Alzheimer’s Behaviors or Coincidences?

Allan Vann*
Retired School Principal, 28 Abbey Drive, Commack, New York, USA

Letter to the Editor

My wife, Clare, has Alzheimer’s disease (AD). I have lived with Clare’s Alzheimer’s for seven years. Three years observing symptoms prior to her diagnosis and four years since her diagnosis in 2009, a month after she turned 63. Except for a few hours of respite time each week, I am with Clare, 24/7. Caregivers for AD spouses living at home often notice AD behaviors that doctors may not observe during routine office visits, and sometimes we observe behaviors not reported in any AD books or research. Perhaps researchers should give closer attention to our collective observations in an attempt to diagnose or treat AD more effectively.

Brief Periods of “Awakening”

Many in my spouse support groups note that our spouses often demonstrate brief “awakenings” when they seem to exhibit no “brain fog” for a period of time. Even on their foggiest days, our spouses sometimes have brief periods of perfect lucidity. This aspect of Alzheimer’s is noted in the professional literature. What is not found in the literature, however, is that many caregivers notice that such awakenings occur most frequently during doctor visits. When that happens, our reports of worrisome behaviors are often dismissed or ignored because doctors themselves see no evidence of such behaviors. We also often see awakenings when our spouses are with close relatives and friends.

Why do our spouses sometimes fail to demonstrate many of their routine AD behaviors in the presence of their doctors, close relatives, and friends? Is it due to a very strong denial instinct that enables them to mask their symptoms and override AD behaviors for a brief period of time? Is it due to a strong subconscious desire to appear well in front of their doctors, close relatives, and friends? Is it possible that some people with AD can have denial instincts or subconscious thoughts so strong that they can stimulate the release of certain chemicals in their brains to cause a brief awakening? If so, could a medication be devised to stimulate similar brain activity that could, perhaps, diminish some AD symptoms even if only for brief periods of time? All I know for sure is that every member of my spouse support group observes these brief awakenings most frequently in the presence of doctors, and also often when in the presence of close friends and family. Why?

Forgetting to Brush Teeth

My support group is for spouses of people with early to moderate stage AD. We have commented several times about how the first personal hygiene habit that our spouses seem to forget is the daily brushing of their teeth. Some of our spouses are incontinent. Some are not. Some go to bathrooms by themselves. Some cannot. Some bathe or shower, shave or groom, all without difficulty. Some cannot. Some dress themselves. Some cannot. But all seem to need daily reminders to brush their teeth. After such reminders, some will brush their teeth fine by themselves while others still require some assistance. Many who cannot remember to brush their teeth without prompting can handle much more complicated personal hygiene tasks without any prompting whatsoever. For example, Clare still remembers how to insert/remove her daily contact lenses properly by herself and see to their daily maintenance.

Is brushing one’s teeth a habit so easily forgotten because of the repetitive physical motion of the act of brushing? Is it because brushing one’s teeth is one of the earliest learned personal hygiene behaviors, so it is the first to be forgotten? Is it because multiple steps are involved: locate the brush, locate the toothpaste, open the cap and squeeze just the right amount of toothpaste onto the brush, etc.? All I know for sure is that every member of my spouse support group said that brushing their teeth was the first personal hygiene behavior our spouses had forgotten. Why?

Sleeping Diagonally in Bed

With few exceptions, people in my support group still sleep in the same bed with their spouses, and those who do have all reported that our spouses lie diagonally across our beds when sleeping, crossing into our own personal "bed space." Our spouses all start off sleeping on their sides of the bed. But, slowly but surely, during the night they end up sleeping diagonally across the bed.

Is this due to some sort of psychological need for our spouses to remain physically close to us even while asleep, much as many people with AD "shadow" their spouses when awake? We all report how our spouses often follow us into another room just to remain close to us. Is sleeping diagonally their way of using us as their security blankets in bed at night? Is this a neurological reaction to something? Is this due to loss of orientation of their body in space? All I know for sure is that many members of my spouse support group have said that their spouses sleep diagonally across their beds. Why?

Dreaming and Sleep Talking

Although Clare is already in moderate stages of AD, she remains highly verbal despite increasing episodes of aphasia. Perhaps that is due her strong language background as a former high school teacher of English, English as a Second Language, and Spanish. Perhaps this is simply the course her disease is taking. However, as Clare’s memory and executive functioning skills have declined over time, she has begun a new behavior that is getting “stronger;” dreaming and talking aloud in her sleep.

Prior to her AD diagnosis, Clare often commented to me about how she never remembered having had any dreams. Although Clare still has no memory of any dreams, I cannot sleep through even one night anymore without being awakened several times by her sleep.

*Corresponding author: Allan Vann, Ed D, Retired School Principal, 28 Abbey Drive, Commack, NY 11725, USA, Tel: 631-864-6448; E-mail: acvann@optonline.net

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talking! Prior to her AD diagnosis, whereas she may or may not have been having many dreams each night, she had never talked aloud in her sleep! Her sleep talking began about two years after diagnosis. At first, she only expressed a few softly mumbled words and then her mumbling evolved into a few quiet sentences. After several months, however, this sleep talking has progressed to clearly spoken conversations, albeit only the one sided dialogue that I hear. This dialogue is now routinely accompanied by hand gestures, laughing, crying, singing, whispering, or shouting ... all dependent, I suppose, on the nature of Clare’s particular dreams at the time. She even occasionally appears to be conducting a choir or orchestra in her sleep!

What I find most fascinating is that I have yet to detect any instances of aphasia when Clare is sleep talking. Sentence after sentence is spoken clearly, with no hesitation in her speaking aloud to “find” words that she otherwise “loses” when she is awake. This observation of fluent sleep talking, and the way it has progressed over time, is a pattern also observed by several others in my support group. Not by all members ... but by several ... and for those who have observed it, the pattern is identical. Each of us first observed the quiet mumbling of a few words expand into quietly spoken sentences and then into clearly spoken sentences and dialogue ... and always completely fluent with no episodes of aphasia. For some people with AD, is sleep talking itself an indicator of something else? For those with AD who do sleep talk, is the lack of aphasia episodes during their sleep talking indicative of something that can eventually be helpful with additional research? All I know for sure is that several members of my group whose spouses are also aphasic report no instances of aphasia during their spouses’ sleep talking. Why?

So What Does this All Mean?

Perhaps these four observations, when awakenings seem to occur most often, forgetting to brush one’s teeth, sleeping diagonally in bed, and sleep talking, should be dismissed as “interesting” but relatively meaningless observations of a group of spouse caregivers. Perhaps none of these four behaviors are related to Alzheimer’s. But perhaps one or more of these four behaviors are related to Alzheimer’s and have simply not been studied because researchers have not been made aware of them.

A recent study conducted with mice by researchers at Washington University School of Medicine in St. Louis reported that sleep problems may be among the earliest indicators of Alzheimer’s. Senior author David M. Holtzman, head of Washington University’s Department of Neurology, stated: “If these sleep problems exist, we don’t yet know exactly what form they take - reduced sleep overall or trouble staying asleep or something else entirely. But we’re working to find out” [1].

Perhaps “something else entirely” could be sleeping diagonally in bed. Or, perhaps, “something else entirely” could be sleep talking. All I know is that when a group of caregivers whose spouses range in age from the early 60s to the late 80s all report similar or identical observations that are not mentioned in the professional literature, it stretches belief to simply dismiss all such observations as coincidences. When we can learn nothing about these observations from our doctors or from the professional literature, and we hear nothing about similar observations from friends who are not dealing with a spouse with Alzheimer’s, we are left with one simple question: Why?

Reference