Financial Planning a Key But Neglected Component of Alzheimer’s Care, Say Researchers
By Steve Tokar on February 15, 2011

Patients newly diagnosed with Alzheimer’s disease or other dementias, and their families, need better guidance from their physicians on how to plan for the patient’s progressive loss of ability to handle finances, according to a study led by a physician at the San Francisco VA Medical Center and the University of California, San Francisco.

“When a patient is diagnosed with Alzheimer’s disease or dementia, the chance that their physician will discuss advance planning for finances is miniscule,” said lead author Eric Widera, MD, a geriatrician at SFVAMC. “And yet when family members and caregivers are asked what’s important to them, finances are near the top of the list.”

Writing in the Feb. 16, 2011 issue of the Journal of the American Medical Association, the authors use a case study of an Alzheimer’s patient who progressively lost the ability to handle finances as a springboard for a review of medical literature on the topic of dementia and financial impairment.

“The literature tells us that financial incapacity occurs very early and very rapidly in Alzheimer’s disease and other dementias,” said Widera, who is also an assistant clinical professor of medicine in the Division of Geriatrics at UCSF. “Patients start having difficulty managing bank statements and paying bills in the pre-dementia phase -- mild cognitive impairment -- and then, often within a year, lose more basic financial skills like counting coins and paying with cash.”

This rapid progression of financial incapacity, said Widera, makes it “essential” that physicians proactively counsel patients and their families on financial planning “early in the disease, while the patient still has the capacity to make the decisions” that will allow trusted caregivers to take over finances.

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A message from the EXECUTIVE DIRECTOR

On occasion I’ve been asked by our caregivers how I became involved with ADRC. Like all of the staff at our agency, I’ve had personal experience caring for a loved one diagnosed with Alzheimer’s or some form of dementia.

Two family members…..my father and my grandfather on my dad’s side…..suffered from Alzheimer’s disease. At least that’s what they were diagnosed with, although no autopsy ever confirmed this assessment.

My grandfather was diagnosed with “senility” in the 1960s when they simply locked folks away in a mental ward. My father visited Grandpa every Sunday, bringing him a special meal from his favorite restaurant. But Grandpa was kept behind bars in a room with nothing to remind him of home. Programs and activities geared toward the patient suffering from the disease were nonexistent.

My dad was diagnosed in the late 1980s and passed away in 1999. His situation was slightly better than his father’s because by then more was known about the disease, although there were still limited programs and services available for the families. The stigma of Alzheimer’s was very real back then and patients were not provided with much to improve their quality of life.

When I heard about the Alzheimer Resource Center (our agency’s name at that time) through my position as director of the community helpline, I was thrilled to see the wide range of programs it had developed to support families and directly improve the lives of caregivers as well as patients. Needless to say, I became an avid supporter of the center’s work.

Then in 2004 Shellie Brassler, the Executive Director at that time, and member of the family who developed the agency, asked me to interview for her position as she was leaving the agency. I became the first “non-family” member to head the agency, which was a tremendous opportunity and obligation for me.

My personal bottom line is that I never want any family to go through the difficulties my family experienced with my dad and grandfather. Anything ADRC can do to make life worth living for these families and their loved ones is our goal. We are proud to be of service to this special population and the wonderful folks who care for them.

Warmest regards,

Nancy Squillacioti

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“This is about giving patients with dementia a choice, respecting them as individuals, and working to maintain their autonomy even beyond the point where they can’t make decisions anymore,” Widera said. “Proper financial planning will leave both the patient and the caregiver with more financial resources to deal with the consequences of the disease.”

As a first step in financial planning, the authors recommend that early in the course of the disease, the patient sign a durable power of attorney authorizing a family member or other trusted caregiver to make financial decisions on the patient’s behalf. “If you wait until it’s too late for the patient to be involved in the decision-making, you have to go to court, which makes it much more difficult and expensive” for the caregiver to take over financial responsibilities for the patient, warned Widera.

Another strategy is for the patient and a trusted caregiver to open joint financial accounts. “The caregiver can go online and see where the money is going,” noted Widera. “This can protect the patient’s autonomy while giving the caregiver a bit of oversight, and provide an early warning system as the disease progresses.”

Co-authors of the paper are Veronika Steenpass, MD, of UCSF, primary investigator Daniel Marson, JD, PhD, of the University of Alabama at Birmingham, and Rebecca Sudore, MD, of SFVAMC and UCSF. The study was supported by funds from the Health Resources and Services Administration, the Hartford Foundation, the National Institute on Aging, the National Institute of Child Health and Human Development, the Department of Veterans Affairs, and a Pfizer Fellowship in Clear Health Communication.

SFVAMC has the largest medical research program in the national VA system, with more than 200 research scientists, all of whom are faculty members at UCSF. UCSF is a leading university dedicated to promoting health worldwide through advanced biomedical research, graduate-level education in the life sciences and health professions, and excellence in patient care.
Occupational therapist Teepa Snow slips into “becoming” a person with dementia and directly challenges participants at her workshops.

“This is not my home,” she might blurt, bending over and staring hard at a person in the front row. “Why did you bring me here?” she shouts. She pauses, looks away, looks back and fires off: “I hate you!”

Her “show don’t tell” approach to communicating information about dementia is visceral and effective. The person in the audience who is the “target” of her encounter is often visibly unsettled and the interaction sets up a learning opportunity.

Snow is a dementia education and care specialist from North Carolina whose teaching style has won her fervent admirers in the caregiver community in North America. A tireless advocate, she is determined to better the lives of people with dementia (and the lives of their caregivers) by sharing what she has learned. She has spent more than 30 years working with people with dementia, figuring out what helps them, and fine-tuning ways to engage her audience. (You can watch her in action: segments from many of her presentations are available on her own channel on YouTube.)

She has kept up the pace for many years because she is on a mission. “I am just so frustrated that there seems to be no political will to dig in and prepare for what lies ahead”— namely the growing proportion of the population that will be elderly and hence the increased numbers of people with dementia. The political attitude seems to be that scientists will discover a magic bullet to eliminate or cure dementia, she says, and so the task of planning services to address this crisis has been neglected.

“I see people’s lives being torn apart now. We need risk reduction.” To further her activism, she joined with the U.S. Dementia Action Alliance, which is affiliated with the World Health Organization’s Global Alzheimer’s and Dementia Action Alliance.

Snow has developed a classification system called GEMS™, which is based on her philosophy “to meet people where they are” and the understanding that “the task is not more important than the relationship.”

The GEMS™ system describes six stages of dementia and, for each stage, sheds light on what people with dementia are experiencing, and on appropriate caregiving strategies.

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Upcoming Events

Free Community Workshop
Caregiving Matters

Friday: May 1, 2015
“Parkinson’s Disease: More than Just a Movement Disorder”
Registration: 9:30 am
Workshop begins: 10:00 am – 12:00
Please RSVP for more information call 407-843-1910

Location:
Reeves United Methodist Church
1100 N. Ferncreek Avenue
Orlando, FL 32803

Free Community Workshop
Caregiving Matters

Friday: June 5, 2015
“How to Survive Your Role as Caregiver”
Registration: 9:30 am
Workshop begins: 10:00 am – 12:00
Please RSVP for more information call 407-843-1910

Location:
Reeves United Methodist Church
1100 N. Ferncreek Avenue
Orlando, FL 32803

Free Community Workshop
Caregiving Matters

Friday, August 21, 2015
“How to Communicate When Logic Doesn’t Work”
Registration: 9:00 am
Workshop begins: 9:30 am – 11:30 am
Please RSVP and for more information call 407-843-1910

Location:
Renaissance Senior Center
3800 S. Econlockatchee Trail
Orlando, FL 32829

Free Community Workshop
Caregiving Matters

Friday, September 4, 2015
“How to Communicate When Logic Doesn’t Work”
Registration: 9:30 am
Workshop begins: 10:00 am – 12:00
Please RSVP and for more information call 407-843-1910

Location:
Reeves United Methodist Church
1100 N. Ferncreek Avenue
Orlando, FL 32803
Upcoming Events

Free Community Workshop
Caregiving Matters

Friday, September 18, 2015
“How to Survive Your Role as Caregiver”
Registration: 9:00 am
Workshop begins: 9:30 am – 11:30 am
Please RSVP and for more information call 407-843-1910

Alzheimer’s & Dementia Resource Center’s
22nd Annual Caregiver Conference
Teepa Snow – Making a Difference One Mind at a Time
Friday, November 13, 2015
8 a.m. – 4:00 p.m.
Community United Methodist Church
4921 South US Highway 17-92 • Casselberry, FL 32707

Keynote Speaker
Teepa Snow

As one of America’s leading educators on dementia, Teepa Snow’s philosophy is reflective of her education, work experience, available medical research, and first hand caregiving interactions. Working as a Registered Occupational Therapist for over 30 years, her wealth of experience has led her to develop Positive Approach™ to Care techniques and training models that now are used by families and professionals working or living with dementia or other brain changes throughout the world.

Come join us as Teepa shares her valuable experiences!

Conference schedule:

8:00 a.m. – 9:00 a.m. Registration/Refreshments/Visit with sponsors
9:00 a.m. – 12:00 p.m. Morning presentation: Challenging Behaviors
12:00 p.m. – 12:45 p.m. Lunch and visit with sponsors
1:00 p.m. – 4:00 p.m. Afternoon presentation: Tips on Handling Caregiving Role

Registration Fee: $25.00 per person
(Limited scholarships available for family caregivers)

You can register over the phone with a credit card; go to www.ADRCcares.org and click on Events and use the PayPal account or send a check and registration form to the address below:
Alzheimer’s & Dementia Resource Center
1506 Lake Highland Drive
Orlando, FL 32803
For more information and/or to register call Cindi Spurgeon: 407-843-1910, ext. 301
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Sapphire is the first stage, characterized by changing abilities that are creating new challenges in life, and caregivers should “allow processing time and discuss, not demand.” The last stage is Pearl, where the individual is “hidden in a shell, immobile, reflexive” and caregivers should use a soft voice and interact with “slow rhythmic movement.”

Snow explains that she has learned from trial-and-error caring for people living with dementia. She has also studied the neurophysiology of what happens in the brains of people whose dementia results from conditions such as long-term alcoholism, Parkinson’s or Alzheimer’s. “But I try to stay away from jargon. If I use a lot of fancy words, it creates distance with my audience.”

In the same way, Snow doesn’t set herself apart from her audience — she dresses in a trademark shirt and slacks, with her greying hair pulled back in a pony tail. She got her unusual first name when she was a teenager, working with an autistic boy who couldn’t pronounce, Teena, her given name. He called her Teepa, her family and friends began doing the same, and she legally changed her name.

Here’s how she explains her teaching style: “I interact and role play, and if I can get people to recognize someone — ‘Hey, that’s just like the woman in room 107!’ — then what I share has much more immediacy, and participants are a lot more interested in what happens next.”

For example, the angry woman with dementia that Snow portrays, startling her audience? This woman may in fact be in her own home, but she thinks that “home” is the house she grew up in; she “is” a young girl again, and she’s scared.

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WITH GRATITUDE:

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Snow might show how to hold this woman’s hand in a calming and reassuring way, or demonstrate that, in a difficult encounter, you need to take one step back and several deep breaths. “Your brain works better than her brain: you need to figure out how to interact — you can change the environment, the task, or your own behaviour.”

In this way, Snow provides insight into what a person with dementia might be thinking and feeling, and demonstrates ways to avoid or defuse confusing and hostile situations. Participants become willing to try different approaches.

“There’s a kind of attitude shaping that occurs,” says Christine Stardom, executive director of the A.S.K. Friendship Society in Vancouver, B.C., who has witnessed the Snow effect first-hand.

A.S.K. runs a small day program (25 to 35 people) for people with dementia, and is bringing Snow in to give two day-long sessions this fall. A few of the centre’s caregivers have attended these sessions before.

Snow has also developed the Positive Approach Certification, a “train the trainer” program for working with people who have dementia. Eighty people in Sydney, N.S., are completing the program now, which was partly organized by Brian McIissac, who is with the seniors’ mental health department of the Cape Breton District Health Authority.

“As nurses, we are task oriented,” he says. “But when we see people react with fear and agitation, we are learning to understand the deeper meaning behind the behaviour.”

Snow’s fans are legion. “Teepa Snow manages to decode dementia in a captivating and painfully honest way,” says Romina Oliverio, a dementia consultant in Toronto. “She infuses her talk with humour and gets people participating. She communicates in a way that is not medicalized and not complicated.”
Support Groups

The Alzheimer’s & Dementia Resource Center provides support groups for caregivers and family members as noted below.

3rd Monday @ 10:00 A.M.
Reeves United Methodist Church
For caregivers and their care recipients
1100 N. Ferncreek Avenue
Orlando, FL 32803
(Please use the Fellowship Hall entrance in the back of the church)

1000 W. Colonial Drive
Ocoee, FL 34761
(Suite 281 Conference Room - Nest to South Entrance Elevators on the Second Floor)

2nd Tuesday @ 6:00 P.M.
West Orange: Health Central Hospital
10000 W. Colonial Drive
Ocoee, FL 34761

1st Tuesday @ 10:00 A.M.
Easter Seals Daybreak at the Miller Center
2010 Mizell Avenue
Winter Park, FL 32792
(Respite care available during the meeting, call ahead at 407-629-4365)

1st Tuesday @ 6:30 P.M.
Atria at Lake Forest
5433 West State Road 46
Sanford, FL 32771

2nd Tuesday @ 10:00 A.M.
Reeves United Methodist Church
1100 N. Ferncreek Avenue
Orlando, FL 32803
(Please use the Fellowship Hall entrance in the back of the church.)

2nd Wednesday @ 9:00 A.M.
Eastbrooke Gardens
201 North Sunset Drive
Casselberry, FL 32707
(Respite care available during the meeting, call ahead at 407-699-5002)

3rd Wednesday @ 10:00 A.M.
First Baptist Church of Apopka
441 S. Highland Avenue
Apopka, FL 32703

1st Thursday @ 10:00 A.M.
Men’s Breakfast Club
(An informal and unstructured gathering of male caregivers)

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Spring 2015