

“In the 22 years that I have known her, I have never seen her so happy.” The Positive Effects of an Intimate Relationship Between Two Residents with Dementia in an Assisted Living Residence

Eilon Caspi Ph.D.

Ms. Edwards is a 75-year old divorced woman who developed vascular dementia and Alzheimer’s disease (AD) in 2002/3. I learned about Ms. Edwards’s background from a meeting with her daughter, reviewing her clinical records, and staff reports.

Life Background. Ms. Edwards, who was the oldest of three children, studied and worked in Interior Design. She married at age 24 and had a daughter and a son from this marriage. She was subsequently divorced and married a second time, but this marriage lasted only three years. Her daughter reported that she “lived alone most of her adult life...and managed to be okay financially...and she is savvy about that. She lived in a condo...didn’t get along with her neighbors...and was a very negative person.”

Ms. Edwards had an “incredible style with clothing...always ahead of her time. She used to be all put together with jewelry and makeup...and she likes to have her hair done.” She was also a fabulous cook.

Mental Health. Ms. Edwards was emotionally volatile and had mood swings all her life. She might have had an untreated bipolar disorder. She definitely had episodes of depression. The daughter reported that, “She medicated her depression by alcohol use. She used to have suicidal thoughts, but never so far to do anything about it.”

Sequence of Events Leading up to Admission to the Current Assisted Living. Ms. Edwards stopped working in 2002/3 when she developed dementia. Later on she lived with her daughter, and then, in the Spring of 2006, she moved to an Assisted Living Residence (ALR) (not the current one) where she became sick, was depressed, and did not

get out of bed for three weeks. During this time period, she became weak in her legs and fell a few times. Around Thanksgiving 2006, she became depressed again. She isolated herself and spent all her time in bed. In the Spring of 2007, Ms. Edwards was brought to the emergency department because of increasing confusion, generalized weakening, and poor functioning at her ALR. She was not eating and was not getting dressed and stayed in bed all the time. The following was reported in the hospital discharge summary: “Her relatively preserved verbal skills may give others the impression that she is able to function at a higher level functioning than is realistic given substantial memory problems. Her insight is lacking and her judgment is impaired.” At that time, she was evaluated as being in the mid-stage of AD. Two weeks later she was admitted to the current ALR. At the onset of the study (August 2007) (Caspi, 2010), she had lived at the Higher Cognitive Function Unit (HFU) of the ALR for 3.5 months.

Cognitive Deficits. In terms of spatial orientation, the following was reported in Ms. Edwards’s Service Plan of July 2007: “She is not oriented to where her bedroom is located.” The Team Leader reported that, “She doesn’t know how to find her room...and that’s why she doesn’t leave her room.” In addition, her daughter reported that, “While her mother is dead...she thinks she is alive...and wants to see her.” Furthermore, during a care plan meeting (April 2008) her daughter reported that, “Her brother came on Saturday and she needed to sign something...it took her 10 minutes...she misspelled her name. Later I found her with a piece of paper practicing her name...it was heartbreaking.”

Physical Health. Ms. Edwards’s suffered a host of chronic health conditions, including kidney atrophy, hypertension, peripheral vascular disease, chronic obstructive

pulmonary disease. In addition, she suffered from frequent urinary tract infections, and lower-back pain.

Daily Function. Mrs. Edwards was independent in walking, eating, and using the toilet. However, as reported by the staff, “At night she needs assistance to get her pajamas on and to brush her teeth. If left alone, she won’t get undressed or dressed...and she’ll procrastinate brushing her teeth. She needs cueing to get showered and dressed.” In one of the care plan meetings, her daughter expressed concern about her oral health. She said that she forgets to brush her teeth and needs reminders to do so.

Emotional State. One of the managers reported that Ms. Edwards is “going through cyclical ups and down every three months or so.” Her daughter reported that she “is very social but very private. If you’ll put her in a social situation, she will be the life of the party but when she is by herself she hermits.” She added, “She doesn’t like the setting here because she needs to interact with others.” Ms. Edwards described her roommate a “raving nut,” and said that her neighbors “steal all her belongings.”

Care challenges. In one of the management meetings, the Team Leader reported that the staff is experiencing “difficulties in bringing her out of her apartment. Will nap all day if she is allowed. Then tends to pick up at night. Refuses to take a shower (thinks everything is dirty so staff put three towels on the floor).” One of the managers reported that she is “completely resistant to care,” while the Team Leader reported that, “Nothing that you will do for her will work...only if she will want...” [and then added] “Sweetheart, but we don’t know how to work with her...yet.” In addition, the Team Leader reported that many times during meals Ms. Edwards calls the food “dog food” and other residents do not eat because of that.

Lack of adjustment to the Assisted Living. Mrs. Edwards “blames her daughter for putting her here.” The Team Leader quoted her saying, “This is one of the worst places.” Her daughter said that, “She takes down all the pictures and personal belongings as part of her unwillingness to be here.” One of the staff members reported that she “hoards and hides her clothing and other personal items.” One day Ms. Edwards asked her daughter, “Why am I here? I haven’t done anything wrong.”

Organized Activities. Her daughter wrote: “My mom shies away from group activities, but she can be very social. She likes her quiet time. She likes to read. She doesn’t care for the group activities. However, once engaged, she seems to do fine. Loves to dance.” In addition, she “loves music and flower arrangement.” Then she added, “She is bored...not motivated to do anything.”

The Turning Point. In late August 2007, a male resident, Mr. Newman, was admitted to the HFU. Shortly after his admission, Ms. Edwards’s emotional state and general daily function improved dramatically. On a continual and consistent basis, Ms. Edwards and Mrs. Newman were seen spending significant portions of the day and evening together. An intimate relationship quickly developed between the two, as was reflected by frequent expressions of affection one towards the other. Several examples include, consistently sitting together during meal times and organized activities, walking together in the hallway hugging, holding hands during group activities, dancing together, giving each other a shoulder massage, smiling frequently to each other, laughing together, occasionally kissing, and snuggling together in bed while watching television.

Less than a month after Mr. Newman moved into the HFU, Ms. Edwards’s son-in-law said, “In the 22 years that I have known her, I never seen her so happy.” In late

September 2007, her daughter reported the following: “Total change of personality...to the better...nice now...,” and then added, “Well, she has her moments...” A month later, one of the managers quoted Ms. Edwards’s daughter saying: “My mother was never interested in men...this is just great.” Further, in mid-October 2007, the daughter said, “She just never liked men...I think that in the past she had to be protective of herself...defense mechanism...but now with Alzheimer’s all that is gone.” The morning shift Team Leader described the changes as follows:

“When Ms. Edwards first came here it was the adjustment period for her and it seemed like it just was not working. She would stay in her room until late in the morning, eat very little, her eating habits weren’t as good as they are now. We were thinking about moving her to the Lower Cognitive Functioning Unit but since Mr. Newman came, she changed a lot. She gets up in the morning...not every single morning...there are still challenges...she’ll stay in bed...but when he is around, she’ll get up and they’ll have their breakfast some mornings together. She seems very happy. They walk around together holding hands, they eat lunch and supper together...I mean it is a big change in her...for the better.”

In summary, the main changes in Ms. Edwards after forming the relationship with Mr. Newman included: asking to leave the ALR and go home much less frequently; waking up much earlier (though during the winter she woke up later, which was consistent with her lifelong sleep habits); cooperating with and taking more showers; leaving her apartment more often; paying more attention to the way she looked (e.g., clothes, hair, jewelry, and make up); participating and enjoying group activities more often (e.g. music therapy; exercise); still criticizing the food, but less often; and generally being more content and happy.

* All the names used in this manuscript are fictitious.

Reference

Caspi, E. (2010). Preventing agitated behaviors and encouraging positive emotions among elders with memory-loss in an assisted living residence. Unpublished Doctoral Dissertation: University of Massachusetts Boston.