diagnosed with dementia. A year after the initial enrollment, we send an invoice for a thirty five dollar annual fee. At that point

they update their records with medications and contacts, and tell us if the person has moved or died.

Our program is important in the event of a disaster. One example is when we received a call from the police department after the large explosion that happened on 116th Street. They wanted to know whether we had any people with dementia or caregivers enrolled in our program living in that vicinity. If we had people enrolled in the program who lived in that neighborhood, officers would try to locate them to make sure they were ok.

JG: Do the police report back to you?

ES: If they do not report back to me I call for a follow up. This is why we must maintain updated records. If there is a disaster and I report that we have a person with dementia at the location but the person has moved, we put lives in danger for no reason. We would wrongly assume the person was missing.

JG: Do you find that people living with dementia try to take the bracelet off?

ES: Sometimes they do. There is a choice between a necklace and a bracelet, but the necklace is not visible when someone is walking on the street. The bracelet that dangles is much more visible. The latch on the bracelet makes it difficult to remove. We ask that people wear the bracelet on the dominant wrist and lock it.

JG: What is on the bracelet?

ES: MedicAlert® is on the front. On the back we engrave an alphanumeric code beginning with the country and ending with WR to indicate they are in the Wanderer's Program. We use the code system for anonymity.

JG: Do the police and others understand what the code means?

ES: Yes. Part of my job is conducting roll call training for the police departments, transit police, and housing police. We are part of the New York City Police Department Protocol Guide on missing persons and community affairs. I reach out to the Community Affairs Department and ask if I may come in and do a roll call. I speak to the police officers on their seven to three tour or eight to four tour and then I go back at three in the afternoon. I show them the identification bracelet. I give them the MedicAlert® phone number and my business card.

JG: How many people are registered in your program?

ES: Over twenty five thousand.

JG: How many calls do you receive monthly?

ES: It fluctuates. I receive on average thirty seven to forty two incidents of missing persons or missing persons found in a month.

I also receive Silver Alerts. Anyone can receive Silver Alerts in New York City by calling 311 and registering for Notify NYC. When the police department receives a missing person report for someone sixty five or older, they issue a Silver Alert. In this case, the person does not necessarily have dementia. This morning I received a notification for someone who has dementia. I contacted the police department for the information on the missing individual and began the case work of checking our system for the person and contacting the caregiver.

JG: If you receive twenty one calls in a given month, on average how many people do you locate?

ES: Twenty one.

JG: You locate them all?

ES: Yes.

JG: Are most of the wanderers found alive?

ES: Most of them. In my thirteen years heading the program I think we have had only two deceased wanderers. In the rare event that a person is found deceased, we provide bereavement services to the caregiver and family.

JG: Do caregivers wear MedicAlert® bracelets also?

ES: Both formal and informal caregivers have an option to enroll. They might be in perfect health but want to have the information of the person with dementia on them at all times. Normally they choose the necklace so they can take it off when they wish.

I will tell you a story that demonstrates how effective it can be when a caregiver wears the MedicAlert® necklace. One afternoon a husband and wife left the Veterans Administration Hospital on Kingsbridge Road. They boarded the twenty two bus. They were returning to the Castle Hill area of the Bronx. She told me the story in Spanish because she only spoke Spanish, "I got on the bus with my

husband,” she said. They had been married for many years. She continued, “I put my head down for just a quick minute and closed my eyes. When I opened up my eyes, he was gone.” She panicked. All she could do was take the necklace and show it to the bus driver. The necklace is engraved with “Caregiver for,” so even though she could not speak English, her necklace told the story. The bus driver did not remember seeing the man leave from the front door. The bus driver dialed 911 and the police came. They took a report. She was able to give a description of her husband and his identifier code, which is also on the caregiver’s ID necklace or bracelet. The caregivers have their own code too. Both codes are linked in the same file. They canvassed the area. We contacted the hospitals and sent out a bulletin. He was located at a local hospital within several hours.

JG: Does the program require a large staff?

ES: I have a staff of two. The reason we can serve so many with so few is that we are linked to the police department and MedicAlert®. The program is a collaboration between CaringKind, the New York City Police Department, the New York City Office of Emergency Management, the New York City Department for the Aging, the Port Authority, the Transit Authority, the New York City Police Department Housing Bureau, and other emergency responders.

JG: Have you ever had a person use the alert outside the country?

ES: Yes. We had someone enrolled who walked into a beauty parlor in Jamaica and just sat down. The owner of the beauty parlor did not think anything of it. At closing time he was still sitting there. He told the owner that he was waiting for his wife. She noticed the bracelet and called MedicAlert® and then MedicAlert® contacted me. We ask caregivers to notify us if they will be traveling. We would like to know the dates of their travel and where they will be staying. In this case, the family had not notified us. We contacted them and they brought their father home.

We had another incident with a woman on the beach in Puerto Rico. She was traveling with her daughter. Her daughter went to buy some lunch. The mother walked away from the beach blanket and a police officer found her on the road. The officer noticed the bracelet and called MedicAlert®. From there, I was able to provide him with the family information. We contacted the daughter, who was on the beach looking for her mom.

JG: Is there anything else you would like to discuss?

ES: I wish people would understand that low tech solutions can have great impact. Simple can be better. We make wonderful use of technology through the alert system and social media. The person reading the MedicAlert® bracelet or necklace does not need anything more than the ability to read. The person wearing it often just needs to keep it on their person. Our system is simple, but it works.

JG: Thank you for this interesting discussion.

ES: Thank you for your interest in the Wanderer's Safety Program.

END