

Pathways

SERVING FAMILIES AND CAREGIVERS OF BRAIN IMPAIRED ADULTS AND THE FRAIL ELDERLY

Dealing with the Dreaded Sundowner's Syndrome

By John F. Miglio

SUNDOWNER'S SYNDROME is a condition that usually occurs in the late afternoon and causes a person with Alzheimer's disease to exhibit extreme confusion and agitation, sometimes to the point of becoming physically confrontational with the caregiver.

As the caregiver to my wife Sandy, I first noticed her symptoms of this dreaded syndrome during the middle stages of her battle with Alzheimer's. Needless to say, it was one of the toughest challenges for me and for male caregivers in general.

Let's face it, men usually aren't as patient or nurturing as women, and we're not used to the role of caregiver with all its attendant problems. And the problem for me was that like clockwork, every day around 3:30 in the afternoon, my wife would suddenly become quite agitated and start to pace around our house and backyard repeatedly saying, "I want to go home!"

"But you are home," I would reply.

"No, I'm not!" she would insist and head to the front door. I would cut her off and try to divert her attention, which made her even more agitated. Then I would grab her arms and hold her back, but she would struggle with



me and start screaming. For someone in her seventies who was only 5'2 and weighed about 100 pounds, she was remarkably strong!

Finally, she would run out of steam and calm down, only to do it again a little later. Some days when I was in another room or in the backyard, she would slip out the front door and take

off down the street. Usually, I would catch up to her before she got very far, but one time she disappeared and I couldn't find her. I got in my car and drove around the neighborhood for about a half hour with no success. Fortunately, by the time I got home, there was one of my neighbors waiting on the front porch with her.

It was clear I needed a new strategy. The next day at 3:30 when she started to walk around the house demanding she wanted to go home, I said, "OK, let's go. Show me where it is." So we walked down the block, turned the corner and walked another couple of blocks. "Do you see your home?" I asked. She looked at me blankly and we walked back.

I was hoping this would solve her "going home" problem, but it didn't because, as I learned, you can't solve a problem with an Alzheimer's sufferer by using logic. It doesn't work. Besides, even if it did, the person would forget the solution by the next day because of short-term memory loss.

So I had to come up with something else. In the meantime, I double-locked all the doors in the house and the backyard gate so she couldn't get out on her own. One day, she nearly

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Sundowners Syndrome, continued from page 1

kicked down the gate before she ran out of energy. She actually broke one of the redwood slats in half as if she were some kind of kung fu expert!

As I researched the subject further, I realized that "going home" is a metaphor, a state of mind. What she really wanted was to go back to a place and time when she still was in control of all her faculties. But of course that was impossible.

Her doctor didn't have a solution other than to prescribe drugs like Resperidal, an anti-psychotic, and valium, a muscle relaxant, neither of which worked. Of course by this time I was already on valium myself to deal with the daily stress of taking care of Sandy. I was also beginning to drink alcohol more frequently and use medicinal marijuana to calm my nerves.

Overusing alcohol and drugs can be a problem for caregivers, especially men, and the risk of addiction is very real. I balanced my alcohol and drug use with meditation, exercise, and prayer. But even using all those methods to ameliorate the stress of care giving, it still took every ounce of my energy and will power to keep going. And I knew I had to find a better way to deal with her Sundowner's Syndrome, otherwise I might crack up myself.

So I did more research and came up with a new plan. The plan included giving her a combination of ginkgo biloba and inositol in high doses. Ginkgo is an herb that helps the memory and inositol is a component of vitamin B-complex that produces a calming effect. The combination of these two natural remedies seemed to help her frenetic behavior, although it's difficult to know for sure since individuals with Alzheimer's are on a steady downward spiral and their behavior patterns are constantly changing.

In addition to ginkgo and inositol, I played her favorite music most of

the mornings and afternoons using the computer site Pandora, and we went for a walk with our dog every day to give her exercise. I also gave her a snack at about 3:15 and had her two sisters and my sister divide up the week and call Sandy on the phone at 3:30 every day to talk to her. This created a nice long diversion until dinner. Usually by dinner, her agitation had passed and she was OK for the remainder of the evening.

The experts aren't sure what causes Sundowner's Syndrome. They think it may have something to do with the disease disturbing the body's internal circadian rhythm, but they don't have a way to stop the disruption and believe there are also other factors involved. The thing that surprised me the most was how it happened at almost the same time every day, regardless of the weather or Sandy's previous activities.

Alzheimer's experts are fond of saying, "every case is different" in the way an Alzheimer's sufferer deals with each stage of the illness. While this is true, my own research has led me to believe that most Alzheimer's sufferers follow the same stages of decline (listed by the Alzheimer's Association) with only minor variations in behavior patterns. This was certainly true of my wife, who I took care of for over eight years before I had to place her in a skilled nursing facility.

So my advice to all my fellow male (and female) caregivers is to research and read about this subject as much as possible, anticipate the next stage of the disease and plan a strategy before it arrives. And if that strategy doesn't work, figure something else out—quickly! Don't forget, your own sanity and physical health are at stake, and the easier you can make your job, the less stress you'll have and the better you'll be able to care for your loved one.

*In addition to being a caregiver and supporter of the Alzheimer's Association, John F. Miglio has been an entrepreneur, university professor, and freelance journalist. He is the author of the dystopian thriller, *Sunshine Assassins* and the editor of the *Online Review of Books & Current Affairs*.*

*His articles and stories have been published in a variety of periodicals, including *Los Angeles Magazine* and *LA Weekly*. His most recent stories have appeared in *Truthout*, *Counterpunch*, *Hippocampus*, and *Op/Ed News*. He also has appeared on *Air America Radio* and *Radio Power Network*.*

*His novel, *Sunshine Assassins*, has been called "a bone-chilling political morality fable," "wickedly entertaining," and "unforgettable."*

Caregiver's Column

Acceptance Brings Change

Clinging to how we think things should be brings confusion and despair.

Seeing things be as they are brings clarity.

Clarity leads to effective action.

Trying to change others leads to resistance and frustration.

Seeing others as they are leads to acceptance.

Acceptance leads to change.

From: The Caregiver's Tao Te Ching by William and Nancy Martin, p. 10.

INVITATION TO CONTRIBUTE TO CAREGIVER'S COLUMN

Please feel free to submit your contribution to email address. It is best to type your review in a Microsoft Word document. Be sure to include the title, author, a brief description, and mention how this was beneficial for you. The newsletter editor may need to make changes to your submission for various reasons, including spelling/grammar check and to adjust article to meet spacing requirements.

A Dose of Inspiration

One person caring about another represents life's greatest value.

JIM ROHN

Be determined to handle any challenge in a way that will make you grow.

LES BROWN

"Sometimes asking for help is the most meaningful example of self-reliance."

UNKNOWN

"If you want others to be happy, practice compassion. If you want to be happy, practice compassion."

DALAI LAMA



New Workshops for Family Caregivers Coming Soon!

AS A CAREGIVER anticipating having to move your loved one is a difficult time. After the move can be challenging as well. Carol Kinsel, GCM, and Stefani R. Wilson, MS, MFT, invite you to join the conversation where we will explore what can feel like an emotional roller coaster ride for the primary caregiver and discuss strategies promoting a smooth transition before and after "the move." In order to address individual concerns, we are keeping the group size small and recommend that you register by September 30th to (916) 965-5565 for the workshop that best suits your needs:

ANTICIPATING THE TRANSITION TO A CARE HOME:

When: Wednesday, October 7th
Time: 1-4 p.m.

COPING WITH THE CARE HOME TRANSITION:

When: Wednesday, October 14th
Time: 1-4 p.m.

Cruise Around the World a Big Success!

ON JULY 18TH, Del Oro Caregiver Resource Center held our 10th Annual Cruise Around the World Cook-off and Fundraiser in Orangevale. This fun and festive event is an opportunity to support the efforts of Del Oro, a private, non-profit agency dedicated to serving families and people who are providing care for brain-impaired adults and the frail elderly.

At the heart of the event is a cook-off competition between local senior care providers. There were two phases to the competition—professional judges and crowd favorites. The professional judge panel consisted of Teresa Urkofsky, Chef and Culinary Faculty at American River College, Tina Macuha, Anchor and Reporter for Good Day Sacramento, and Keith Breedlove, Culinerdy Cruzer. The panel of judges scored each participant on presentation of the food, taste, originality, and authenticity to the region or country the culinary partner chose. We are pleased to announce this year's winners:

FIRST PLACE: Atria El Camino Gardens with their Switzerland-Raclette with Jabon Cru and Pickled Season Fruits

SECOND PLACE: Inspired with Borsch

THIRD PLACE: Alta Manor with Hawaiian-Kalua Pork over Rice with Pineapple Sauce and Hawaiian Haupia Dessert with Tropical Fruit

The event attendees chose Carlton Plaza as the overall "Crowd Favorite" with their Deck Hand Special featuring Lobster Rolls and Sea Salt Kettle Chips. Congratulations to all of our winners!!

Thanks to the generous support of our sponsors, culinary partners, and attendees, Del Oro raised \$33,000 to provide vital services to family caregivers in our community. We appreciate your support of our mission and goal to improve the well-being of family caregivers throughout their journey.

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and tired of going to the hospital?**

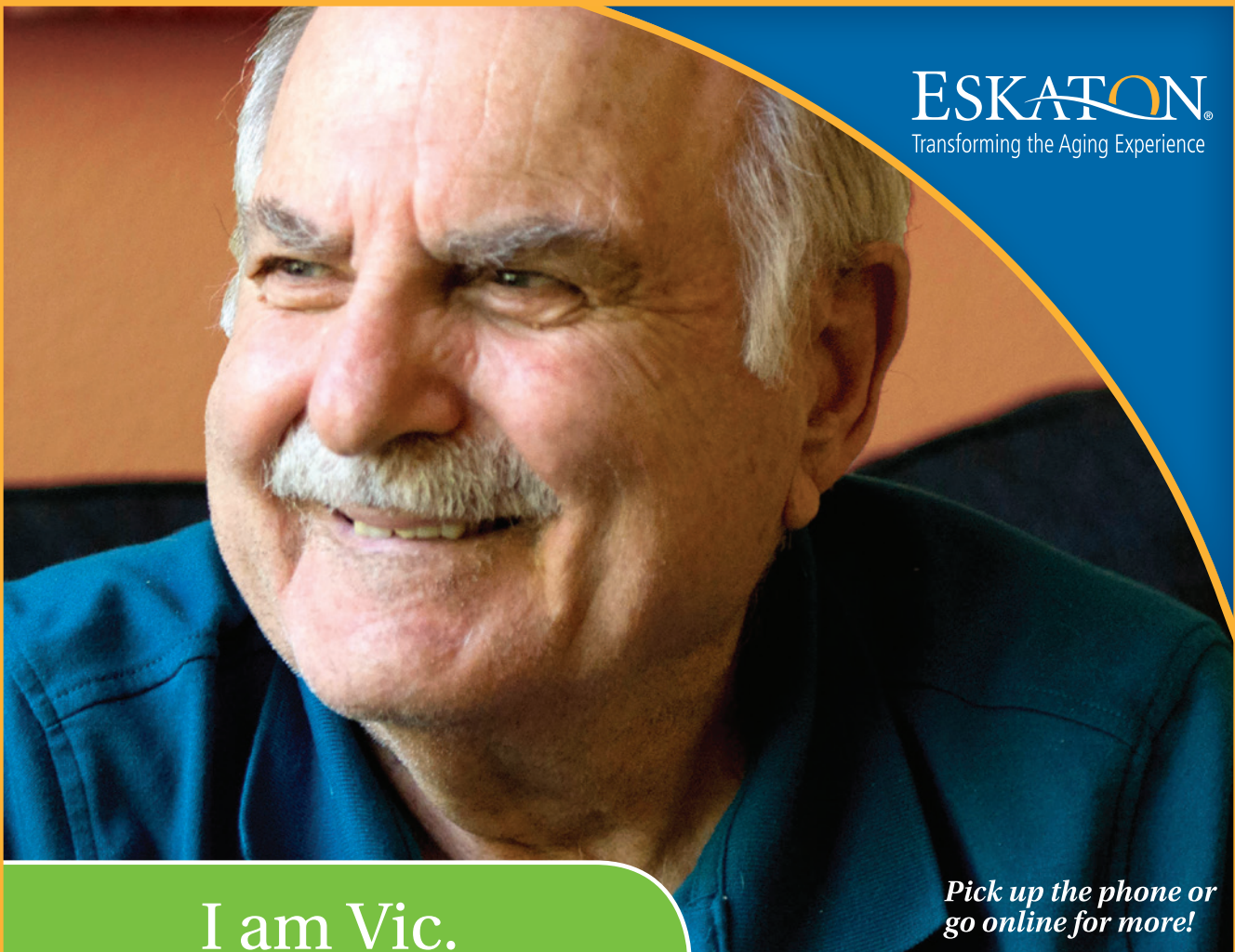
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November is National Family Caregivers Month

THE ECONOMIC VALUE of the nation's family caregivers' unpaid work is an estimated \$470 billion a year — an amount about equal to the annual sales of Wal-Mart, the world's largest company. That's the top finding from the AARP Public Policy Institute's new report, "Valuing the Invaluable: 2015 Update." The survey found that an estimated 40 million U.S. caregivers devote about 37 billion hours to assisting adult relatives or close friends. If you are a family caregiver, this is likely news you can relate to.

National Family Caregiver Month provides the perfect opportunity for Del Oro to honor and recognize the family caregivers in our community with the "Essence of Care" retreat on Saturday, November 7th from 10:00 a.m. to 3:00 p.m. at the Town and Country Lutheran church in Sacramento. Join us for a day celebrating the love and hard work of the family caregiver. Learn about the importance of self-care, healthy ways to express authentic caregiving emotions, strategies for maintaining your physical and spiritual well-being, and creative ways to use the arts to communicate and connect with your loved one. Space is limited, registration is \$40; to register for this worthwhile event, please contact Del Oro at (916) 728-9333.

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We are thrilled to announce that Governor Brown signed the California State Budget (2015-16) today, with an increase of \$2 million for the eleven California Caregiver Resource Centers! These funds are a partial restoration (23%) of the 72% cut we sustained in 2009. Del Oro will receive approximately \$180,000, and funds will be used to increase our organizational capacity and direct services in the community.

A HUGE thank you to all who faxed, phone and emailed the legislature on behalf of our statewide system of Caregiver Resource Centers. This is a positive step in recognizing the important work of family caregivers in our community.

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