Dealing With Resistance to Care

Patients living with dementia may have a general notion that their cognitive levels have declined, but they are often unaware of exactly how dementia affects their ability to live independently. It is said that they lack of insight. Although they may notice that it is getting harder to keep track of their bills, they will not notice sending blank checks on the mail. They may realize that attending social events is becoming uncomfortable, but they may not notice introducing themselves to the same person multiple times. They may even be convinced that they are able to care for themselves and for the household, but they will not notice the expired food in the refrigerator or the piles of clothing waiting to be laundered.

Inexperienced caregivers will take upon themselves the task of pointing out these shortcomings to their loved ones with dementia. They will quickly learn that doing so not only fails to solve the problem, but aggravates it, when the reaction they get is one of shame, humiliation, denial, confabulation or just plain stubbornness. And everybody gets upset. And the bills remain unpaid. And the dirty laundry still lies in piles.

Lack of insight often results in resistance to care, a failure to admit they need assistance and refusal to accept it. Most caregivers for dementia patients will encounter the problem of resistance to care at some point, typically in the early and middle stages of the disease.

RESISTANCE IN EARLY-STAGES

In the early stages of dementia resistance to care is most likely related to the desire to remain in control. It is scary to contemplate relinquishing control over your finances, giving up driving, quitting social gatherings, having to rely on others to organize your calendar and household. Some patients at this stage will do everything they can to hold on to their independence and make their own decisions. And their decisions are not always the most sound.

If they do not have a care-partner to assist them and verify that their activities are safe and effective, they may not even notice when trouble starts to happen. A long-term care insurance policy may get cancelled for lack of payment. The pet dog may become ill for lack of appropriate diet. The automobile may blow a gasket for lack of oil change.

RESISTANCE IN MID-STAGES

In the mid-stages of dementia resistance to care turns into a more personal note. Having already relinquished control over major executive decisions, patients now cling to control over their individual everyday choices. What to wear, what and when to eat or drink, bathing, where to go and what to do with their free time. The more cognitively impaired they are the poorer their personal choices will be. And again, if they do not have a caregiver assisting them, problems start to happen. They may wander and get lost; they may neglect drinking water and develop urinary tract infections; they may confine themselves into a single room in the home and never leave.

Dementia patients require assistance. Whether they admit it or not, this is the nature of the
condition. They need help. But how does a caregiver assist a person who adamantly refuses to be assisted, refuses care?

Caregivers in general need to develop skills in communication and understanding dementia. When encountering resistance to care, caregivers must also develop strategies to provide care without confronting, offending or overwhelming the patient. Here are some strategies that may be useful:

♦ Do not argue. This is not about being right, this is about helping a person with a serious disability. They will not be able to follow logical reasoning, so do not try to convince them, or explain the reasons why they should accept help.

♦ Make a thorough assessment on the conditions surrounding the refusal of care. Is it based on old habits, or events that happened during your loved ones younger years? People say that old habits die hard, but in dementia rather, old habits resurface. You really need to know who the person is and their personal history, when addressing the reasons why they are resistant.

♦ Consider the possibility of physical limitations, such as arthritic pain or poor hearing or eye sight. Remember that the person with dementia may not be able to tell you what is bothering them.

♦ Pick your battles. Is it a matter of safety or rather personal preferences? Is it really necessary that they bathe every day, or would a sponge bath suffice in between baths? Can you make some adaptations to make the activity more enjoyable for them?

♦ Select a time when your loved one is more likely to be relaxed. In general, brains affected by dementia work better in the morning, right after a few hours of deep sleep, than in the evening, after a whole day of straining to make sense of everything. Do not wait until they are really tired to bring up an activity.

♦ Make your loved one feel included in the decision making process. They may not be able to select which outfit to wear today, but they may be able to answer to “Do you want the red or the blue shirt?”

♦ Use visual cues rather than verbal ones. A note from the doctor stating “No driving” may be far more effective than you telling them not to drive.

♦ Be subtle and use finesse. They do not always have to know they are being helped. The laundry can be done when they are out to lunch, mail can be presorted before they get to it, a caregiver can be hired under the pretenses of having a cleaning lady, prescribed pills can be taken as if they were vitamins.

♦ Use fiblets, or make up a story to help them relax. If he does not want to go to the doctor, you may say that changes in social security now require it. If he wants to drive the car you can say that it is broken and suggest waiting until the store brings the part.

♦ Use the help of professionals. The advice from a lawyer, doctor or law enforcement agent may carry more weight.

♦ Put in place systems to help coping with the loss of independence. Connect with transportation services, GPS tracking systems, friends and family members who can assist your loved one stay active and maintain social relationships. Contact the Alzheimer’s Association to learn about resources and strategies.

♦ Don’t give up. You can always try again later or another day.

Resistance to care is more uncommon in the late stages of dementia, when it is more likely a matter of adjusting the caregivers’ approach and expectations to the patient’s limitations and personal habits. Studies report that only 9% of patients residing in nursing homes exhibit resistance to care.

For extreme cases of continuous resistance to care, please consult your neurologist. There are safe and effective medications that can help alleviate the anxiety caused by dementia and reduce the petulance related to refusal of care.

And above all, make sure YOU get plenty of rest and meaningful, enjoyable activities. Caring for a loved one with dementia is a long arduous process, with many ups and downs. You need to take good care of yourself first and be a caregiver second.

Written by Luciana Cramer, Educator and Care Specialist.

This month’s recommended reading:
Thoughtful Dementia Care: Understanding the Dementia Experience by Jennifer Ghent-Fuller
Events and Workshops

Understanding Dementia
With Luciana Cramer, Care Specialist
Monthly workshops exploring different aspects of dementia, including a presentation and group discussion.

This month’s topic:
Resistance to Care

Thursday, November 20, 4:30 - 6 p.m.
Sansum Clinic
215 Pesetas Lane, 3rd Floor Conf. Room
Santa Barbara
RSVP: SansumClinic.org/Classes or call 866.829.0909.
Free of charge and open to the community.

We All Have a Reason to End Alzheimer’s

Please join us at the 2014 Santa Barbara Walk to END Alzheimer’s

Saturday, November 8
Earl Warren Showgrounds

Register at
act.alz.org/santabarbara

Basics of Alzheimer’s and Dementia

Thursday, November 13
1:30 - 2:30 p.m.
Maravilla Club House
5486 Calle Real
Goleta
Free presentation, open to the public.

For my mom
Breakthrough Replicates Human Brain Cells for Use in Alzheimer’s Research

For the first time, and to the astonishment of many of their colleagues, researchers created what they call Alzheimer’s in a Dish — a petri dish with human brain cells that develop the telltale structures of Alzheimer’s disease. In doing so, they resolved a longstanding problem of how to study Alzheimer’s and search for drugs to treat it; the best they had until now were mice that developed an imperfect form of the disease.

The key to their success, said the lead researcher, Rudolph E. Tanzi of Massachusetts General Hospital in Boston, was a suggestion by his colleague Doo Yeon Kim to grow human brain cells in a gel, where they formed networks as in an actual brain. They gave the neurons genes for Alzheimer’s disease. Within weeks they saw the hard Brillo-like clumps known as plaques and then the twisted spaghetti-like coils known as tangles — the defining features of Alzheimer’s disease.

“It is a giant step forward for the field,” said Dr. P. Murali Doraiswamy, an Alzheimer’s researcher at Duke University. “It could dramatically accelerate testing of new drug candidates.”

Of course, a petri dish is not a brain, and the petri dish system lacks certain crucial components, like immune system cells, that appear to contribute to the devastation once Alzheimer’s gets started. But it allows researchers to quickly, cheaply and easily test drugs that might stop the process in the first place. The crucial step, of course, will be to see if drugs that work in this system stop Alzheimer’s in patients.

Dr. Tanzi is now starting an ambitious project to test 1,200 drugs on the market and 5,000 experimental ones that have finished the first phase of clinical testing — a project that is impossible with mice, for which each drug test takes a year. With their petri dish system, Dr. Tanzi said, “we can test hundreds of thousands of drugs in a matter of months.”

He already has used his system to look at drugs designed to prevent the formation of amyloid, the protein that clumps into plaques. The drugs, he reports, prevented both plaques and tangles in the petri dishes. Some are in clinical trials, and it is not known if they work in people. One was tested in patients and failed because it was too toxic. One hope is to find drugs for other diseases that are known to be safe and work on Alzheimer’s in the petri dish.

He also found an enzyme needed to make tangles after plaques are present. When he blocked that enzyme, plaques formed but not tangles. The enzyme is another potential drug target, he said.

Dr. Tanzi said that once his group had gotten the idea of growing neurons in a gel, setting up Alzheimer’s in a dish system had been straightforward. Group members used human embryonic stem cells — those cells that can become any cell of the body — and grew them with a mixture of chemicals that made them turn into neurons. They gave those neurons Alzheimer’s genes and grew them in wells in petri dishes that were lined with a commercially available gel. Then they waited.

“Sure enough, we saw plaques, real plaques,” Dr. Tanzi said. “We waited, and then we saw tangles, actual tangles. It looks like you are looking at an Alzheimer brain.” Now, the challenge is to show that drugs that work in this system also help patients.

Extracted from Gina Kolata’s report to The New York Times.
**Family Caregivers - 1**
Heritage House
5200 Hollister Ave.
First Monday of each month, 4:30 - 6 p.m.
And third Tuesday of each month, 5:30 - 7 p.m.
Facilitator: Jordana Lawrence

**Family Caregivers - 2**
Friendship Adult Day Center - Montecito
89 Eucalyptus Road
Third Monday of each month, 2 - 3:30 p.m.
*Free Onsite Respite Care:*
Call the Friendship Center the week before to reserve: 805.969.0859
Facilitator: Kai

**Family Caregivers - 3**
Friendship Adult Day Center - Goleta
820 North Fairview Ave
First Wednesday of each month, 10 - 11:30 a.m.
*Free Onsite Respite Care:*
Call the Friendship Center the week before to reserve: 805.969.0859
Facilitator: Barbara Davies

**Caregivers for Parents with Dementia**
Alzheimer’s Association
1528 Chapala St, 2nd floor Conference room
First Wednesday of each month, 5 - 6:30 p.m.
Facilitator: Luciana Cramer

**Persons with Early Stage Memory Loss**
(and their caregivers)
First and Third Wednesday of each month, 2 - 3:30
Pre-registration required. Call 805.892.4259 x 111 to register.
Facilitators: Joe Wheatley and Mark Watson

**Spouse Caregivers - 1**
Grace Lutheran Church
3869 State St.
First and Third Tuesday of each month, 3 - 4:30 p.m.
Facilitators: Deborah Brown and Karen Aldenderfer

**Spouse Caregivers - 2**
Maravilla, Sun Room
5486 Calle Real, Goleta
Second Monday of each month, 3:30 - 5 p.m.
Facilitator: Karen Aldenderfer

**Cuidadores de Personas de Tercera Edad**
Family Service Agency - Santa Barbara
123 W Gutierrez St - Mondays, 5 - 6:30 p.m.
*Para inscribirse llame al: 805.965.1001 x223.*
Facilitator: Marco Quintanar

**Carpinteria Alzheimer's Caregivers**
Faith Lutheran Church
1335 Valecito Pl.
First and Third Wednesday of each month, 2 - 4 p.m.
Second Monday of each month, 6 - 7:30 p.m.
Call 808.684.9328 or 805.684.5665
Facilitator: Donnie Nair

**Solvang**
**Family Caregivers**
Solvang Friendship House
880 Friendship Lane
First and Third Tuesday of each month, 2 - 3:30 pm
*Free Onsite Respite Care:*
Call the Friendship House the week before to reserve: 805.688.8748
Facilitator: Luciana Cramer

**Lompoc**
**Family Caregivers**
Lompoc Skilled Nursing and Rehabilitation Center
1428 West North Ave
Second Wednesday and forth Monday of each month, 1 - 2:30 pm
Facilitators: Denise Daniel and Mary Lou Parks

**Orcutt**
**Family Caregivers**
Magnolia
4620 Song Lane
Second Tuesday of each month, 6 - 7:30 pm
Call 805.937.3332 for details.

**Santa Maria**
**Family Caregivers**
Merrill Gardens
1350 Suey Road, (in the Wellness Center)
Third Tuesday of each month, 10:30 - noon
Facilitator: Gary Gross

*Note: The groups “Cuidadores de Personas de Tercera Edad” and “Carpinteria Alzheimer’s Caregivers” are not co-sponsored by the Alzheimer’s Association. They are important resources for family caregivers and therefore included in this listing.*
Please join us on
Friday, November 21, 2014 at 11:30 a.m.

Alzheimer’s Women’s Initiative
‘Your Brain Matters’
2014 Inaugural Luncheon
Honoring Caregivers

Fess Parker DoubleTree Resort
633 E Cabrillo Blvd. • Santa Barbara, CA 93103

Celebrity Guest Speaker
Kimberly Williams-Paisley

Honorary Chair
Lady Leslie Ridley-Tree

Alzheimer’s Women’s Initiative Luncheon Committee Co-Chairs
Gerd Jordano & Anne Towbes

Special guest, Laurel Coleman, M.D., FACP
Former Member Alzheimer’s Association National Board of Directors,
Board Member of the Alzheimer’s Impact Movement (AIM), Appointee to the Federal Alzheimer’s Advisory Committee.

Purchase Tickets online at act.alz.org/awisb

alzheimer’s association™
The Brains Behind Saving Yours.”
This first annual seminar will provide you with the tools, information and motivation to take charge of your personal, health and financial plans. You will learn strategies to talk with family, friends and doctors about your choices and take home the documents to put your choices in place. Join us for expert presentations, valuable take-home materials and healthy refreshments. Tours of the mausoleum will be offered at the end of the program for anyone who is interested. This event is open to the community.

SPEAKERS INCLUDE:

- Peter MacDougall, Ed.D.
- Sean Mason, Esq.
- Vicki Johnson, Deputy District Attorney
- Michael Bordofsky, M.D.
- Fr. Charles Talley, OFM
- The Reverend Mark Asman

THURSDAY
NOVEMBER 6, 2014
9:00 am – 1:00 pm
OLD MISSION
SANTA BARBARA
Closest parking at
2300 Garden Street

$10/GUEST
RSVP required by October 31, 2014

To make a reservation please visit
www.SansumClinic.org/classes
or call toll-free
866-829-0909